

RECOMMENDATIONS FOR STANDARDS DEVELOPMENT

Dementia-Inclusive Home and Community Care in Canada

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Participant Consent

All research participants gave consent for their information to be used for the purposes of this report. In accordance, all responses have been treated in confidence and have been anonymized in this report.

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Glossary

Terms included in the glossary were identified in consultation with the Advisory Panel and CSA project team. Definitions were selected from government sources, academic and grey literature, as well as previous standards. It should be noted that in the development of CSA standards, these terms and definitions will need to be reviewed and modified to the meet not only the evolving terminology in this subject area but also the terminology guidelines of CSA Group.

2SLGBTQI+: 2SLGBTQI+ is an acronym that stands for Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer and Questioning, and Intersex. A plus sign or asterisk added to any acronym indicates the inclusion of identities not explicitly included in the acronym. There are many acronyms that may be preferred by different individuals [1].

Assistive technology for persons living with dementia: Any item, piece of equipment, product, or system driven by electronics, whether acquired commercially, off-the-shelf, modified, or customized, that helps persons living with dementia deal with the consequences of dementia [2].

Care partner: A person who provides care and support to a person living with dementia, such as a family member or friend, in partnership with the person living with dementia [3]. The concept of a care partner recognizes the key role that the person living with dementia plays in their own care [4].

Community care: Community care services help people to receive care in the community through community-based programs and health and social services [5]. Examples of community care services may include day programs or specialized transportation services.

Culturally appropriate care: Culturally appropriate care (also called culturally competent care) is sensitive to people's cultural identity or heritage. It means being alert and responsive to beliefs or conventions that might be determined by cultural heritage [6].

Dementia: 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. There are many diseases that can cause dementia, with Alzheimer's being the most common [7].

Dementia-inclusive care: Dementia-inclusive care signifies care where persons living with dementia and their care partners experience respect, freedom, dignity, equality, accessibility, and quality of life. Persons living with dementia and their care partners are empowered to live independently, free from stigma, discrimination, exploitation, violence, or abuse [3].

Education: Education is the systematic process of learning something with the goal of acquiring knowledge [8].

Home care: Home care services help people receive care at home (including retirement homes), rather than in a hospital or long-term care facility, and to live as independently as possible in the community [5]. Home care is delivered by care providers (e.g., nurses, personal support workers), volunteers, friends, and care partners. Examples of home care services may include home visits from a care provider such a nurse or therapist.

Home and community care provider: Any person involved in the delivery or provision of home or community care services to a client. This includes, but is not limited to:

- Nurses
- Personal Support Workers
- Developmental Service Workers
- Case Managers and Care Coordinators
- Best Practice and Education Specialists
- Physiotherapists
- Occupational Therapists
- Speech Language Therapists
- Social Workers
- Dieticians
- Community Paramedics

Indigenous-specific cultural safety: In contrast to cultural sensitivity (e.g., raising awareness of cultural differences), cultural safety explicitly focuses on addressing health inequity by recognizing that sociopolitical power structures (e.g., historical, social, political, structural, and power imbalances) shape the health care experiences of Indigenous Peoples [9].

Person-centred care: Person-centred care is a philosophy that recognizes that individuals have unique values, personal history, and personality, and that each person has an equal right to dignity, respect, and to participate fully in their environment [10].

The ultimate goal of person-centred care is to create partnerships among providers, persons living with dementia, and their families to enhance the quality of life and the quality of care of people living with the disease. Services and supports are designed and delivered in a way that is integrated, collaborative, and mutually respectful of all persons involved [10].

Person living with dementia (PLWD): An individual who has been diagnosed with dementia.

Training: Training is the process of learning how to perform a specific skill or behaviour [8].

Executive Summary

An estimated 600 000 Canadians are currently living with dementia [11]. While this is already a substantial proportion of the older adult Canadian population, the figure is expected to triple over the next 30 years as the Canadian population ages [11]. As the number of Canadians with dementia is expected to increase, so too is the demand for dementia-inclusive home and community care [12]. Although provinces, territories, and organizations across Canada are working toward their own home and community care strategies, a coordinated effort is needed to identify existing gaps in the provision of home and community care for persons living with dementia (PLWD) and their care partners. This could be addressed by developing standardized Canada-wide guidelines.

The objectives of this research project were to identify: (1) existing legislation/regulations and associated gaps; (2) best practices, guidelines, and initiatives for dementia-inclusive home and community care; (3) barriers, gaps, challenges, and needs experienced by PLWD, care partners, and home and community care providers; and (4) priority areas for dementia-inclusive home and community care standards development.

A mixed-methods approach was used, allowing for the triangulation of both quantitative and qualitative data to inform emerging recommendations. The research project consisted of four components: an environmental scan; a literature review; an online stakeholder survey; and semi-structured stakeholder interviews. Data were collectively integrated and analyzed to inform recommendations. We received 102 survey responses from across Canada. This included 8 PLWD, 36 care partners, and 58 home and community care providers. A total of 12 interviews were conducted with PLWD (4), care partners (3), and home and community care providers (5).

The research project identified existing regulations and legislation pertinent to the home and community sector and noted the lack of dementia-specific considerations in most Canadian regulations and legislation. Moreover, although Canada has Harmonized Principles for Home Care, it does not currently have pan-Canadian standards for home and community care, either general or specific to dementia-inclusive care. Best practices and innovative models for dementia-inclusive care have been identified; however, implementing them has proved challenging, as has delivering dementia-inclusive care. These challenges include an unstable workforce and staff shortages, as well as insufficient time for the delivery of dementia-inclusive care. PLWD and care partners also expressed the need for tailored, person-centred care; integrated and collaborative care; consistent and reliable care; equitable access to care; and support and respite for care partners. The research project also identified the needs of home and community care providers. Providers expressed a need for dementia-specific education and training, pay equity with home and community care providers working in other sectors (e.g., long-term care), and safe working conditions.

Analysis of the barriers, challenges, and needs experienced by PLWD, care partners, and home and community care providers in the context of the current Canadian home and community care system revealed gaps to be addressed to enable the provision of dementia-inclusive home and community care. The development of Canadian standards for dementia-inclusive home and community care would serve to bridge the gap between the current system and a dementia-inclusive system. Four priority areas for standards development are recommended:

1. **Education and training**
   a. Foundational knowledge and practical skills
   b. Combatting stigma and building awareness

2. **Support for care partners**
    a. Including adequate respite, practical information about caregiving, education and support in system navigation, and guidance regarding available financial supports
3. **Access to quality care**
    a. Consistency in the delivery of care
    b. Recognizing autonomy of PLWD
4. **Human resources for home and community care**
    a. Equitable pay for home and community care providers
    b. Supports for home and community care providers
    c. A stable, skilled workforce



"While a substantial proportion of the older adult Canadian population live with dementia, this number is expected to triple over the next 30 years as the Canadian population ages."

1 Introduction

An estimated 600 000 Canadians are currently living with dementia [11], costing the health care system approximately $15 billion annually [13]. While a substantial proportion of the older adult Canadian population live with dementia, this number is expected to triple over the next 30 years as the Canadian population ages [11]. Persons living with dementia (PLWD) and their care partners frequently engage with the health care system. They experience higher rates of hospitalizations, stays in long-term care facilities, and home care visits than do other older adults [14, 15]. Care partners also experience significant physical and psychological impacts, including higher rates of stress, depression, and poor health, as well as lower self-efficacy and subjective well-being [16]. The challenges experienced by PLWD and their care partners throughout their dementia journey are well-documented [17].

As the number of Canadians with dementia is expected to increase, so too is the demand for dementia-inclusive home and community care [12]. Home and community care services allow individuals to receive care at home or in the community, as opposed to receiving care in an acute care setting or long-term care home [5]. Home and community care can be delivered by regulated health care professionals (e.g., nurses) and non-regulated workers (e.g., personal support workers or health care aids). Home care services can include personal care services, physiotherapy, occupational therapy, nursing care, speech therapy, social services, nutritional support, and support with domestic tasks.

Community care services can include services that are similar to home care but that are delivered in a community setting (e.g., physiotherapy, occupational therapy, nursing care), as well as community programs (e.g., respite services) and specialized transportations services. Sixty-one percent of older adults living with dementia live outside of long-term care homes [18]. It is estimated that care partners spend an average of 26 hours each week supporting the daily activities and care needs of PLWD [11]. Home and community care providers have experienced a number of challenges in the provision of care, including insufficient training in dementia care, low wages with limited benefits leading to high staff turnover and staff shortages, and a lack of standardized programs and guidance [19].

1.1 Problem Statement

The National Dementia Conference conducted by the Public Health Agency of Canada identified the need for national guidance on providing equitable access to home and community care for PLWD [20]. Although provinces, territories, and organizations across Canada are working toward their own home and community care strategies, a coordinated effort is required to identify gaps in the provision of home and community care for PLWD and their partners. This could be addressed through the development of standardized guidance. There is an immediate need to encourage innovation by bringing together relevant stakeholders to examine best practices and existing gaps. This will allow for better coordination and consistency, enabling dementia-inclusive care that respects the rights of PLWD and their care partners in home and community settings, including their right to dignity, autonomy, and inclusion.

1.2 Objectives

The objectives of this research project were to identify:

1. Existing provincial, territorial, and/or national legislation/regulations, as well as gaps in current legislation/regulations that could be addressed with standards;
2. Current best practices, guidelines, and initiatives for dementia-inclusive home and community care programs that support PLWD to age in place and enhance their safety, while respecting their rights to autonomy and dignity;
3. Improvements that can be made to existing home and community care services to better address gaps and challenges experienced by PLWD, care partners, and home and community care providers;
4. Gaps in the provision of equitable, diverse, and inclusive care for PLWD and recommendations to address these gaps; and
5. Priority areas that would benefit from dementia-inclusive home and community care standards development.

2 Methods

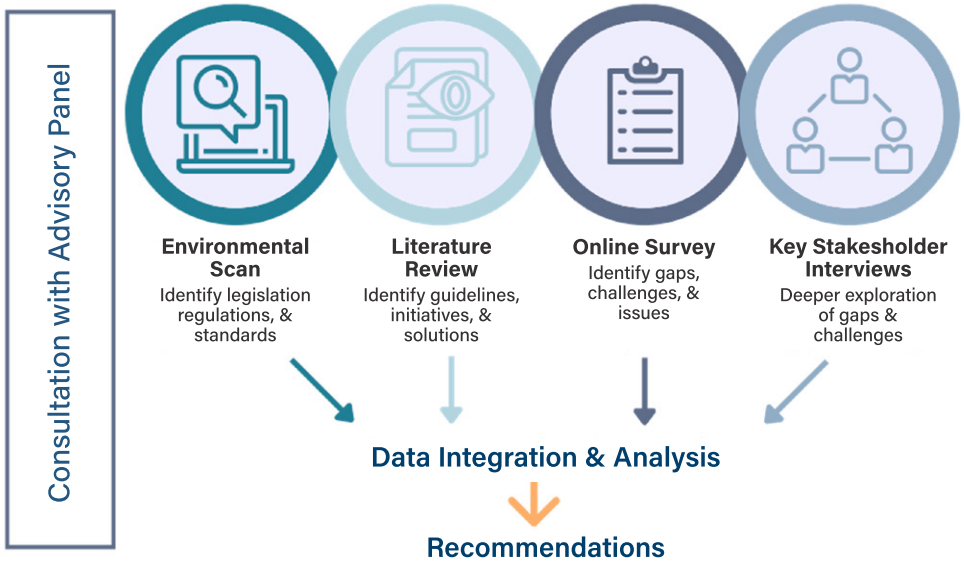
We used a mixed-methods approach using both quantitative and qualitative data to inform key recommendations. The research project consisted of four components (see Figure 1): an environmental scan; a literature review; an online stakeholder survey; and in-depth key stakeholder interviews. Data were collectively analyzed and integrated to inform these recommendations. The Advisory Panel was consulted regularly throughout the research project to provide input and guide the project.

2.1 Environmental Scan

The purpose of the environmental scan was to identify existing provincial, territorial, and/or national legislation, regulations, and standards related to dementia-inclusive home and community care. We aimed to describe: 1) the scope of the legislation and regulations; 2) differences and/or similarities across jurisdictions; and 3) gaps in current legislation and regulations that could be addressed with standards.

To identify pertinent grey literature sources, we conducted an initial search using Google and Canadian e-laws, and combinations of the following keywords: dementia, home care, community care, legislation, regulation, and standards. Location-specific searches were also conducted using the same keywords followed by: Canada, British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, Newfoundland and Labrador, Prince Edward Island, Yukon, Northwest Territories, and Nunavut. International dementia-

Figure 1: Research project components



specific home and community care standards were searched through Google using similar keyword combinations. Date limits were not used for this search since the relevance of the literature was the key criterion for inclusion or exclusion. We also searched national and international standards development organization websites (e.g., Health Standards Organization, Accreditation Canada, Canadian Standards Association, British Standards Institution, International Organization for Standardization) for publications relevant to dementia care in home and community settings.

The identified literature was cross-referenced to select documents that reference legislation and regulations for dementia-inclusive care in the home and community. The analysis included government documents and national, provincial, and territorial policy documents. We reviewed open access articles and copies of standards with permissions from publishers.

2.2 Literature Review

The purpose of the literature review was to identify guidelines, initiatives, solutions, and best practices in dementia-inclusive home and community care implemented in provinces and territories in Canada, as well as internationally. We also sought to identify issues and challenges faced by key stakeholders (e.g., PLWD, care partners, and home and community care providers) in the dementia-inclusive home and community setting.

Two separate searches of academic (i.e., peer-reviewed articles published in journals) and non-academic sources (i.e., grey literature) were performed to target each of the literature review objectives. Academic literature searches were conducted in the Medline, PsycINFO, Embase (through OVID), and CINAHL (Cumulated Index to Nursing and Allied Health Literature) electronic databases. Searches were restricted to English-language literature published in the past five years (2017 to present) to ensure that the most current documents were identified, while providing sufficient coverage of the pre-COVID-19 pandemic period. Terms used in the search were (dementia, Alzheimer) and (home care) and (community care) and (caregiver, family carer, informal caregiver) and (home care nurse, formal caregiver, community care provider, home care worker, aide). These terms were combined with (evidence-based practice, best practice, guideline) and (initiative, program, strategy, intervention, solution) and (framework, model, approach) or (challenges, barriers, difficulties, issues, problems, limitation, obstacles) to address our research objectives.

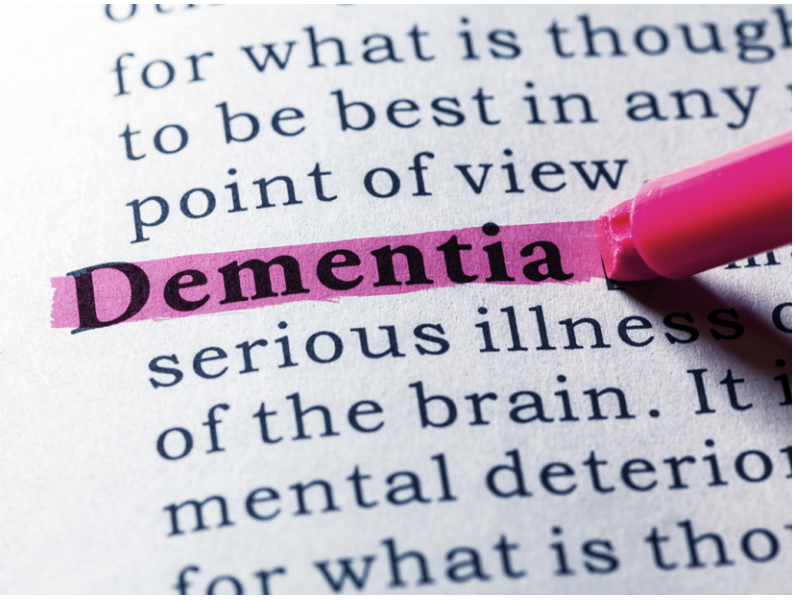
Grey literature was searched using Google with similar keyword combinations as those used for the academic search. We also included searches of provincial and territorial health ministry and department websites, along with key organization websites for relevant research and policy reports (Alzheimer Society of Canada, provincial Alzheimer Societies, Canadian Home Care Association, brainXchange, and World Health Organization). We reviewed organization-level reports on best practice guidelines, as well as documents describing innovative practices and programs across Canada.

Additional database and hand searches were conducted for topic areas that yielded few results: Indigenous, First Nations, 2SLGBTQI+, queer, ethnic, rural, remote, assistive technology, medication management, and COVID-19.

2.3 Survey

The purpose of the survey was to elicit stakeholders' perspectives on existing gaps that could be addressed through national standardized solutions. Additionally, stakeholders were given the opportunity to share guidelines, initiatives, and solutions that could inform standards development and to provide insights into perceived challenges and issues in home and community care. Different versions of the survey were created for each stakeholder group: PLWD, care partners, and home and community care providers (Appendix A). Preliminary results from the literature review and the environmental scan informed the development of survey questions. The survey was piloted with a group of PLWD who provided feedback regarding the content, clarity, and layout of the survey. Recommended modifications were incorporated into the final survey. The survey was administered online, in both English and French, using Qualtrics survey software. Hard copies were available upon request; however, none were requested.

Over 90 associations, organizations, and research centres operating in the home and community care and/or aging fields were contacted and asked to distribute the survey through their networks. Social media channels and paid social media advertisements were also used to assist in recruitment.



"Most legislation and regulations in home and community care do not explicitly reference dementia."

Quantitative data were summarized using descriptive statistics, and qualitative data were examined using content analysis, as appropriate.

2.4 Interviews

Semi-structured interviews were conducted to gain a deeper understanding of gaps in the provision of home and community care for PLWD and their care partners. PLWD, care partners, and home and community care providers were invited to take part in these interviews. An interview guide was developed for each of the stakeholder groups (Appendix B). Preliminary results from the literature review and the environmental scan informed interview question development. Interviews were conducted via Zoom and by telephone. Interviews were audio-recorded and transcribed. All interviews were conducted in English, as no interviews in French were requested.

Interview recruitment was conducted concurrently with survey recruitment through the mechanisms described in Section 2.3, meaning that individuals were invited to participate in both the survey and an interview. Interview transcripts were analyzed using thematic analysis in NVivo qualitative analysis software.

3 Results

3.1 Environmental Scan

The environmental scan indicated that there was a paucity of legislation for dementia-inclusive home and community care at the federal, provincial, and territorial levels of government. Most legislation and regulations in home and community care do not explicitly reference dementia. Our search did not reveal any Canadian regulations for care partners and home and community care providers for PLWD. We sought to identify legislation and regulations that address culturally appropriate delivery of home and community care for PLWD; however, we did not find documents to support the provision of equitable, diverse, and inclusive dementia care. Similarly, we were unable to find any regional or national dementia-inclusive regulations for care providers who work in home and community care settings.

Canada and its provinces and territories are addressing the needs and challenges of dementia-inclusive home and community care by developing dementia-specific strategies. Although each jurisdiction has slightly different objectives, all of the dementia strategies highlight both the need and government support for improving the quality of life of PLWD and their care partners.

In our search for standards addressing this area, we identified national dementia care standards developed by other countries, as well as the ISO Ageing Societies – Framework for Dementia-Inclusive Communities.

There is policy research that describes the need for improvements in the provision of dementia-inclusive home and community care in Canada. Although beyond the scope for the current project, we identified policy papers that describe the challenges and opportunities of implementing legislation and regulations to support and protect PLWD, care partners, and home and community care providers [19, 21-23].

3.1.1 Canadian Legislation and Regulations

Public home care in Canada is not insured as part of the Canada Health Act. Consequently, home and community care services are fragmented as each province and territory has a different strategy for determining eligibility and delivery. Various legislation, policies, orders-in-council, and guidelines direct home care provision in Canada [24] due to jurisdictional differences both in the amount and type of services provided and their models for payment and reimbursement. This approach permits each province and territory to determine how best to serve its population; however, it presents challenges in implementing a pan-Canadian standard for dementia-inclusive home and community care.

Without a national legislative framework for home and community care, the Canadian Home Care Association established the Harmonized Principles for Home Care in 2016. Despite notable differences in the delivery of home care programs across provinces and territories, the Harmonized Principles for Home Care promote equitable access to high-quality home care for all Canadians [25]. These principles are not specific to dementia, but include statements related to providing the fundamentals of home care in Canada. The six statements guide program and policy development to help ensure that evidence-informed care is accessible, accountable, integrated, and sustainable within a person- and family-centred care model.

Dementia-inclusive care in the home and community presents unique challenges to care partners and home and community care providers. PLWD who reside in either their home or a retirement home typically have more diverse and shifting needs that require greater coordination and integration of services, as compared to people without dementia receiving home and community care [11]. The role of the care partner for a PLWD is associated with higher levels of stress, strain, and social isolation, compared with care partners of people without dementia [26].

Ontario is the only province that formally mentions dementia with respect to home and community care service provision (Table 1). The following pieces of legislation in Ontario directly refer to PLWD and their care providers: the Retirement Homes Act (2010) and the Connecting Care Act (2019). Legislation and regulations citing dementia-inclusive home and community care include the requirement for additional training for direct care staff [27], as well as for ensuring public education services and psychogeriatric consulting services related to Alzheimer's disease and related dementias [28]. The legislative foundations for equitable care for those in the home and community care sector are supported by a Patient Bill of Rights within the Connecting Care Act (2019). The Patient Bill of Rights states that the patient has the right to "be dealt with by the provider of the home and community care service in a manner that recognizes the patient's individuality and that is sensitive to and responds to the

Table 1: Sections of Ontario legislation that mention dementia-inclusive home and community care

Retirement Homes Act, 2010.	**Connecting Care Act, 2019.**
Regulation under this Act: 166/11 *Additional training for direct care staff*	Regulation under this Act: 187/22 *Home and Community Care Services*
(5) The licensee shall ensure that all staff who provide care services to residents receive training in the following matters and at the times required by the regulations, as a condition of continuing to have contact with residents, in addition to the other training that they are required to receive under this section: **1.** Abuse recognition and prevention. **2.** Mental health issues, including caring for persons with dementia. **3.** Behaviour management	"community support services" means the following services: **15.** Psychogeriatric consulting services relating to Alzheimer's disease and related dementias. **16.** Public education services relating to Alzheimer's disease and related dementias.

patient's needs and preferences, including preferences based on ethnic, spiritual, linguistic, familial and cultural factors" and "the right to clear and accessible information about their home and community care services." Although this legislation is important for the ethnocultural diversity of Canadians receiving home and community care, it is not specific to PLWD.

3.1.2 Dementia Strategies in Canada

Canada's first national dementia strategy was published in 2019 [29], and updates on the strategy's effectiveness are presented to Parliament by the Minister of Health annually [30, 31]. The strategy has three key objectives: 1) prevent dementia; 2) advance therapies and find a cure; and 3) improve the quality of life of PLWD and their care partners [29]. For the purposes of this report, we describe the focus areas of the third objective, as this aligns closely with the provision of dementia-inclusive home and community care.

There are five areas of focus that can support improving the quality of life of PLWD and their care partners (Objective 3):

1. Eliminate stigma and promote measures that create supportive and safe dementia-inclusive communities;
2. Promote and enable early diagnosis to support planning and action that maximizes quality of life for PLWD and their care partners;
3. Address the importance of access to quality care, from diagnosis through end of life;
4. Build the capacity of care providers, including through improved access to and adoption of evidence-based and culturally appropriate guidelines for standards of care; and
5. Improve support for family/friend care partners, including through access to resources and supports [29].

Although home care is not federally governed, the need for dementia-inclusive home and community care across Canadian jurisdictions is evident. Any approach to providing dementia care in the home and community setting must include a focus on minimizing the stigma associated with dementia by supporting the development of dementia-inclusive communities (Section 3.2.6). Another focus should be to address the importance of access to quality care from diagnosis through to end of life. The availability of dementia-inclusive home care supports and community-based services to Canadians is another important element of helping PLWD live well at home, preventing unnecessary and lengthy hospital admissions and preventing (or delaying) the admission to long-term care. Effective care coordination throughout an individual's journey with dementia is central to ensuring continuity of care. For care partners, care coordination is critical for supporting PLWD to live well in their home and community for as long as possible. This includes supporting the availability of and access to respite services for care partners. Care coordination also plays an important role in understanding when care needs become too complex to manage in the home and more supportive care arrangements are required.

As of fall 2022, several provinces have developed dementia strategies [32-39]. These strategies, while in various stages of implementation [23], symbolize a recognition and intention to improve the quality of life of PLWD and their care partners. The priorities outlined in these strategies aim to inform and guide dementia prevention, treatment, research, and awareness. Provincial and territorial dementia strategy priorities reflect the unique culture, demographics, and geography of each jurisdiction. Nevertheless, the provincial strategies have several commonalities with respect to providing home and community care services, including increasing capacity to provide quality care closer to home through care providers with appropriate knowledge and skills, and supporting care partners (Table 2).

Some jurisdictions, such as Newfoundland and Labrador and New Brunswick, are still in the process of developing dementia strategies. However, some existing healthy aging strategies include actions specific to dementia [40]. For example, New Brunswick's healthy aging strategy includes an initiative that will deliver essential dementia care services in the community by collaborating with community partners such as geriatricians, allied health professionals, the Alzheimer's Society, and service providers. Moreover, this healthy aging strategy aims to support inclusiveness by aligning the age-friendly community initiatives with dementia-friendly community initiatives (Section 3.2.6) to create places where PLWD can remain independent and participate fully in their community for as long as possible.

Table 2: Comparing and contrasting provincial and territorial dementia strategies for priorities related to home and community care

Strategic Priorities and Objectives	BC	AB	SK	MB	ON	QC	NB	NS	NF	PEI	YT	NT	NU	CAN
Support PLWD and care partners to live safely at home for as long as possible	✓	✓	✓	✓	✓	✓		✓	✓					✓
Increase public awareness and early recognition of cognitive changes	✓		✓		✓	✓		✓						✓
Increase system supports, education, and adoption of best practices in dementia care	✓	✓	✓	✓	✓	✓		✓	✓					✓
Expand access to mental health supports for PLWD and care partners		✓			✓				✓					✓
Build capacity to create dementia-friendly communities and/or health care settings		✓		✓				✓						✓
Develop mobile dementia community outreach teams/ services				✓	✓									
Develop and implement a plan for diverse needs groups				✓				✓						✓
Develop community support models for PLWD and care partners			✓	✓										
Develop flexible workplace policies				✓										
Provide ongoing education for PLWD and their care partners			✓	✓		✓		✓	✓					✓
Develop policies to support and recognize the role and commitment of care partners			✓	✓		✓		✓						
Develop care partners supports that are based on the care partner's needs			✓											✓
Ensure improved system navigation for PLWD					✓									

3.1.3 Canadian and International Standards

Canada does not have national standards to inform dementia-inclusive home and community care. However, Accreditation Canada's Home Care Services Standards were developed by the Health Standards Organization to inform the assessment of home care organizations offering clinical and non-clinical services to clients, families, and care partners in the community [41]. The on-site assessment aims to improve the quality, safety, and organizational effectiveness of home care organizations. These standards do not explicitly mention PLWD, care partners, or care providers.

Only one province has standards pertaining to dementia-inclusive care in home and community care. Health Quality Ontario developed Dementia Quality Standards for people living in the community [42]. Ontario's Dementia Quality Standards focus on primary care, specialist care, hospital outpatient services, home care, and community support services. Additionally, they provide guidance on support for care partners of PLWD.

Several provinces, as well as Nunavut and the Northwest Territories, have Continuing Care Standards in place to evaluate home and community care programs, service delivery, and organizational systems against best practice and accountability; however, dementia-inclusive care in home and community settings is not explicitly discussed [43-47].

Countries and regions around the world, including Australia, Scotland, and the United Kingdom, have standards to help PLWD, older adults, and their care partners understand their rights, including how these rights can contribute to ensuring they receive quality care and access to the necessary supports [48-50]. These national standards for dementia care and home and community care help ensure that systems are in place to promote independence and provide comprehensive and personalized services for PLWD and their care partners (see Table 3).

Recognizing the need for a global response to the need for individuals, families, and communities to be more inclusive for PLWD, the ISO developed ISO 25552, an international standard for an interdisciplinary framework to develop a dementia-inclusive community [52]. The standard outlines process elements for the development, implementation, and evaluation of dementia-inclusive communities. It also describes the critical elements of a community and its members that must be considered to empower collaboration among service sectors to develop, mobilize, raise awareness, and sustain a dementia-inclusive environment.

There are also Canadian and International Standards which provide guidance on workplace policies and practices to support care partners who are balancing work with a caring role. CSA B701, *Carer-inclusive and accommodating organizations* was published in 2017 [53] and this Canadian Standard was the basis for the development of ISO 25551, *General requirements and guidelines for carer-inclusive organizations* [54]. While these standards do not focus on specific needs of care partners of PLWD, the general guidance on working caregiver supports could help to inform the development of a Canadian standard on dementia-inclusive home and community care.

3.1.4 Environmental Scan Summary

There are significant gaps in Canadian legislation, regulations, and standards for dementia-inclusive care in the home and community. PLWD, care partners, and home and community care providers are inadequately represented within provincial legislation or regulations. As such, members of and communities with equity-deserving groups are also lacking representation in dementia-inclusive home and community care legislation and regulations. Provinces and territories have distinct priorities that frame dementia-inclusive care to ensure attributes of local culture, demographics, and geography are considered.

This presents an opportunity to develop national standards to help inform, support, and protect all stakeholders involved in the delivery and receipt of dementia-inclusive home and community care. A standard would benefit PLWD and their partners by clearly defining the characteristics of quality of care and services that are the responsibility of home and community care service organizations. For home and community care providers, a standard would help ensure that home and community care service organizations in all jurisdictions have a workforce that has achieved adequate dementia-inclusive education requirements and training. Ultimately, a dementia-inclusive standard for home and community care would foster accountability, promote integrated and coordinated care, and improve navigation of care and services from early to late stages of the disease.

Table 3: Comparison of select elements and guiding principles for the following standards: Australia Aged Care Standard (AUS) [51]; Standards of Care for Dementia in Scotland (SCT) [48]; the United Kingdom (UK) Dementia Quality Standard [49]; Ontario Dementia Quality Standards (ON) [42]; and the International Organization for Standardization (ISO) Ageing Societies Framework for Dementia-Inclusive Communities [52]

Elements and Guiding Principles in Certain Sections of Various Standards	AUS	SCT	UK	ON	ISO
PLWD are treated with dignity, respect, and choice; care includes culturally safe care and services	✓	✓			✓
Information, education, and training that is current, accurate, and timely is accessible and readily provided to PLWD and their care partners	✓	✓		✓	✓
Care and services for PLWD are reviewed regularly for effectiveness	✓	✓		✓	
Effective management of high-impact or high-prevalence risks associated with the care of PLWD	✓				✓
Timely and appropriate referrals to individuals, other organizations, and providers	✓	✓		✓	✓
PLWD get safe and effective services and supports for daily living that meet their needs, goals, and preferences, and that optimize their independence, health, well-being, and quality of life	✓	✓	✓		✓
Services and supports for daily living promote emotional, spiritual, and psychological well-being for PLWD and their care partners	✓				✓
Services and supports for daily living assist PLWD to participate in their community, have social and personal relationships, and do the things of interest to them	✓	✓	✓	✓	✓
PLWD have the right to care partners and providers who are supported and educated about dementia		✓	✓	✓	✓
PLWD have the right to advance care planning and end-of-life care that respects their wishes		✓	✓		✓
PLWD have a named practitioner who serves as a main point of contact and coordinates their care			✓	✓	
PLWD have structured assessments before starting non-pharmacological treatments for distress			✓		
PLWD have individualized care plans developed by and together with the PLWD and their care partners				✓	
Built environment, activities, and services should be accessible for PLWD and their care partners					✓
Workplaces should foster inclusion of PLWD and their care partners					✓



"Research suggests that both person- and family-centred care, as well as interdisciplinary team-based primary health care, are considered best practices for dementia-inclusive home and community care."

To inform the development of a Canadian standard, the core principles of the Australian aged care standards [51], as well as the ISO 25552, Framework for Dementia-Inclusive Communities [52], could be reviewed and adapted to the Canadian health care landscape and the needs of Canadian stakeholders. For instance, core tenets of the Australian and ISO 25552 include providing appropriate clinical care and personal care services, person-centred support, dignity, and autonomy for care recipients; reducing stigma; and managing staff and their competencies to reflect the diverse needs, abilities, preferences, and lived experiences of the care recipients.

3.2 Literature Review

The literature review showed that Canada's best practices for dementia-inclusive home and community care are based on a foundation of evidence that is not exclusively based on the needs of PLWD and their care partners. Research suggests that both person- and family-centred care, as well as interdisciplinary team-based primary health care, are considered best practices for dementia-inclusive home and community care. Canada's best practices for medication management are informed by each jurisdiction's legislation, regulatory bodies for health care professionals, and employer policies. Innovative models of dementia care (e.g., Eden Alternative, Butterfly Care) are emerging; however, they were designed to transform the dementia-inclusive care for long-term care residents, rather than PLWD receiving home and community care. These innovative dementia care models share several meaningful attributes that can be adopted and applied to improving the delivery of home and community care for PLWD. Examples include focusing on lifestyle preferences and promoting autonomy for PLWD, as well as providing specialized training for care providers to encourage relational care. We found that uptake of innovative dementia care models in Canada is slow and there is a paucity of research related to the effect of these care models on PLWD. The body of research related to assistive technology for dementia-inclusive home and community care suggests that there is interest in and opportunity for continued innovation to develop products that address the specific needs and experiences for PLWD, care partners, and home and community care providers.

The literature search revealed that PLWD, care partners, and home and community care providers all have distinct needs and challenges in the context of dementia-inclusive home and community care. Emerging research about dementia in groups facing barriers to equitable care, such as members of Indigenous and 2LGBTQIA+ communities, indicates that they have unique experiences that frame their needs for receiving dementia-inclusive home and community care. Finally, we found evidence that describes the burden of the COVID-19 pandemic on PLWD, care partners, and home and community care providers. Challenges specific to the COVID-19 pandemic included long periods of isolation that disrupted daily routines and increased responsive behaviours for PLWD, issues for care partners related to navigating available home and community care supports, and difficulties related to maintaining a safe work environment for home and community care providers.

3.2.1 Best Practices in Dementia-Inclusive Home and Community Care

Canada boasts a breadth of research and emerging best practices in dementia-inclusive home and community care. As best practices evolve based on available evidence and ongoing expert perspectives and experience, they must be translated to accommodate practical and effective mobilization in home and community care settings across the country. Given the immense diversity in people, culture, and geography of Canada, the implementation of the following best practices must be tailored to meet local needs and values.

Person- and family-centred care: Person-centred care is a tailored, comprehensive approach that focuses on the care recipient, rather than their diagnosis. In the context of dementia, the practice underscores a continually evolving relationship between PLWD and their care providers, where the provision of care is based on individual needs, preferences, and engagement in the care process. Family-centred care, also referred to as relationship-centred care, is considered an extension of person-centred care, whereby the needs of the person being cared for are extended to their family or loved ones, as well as their health and social providers [55]. The Registered Nurses Association of Ontario Clinical Best Practice Guideline for Person- and Family-Centred Care consists of 15 practice recommendations that include engaging with PLWD in a participatory model of decision making and obtaining feedback from PLWD to determine their satisfaction with care and whether it was person- and family-centred [56]. The goal of dementia-inclusive home and community care in Canada is to be person-centred [57].

Interdisciplinary team-based primary health care: Interdisciplinary team-based primary health care is a collaborative strategy that designates primary health care teams as hubs for coordinating all aspects of prevention, diagnosis, treatment, and coordination of care for PLWD. This collaborative approach has been identified as a best practice to delivering dementia care [58, 59]. In some cases, the primary care teams, together with specialists (e.g., geriatricians, neurologists) and community-based services, provide personalized and coordinated services through a nurse navigator who forms a close and ongoing relationship with the care recipient and their care partner. Operationally, the common elements associated with team-based care are clear roles for all team members, working together as a team toward a common goal, strong understanding of team members' roles and expertise, shared decision-making processes, and established information-sharing procedures [60-62]. Across Ontario, and among a few sites in British Columbia, Alberta, and Saskatchewan, interdisciplinary team-based primary health care for PLWD is supported by memory clinics. For example, MINT® Memory Clinics provide comprehensive assessments and quality dementia care to patients using an interdisciplinary team of physicians, allied health care professionals with training in dementia, and Alzheimer Society team members [63]. The care model integrates community services with primary care to improve care coordination and access to information about education and community support services [64].

Best practices in dementia-inclusive health and social care are supported by evidence-informed care and home and community-based care. Evidence-informed care is an approach grounded in the diagnosis and management of dementia using current and comprehensive practice guidelines. These practice guidelines inform clinical care for PLWD, as well as health care provider training for optimal treatment of PLWD. In addition, dementia strategies serve as the platforms for developing action plans that highlight evidence-informed approaches to improve the quality of dementia care [29].

Home and community-based care is the provision and coordination of services that provide the appropriate support for the diverse needs of PLWD to continue to live at home. In this context, home may include a retirement home with supports in place; however, PLWD may require additional supports through home and community care. This practice often relies on the availability of a care partner, care coordination, peer support, and technology [57]. Central to the practice is typically a case manager or care navigator who is anchored in primary care and whose role it is to integrate health and social care with the available community services. The case-management approach

to assessment, planning, and facilitation of care relies on a small caseload, regular follow-up, and transparent communication with the PLWD and their family [65]. Peer support, specifically in the form of dementia-friendly communities (Section 3.2.6), provides the opportunity for PLWD and their care partners to belong to a group that understands experiences, shares feelings, and can provide information about coping with dementia.

Most dementia-inclusive home and community care in Canada supports the best practices and care approaches described above. For example, the Alzheimer Society's First Link® Dementia referral program provides support, information, and education for PLWD and their care partners as soon as a dementia diagnosis occurs. First Link® was launched in 2007 and is regarded as an innovative program that enhances linkages between the Alzheimer Society and diagnosing primary care physicians and other health care providers (e.g., allied health professionals), diagnostic and treatment services, and community service providers, and also improves coordination of care and linkages to community services for non-medical management issues from the time of diagnosis [66].

3.2.2 Best Practices in Medication Management

Medication management is client-centred care that optimizes safety, effectiveness, and appropriate drug therapy that is provided in collaboration with clients and other health care teams. Among home and community care providers, best practices in medication management are defined by federal and provincial legislation for specified health professionals and informed by the standard Medication Management for Community-Based Organizations [67], employer policies, and each jurisdiction's health care professional regulatory bodies' practice guidelines, directives, and standards for medication management.

Compared to acute care and long-term care settings, certain aspects of medication management in the home and community add complexity. Examples include, but are not limited to, many medications having similar names and labels that are difficult to distinguish from one another; the same medication being manufactured by different firms in different shapes, colours, and sizes; the fact that the way to make up missed doses varies by medication and is complicated when taking multiple medications; and the fact that some medications can become damaged if stored improperly [24].

Although not specific to PLWD, best practices in medication management in the home and community care setting are in place to ensure that clients receive safe and appropriate treatment, understand their medications and the importance of taking them as ordered, store medications safely, and identify possible side effects related to taking other medications or supplements. For home and community care providers with medication management within their scope of practice, best practices support all stages of medication practices from prescription, selection, preparation, and handing out medication, to taking the medication and evaluating client medication management activities.

Among PLWD receiving home and community care, research suggests that avoiding medication errors and maximizing medication adherence requires that care partners and home and community care providers pay special attention to factors affecting PLWD [68]. For example, as cognitive abilities decline, PLWD are less likely to remember to take their medications and may become less able to open and close some medication packaging. As memory and dexterity decline, some PLWD will develop coping strategies, such as relying on administration aids (e.g., blister packs) that provide standardized packaging to assist in organizing medication dose, timing, and frequency [69]. Yet as dementia progresses, so too does the complexities of managing medications due to polypharmacy (i.e., taking five or more medications) and the increasing likelihood of medication avoidance behaviours among PLWD [70]. The challenges related to medication management with dementia progression, as reported by care partners, is described in Section 3.2.8.2.

3.2.3 Innovative Models of Care for PLWD

Culture shifts in dementia care are evidenced by the emergence of innovative models for dementia care. Due to a number of complex factors that are beyond the scope of this report, the implementation of

innovative care models is slow, yet it is emerging, in select long-term care homes across the country. As a result of slow implementation at only a few sites, long wait lists for the homes that have adopted innovative models of care for PLWD are a significant barrier for PLWD accessing innovative dementia care [71]. While the following models were intended to transform the culture of dementia care for long-term care residents, they have several meaningful attributes that can be adopted and applied to improving the delivery of home and community care for PLWD. The models share several commonalities, yet there are distinguishing features that characterize each as unique (Table 4).

The Eden Alternative is a model centred around preventing the "plagues of loneliness, helplessness, and boredom" [72, 73]. To alleviate those feelings, this model focuses on providing (human and animal) companionship to PLWD, enabling PLWD to give (rather than only receive) care within the community, and creating an environment that encourages spontaneous events and interactions. The Eden Alternative supports PLWD to participate in meaningful activities. Medical care is guided by genuine caring and is informed by shared decision making with the PLWD and/or their care partner.

The Green House Project is a small-scale residential care model that stresses the importance of seeing PLWD as a whole person rather than as a medical label [74, 75]. The model creates a real home environment and aims to enable a meaningful life for PLWD based on individual needs and abilities. The nursing staff at Green House locations provide housekeeping, meal preparation, and personal care for PLWD [74]. Green House locations feature private bedrooms with communal living spaces where PLWD can enjoy flexible routines without medicalized equipment or personnel in their surroundings.

Table 4: Comparing and contrasting attributes of innovative models of care for PLWD

Attributes	Eden Alternative	Green House Project	Butterfly Care	Dementia Villages
Focus on person-centred care	✓	✓	✓	✓
Enables PLWD to give and receive care	✓			
Engagement in meaningful activities for PLWD	✓	✓	✓	✓
Flexible daily routines that promote autonomy for PLWD	✓	✓	✓	✓
Specialized training for care providers to promote teamwork and relational care	✓	✓	✓	✓
Medical personnel wear plain clothes and perform non-medical tasks		✓	✓	✓
Non-institutional, home-like environment	✓	✓	✓	✓
Features a village area			✓	✓
Communal living spaces		✓		
Outdoor areas accessible	✓	✓		✓
Linked to the local community		✓		

Butterfly Care (Dementia Care Matters) is based on the concept that "feelings matter most." The model promotes the incorporation of bright, home-like environments where a PLWD reside with 10 to 12 persons with a similar level of dementia [76, 77]. PLWD are encouraged to connect with the activities they enjoyed before their dementia diagnosis. The care for PLWD is provided in an environment free of institutional signs by staff who are trained to focus on recognizing the individuality and emotions of PLWD. Staff create family-like relationships with PLWD and are primarily tasked with being present on the emotional journey as they enable PLWD to engage in meaningful activities instead of being a spectator.

Dementia Villages (also referred to as the Hogeweyk Care Concept) were developed in the Netherlands and aim to create an environment whereby persons living with advanced-stage dementia can live an ordinary life, as much as possible, by creating surroundings that closely resemble familiar home and community spaces [78]. Dementia Villages consist of smaller congregate settings of up to seven residents per house, and provide PLWD with the freedom to choose a home designed according to their lifestyle, interests, and backgrounds. These personalized living environments create and foster social relationships, as well as participation in meaningful activities. Support from plain-clothed trained professional staff and volunteers is provided in a manner that promotes normalcy and minimizes the medicalization of care.

3.2.4 Adopting Innovative Dementia Care Models to Home and Community Settings

Home settings already have the benefit of being familiar, comfortable, and navigable. However, PLWD receiving home and community care could benefit from adopting aspects of these innovative dementia care models intended for long-term care settings. First, dementia-inclusive home and community care would be improved by honouring the personal preferences of PLWD with respect to daily routine, participation in meaningful activities, lifestyle and cultural background, and care needs. To improve the quality of life of PLWD, adoption of these personal preferences in home and community care may include allowing the care recipient to select the types of services provided on certain days and at specific times. The care providers could also spend more time being engaged with the care recipient, beyond a personal care context, to facilitate involvement in meaningful activities around the home and garden. Next, dementia-inclusive home and community care could benefit from offering and ensuring that all direct care providers receive education and training on the aspects and trajectory of dementia care, roles of care partners, facets of culturally appropriate care, and the role of emotional intelligence in caring for PLWD. Part of this education should include understanding the effect of an "us versus them" culture of care and how to minimize that divide to improve the quality of life of PLWD, increase staff and family satisfaction with the care provided, and strengthen the relationships and trust between care providers and care recipients.

3.2.5 Assistive Technology for Dementia-Inclusive Home and Community Care

Growing awareness of, interest in, and positive attitudes toward the role of assistive technologies to improve the health and social wellness for PLWD and their care partners indicates a significant potential for assistive technologies to enable dementia-inclusive home and community care [2, 57, 79]. Examples of assistive technologies that present opportunities for continued innovation include products related to remote home monitoring, tracking, care coordination, communication, and medication management [2, 57]. Many of the assistive technologies that help PLWD to age safely at home and receive appropriate home and community care supports also provide benefits to care partners. For instance, care partners reported improved family engagement and lower stress levels when the PLWD who they care for used tracking and networking technologies [80, 81].

The COVID-19 pandemic accelerated the adoption of technology across all sectors, and home and community care for PLWD is no exception. As an example, telehealth services became increasingly common replacements for in-person health and wellness appointments. Telehealth services, like other assistive technologies available for PLWD, were not designed specifically for PLWD. As such, the specific needs and experiences of PLWD have not been

integrated with design and functionality features. Instead, mainstream technologies (e.g., smart phones, webcams) have been adapted for PLWD to align more closely with their needs and capabilities [57]. Nevertheless, dementia-inclusive assistive technologies are emerging. One promising example is Winterlight Labs' tablet-based assessment of speech and tone that can detect progression in cognitive impairment. This type of assessment may become an important way for home and community care providers to determine changing needs.

One of the biggest obstacles in developing assistive technologies for dementia-inclusive home and community care is designing products that reflect the changing needs and abilities of PLWD [2]. However, as greater end-user involvement is required for technology research and development, it is anticipated that acceptance and usability of the technologies will similarly increase. Other challenges include cost-effectiveness and ethical dilemmas associated with widespread implementation of assistive technologies for PLWD in home and community care [2]. Examples of ethical dilemmas include autonomy and risk versus privacy reduction, challenges in obtaining informed consent at later stages of dementia, or when the role of technology is not understood. Future endeavours related to assistive technology and dementia-inclusive home and community care should focus on availability for low-income families, as well as the sustainability and ethical use of technologies for PLWD, care partners, and home and community care providers.

3.2.6 Dementia-Friendly Communities

The World Health Organization (WHO) identified that public health campaigns can play an important role in reducing the stigma associated with dementia [82]. By reducing the stigma associated with the disease, PLWD, their families, and care partners feel more supported, accepted, and meaningfully involved in their community. Dementia-inclusive home and community care situated within dementia-friendly communities is one way to promote inclusiveness, respect, and involvement for PLWD. According to the WHO, dementia-inclusive societies are ones where PLWD and their care partners have a place and can fully participate in society.

To promote the creation of dementia-inclusive communities, the WHO developed a Dementia Toolkit that helps users understand dementia and helps communities navigate the implementation and evaluation processes [3]. The WHO Dementia Toolkit consists of four modules that apply a rights-based and person-centred framework to conceive, implement, and evaluate dementia-inclusiveness. The key principles addressed include: 1) addressing stigma associated with dementia; 2) meaningful participation of PLWD; 3) collaboration of multiple sectors, key partners, and levels of government; 4) coordination of a team in implementing, integrating, evaluating, and/or scaling; and 5) sustainability for lasting impact over time. The Toolkit is intended to be a practical guide to navigating discussions with community members and working toward building a dementia-inclusive society.

Canadian Dementia-Friendly Community Initiatives

In 2019, as part of the Dementia Community Investment, the Public Health Agency of Canada provided funding to the Alzheimer Society of Canada to support a four-year "Dementia Friendly Canada" project. The intent was to build on the success of provincial dementia-friendly initiatives to extend impact at the national level. The project involves four provinces (BC, SK, MB, and ON) and aims to achieve three main objectives:

1. Train Canada's workforce to be dementia-friendly.
2. Promote and educate the general public about dementia through awareness campaigns and resources.
3. Achieve sustainability and ensure growth of the Dementia-Friendly Canada initiative across the country.

Examples of specific resources created through the Dementia-Friendly Canada initiative include tip sheets, videos, and online education courses that provide individuals, as well as community businesses and organizations, with foundational knowledge about dementia and approaches for promoting dementia awareness, education, and communication. Specific examples of how to promote dementia-friendly principles in the community include reaching out to

PLWD and their care partners to offer support, challenging myths and misconceptions about dementia to reduce stigma, incorporating PLWD and their care partners in addressing community efforts, and using dementia-friendly language [83].

Another example of a Canadian dementia-friendly initiative is the Blue Umbrella program [84]. This program allows businesses to place a blue umbrella symbol in their window to signal that their business provides dementia-friendly service. Although the type of training received by staff differs by business type, the overarching goal of the program is to create an inviting environment for PLWD and their care partners.

An example of a Canadian resource to guide municipalities is the *Guide for Creating Dementia Friendly Communities in Alberta* [85]. This resource is the culmination of a pilot project to develop dementia-friendly communities in Calgary Westhills and Okotoks, Alberta. Funded by a partnership between the Government of Alberta, Alberta Innovates and Alberta Health Services, and The Brenda Strafford Foundation, the guide outlines a phased process for identifying and meeting the unique needs of a community as they create a dementia-friendly community. The guide includes recommended steps, helpful tips, case studies, and resources to guide stakeholders through the process. It provides step-by-step recommendations for communities interested in becoming dementia-friendly, from the initial phase of understanding the current state of the community and its readiness to change to the final phase of how to ensure the project leaves a legacy in the community.

3.2.7 Care Approaches for Older Adults, Non-Specific to Dementia

Integrated model of community care: Integrated models of home and community care are gaining momentum across Canada, as they support primary care and acute care with a network of community services using a case management approach [86]. Examples include Home First (ON), Home Again (NS), and Home is Best (BC). Each model is designed for patients transitioning from acute care hospitals to their home and provides the necessary community supports for them to maintain an appropriate level of care in the comfort of their own home. An integrated model for dementia care would include early detection and diagnosis, promotion of a self-management approach and care partner support, coordinated pathways of support in the community, and system navigation to ensure PLWD and their care partners know where to find relevant information.

Chronic disease prevention and management: This practice relies on interactions between informed patients and prepared, proactive practice teams [87]. Applied to dementia care, integration of the chronic disease prevention and management practice would provide PLWD with multi-faceted, planned, and coordinated care that facilitates access to the appropriate provider at the right time.

Inclusive care for 2SLGBTQI+ older adults: *Leading & Learning with Pride: A revitalized toolkit on supporting 2SLGBTQI+ Seniors* [87] is a comprehensive resource that should be considered as best practice for reducing stigma, as well as building capacity, skills, and knowledge to improve the lives of 2SLGTBQI+ older adults. The toolkit provides a context, or framework, to promote respectful, inclusive, and affirming care to 2SLGTBQI+ older adults across the care continuum. Implementation of the toolkit as part of best practice in dementia-inclusive home and community care would benefit from contextualization with *Coming out and coming in to living with dementia* [88], which is an extensive research report with e-learning modules based on in-depth conversations with 2SLGTBQI+ community members living with dementia, care partners of 2SLGTBQI+ PLWD, and community care provider stakeholders. Together, these resources are powerful tools to educate Canadians on dementia-inclusive home and community care based on the unique needs of 2SLGBTQI+ communities.

3.2.8 Needs and Challenges in Dementia-Inclusive Home and Community Care

Highlighting the needs and challenges in dementia-inclusive home and community care faced by various stakeholder groups affords an opportunity to support and empower PLWD, care partners, and home and community care providers.



"As a disease associated with advancing age, dementia care is often entangled within complex care requirements associated with age-related comorbidities."

3.2.8.1 Persons Living with Dementia

PLWD face a gradual loss of function, cognition, and independence, with the increasing severity of their dementia symptoms. The need for additional care for PLWD over time is inevitable, and the fluidity of the disease profoundly impacts when appropriate home and community care supports are required. The needs and challenges of PLWD are different from the needs of care recipients with other chronic diseases. For instance, PLWD face challenges from the stigma associated with living with dementia. Despite being a heterogenous group, many PLWD are stereotyped as a highly vulnerable group of people who are near the final stages of their life; while, in reality, these same individuals may be in the early onset or mild stages of disease progression and often have long lives ahead of them [89].

As a disease associated with advancing age, dementia care is often entangled within complex care requirements associated with age-related comorbidities [90]. PLWD experience challenges in accessing and navigating the information related to health care and social services available in their community [91]. Long wait lists and the need to "fight" to access care are noted as an additional layer of complexity and a deterrent to reaching out and accessing community care programs and services [92].

These needs and challenges are far-reaching. Together, they negatively impact the day-to-day experiences of PLWD navigating their communities and arranging timely access to appropriate health and social care.

The challenges discussed transcend geographic regions, as well as community and socio-demographic characteristics. Given the above-mentioned challenges facing PLWD, there is a need for dementia-inclusive communities that include comprehensive public awareness campaigns to diminish stigma and support PLWD as active members of society. According to the ISO Standard for Ageing Societies Dementia-Inclusive Communities, PLWD should be afforded the opportunity to be actively involved in planning, making decisions, and evaluating processes in their communities [52]. By doing so, PLWD and their care partners feel empowered, included, and supported. Slightly modified communication strategies can also enhance the experience of PLWD navigating their communities [85]. For instance, approaching PLWD from the front in a friendly and open manner and avoiding speaking until you have the person's attention. Lastly, to encourage active participation in community programs, PLWD require timely notice about available supports, as well as viable transportation options for themselves and their care partners. Communities can support public transportation options for PLWD by assessing sensory and cognitive accessibility in the community. This includes the built environment, as well as technological navigation supports [85].

3.2.8.2 Care Partners

Care partners of PLWD face greater challenges than those reported by care partners for persons living with other diseases [30, 49]. In providing daily care to a PLWD, care partners' responsibilities may include

taking on tasks that were once completed by the PLWD, including housekeeping, shopping, managing finances, helping with essential daily activities, managing medications, and overseeing other health care needs.

Tasks related to medication management are complex due to the greater number of comorbid conditions among PLWD compared to persons living at home without dementia [93]. Medication management performed by care partners includes administering medications, keeping track of medication supply, and managing medication side effects [94]. Specific challenges associated with medication management by care partners for PLWD include difficulty monitoring medication adherence, identifying early signs of common concerns (i.e., bladder infection), and dealing with the paranoia or suspicion about medications that PLWD may exhibit [93-97]. Often citing a lack of training and education related to medical/nursing tasks, many care partners report emotional distress, such as anxiety, worrying, and sleep disturbances associated with medication management for PLWD [93, 96]. Canadian jurisdictions have varying access to dementia-inclusive home care specialists who can assist with medication management for complex dementia cases [98]. The lack of support for dementia-inclusive medication management for care partners of PLWD is noted as a tremendous hurdle, especially as dementia progresses and PLWD experience greater cognitive challenges, behavioural changes, and increasingly complicated medication regimens [69, 94, 96].

Care partners of PLWD experience challenges related to navigating the fragmented health and social care system and coordinating their services with unclear eligibility criteria [47, 99]. Once appropriate home and community care services are identified, many care partners express concerns over long wait lists, which preclude access to support at the appropriate time [99, 100]. Often care partners are notified of service availability once the care recipient's needs have changed and the resources are no longer relevant. Given that the role of caring for a PLWD often occurs unexpectedly, there is a need for educational resources about providing care for a PLWD, the dementia disease trajectory, caring for older adults, and self-care [101].

Resources to help care partners with care provision were mentioned in the context of home care provider time constraints, which lead to insufficient quality of relational care, inconsistent care provision arising from care coordination difficulties, and lack of access to interdisciplinary teams [29].

In light of the above-mentioned challenges, care partners require timely access to credible information about dementia programs and how to navigate the system. They often feel like the managers of dementia care and want information on the kinds of support and programs that are available within their community [57]. More support hours and flexible support hours for home care are needed and should include evenings, weekends, and overnight [97, 102, 103]. Care partners specifically expressed a desire for:

- More follow-up by health care providers to ensure that the services are appropriate for the PLWD's stage of disease and that anticipatory needs are discussed to understand next stage of care and support needs;
- More support for medication management;
- Recognition by care providers and agencies about their integral role/contribution and its implication on all aspects of their lives;
- Increased support in the form of incentives (i.e., tax credits) to become a care partner and to relieve financial strain associated with caring; and
- Workplace policies that acknowledge and accommodate the various needs of care partners [69, 88, 104-106].

3.2.8.3 Home and Community Care Providers

Personal support workers (PSWs), also referred to as continuing care aides in Nova Scotia, are the most common care providers working in the home and community care sector [107, 108]. They generally report low wages and limited employment benefits [23]. As a result, retaining care providers in the home and community care sector is difficult, and those who are retained often work more than one job to ensure income stability. Although many common issues face care providers, those working in dementia-inclusive home and community care face a unique set of challenges.

Home and community care providers of PLWD report insufficient training in seniors' health and the dementia care trajectory. They find it difficult to navigate the complex and evolving care needs of PLWD without educational resources and training opportunities to gain knowledge and skills in seniors' health and dementia [109]. Care providers report that a lack of national standards, programs, and exams affects the quality of complex dementia care they can provide in home and community settings [109].

The key needs of care providers that emerge from the literature were access to and information about awareness programs, mental health training, and education, as well as cultural competency training [100]. They describe the increasing diversity of PLWD as a challenge for person-centred care because providing culturally safe and appropriate care requires access to information, tools, training, and professional resources [97].

Care providers describe challenges in delivering quality care to PLWD due to insufficient time and the need to provide more hours of care per care recipient to ensure greater quality of and relational care to PLWD [56, 91, 110]. PLWD may also exhibit responsive behaviours, which threaten the safety of home and community care providers. Since the majority of home and community care providers are older women [18], there is concern about exposure to physical violence when visiting the homes of PLWD who are experiencing behavioural changes [111]. Despite the elevated risk of harassment and/or violence from PLWD with complex and responsive behaviours compared to other home and community care clients, there are no mental health supports in place for home and community care providers [112].

3.2.9 Needs and Challenges of Individuals and Groups Facing Barriers to Equitable Care

PLWD and their care partners are not a homogenous group. Rather, they represent diverse cultures and ethnicities, identify with various sexual orientations and gender identities, and reside in varied geographies. In addition to the needs and challenges described in Section 3.2.8, the following individuals and communities have unique needs and challenges in accessing equitable dementia-inclusive home and community care.

3.2.9.1 Considerations for Indigenous Communities

The prevalence of dementia among Indigenous peoples is not well characterized because there are challenges in obtaining reliable epidemiological data on this population [113]. However, one study in Alberta found that the prevalence of dementia is 34% higher among First Nations populations and that this rate is increasing more quickly when compared to the general population [114]. Important cultural influences frame some of the challenges for dementia-inclusive home and community care for Indigenous communities [100]. One key aspect of Indigenous culture is their perception of dementia as a natural part of an individual's life course [115]. Given this perspective, medical intervention is often not considered necessary. Another element that is a barrier to members of Indigenous communities is the deep-rooted colonial trauma that may impede their trust in medicalized western approaches to care [115].

Geographic isolation also presents challenges to dementia-inclusive home and community care for Indigenous communities. For instance, social challenges associated with younger Indigenous peoples moving far away from their community to seek education and/or work opportunities presents challenges to their Elders who remain in the community and require a care partner [116]. Nevertheless, Indigenous peoples residing in urban and rural environments express similar needs. Indigenous PLWD and their care partners desire more access to support hours and support offerings from home and community care providers. They express a need for in-home respite care on reserve that is both accessible and adequate [105].

Given their rich culture, beliefs, traditions, and differences in perspectives on aging and dementia, many Indigenous individuals and communities describe a need for culturally appropriate programs, practices, and service delivery to ensure preservation of familiar and meaningful activities [100, 105]. They express a need and desire for a stable and skilled workforce that has received appropriate and ongoing education related to cultural safety that acknowledges the colonial history that impacts present-day health care delivery, power dynamics, and imbalances [105, 117]. In alignment with their beliefs and historical context, it may be necessary

to consider developing an Indigenous model of dementia-inclusive home and community care that more closely aligns with and respects their community needs, values, and cultural preferences.

3.2.9.2 Considerations for Ethnic and Cultural Communities

Diversity in cultures, populations, and languages necessitates that evidence-informed services and resources be available in more than one format. Many members of ethnic and cultural communities have difficulty finding the right information about available home and community care services and programs [118]. There is insufficient information sharing in languages other than English. For example, language barriers emerge when PLWD and their care partners express difficulty communicating with home and community care providers [118, 119]. Care partners and families with limited English proficiency also report being frustrated by limited outreach and information sharing in languages other than English; this results in a lack of knowledge about available health and social supports in the community [118]. As it is common for PLWD to revert to their first language, this can result in an additional burden for the care partner who takes on the role of translator and is often required to be present for interpretation when a home and community care provider is present [119]. Cultural barriers to receiving quality care include limited availability and long wait lists for ethnic community care programs and services [118].

3.2.9.3 Considerations for 2SLGBTQI+ Communities

For those PLWD who identify as members of 2SLGBTQI+ communities, one of the most important needs is access to service providers who offer care and support in an inclusive, understanding, and non-judgmental manner. As part of this inclusive care, 2SLGBTQI+ PLWD describe the need for care providers and support networks to understand that an individual's sexual orientation and gender identity can be fluid and can change over time, just as their dementia will progress over time [88]. Care partners to 2SLGBTQI+ PLWD express a need for support groups that are open to any person in a caring relationship with 2SLGBTQI+ PLWD [88]. Importantly, there is a need for members of support groups and the larger dementia community to recognize that caring relationships go beyond spousal or parental relations.

3.2.9.4 Considerations for Rural and Remote Communities

PLWD and their care partners living in rural and remote communities face unique challenges in locating and accessing dementia-inclusive home and community care services due to limited availability and inconsistent provision of services [110, 120]. Further, PLWD and their care partners in rural and remote communities tend to wait longer to seek home and community care due to limited individual anonymity, which increases the potential for stigmatization in the community [56]. Care partners in rural and remote communities also express a need for more hours and flexibility of home and community care support services, such as evening, weekend, and overnight nursing and respite services [57, 120, 121]. The need for more flexibility in home and community care arises from adult children, family members, and peers living in other communities [57]. Assistive technology may reduce the burden and stress of rural and remote care partners for PLWD, but the benefits rely on implementation success and uptake, affordability of such platforms, and the availability of suitable network connectivity [122, 123]. Finally, PLWD and their care partners who live in rural and remote communities and who are also members of equity-deserving groups, such as those who are 2SLGBTQI+ and/or ethnic minorities, indicate a need for establishing community support groups that reflect their identities, cultures, and the unique experiences of living with dementia [88].

3.2.10 Effect of the COVID-19 Pandemic

The COVID-19 pandemic placed an unprecedented burden on PLWD, care partners, and home and community care providers [124]. A culmination of factors, including older age, frailty, and health conditions often associated with dementia, increased the risk for complications from COVID-19 among PLWD. Accordingly, Canadian public health guidelines urged older adults, including PLWD, to avoid leaving their place of residence. Public health messaging invoked fear, anxiety, and agitation among many PLWD, and without clear messaging about being able to safely

return to visiting public spaces as restrictions were lifted, many PLWD continue to be fearful about leaving their homes [125-127].

Public health measures implemented to prevent the spread of COVID-19 resulted in limited and/or terminated access to home care, day programs, meal programs, and other health and social supports. The disruption in usual programming was particularly challenging for PLWD because this resulted in a loss of familiar and meaningful routines [128]. The service disruptions and program cancellations for PLWD further increased the incidence of care partner fatigue and symptoms of burnout because they also experienced an erosion of formal and informal care partner supports, such as respite [128]. The COVID-19 pandemic shutdowns resulted in added stress for care partners because they were essentially left alone to provide care at home. As sole care partners for PLWD, stress stemmed from difficulty recruiting formal/paid help and issues with learning how to manage complex day-to-day personal care tasks (e.g., incontinence issues, medication management, feeding, bathing) without care providers [129].

The COVID-19 pandemic forced medical appointments and home care assessments to transition from in-person to video-conferencing formats. Care partners report fewer opportunities to have frank one-on-one discussions with the physician and expressed concern that body language and non-verbal communication could not be adequately interpreted [130]. Fears about entering public spaces led to general anxiety among care partners about needing to leave the house. Challenges related to navigating public spaces with a PLWD during the COVID-19 pandemic include following public health directives, such as social distancing and mask wearing, which were not always understood by the PLWD [128, 130]. The challenges of caring for PLWD were further compounded during the pandemic by the continually shifting COVID-19 public health guidelines and restrictions. Receiving home and community care became increasingly difficult to navigate due to decisions about care providers entering the home. Knowing that the home and community care staff enter several homes per day, PLWD and their care partners had to determine their level of comfort in terms of the number and frequency of home care visits [128].

Home and community care, particularly personal care service provision for PLWD, was adversely affected by the COVID-19 pandemic [131]. For home and community care organizations, the COVID-19 pandemic exacerbated understaffing of trained home and community care providers (e.g., PSWs, continuing care aides). As front-line staff during the COVID-19 pandemic, home and community care providers experienced challenging work conditions, insecure schedules (e.g., due to last-minute cancellations), concerns about job security, and few benefits (e.g., no paid sick days) [112]. Safety concerns of home and community care providers include anxiety about contracting COVID-19 and infecting their families with the virus, which may be partly attributed to poor adherence to infection protection and control protocols regarding facial protective equipment (e.g., mask, face shield) [132]. Notably, many home and community care providers were concerned for their personal safety because there was an increase in responsive behaviours among PLWD due to their increased agitation caused by extensive periods of isolation [127].

3.2.11 Literature Review Summary

Despite considerable variation in how dementia-inclusive home and community care provision is structured across Canada, it is informed by best practices that reflect the need for a person-centred approach driven by evidence and supported by interdisciplinary teams. Innovative models of dementia-inclusive care are being introduced across Canada; however, implementation is generally slow and lagging far behind the demand for such dementia care models. Despite the good intentions and well-informed approaches to dementia-inclusive home and community care, the complexity of the disease and significant demands related to caring for PLWD mean that all stakeholders face substantial challenges. PLWD and their care partners who are members of communities facing inequitable access to dementia-inclusive home and community care face additional barriers to home and community care, which underscores the complexity of quality care delivery. Together, the literature supports a role for standardizing dementia-inclusive care to harmonize critical components of the home and community care sector in Canada and ensure the highest quality of care for PLWD and their care partners.

3.3 Survey Results

3.3.1 Survey Respondents

One hundred and two (102) responses to the survey were received from across Canada, including PWLD, care partners, and home and community care providers. Home and community care providers who responded to the survey included nurses, PSWs, case managers, care coordinators, social workers, occupational therapists, best practice/education specialists, physiotherapists, dieticians, First Nation Liaison workers, and others. Tables 5 through 7 and Figure 2 provide details about the survey respondents. All questions in the survey were optional and did not require a response.

3.3.2 Utilization of and Satisfaction with Home and Community Care Services

Sixty-two percent (62%) of PLWD surveyed indicate that they have received home care services (Appendix C.1), such as nursing visits, personal support, and social care. This contrasts with community care, where only 12% of PLWD surveyed indicate that they have received community care services (Appendix C.1), such as community-based support programs. A similar trend was seen among care partners, where 71% of those surveyed indicate that they have made use of home care services (Appendix C.1), and only 35% have made use of community care services (Appendix C.1).

Of the PLWD who have received home care services, only 25% were very satisfied with the care received, while the remaining 75% were either somewhat dissatisfied or very dissatisfied (Appendix C.2). Only one PLWD surveyed indicates receipt of community care services and was very satisfied with these services.

Care partners show greater variability in their satisfaction with home care services. Nearly half (48%) of care partner respondents were somewhat or very satisfied with home care services, while 43% were somewhat or very dissatisfied (Appendix C.2). Care partners demonstrate greater satisfaction with community care services, with 70% being either somewhat or very satisfied (Appendix C.2).

PLWD and care partners' responses to open-ended questions regarding their home and community care experiences demonstrate several factors that could render a care experience positive or negative (Table 8).

Figure 2: Geographic distribution of survey respondents

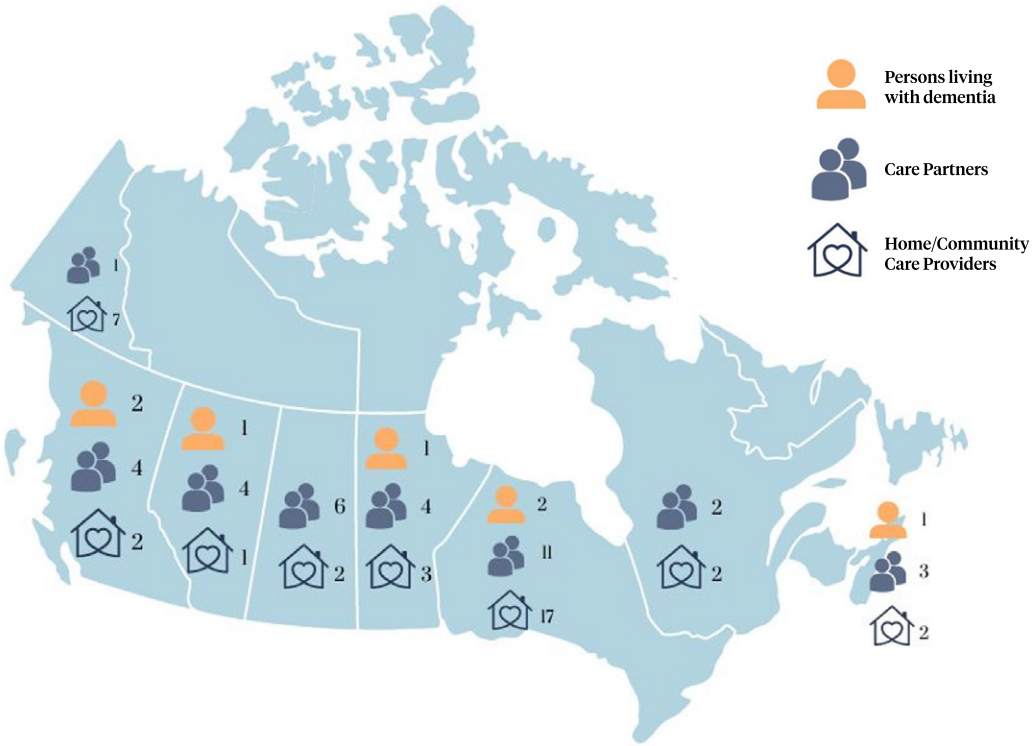


Table 5: Demographic profile of PLWD survey respondents

Age Range	Gender	Sexual Identity	First Nations, Inuit, and Metis	Black or Person of Colour	Disability	Education	Income Level
Persons Living with Dementia (n=8)							
50-59: **2** 60-69: **3** 70-79: **2**	Man: **1** Woman: **6**	Heterosexual/ Straight: **75%** Lesbian: **12%** No response: **13%**	First Nations: **0** Inuit: **0** Metis: **0** No: **7**	Yes: **0** No: **4** Prefer not to say: **3**	Yes: **6** No: **1** Prefer not to say: **1**	High school: **25%** College: **37%** Some university: **12%** Bachelor's degree: **13%** No response: **13%**	< $25 000: **2** $25 001 – $50 000: **2** $50 001 – $75 000: **2** $75 001 – $100 00: **1** No response: **1**

Table 6: Demographic profile of care partner survey respondents

Age Range	Gender	Sexual Identity	First Nations, Inuit, and Metis	Black or Person of Colour	Disability	Education	Income Level
Care partners (n=36)							
18-29: **2** 40-49: **2** 50-59: **4** 60-69: **14**	Man: **4** Woman: **31**	Heterosexual/ Straight: **97%** Bisexual: **3%**	First Nations: **2** Inuit: **0** Metis: **1** No: **33**	Yes: **0** No: **36**	Yes: **4** No: **31**	Some high school: **3%** High school: **8%** 2e cycle du secondaire: **3%** College: **8%** Some university: **11%** Bachelor's degree: **47%** Graduate degree: **20%**	< $25 000: **1** $25 001 – $50 000: **6** $50 001 – $75 000: **6** $75 001 – $100 000: **8** >$100 000: **7** Prefer not to say: **8**

Table 7: Demographic profile of home and/or community care provider survey respondents

Age Range	Gender	Sexual Identity	First Nations, Inuit, and Metis	Black or Person of Colour	Disability	Education	Income Level
Home and/or Community Care Providers (n=58)							
18-29: **1** 30-39: **6** 40-49: **9** 50-59: **10** 60-69: **7** 70:79: **4** 80+ : **1**	Man: **5** Woman: **33**	Heterosexual/ Straight: **57%** Gay: **4%** Queer: **3%** Pansexual: **3%** Bisexual: **2%** Another sexual orientation: **2%** No response: **29%**	First Nations: **2** Inuit: **0** Metis: **1** No: **34**	Yes: **6** No: **32** Prefer not to say: **2**	Yes: **4** No: **33** Prefer not to say: **1**	High school: **5%** Some college: **4%** College: **22%** Some university: **4%** Bachelor's degree: **17%** Graduate degree: **17%** No response: **31%**	< $25 000: **5** $25 001 – $50 000: **5** $50 001 – $75 000: **5** $75 001 – $100 000: **6** >$100 000: **11** Prefer not to say: **6** No answer: **20**

Table 8: Common themes in open-ended survey responses

Question	PLWD	Care partners
What did you like about your experience with home care services?	**Consistency in provider** ▪ Same provider over time **Opportunity for social interaction** ▪ Care visits offer a chance to speak with someone	▪ Accessible ▪ Affordable services available (subsidized) ▪ Provider characteristics ("caring", "kind", "professional", "pleasant")
What could be improved about your experience with home care services?	**Communication** ▪ Clear, open channel of communication between clients and providers **Taking more time with clients** ▪ Treating the client as a person rather than a checklist of tasks to complete **More inclusive care** ▪ Provision of non-judgmental care to members of 2SLGBTQI+ communities ▪ Inclusive and understanding care regardless of age (e.g., individuals with young onset dementia) **Increased client autonomy** ▪ Allow client to make decisions regarding choice of provider and care needs	**Need for reliable services** ▪ Visits cancelled often and at last minute **Insufficient care** ▪ Not enough hours of care to meet care needs **Communication** ▪ Need for dementia-friendly, person-centred approaches **Cost** ▪ Cost of services prohibitive and limit access to care **Consistency in care providers** ▪ Consistency in provider allows for building of trust between provider, PLWD, and care partner

Question	PLWD	Care partners
What did you like about your experience with community care services?	**Opportunity for social interaction** ▪ Engagement with others in community	▪ Provider characteristics ("friendly", "kind", "supportive")
What could be improved about your experience with community care services?	**Greater availability of funding** ▪ Stable funding to support growth of services in other communities	**Cost** ▪ Cost of services are prohibitive and limit access to care **Need for more community services** ▪ Day programs and social activities

Survey responses indicate a need for consistent, reliable, inclusive, and accessible care. Respondents repeatedly mention consistency in provider as particularly important for dementia-inclusive home and community care. According to one care partner:

> "There is absolutely no continuity of personnel so it is extremely hard to count on, trust an appropriate interaction – a total stranger is more difficult for a person with dementia to trust (and for me, given the inability to book an individual vs a company), I cannot even build up awareness on the part of my Mom and the caregiver over time."

Respondents appear to value care providers who demonstrate effective communication strategies, utilize person-centred care principles, take their time with clients, and appear kind, caring, and professional.

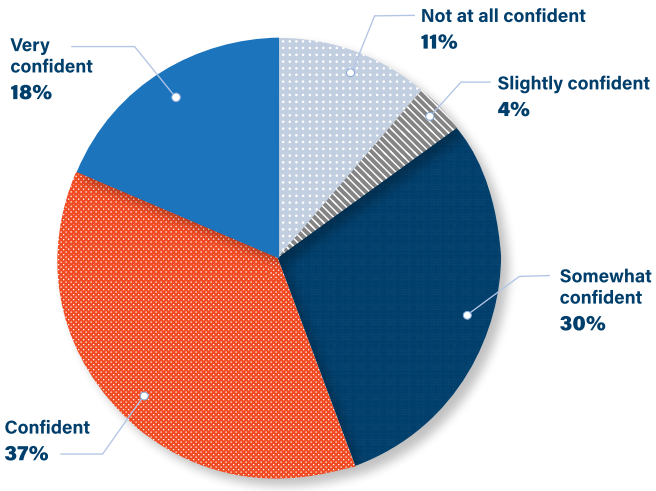
PLWD and care partners cite the following reasons for not making use of home and community care services: a lack of awareness of available services and services not yet needed at their stage of the dementia journey. Respondents also report difficulty accessing services. This was due to challenges with system navigation, lack of services in their area, or shortages of home and community care providers.

3.3.3 Perspectives of Home and Community Care Providers

When asked to indicate their confidence in their ability to provide dementia-inclusive home and community care, only 18% of home and community care providers indicate that they feel very confident (Figure 3).

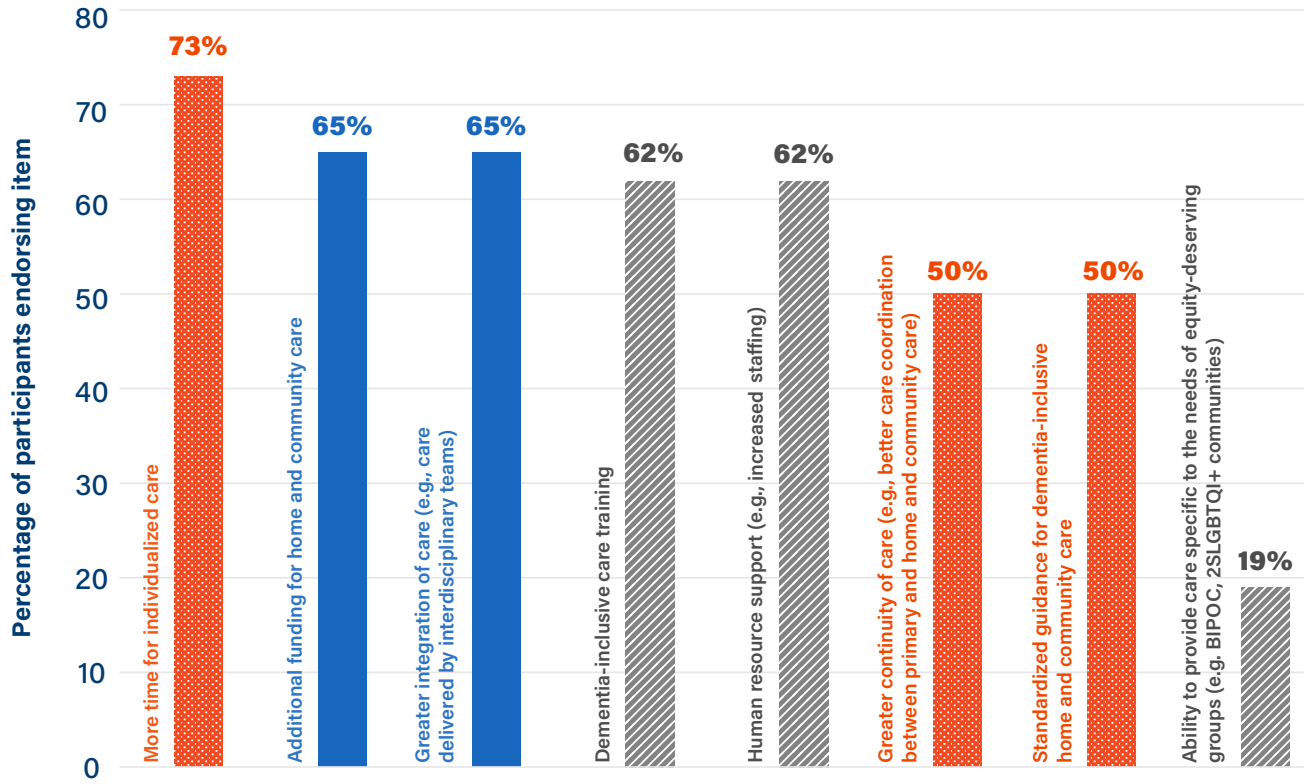
Figure 3: Home and community care providers' confidence in their ability to provide dementia-inclusive home and community care

How confident are you in your ability to provide dementia-inclusive home and community care?



When asked what could improve their capacity to provide dementia-inclusive care, nearly three-quarters of respondents (73%) indicate "more time for individualized care." This is followed closely by additional funding for home and community care (65%), which could serve to address the pay inequities experienced by home and community care providers compared to comparable providers working in other sectors, as well as greater integration of care (65%). Figure 4 demonstrates levels of endorsement for the remaining responses.

Figure 4: Improving capacity to provide dementia-inclusive home and community care services



When asked how they promote dementia-inclusive care, responses from home and community care providers fall into the following categories: use of dementia-specific approaches; being supportive; providing or participating in education/training; and use of effective communication strategies and skills. Dementia-specific approaches include working from a strengths-based perspective, utilizing the gentle persuasive approach (a strategy that focuses on personhood, brain and behaviour, interpersonal environment, and gentle persuasive techniques), and individualized approaches based on a person's life story and interests. Home and community care providers also indicate that they aim to be supportive to PLWD and their care partners by demonstrating patience and flexibility in approaches to care and by educating PLWD and their care partners when needed.

Home and community care providers providing education or training to other care providers or participating in education and training themselves also emerges as a way in which home and community care providers feel they promote dementia-inclusive care. Education and training include training in the gentle persuasive approach, PIECES training (an evidence-informed team-based approach to shared assessment and supportive care), and education offered through the Alzheimer Society or other organizations. Finally, home and community care providers indicate that they aim to use effective verbal and non-verbal communication strategies and skills. These include eye contact, active listening, using the person's name, and taking a validation approach (an empathetic way of communicating with PLWD that promotes dignity and self-worth).

The challenges to dementia-inclusive care expressed by these respondents include: inadequate staffing; not having the proper education and training; difficulty accessing specialty care (e.g., for consultation); lack of continuity of care (e.g., poor care coordination between various care providers involved in client's care); and stigmatization of clients by team members. Gaps that should be addressed to enable dementia-inclusive home and community care as identified by respondents include:

- **Culturally safe and competent care**
  - Need for standardized and culturally safe/competent assessment tools to determine diagnosis or prognosis
  - Recognition of cultural understandings of dementia
- **Education and training**
  - Education regarding dementia, diagnosis, prognosis, and common behaviours
  - Improved access to dementia-specific training such as the Gentle Persuasive Approach (e.g., some respondents indicated that their organizations do not have funds to support training for all staff)
- **Funding**
  - Increased funding for rural home care programs to increase staffing so PLWD and their care partners receive the support necessary to age in place
  - Increased financial support for PLWD and their care partners to access services (e.g., respite support)
  - Greater investment in home and community care by government, recognizing that supporting PLWD to live in the community is more cost-effective than admission to long-term care homes
- **Increased collaboration**
  - Facilitation of shared knowledge and expertise among care providers
  - Providing team-based care whenever possible
  - Identifying and implementing communication strategies to ensure information is effectively shared between team members. These strategies may vary depending on team resources and preferences; however, they should ensure important information regarding the PLWD and/or care partner is communicated to all team members
- **More time for care**
  - Recruiting and hiring more home and community care providers to decrease provider-to-client ratios and allow for more time for individualized care

3.3.4 Survey Results Summary

Results of the survey indicate that PLWD and their care partners access home care services more than they do community services. PLWD and their care partners who do not make use of home or community care services are often not aware that these services are available in their area or have not applied for services. PLWD and their care partners who have made use of either home or community care services demonstrated a range in satisfaction with services. Responses to open-ended questions in the survey reveal that PLWD and their care partners value consistency, flexibility, affordability, and inclusivity in the care provided to them. Home and community care providers responding to the survey identify a number of challenges to providing dementia-inclusive care, as well as strategies that could improve their capacity to provide dementia-inclusive care. Challenges include inadequate staffing, lack of education and training, and lack of continuity of care. Nearly three-quarters of respondents indicate that more time for individualized care would improve their capacity to provide dementia-inclusive care. Home and community care providers' confidence in their ability to provide dementia-inclusive care varies. Overall, the survey provides a snapshot of the use of and satisfaction with home and community care services, as well as challenges with the system and ways dementia-inclusive home and community care could be improved.

3.4 Interview Results

3.4.1 Interview Participants

Twelve (12) interviews were conducted with PLWD (4), care partners (3), and home and community care providers (5). This included participants from British Columbia, Alberta, Saskatchewan, Ontario, and Quebec (Tables 9 to 11). All interview questions were optional and did not require a recorded response.

Table 9: Demographic profile of PLWD interview participants

Age Range	Gender	Sexual Identity	First Nations, Inuit, and Metis	Black or Person of Colour	Disability	Education	Income Level	Geographic Location
Persons Living with Dementia (n=4)								
50-59: **1** 60-69: **1**	Man: **1** Woman: **1**	Heterosexual/ Straight: **1** Lesbian: **1**	No: **2**	No: **1** Prefer not to say: **1**	Yes: **2**	Some university: **1** Bachelor's degree: **1**	$50 001 – $75 000: **2**	BC: **1** AB : **1** ON: **2**

Table 10: Demographic profile of care partner interview participants

Age Range	Gender	Sexual Identity	First Nations, Inuit, and Metis	Black or Person of Colour	Disability	Education	Income Level	Geographic Location
Care partners (n=3)								
60-69: **1** 70-79: **2**	Woman: **3**	Heterosexual/ Straight: **3**	No: **3**	No: **3**	Yes: **2** No: **1**	College: **1** Some university: **1** Graduate degree: **1**	$50 001 – $75 000: **1** $75 001 – $100 00: **2**	ON: **3**

Table 11: Demographic profile of home and/or community care provider participants

Age Range	Gender	Sexual Identity	First Nations, Inuit, and Metis	Black or Person of Colour	Disability	Education	Income Level	Geographic Location
Home and/or Community Care Providers (n=5)								
40-49: **1** 50-59: **2** 60-69: **1**	Woman: **4**	Heterosexual/ Straight: **4**	No: **4**	Yes: **1** No: **3**	No: **4**	High school: **1** Graduate degree: **3**	< $25 000: **1** $75 001 – $100 000: **1** >$100 00: **2**	BC: **1** SK: **1** ON: **2** QB: **1**

3.4.2 Experiences of PLWD, Care Partners, and Home and Community Care Providers

Interviews were initially analyzed according to stakeholder group (PLWD, care partners, and home and community care providers). However, several themes emerged that were common among the stakeholder groups:

- Access and availability of care;
- Consistency;
- Quality and quantity of care;
- Cost of care and pay equity;
- Care for individuals in rural and remote regions;
- Education and training;
- Inclusive care for all;
- Rapport and relationships between clients and providers;
- Effects of the COVID-19 pandemic; and
- Care partners in the home and community care system.

3.4.2.1 Access and Availability of Care

Interview participants across stakeholder groups reported the need for greater availability of care, regarding both flexibility in scheduling and availability 24 hours a day. The limited number of staff are often fully booked, making it challenging to rearrange care schedules as needed. Similarly, care is not available at all hours of the day, including times when it may be needed most. Staffing shortages are a key factor in limiting access and availability of care. A home and community care provider, working in a director role, indicated that they are not able to fill the necessary staff positions, which has led to inequitable access to care among older adults:

> "I cannot send enough PSWs to provide the services and care to those people. And some seniors lucky enough to hire the private caregiver 24/7. But some of them with low income seniors, of course, they cannot afford."

Interview participants also shared that a lack of awareness of resources contributed to difficulties in accessing care. Additionally, participants expressed that their access was limited by not qualifying for care despite feeling that they have care needs. For example, a PLWD shared that when they had applied for services, they were told that they were not yet in need of services and did not qualify for support. This individual shared that, as their dementia journey progressed, they were then reluctant to seek support again after having been previously turned away.

Several PLWD from across Canada shared challenges with system navigation. This includes a lack of awareness around how to access services and information, such as support with paperwork or setting up financial help. The individuals who had a positive experience credited access to a case manager who helped them navigate the system, and they often had regional dementia programs available to them to help with system navigation.

Individuals with positive experiences in accessing care said that they were able to access services rapidly. This was largely due to the presence of a care coordinator and anticipatory planning for services that might be needed in the future.

3.4.2.2 Consistency

The need for consistency was a theme that emerged repeatedly across stakeholder groups. This included a need for consistency in providers, consistency in scheduling, and care that is reliable. One PLWD shared:

> "There's never the same person that comes twice. And so caregivers – or people with dementia – feel very uncomfortable with a new person wanting to help them with intimate things. That's a major problem."

PLWD and care partners also reported frequent changes in scheduled care, often without them being consulted. Participants in all stakeholder groups commented on care being unreliable. Participants shared experiences of care providers not showing up when scheduled and, in some cases, not at all. Inconsistency in care was a significant challenge to the provision of dementia-inclusive home and community care.



"Interview participants commented on the need for individualized, person-centred care that was delivered in an integrated way using a team-based approach."

3.4.2.3 Quality and Quantity of Care

Interview participants commented on the need for individualized, person-centred care that was delivered in an integrated way using a team-based approach. To deliver care in this manner, more time is needed than is currently available to most home and community care providers. PLWD shared that although resources and tools exist that would allow care providers to learn more about the PLWD, the quantity of allotted care duties doesn't allow for home and community care providers to make use of these resources and tools.

PLWD and care partners also expressed a need for more care. Additionally, care partners in rural/remote areas indicated that some of their allotted care/respite time is spent travelling, further decreasing their available time.

> "I live in the country so that three hours consists of a half hour drive into town and a half hour drive home so I have two hours to do something in town."

3.4.2.4 Cost of Care and Pay Equity

Both PLWD and care partners commented that the cost of home and community care can be prohibitive, with one care partner going so far as to say, "It's just wiping us out." Home and community care providers have found that this results in inequities in care.

Despite care being prohibitively expensive, PLWD and care partners commented on inadequate pay for home and community care providers. Home and community care providers commented on this as well, particularly the discrepancies in pay between those working in the long-term care sector versus the home and community care sector. They described the pay gap as huge, with those working in long-term care earning more. This is a significant fact that needs to be addressed.

3.4.2.5 Care for Individuals in Rural and Remote Regions

Home and community care in rural and remote regions has its own unique set of challenges. PLWD and care partners reported challenges with transportation to services or lack of nearby services. As a remedy to the lack of nearby services, one PLWD shared that "no program is too small," and added that running services, even for a small number of individuals, would be well-received. For home and community care providers, accessing individuals living in rural and remote regions requires additional time and consideration in the scheduling of providers and visits.

Additional considerations for home and community care providers include safety concerns (e.g., working in remote areas without cell phone reception, poorly maintained properties/drives) and access to vehicles that are winter-ready for rural/remote areas and/or are "off-road friendly".

3.4.2.6 Education and Training

Dementia-specific education and training was identified as a need, both in terms of foundational education and practical skills training. Foundational education includes an understanding of dementia and

the associated behaviours a provider may see when working with PLWD. Training included knowledge and skills development regarding approaches to working with PLWD, such as the Gentle Persuasive Approach, which helps care providers deliver person-centred compassionate care to PLWD by focusing on personhood, brain, and behaviour, the interpersonal environment, and gentle persuasive techniques. PLWD indicated that they are deserving of such care: *"You know we're real people that deserve proper care from people who have been trained."* The need for education and training was not limited to education and training for home and community care providers, but also included education and training for care partners. Education may also serve to combat the stigma experienced by many PLWD.

3.4.2.7 Inclusive Care for All

Interview participants stressed the importance of inclusive care for all. This included identifying a need for awareness and training. A PLWD shared:

> "Probably some training that you might have a client that is part of that community [2SLGBTQI+] because I've had some uncomfortable encounters, I know they probably don't have an issue, it's just really uncomfortable."

A home and community care provider also reiterated the need for awareness and training, stating that it should be provided to people working at all levels of care regardless of their role.

Home and community care providers also stressed the importance of finding ways to help marginalized populations living with dementia and incorporating the needs and concerns of these populations into the standards.

Indigenous communities were identified specifically as an equity-deserving group experiencing additional challenges in the delivery of dementia-inclusive home and community care. The primary challenge for PLWD and their care partners in Indigenous communities was a lack of resources. Home and community care providers commented on the resiliency of Indigenous communities in providing dementia care in their communities. Providers shared that Indigenous communities in remote areas often had limited access to home and community care services. Despite this, Indigenous community members were able to support one another and, as a community, provide care to the PLWD in the absence of providers. Indigenous knowledge concerning dementia generally includes a greater acceptance of dementia as part of the life cycle, which may contribute to this demonstrated resiliency, along with a greater sense of community.

3.4.2.8 Rapport and Relationships between Clients and Providers

A positive rapport and relationship between clients and providers is essential to dementia-inclusive home and community care. This includes the use of effective communication strategies, demonstrating caring and compassion, and building rapport through social interaction. PLWD expressed the importance of "being treated like a person."

Compatibility between the client and provider was also identified as an important factor. However, given the current structure of most home and community care systems across Canada, many clients accessing publicly funded services do not have the ability to assess compatibility with the provider. Care partners shared experiences where they had little choice in selecting a home and community care provider based on compatibility with the PLWD. Staff shortages also limit the selection of home and community care providers.

3.4.2.9 Effects of the COVID-19 Pandemic

The COVID-19 pandemic has had a marked impact on home and community care services. Interview respondents described a decrease in available services, using descriptions such as *"it was totally cut off"* and *"all came to a grinding halt."* One participant recognized that despite a decrease in services, their experience may still have been better than that of individuals living in rural and remote regions, who have fewer accessible services to begin with. Gaps in services were experienced across both urban and rural/remote areas.

The COVID-19 pandemic also exacerbated the effects of care partner burnout. Home and community care providers shared that although it appeared many care partners managed to cope in the beginning of the pandemic, they are now seeing increasing levels of burnout as a result of the lack of respite for care partners.

3.4.2.10 Care Partners in the Home and Community Care System

Several comments and experiences shared throughout the interviews were specific to the role of care partners in the home and community care system. Both care partners themselves, as well as home and community care providers, identified the burnout and guilt felt by care partners.

A care partner living in a rural community expressed:

> "After five years I am so exasperated and frustrated. My patience is diddlysquat now. I yell at him a lot, don't I dear? And it's very wearing. I just feel like I'm being eaten away, you know, like death by a thousand pinpricks or something."

Care partners were also identified as taking on an important advocacy role in the home and community care system, adding to the many roles they play in the lives of PLWD.

3.4.3 Interview Results Summary

PLWD, care partners, and home and community care providers participating in interviews shared both positive and negative aspects of their experiences with the home and community care system. Analysis of qualitative data revealed several themes common to all stakeholder groups. These included: the importance of access and availability of care; a need for consistent care; provision of quality care and sufficient hours of care to meet care needs; education and training to better equip home and community care providers; cost of care and pay equity; recognition of the importance of developing rapport and relationships between clients and providers; effects experienced by care partners in the home and community care system; inclusive care for all; special considerations for individuals living and working in rural/remote regions; and the impact of the COVID-19 pandemic on PLWD, care partners, and home and community care providers within the home and community care system. Many of the themes that emerged from the interviews aligned with the results of the literature review and survey.

4 Discussion

As the Canadian population ages, there is a projected increased demand for home and community care services. Recent data indicate that over 1.1 million Canadians requested home care services in 2019, with nearly 8% of those being new users of home care [133]. By 2031, this number is projected to increase to over 1.7 million Canadians, representing a 55% increase in demand [133]. Coinciding with increased demands for home and community care services is the rising prevalence of dementia in Canada, which is expected to triple over the next 30 years [133]. This will necessitate the provision of dementia-inclusive home and community care services, allowing PLWD and their care partners to receive care at home or in the community and preventing or delaying admission to long-term care or acute care settings.

4.1 Dementia-Inclusive Home and Community Care in Canada

Currently, home and community care in Canada is fragmented, with varying strategies and approaches to care provision and jurisdictional differences (Section 3.1.1). While Harmonized Principles for Home Care have been established at a national level, these principles are not specific to dementia. A lack of inclusion of dementia-specific considerations was apparent across regulations and legislations examined in this report. Moreover, the provision of culturally appropriate care and the application of equity, diversity, and inclusion principles was also not addressed by most regulations and legislation examined. Inclusion of dementia-specific considerations in pan-Canadian regulations and legislation is a gap that requires attention. Regulators and legislators operating in the home and community care sector must consider the unique situations of PLWD, their care partners, and the care providers who support them when developing or modifying regulations and legislation. This includes respecting the autonomy of PLWD, enabling their participation in decision making, recognizing the variability in dementia journeys, acknowledging the important role of care partners, and addressing the supports needed by home and community care providers to deliver dementia-inclusive home and community care.

A review of existing standards found that dementia-inclusive home and community care standards do not exist at a pan-Canadian level. However, Canada has developed a National Dementia Strategy that has three primary objectives (Section 3.1.2). The development of pan-Canadian dementia-inclusive home and community care standards could serve to address the five focus areas of the third objective of the National Dementia Strategy, while also improving the standard of home and community care for PLWD and their care partners, as well as supporting home and community care providers in care delivery. Development of a dementia-inclusive home and community care standard should consider the five focus areas and the ways in which standards can support the National Dementia Strategy. For instance, one of the five foci of objective three is to build the capacity of care providers. To enable the delivery of dementia-inclusive home and community care, capacity building through dementia-specific education and training will be necessary and should be included in the standards. Aligning the development of Canadian dementia-inclusive home and community care standards with the National Dementia Strategy will facilitate cohesion across the strategy and standards for care.

While best practices in dementia care are well-documented, the application of these practices in home and community care is proving to be a challenge for home and community care providers. Best practices that enable the delivery of person-centred, interdisciplinary team-based, and evidence-informed care require time and resources, all of which is currently scarcely available for home and community care providers. For example, a best practice in the delivery of person-centred dementia care is the involvement of, and support for, family and care partners. Care partners participating in this research study expressed that, in many instances, they have very little interaction with home and community care providers due to the inability to schedule visits to a time when both they and the PLWD are available. Home and community care providers said that their time with clients is often limited to accomplishing necessary care tasks (e.g., bathing), leaving little or no time for implementing best practices such as involving family and care partners. In order for home and community care providers to have the capacity to apply best practices in care delivery and provide the care PLWD and their care partners want and deserve, these challenges must be addressed. The development of dementia-inclusive home and community care standards should consider and mitigate these challenges (e.g., providing sufficient time for care to allow for the application of best practices).

4.2 Needs of PLWD, Care Partners, and Home and Community Care Providers

PLWD, care partners, and home and community care providers clearly identified their needs regarding dementia-inclusive home and community care. While the needs of each group may be specific and unique, they are interconnected. For example, PLWD and care partners stressed the need for care that was reliably available, with consistency in providers. The lack of reliable, consistent care is largely due to instability in the workforce, which many home and community care providers said was the result of pay inequity and staff shortages due to burnout. Home and community care providers expressed a need for pay equitable to that of providers in other sectors. Equitable pay could facilitate stability in the workforce and lead to more reliable and consistent care for PLWD and their care partners. The development of dementia-inclusive home and community care standards should consider the needs of all stakeholders and endeavour to address them, recognizing the relationships and interplay between stakeholders and their needs.

PLWD and care partners also expressed a need to address the stigma associated with dementia. The need to address stigma was raised even more often by members of equity-seeking groups, who shared that not only did they feel stigmatized by dementia, but also because of their sexual orientation, gender, or other characteristics. Dementia-inclusive care standards should incorporate evidence-informed approaches to destigmatizing dementia and to ensuring equity, diversity, and inclusion is respected in the delivery of care. Strategies to destigmatize dementia include education and training, which were identified as a need by home and community care providers.

Home and community care providers also raised a number of needs. As previously mentioned, pay equity and more time for provision of services, which would enable the application of best practices, was identified as a need by home and community care providers. Home and community care providers also expressed a need for further education and training. This included education about dementia (e.g., what is it? what causes it? what are the types?), disease progression (e.g., differences between mild to moderate to severe dementia), and common dementia behaviours. Once foundational knowledge is built through education, training would allow home and community care providers to develop the necessary skill sets to provide dementia-inclusive care (e.g., use of dementia-specific strategies such as the Gentle Persuasive Approach). Incorporation of education and training in care standards should consider these necessary elements. Finally, home and community care providers expressed a need for safe working conditions. This was particularly stressed by home and community care providers working in rural and remote areas. In developing dementia-inclusive home and community care standards, consideration should be given to the scenarios a care provider may find themselves in and how these standards could mitigate the risks they face in providing care. For example, alternative communication options for care providers working in homes in remote areas with limited cell phone reception may need to be identified and incorporated into the dementia-inclusive care standard.

4.3 Bridging the Gap Through the Development of Dementia-Inclusive Home and Community Care Standards

It is evident that home and community care in Canada could better address the needs of PLWD, care partners, and home and community care providers. The development of dementia-inclusive home and community care standards could serve to bridge the gap between the current home and community care system and one that meets the needs of PLWD, care partners, and home and community care providers. Based on the results of the environmental scan, literature review, survey, and interviews, four priority areas have been identified that would benefit from standards development. These priority areas are education and training; support for care partners; access to quality care; and human resources for home and community care (Figure 5).

Figure 5: Priority areas for standards development





"It is evident that home and community care in Canada could better address the needs of PLWD, care partners, and home and community care providers."

As previously mentioned, education should include foundational knowledge about dementia, including common behaviours that providers may encounter. Training programs for home and community care providers should also include strategies for communication and training regarding dementia-specific approaches to care. Education and training should also serve to combat stigma associated with dementia, as well as the stigma experienced by equity-deserving groups. Dementia-inclusive care must be culturally sensitive, recognizing the diversity of Canada's older adult population and variations in culturally safe and appropriate approaches to dementia care, as well as cultural understandings of dementia. Dementia-inclusive care should adhere to equity, diversity, and inclusion principles such as providing culturally safe and competent care that is inclusive of Indigenous, ethno-cultural, and 2SLTGBTQI+ communities. The development of dementia-inclusive home and community care standards must carefully consider all aspects of education and training that would be needed by home and community care providers and help ensure a comprehensive education and training program is provided.

Recognizing the critical role care partners play in the home and community care system and in the care of PLWD, dementia-inclusive home and community care should ensure support for care partners. This support may include adequate respite, practical information about caring, education and support in system navigation, and guidance regarding available financial supports, whether through employers or government sources. It should be noted that the needs of care partners vary significantly and may evolve throughout the dementia journey. Dementia-inclusive care should provide support for care partners that is in keeping with their needs at their stage of caring. Standards development must be cognizant of the varied needs of care partners at each stage of the dementia journey and help ensure support for care partners, addressing the potential needs for support at each stage.

Analysis across the research components identified the importance of access to and delivery of quality dementia-inclusive care. Quality care is generally recognized as care that is effective, safe, person-centred, timely, equitable, integrated, and efficient [134]. Dementia-inclusive person-centred care treats PLWD and their care partners as equal partners in care, together with home and community care providers, to ensure that their care needs are met. Individuals are treated with dignity and their autonomy is respected. Quality dementia-inclusive care should include consistency and continuity of care. This includes consistency in home and community care providers, as this was found to be a significant concern. Support should be offered in system navigation to enable access to available home and community care services. Standards should incorporate best practices that would facilitate the delivery of quality, person-centred dementia-inclusive care.

Human resources for home and community care are central to the provision of dementia-inclusive home and community care. Inequities in pay between care providers in the long-term care sector compared to the home and community care sector, in addition to low pay in general, have contributed to staff shortages in home and community care. In order to enable dementia-inclusive home and community care, a sufficient and skilled workforce that is equitably compensated is necessary. This may also serve to address other existing challenges such as a lack of consistency in care. Additionally, this workforce must have the necessary education, training, and supports to effectively deliver dementia-inclusive care. Dementia-inclusive home and community care standards should address the human resource challenges that have been negatively impacting care.

5 Conclusion

Our findings demonstrate that there is a growing need for dementia-inclusive home and community care in Canada. Although dementia-specific regulations and legislation are limited, Canada has developed a National Dementia Strategy that can serve to guide the development and modification of dementia-inclusive regulations and legislation in the home and community care sector. Innovative models of care have also been identified that could facilitate the application of best practices in dementia care.

Despite the existence of innovative models of care and best practice approaches, implementation of best practices and innovative models is not without challenges, as outlined throughout this report. Moreover, PLWD, care partners, and home and community care providers experience numerous unmet needs with respect to dementia-inclusive home and community care. There is a significant gap between the care that is available to PLWD and their care partners through Canada's current home and community care system and a dementia-inclusive home and community care system that addresses the needs of PLWD, care partners, and home and community care providers working within the system.

Consequently, there is a pressing need for the development of dementia-inclusive home and community care standards. Standards development should include the meaningful participation of PLWD, care partners, home and community care providers, and allied professionals. The development of dementia-inclusive home and community care standards can facilitate the implementation of best practices and help to address the existing gaps and needs experienced by PLWD, care partners, and home and community care providers. Through the development and application of dementia-inclusive home and community care standards, Canada's home and community care system should be able to meet growing demand and care requirements in the years to come.

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Appendix A – Survey Questions

In Canada there are more than 500,000 Canadians that are living with dementia[1]. The National Dementia Conference, held in 2018, identified inconsistent access to dementia care, services and supports across Canada and in particular in Indigenous communities, rural/remote regions, and ethnic, cultural, and linguistic groups[2]. The National Dementia Conference also identified a need to shift away from acute care service delivery, to integrated home and community care.

What is home and community care?

Home and community care services help people to receive care at home (including retirement homes), rather than in a hospital or long-term care facility, and to live as independently as possible in the community[3]. Home and community care is delivered by care providers (e.g., nurses, personal support workers), volunteers, friends and essential family caregivers[4]. Examples of home care services may include home visits from a care provider such a nurse or therapist. Examples of community care services may include day programs or specialized transportation services.

What is the purpose of this survey?

This survey is being conducted on behalf of the CSA Group, as part of a research project on dementia-inclusive home and community care. The survey will ask you for your perspective on best practices in home and community care, as well as existing gaps, perceived challenges and issues. The survey will also ask you to share your knowledge about initiatives and solutions which could inform the development of dementia-inclusive home and community care standards in Canada.

Who can participate?

This survey is open to:

- PLWD
- Primary caregivers [essential family/friend; providing hands-on and hands-off (e.g. appointment scheduling) care] of a PLWD in the community in the past 12 months
- Home and/or community care providers, including:
  - Nurses
  - Personal Support Workers
  - Developmental Service Workers
  - Case Managers & Care Coordinators
  - Best practice & Education specialists
  - Physiotherapists
  - Occupational Therapists
  - Speech Language Therapists
  - Social Workers
  - Dieticians
  - Community Paramedics
  - Other home and/or community care workers

1 Alzheimer Society of Canada. Prevalence and Monetary Costs of Dementia in Canada. Toronto. Alzheimer Society of Canada, 2016.

2 Public Health Agency of Canada. Conference Report. National Dementia Conference: Inspiring and Informing a National Dementia Strategy for Canada. 2018

3 Government of Canada. Home and community healthcare. https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html

4 Government of Canada. Home and community healthcare. https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html

We welcome participation from all stakeholders and invite participation of people with various interconnecting social identifications. We particularly seek to amplify the perspectives of 2SLGBTQI+ individuals, members of BIPOC (Black, Indigenous, people of colour) communities, and those who live in rural areas.

Questions?

If you have any questions, require assistance to complete your survey, or if you prefer to complete a hard copy version of the survey, please contact Jeanette Prorok (Email: info@jproresearchandconsulting.com Telephone: 613-449-7133).

Prize Draw

By participating in the survey, you may choose to enter a draw to win one of three $75 gift cards to an online retailer of your choice (some restrictions apply). If you wish to be entered in the draw, please provide your email address or other contact information in the box below. This information will not be used to link your identity with your responses.

Consent

By proceeding to the next page of this survey, you indicate your consent to participate in the survey. Your responses will remain anonymous and survey results will only be shared in aggregate (overall grouped results).

Demographic Questions

The following questions are meant to allow us to learn more about you and help ensure that we are including the unique experiences of various communities. With the exception of the last question, all questions are optional.

1. What is your years of age?
- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80 years and older
- Prefer not to answer

2. Do you identify as (select all that apply):
- Man
- Woman
- Two-spirit
- Non-binary
- Trans
- Prefer not to answer
- Another gender

3. Do you identify as (select all that apply):
   - Heterosexual/straight
   - Gay
   - Lesbian
   - Bisexual
   - Queer
   - Two-Spirit
   - Pansexual
   - Another sexual orientation

4. Do you identify as being First Nations, Métis, or Inuit?
   - First Nations
   - Métis
   - Inuit
   - Prefer not to answer
   - No

5. Do you identify as Black or a person of colour?
   - Yes
   - No
   - Prefer not to answer

6. Do you identify as being a person with a disability?
   - Yes
   - No
   - Prefer not to answer

7. What is your highest level of education completed?
   - Some Middle School/Elementary School
   - Middle School/ Elementary School
   - Some High School
   - High School
   - Some College
   - College
   - Some University
   - University – Bachelor's Degree
   - University – Graduate Degree
   - Prefer not to answer
   - Other

8. What was your total family income before taxes last year?
- Under $25 000
- $25 001 - $50 000
- $50 001 - $75 000
- $75 001 - $100 000
- Greater than $100 000
- Prefer not to answer

9. What are the first three digits of your postal code? (This data is collected to inform us of the geographic range of our respondents.) _____

10. Do you identify as being a:
- PLWD
- Family member, friend, or essential primary caregiver
- Home and/or Community Care provider
  - Nurse
  - Personal Support Worker
  - Developmental Service Worker
  - Case Manager or Care Coordinator
  - Physiotherapist
  - Occupational Therapist
  - Speech Language Therapist
  - Social Worker
  - Best practice/Education Specialist
  - Dietician
  - Community Paramedic
  - Other

A.1 Questions for PLWD

1. I have received home care services (e.g. home visits from a care provider such a nurse, therapist).
   a. Yes
   b. No
   c. Unsure
   d. Prefer not to answer

2. have received community care services (e.g. day programs, specialized transportation services [not public transit]).
   a. Yes
   b. No
   c. Unsure
   d. Prefer not to answer

3. Overall, how satisfied were you with the home care services you received?
   a. Very dissatisfied
   b. Somewhat dissatisfied
   c. Neither dissatisfied nor satisfied
   d. Somewhat satisfied
   e. Very satisfied

4. Overall, how satisfied were you with the community care services you received?
   a. Very dissatisfied
   b. Somewhat dissatisfied
   c. Neither dissatisfied nor satisfied
   d. Somewhat satisfied
   e. Very satisfied

5. What did you like about your experience with home care services?

6. What could be improved about your experience with home cares services?

7. What did you like about your experience with community care services?

8. What could be improved about your experience with community care services?

9. Please share any other comments you may have about your experiences with home and community care.

If participant answers no to question 1 or 2 above:

1b. Is home care available where you live?

- **a.** Yes
- **b.** No
- **c.** Unsure
- **d.** Prefer not to answer

1b1. Have you requested home care services?

- **a.** Yes
- **b.** No
- **c.** Unsure
- **d.** Prefer not to answer

2b. Is community care available where you live?

- **e.** Yes
- **f.** No
- **g.** Unsure
- **h.** Prefer not to answer

2. **2b1.** Have you requested community care services?

- **a.** Yes
- **b.** No
- **c.** Unsure
- **d.** Prefer not to answer

3. Why have you not requested these services?

4. Please share any other comments or thoughts you may have about home and community care.

A.2 Questions for Care Partners

1. I have made use of home care services (e.g., home visits from a care provider; home-based respite services) in my role as an essential family or friend caregiver.
   a. Yes
   b. No
   c. Unsure
   d. Prefer not to answer

2. I have made use of community care services (e.g., day programs, transportation services) in my role as an essential family or friend caregiver.
   a. Yes
   b. No
   c. Unsure
   d. Prefer not to answer

If participants answer no to either of above 2 question, direct to the questions pertaining to not making use of services on page 7.

3. Overall, how satisfied were you with the home care services you made use of?
   a. Very dissatisfied
   b. Somewhat dissatisfied
   c. Neither dissatisfied nor satisfied
   d. Somewhat satisfied
   e. Very satisfied

4. Overall, how satisfied were you with the community care services you made use of?
   a. Very dissatisfied
   b. Somewhat dissatisfied
   c. Neither dissatisfied nor satisfied
   d. Somewhat satisfied
   e. Very satisfied

5. What did you like about your experience with home care services?

6. What could be improved about your experience with home cares services?

7. What did you like about your experience with community care services?

8. What could be improved about your experience with community care services?

9. Please share any other comments you may have about your experiences with home and community care.

If participant answers no to question 1 or 2 above:

1b. Is home care available where you live?

- **a.** Yes
- **b.** No
- **c.** Unsure
- **d.** Prefer not to answer

1b1. Have you requested home care services?

- **a.** Yes
- **b.** No
- **c.** Unsure
- **d.** Prefer not to answer

2b. Is community care available where you live?

- **a.** Yes
- **b.** No
- **c.** Unsure
- **d.** Prefer not to answer

5. **2b1.** Have you requested community care services?

- **a.** Yes
- **b.** No
- **c.** Unsure
- **d.** Prefer not to answer

6. Why have you not requested these services?

7. Please share any other comments or thoughts you may have about home and community care.

A.3 Questions for Home and Community Care Providers

1. How confident are you in your ability to provide dementia-inclusive home and community care?

   [Response options: 1 – Not at all confident; 2 – Slightly confident; 3 – Somewhat confident; 4 Confident; 5 – Very confident]

2. How do you promote dementia-inclusive care in the services you provide (e.g. education/training you have received, approaches you have utilized)?

3. Which of the following would improve your capacity to provide dementia-inclusive home and community care services (select all that apply):
   - Dementia-inclusive care training
   - Additional funding for home and community care
   - Human resource support (e.g., increased staffing)
   - More time for individualized care
   - Ability to provide care specific to the needs of equity-deserving groups (e.g., BIPOC, 2SLGBTQI+ communities)
   - Greater integration of care (e.g., better care coordination between primary and home and community care; interdisciplinary teams)
   - Greater continuity of care
   - Standardized guidance for dementia-inclusive home and community care
   - Other (please specify):

4. What is the biggest challenge you face in providing dementia-inclusive home and community care services?

5. What gaps should be addressed to enable dementia-inclusive home and community care?

6. Are you aware of guidance, initiatives, models, or frameworks which could inform the development of dementia-inclusive home and community care standards?
   - No
   - Yes
     - If yes, please list below

Appendix B – Interview Guide

B.1 Semi-structured Interview Guide for PLWD/Care Partners

(Probing questions will be asked as appropriate to delve deeper into topics shared by participants)

Thank you for taking the time to meet with me today. We really appreciate your participation in this research project. As you may be aware from the interview invitation, the research project focuses on identifying gaps and challenges, as well as initiatives and solutions, that could inform the development of dementia-inclusive home and community care standards in Canada.

I have a few questions here to help guide our conversation, but it's okay if there are some questions you prefer not to answer or some you'd rather discuss more than others. If it's okay with you, I'd like to audio record our discussions today so that I can focus on our conversation instead of note-taking. None of your comments or thoughts shared today will be linked with your identity. Anything you share today will be made anonymous in reports. Is it okay with you if I audio record?

1. To begin, I'd like to ask you what made you interested in taking part in this interview today on this topic?
2. What has your experience been with home and community care?
3. [If participant has not made use of HOME AND COMMUNITY CARE] Why have you not made use of home and community care services? What would make you seek out home and community care services?
4. [If participant has made use of HOME AND COMMUNITY CARE] What about your experiences could have been improved?
5. [If participant has made use of HOME AND COMMUNITY CARE] What did you like about your experiences with these services?
6. What gaps do you see, know of, or experience in home and community care that, if addressed, could better meet your needs or improve your quality of life?
7. Has the COVID-19 pandemic had an impact on your use of home and community care? If so, how has the COVID-19 pandemic impacted the delivery/your use of home and community care?
8. From your perspective, what can be done to improve home and community care for members of BIPOC, 2SLGBTQIA+ communities, rural/remote regions? [ask this question, modified as appropriate, if participant has identified as a member of one of these communities]
9. Are there any other thoughts you'd like to share before we finish our interview

B.2 Interview Guide for Home and Community Care Providers

(Probing questions will be asked as appropriate to delve deeper into topics shared by participants; questions from interview guide may be selected as appropriate depending on participant's role)

Thank you for taking the time to meet with me today. We really appreciate your participation in this research project. As you may be aware from the interview invitation, the research project focuses on identifying gaps and challenges, as well as initiatives and solutions, that could inform the development of dementia-inclusive home and community care standards in Canada.

I have a few questions here to help guide our conversation, but it's okay if there are some questions you prefer not to answer or some you'd rather discuss more than others. If it's okay with you, I'd like to audio record our discussions today so that I can focus on our conversation instead of note-taking. None of your comments or thoughts shared today will be linked with your identity. Anything you share today will be made anonymous in reports. Is it okay with you if I audio record?

1. To begin, could you please tell me a little bit about your role in the home and community care system?
2. What has your experience been working in home and community care?
3. What has your experience been working in home and community care, specifically with PLWD and their caregivers?
4. What are the gaps, challenges, or barriers, you experience when working in home and community care with PLWD and their caregivers? What are the areas that you can think of for improvement?
5. What could be done to improve your capacity to provide dementia-inclusive care?
6. From your perspective, how has the COVID-19 pandemic impacted home and community care?
7. Has the COVID-19 pandemic had an impact on your use of home and community care? If so, how has the COVID-19 pandemic impacted the delivery/your use of home and community care?
8. From your perspective, what can be done to improve home and community care for members of BIPOC, 2SLGBTQIA+ communities, rural/remote regions? [ask this question, modified as appropriate, if participant has identified as a member of one of these communities]
9. Are you aware of any best practices, models, or solutions for dementia-inclusive home and community care that you could share with us? Are there any priority areas you feel should be focused on in standards development in this topic area?
10. Are there any other thoughts you'd like to share before we finish our interview?

Appendix C – Survey Results

C.1 Use of and access to home and community care services by PLWD and care partners

Survey Question	Yes	No	Unsure
Persons Living with Dementia			
I have received home care services (e.g., home visits from a care provider such as a nurse, therapist).	62%	38%	—
I have received community care services (e.g., day programs, specialized transportation services [not public transit]).	12%	88%	—
Is home care available where you live? (Note: only 1 respondent)	—	—	100%
Have you requested home care services?	—	100%	—
Is community care available where you live?	33%	17%	50%
Have you requested community care services?	17%	83%	—
Care Partners			
I have made use of home care services (e.g., home visits from a care provider; home-based respite services) in my role as a care partner.	71%	29%	—
I have made use of community care services (e.g., day programs, specialized transportation services) in my role as a care partner.	35%	62%	3%
Is home care available where you live?	78%	—	22%
Have you requested home care services?	22%	78%	—
Is community care available where you live?	55%	—	45%
Have you requested community care services?	40%	55%	5%

C.2 PLWD and care partner satisfaction with home and community care services

Survey Question	Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied
Persons Living with Dementia					
Overall, how satisfied were you with the home care services you made use of?	25%	50%	—	—	25%
Overall, how satisfied were you with the community care services you made use of? (Note: 1 respondent)	—	—	—	—	100%
Care Partners					
Overall, how satisfied were you with the home care services you made use of?	17%	26%	9%	22%	26%
Overall, how satisfied were you with the community care services you made use of?	10%	—	20%	20%	50%

CSA Group Research

In order to encourage the use of consensus-based standards solutions to promote safety and encourage innovation, CSA Group supports and conducts research in areas that address new or emerging industries, as well as topics and issues that impact a broad base of current and potential stakeholders. The output of our research programs will support the development of future standards solutions, provide interim guidance to industries on the development and adoption of new technologies, and help to demonstrate our on-going commitment to building a better, safer, more sustainable world.

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