



What We Heard Report

Informing a dementia strategy for Canada

APRIL 2019



Public Health
Agency of Canada

Agence de la santé
publique du Canada

Canada 

TO PROMOTE AND PROTECT THE HEALTH OF CANADIANS THROUGH
LEADERSHIP, PARTNERSHIP, INNOVATION AND ACTION IN PUBLIC HEALTH.

—PUBLIC HEALTH AGENCY OF CANADA

Également disponible en français sous le titre :

Rapport sur ce que nous avons entendu : Éclairer la stratégie sur la démence au Canada

To obtain additional information, please contact:

Public Health Agency of Canada

Address Locator 0900C2

Ottawa, ON K1A 0K9

Tel.: 613-957-2991

Toll free: 1-866-225-0709

Fax: 613-941-5366

TTY: 1-800-465-7735

E-mail: hc.publications-publications.sc@canada.ca

© Her Majesty the Queen in Right of Canada, as represented by the Minister of Health, 2019

Publication date: April 2019

This publication may be reproduced for personal or internal use only without permission provided the source is fully acknowledged.

Cat.: HP25-21/2019E-PDF

ISBN: 978-0-660-29642-5

Pub.: 180818

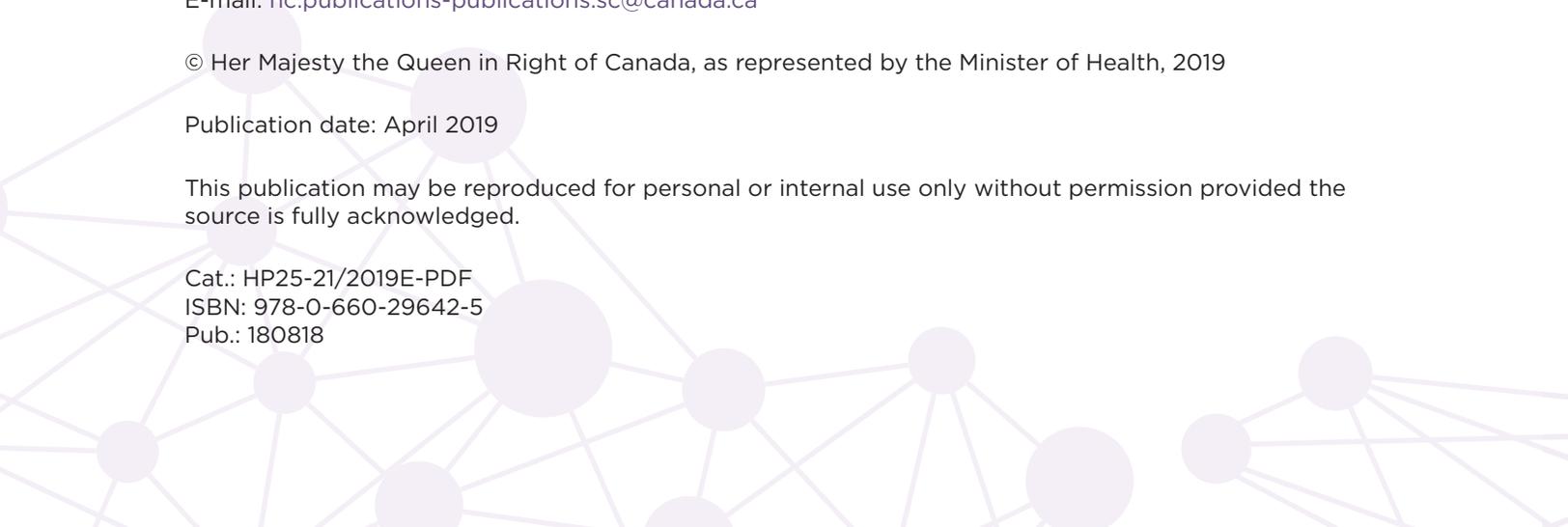
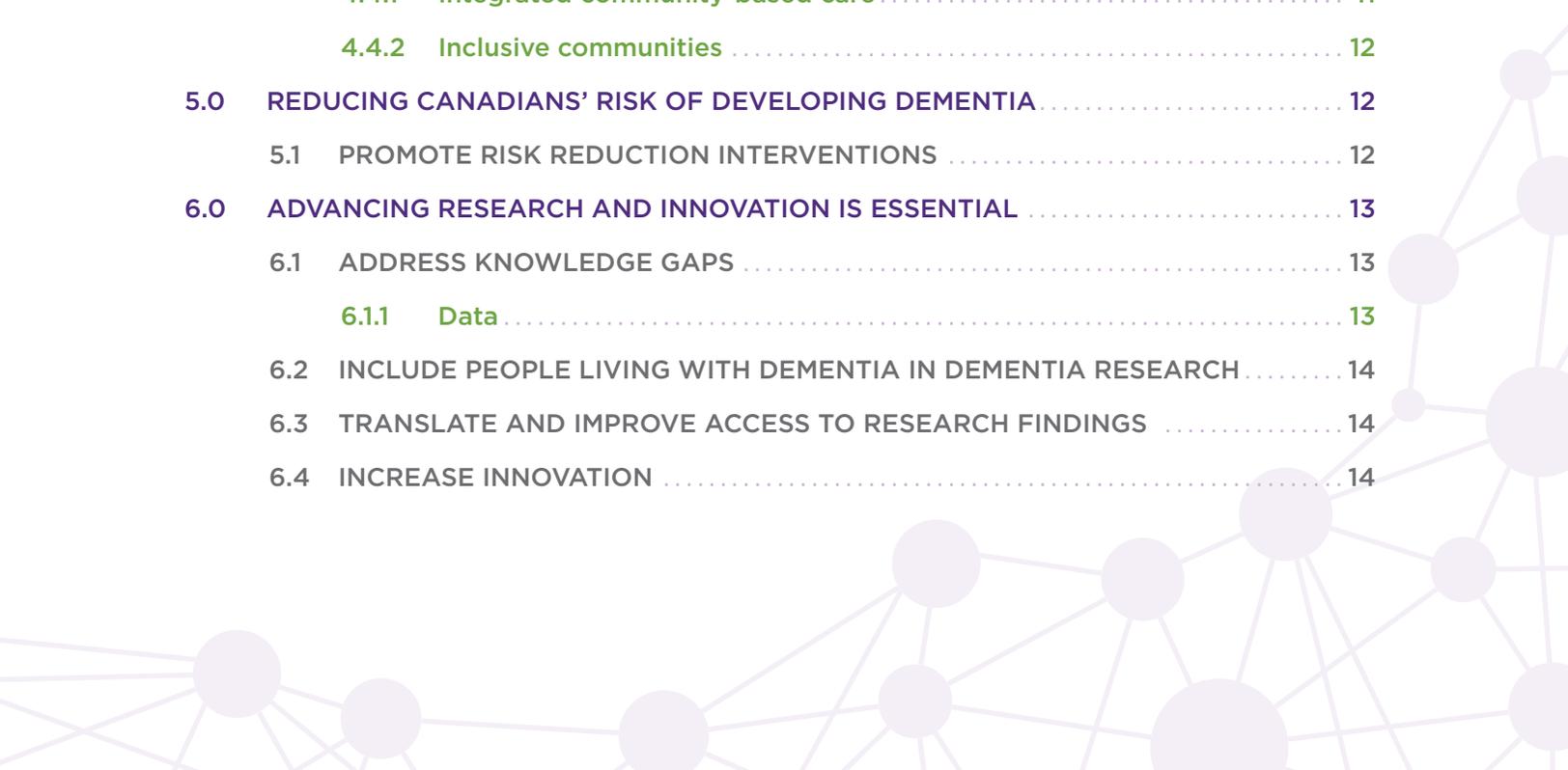


Table of Contents

1.0	EXECUTIVE SUMMARY	1
2.0	OUR DISCUSSIONS WITH CANADIANS	3
3.0	WHAT DOES LIVING WELL WITH DEMENTIA LOOK LIKE?	4
3.1	COMPASSIONATE DIAGNOSIS EXPERIENCE AND ACCESS TO SUPPORT SYSTEMS	4
3.2	QUALITY OF LIFE AT ALL STAGES OF DEMENTIA	6
3.3	INCREASED AWARENESS AND REDUCTION OF STIGMA	7
3.4	REDUCED FINANCIAL HARDSHIP FOR THOSE LIVING WITH DEMENTIA AND THEIR FAMILY/FRIEND CAREGIVERS	8
4.0	FOSTERING IMPROVEMENTS TO HEALTH AND SOCIAL SYSTEMS	8
4.1	EMPOWER AND VALUE CARE WORKERS	8
4.2	DEVELOP GUIDELINES AND TRAINING FOR HEALTH CARE PROVIDERS	9
4.3	PROVIDE MORE SUPPORT TO FAMILY/FRIEND CAREGIVERS	10
4.4	SHIFT TOWARD INTEGRATED COMMUNITY-BASED CARE AND INCLUSIVE COMMUNITIES	11
	4.4.1 Integrated community-based care	11
	4.4.2 Inclusive communities	12
5.0	REDUCING CANADIANS' RISK OF DEVELOPING DEMENTIA	12
5.1	PROMOTE RISK REDUCTION INTERVENTIONS	12
6.0	ADVANCING RESEARCH AND INNOVATION IS ESSENTIAL	13
6.1	ADDRESS KNOWLEDGE GAPS	13
	6.1.1 Data	13
6.2	INCLUDE PEOPLE LIVING WITH DEMENTIA IN DEMENTIA RESEARCH	14
6.3	TRANSLATE AND IMPROVE ACCESS TO RESEARCH FINDINGS	14
6.4	INCREASE INNOVATION	14



IV What We Heard

Informing a dementia strategy for Canada

7.0	ENSURING THE STRATEGY IS MEANINGFUL	15
7.1	APPLYING A HUMAN RIGHTS LENS	15
7.2	CONSIDERING DIVERSITY AND EQUITY	17
7.2.1	Rural and remote	18
7.2.2	Indigenous peoples	18
7.3	FOSTERING PARTNERSHIPS AND COLLABORATION WITH STAKEHOLDERS	19
7.4	CLEAR ACCOUNTABILITY AND QUICK ACTION	20
7.5	FUNDING	20
8.0	FINAL THOUGHTS	22



1.0 EXECUTIVE SUMMARY

Beginning in June 2017, following the enactment of the *National Strategy for Alzheimer's Disease and Other Dementias Act*, the Public Health Agency of Canada sought to further understand the impacts of dementia in Canada by engaging the six stakeholder groups mentioned in the Act: people living with dementia, family/friend caregivers, representatives of provincial and territorial governments, researchers, health care providers, as well as dementia advocacy groups. This report summarizes what we heard from these stakeholders and is informing the development of a dementia strategy for Canada. Given the depth and breadth of information received, this report aims to reflect the essence of the ideas and perspectives that were raised. It is not intended to imply consensus on the part of all participants. The views expressed are those of participants and should not be construed as representative of the Government of Canada's positions or views.

Engagement with stakeholder groups took the form of a National Dementia Conference, in-person roundtables and meetings. We also commissioned reports, reviewed stakeholder submissions and initiated what we anticipate will be an ongoing dialogue with Indigenous organizations. We learned about the experience of living with dementia—from those living with dementia and from caregivers speaking for those who can no longer speak for themselves due to the severity of their condition.

Conference and roundtable participants called for a Canadian dementia strategy that puts people living with dementia and their family and friend caregivers at its core. They told us that it is possible to live well and achieve quality of life at all stages of dementia through compassionate diagnosis, connection to support systems, increased awareness of dementia among all Canadians and reduced financial hardship for those living with dementia and their caregivers.

We heard a great deal about the struggles faced by families and friends who take on the primary caregiving role. The emotional toll is great for these caregivers, as are the financial challenges related to having to leave jobs or work less, and the physical toll that too often includes putting their own health at risk. Conference and roundtable participants suggested that better access to respite care, information and training, financial support and regular assessment of caregiver health are necessary to improve the quality of life for caregivers.

Several challenges were identified that need to be overcome to ensure that compassion, support, hope and meaning are provided to those living with dementia and their caregivers. We heard about solutions such as standardized guidelines and training for physicians, improved employment conditions for care workers, education for employers on workplace accommodation that would allow those living with early-onset dementia to continue working longer, the use of a case management approach to care, a shift toward integrated, community-based care, as well as monitoring of quality of care in long-term facilities, and improved, earlier access to palliative care.

2 What We Heard

Informing a dementia strategy for Canada

The importance of reducing Canadians' risk of developing dementia was also raised, with many Canadians expressing the need for further research into risk reduction measures and their effectiveness in delaying the onset of symptoms.

We heard that more needs to be done to find a cure, treatments and therapies for dementia. Research and enhanced data collection are required to address knowledge gaps. Access to research findings and adoption of best practices need to be improved. There is a strong interest to further explore how innovation can provide technological, biomedical and social solutions. Conference and roundtable participants clearly expressed the need to involve people living with dementia in research at all stages, including setting research priorities to ensure that research is directed toward their greatest needs.

People living with dementia told us that they want their human rights to be respected, including support for their dignity and the autonomy to make their own decisions, to be free from discrimination and stigma, and their full inclusion in society. Changes in decision-making models, scaling up of assistive technologies and standardized policies in long-term care regarding consent, privacy and sexual autonomy were suggested as potentially helpful in ensuring that the human rights of those living with dementia are respected.

We heard that equitable access to diagnosis, treatment, support and care across the country is not always available. Those in rural and remote communities as well as Indigenous peoples were highlighted as being most often impacted by differences in the level of care available. We also heard about barriers to diagnosis and access to care related to language and other cultural factors and that cognitive testing, as well as dementia information and support, need to be developed with diversity in mind.

In addition to getting the content of the strategy right, we heard from our stakeholders about the things that need to be in place for its successful implementation. The multi-stakeholder collaboration that has begun through the development of the strategy needs to continue so that the federal government and stakeholders benefit from sharing knowledge and developing solutions that would not be possible working in isolation. We also heard that clear accountability, quick action, leadership and additional funding are needed to move the yard stick on dementia.

WHAT IS DEMENTIA?

Dementia is a loss of mental function that affects daily activities. It happens when cells in the brain die or important nerve connections are broken. This process is known as neurodegeneration.

Alzheimer's disease is the most common cause of dementia. Vascular dementia, frontotemporal dementia, and Lewy body dementia are other common types.

Symptoms and manifestations of dementia can include memory loss, judgement and reasoning problems, and changes in behaviour, mood and communication abilities.

2.0 OUR DISCUSSIONS WITH CANADIANS

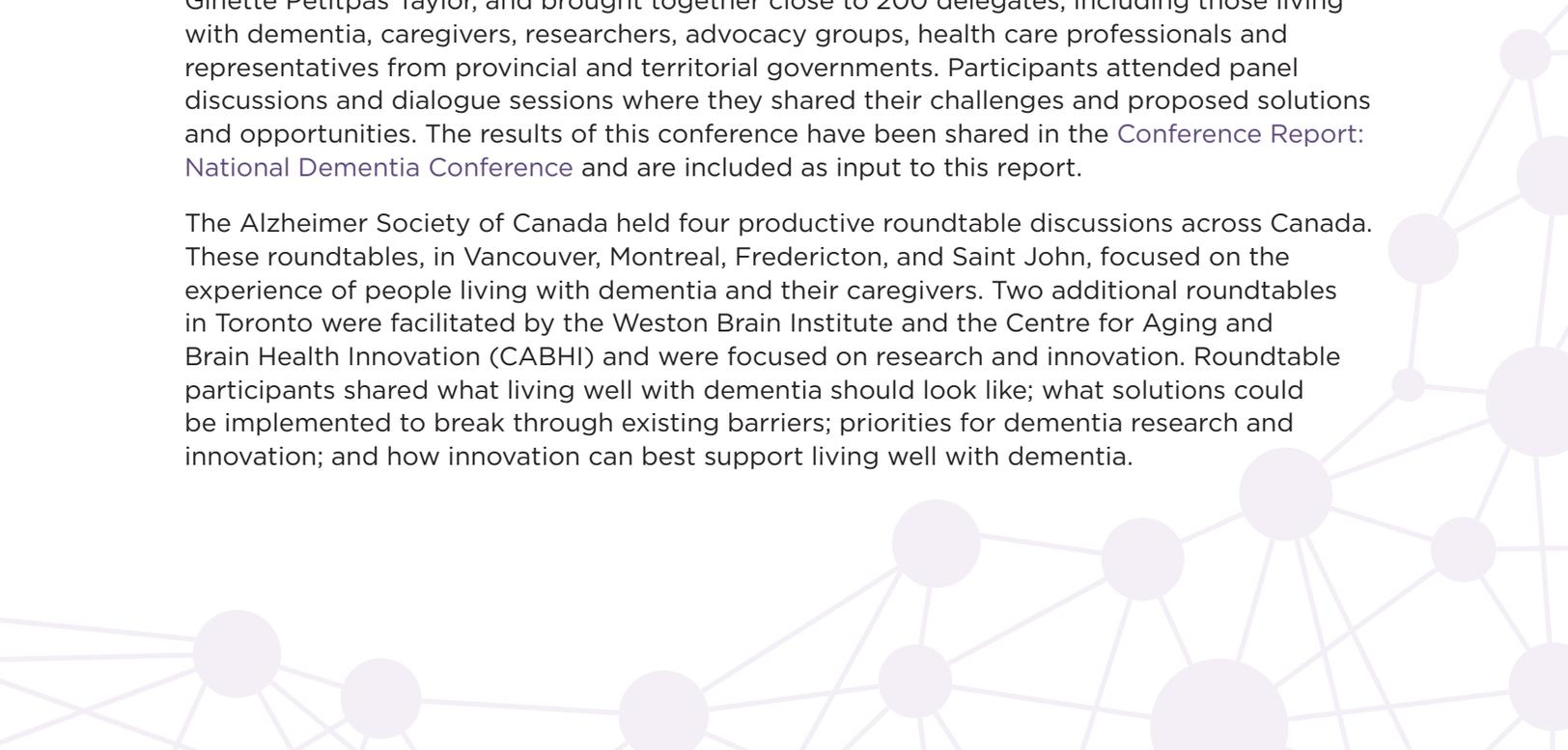
The Government of Canada is grateful for the honesty Canadians have shown in sharing their experiences with dementia and their recommendations of priorities for a dementia strategy for Canada. We have heard about the experiences, challenges and solutions from people living with dementia and family members and/or friends who provide care to them (i.e., family/friend caregivers), from health professionals, advocacy groups, provincial and territorial governments, and dementia researchers. These discussions have provided rich sources of information that are informing the dementia strategy for Canada. This document provides a summary of what we heard between June 2017 and January 2019.

Given the depth and breadth of information received, this report is aimed at reflecting the essence of the ideas and perspectives that were raised during the consultation process. It is not intended to imply consensus on the part of all participants. The views expressed are those of participants and should not be construed as representative of the Government of Canada's positions or views.

The enactment of the *National Strategy for Alzheimer's Disease and Other Dementias Act* in June 2017 marked an important milestone in signalling the Government of Canada's commitment to addressing dementia in Canada. Since then, the Public Health Agency of Canada has heard from numerous individuals and organizations about what it is like to live with dementia in Canada, including the challenges faced by family/friend caregivers, and it has received suggestions for solutions.

Formal, in-person discussions helped us hear from Canadians. The largest of these discussions was the National Dementia Conference: *Inspiring and Informing a National Dementia Strategy for Canada* in May 2018 in Ottawa. The conference was hosted by the Minister of Health, Ginette Petitpas Taylor, and brought together close to 200 delegates, including those living with dementia, caregivers, researchers, advocacy groups, health care professionals and representatives from provincial and territorial governments. Participants attended panel discussions and dialogue sessions where they shared their challenges and proposed solutions and opportunities. The results of this conference have been shared in the [Conference Report: National Dementia Conference](#) and are included as input to this report.

The Alzheimer Society of Canada held four productive roundtable discussions across Canada. These roundtables, in Vancouver, Montreal, Fredericton, and Saint John, focused on the experience of people living with dementia and their caregivers. Two additional roundtables in Toronto were facilitated by the Weston Brain Institute and the Centre for Aging and Brain Health Innovation (CABHI) and were focused on research and innovation. Roundtable participants shared what living well with dementia should look like; what solutions could be implemented to break through existing barriers; priorities for dementia research and innovation; and how innovation can best support living well with dementia.



4 What We Heard

Informing a dementia strategy for Canada

We have contacted more than 60 Indigenous groups across Canada asking how they would like to be engaged in the work to address dementia. We anticipate that this will help lead to comprehensive dialogues on dementia in Indigenous communities. We have also been in discussions with First Nations researchers to learn from their work with Indigenous communities.

The Public Health Agency of Canada received 18 reports, documents and surveys related to dementia submitted by individuals and organizations. Examples of these submissions include the Assessment of Dementia Care in Canada from the Canadian Academy of Health Sciences, the Canadian Home Care Association national survey findings and a review of Sex, Gender, Diversity, and Equity Considerations Related to Alzheimer's Disease and Other Dementias in Canada.

- More than 350 people consulted at events in Vancouver, Montreal, Fredericton, Saint John, Toronto and Ottawa
- 18 reports, documents and surveys provided by dementia advocacy groups, researchers, disability and health care organizations

Provinces and territories are integral partners and have a significant role to play in dementia given their responsibility for delivering health and social services. Through their role, some provinces have led the way in Canada on dementia care and support by creating their own dementia strategies. The best practices being developed through the implementation of these provincial strategies provide a rich knowledge base that serves as a foundation in the development of a national strategy. To strengthen our collaborative work on dementia, the Public Health Agency of Canada established a Federal/Provincial/Territorial Coordinating Committee on Dementia in December 2017. This committee meets monthly to share information on work underway and help inform the development of Canada's dementia strategy.

3.0 WHAT DOES LIVING WELL WITH DEMENTIA LOOK LIKE?

3.1 COMPASSIONATE DIAGNOSIS EXPERIENCE AND ACCESS TO SUPPORT SYSTEMS

Many Canadians living with dementia told us that their diagnosis experience had been a negative one. They were told to go home and settle their affairs and were not connected to any support to assist them as they navigate this new situation for them and their families. We also heard that those living with dementia were often excluded from medical and care conversations, almost like they were non-existent, once a diagnosis was given. Conference and roundtable participants called for changes to the diagnosis experience so that it becomes one that provides a clear message of hope. They asked to have comfort in the knowledge that, with a diagnosis of dementia, they will get the support they need to live well.

“Living well with dementia means living the best possible day, every day, with purpose, joy and dignity.”—ANONYMOUS, TORONTO (CABHI ROUNDTABLE)

The ability to be proactive within the health system and knowing how to access services and support can ease the path for those living with dementia and their family/friend caregivers. Conference and roundtable participants suggested that research is needed to identify what information would be most helpful for people living with dementia and their caregivers to receive at diagnosis. Recommendations from participants included information on specific types of dementia and prognosis; available support (e.g. care, psychological and financial), activities to reduce the risk of contributing factors such as high blood pressure, and how to participate in dementia research. The Alzheimer Society of Canada’s First Link system was highlighted as a best practice in providing information about services and supports to people newly diagnosed with dementia (see text box 1). Another suggestion received from participants was that being assigned a “buddy” at diagnosis who could answer questions, help complete forms and assist with accessing services would be useful.

FIRST LINK® (the Alzheimer Society of Canada)

First Link® is a referral program designed to help newly diagnosed people with dementia get the help they need as soon as possible.

The Alzheimer Society provides services and support both at the time of diagnosis and throughout the duration of the condition. Individuals and their families are linked to learning, services and support as early as possible.

Some provinces provide funding to the Alzheimer Societies across the country to enable access to these services.

<https://alzheimer.ca/en/on/We-can-help/First-link>

(1)

Conference and roundtable participants noted that a compassionate diagnosis is a timely diagnosis. Fear, created by stigma, as well as barriers such as geographic location, financial circumstances, educational levels, and childhood experiences, impact Canadians’ ability to get a timely diagnosis. We heard that men might be even less likely to seek a diagnosis because they are less likely to seek medical interventions for health issues in general¹.

¹ “A narrative review of sex, gender, diversity, and equity considerations related to Alzheimer’s Disease and other dementias in Canada”. Barbara Clow. 2018

6 What We Heard

Informing a dementia strategy for Canada

“In a perfect world, a person living with dementia would get the medication that best suits their needs, good care in the accommodations best suited to them and their family, they would enjoy each day, whatever it brings, and their caregivers would stay healthy.”—ANONYMOUS, NEW BRUNSWICK

(ASC ROUNDTABLE)

With a timely diagnosis, those living with dementia and their caregivers have more time to learn about the condition and supports, such as respite care and to plan for the future. A timely diagnosis should also allow for earlier attention to be paid to other chronic diseases that may be present, such as depression, heart disease, and high blood pressure. These other conditions can impact quality of life and the rate of progression of dementia due to increased social isolation and risk of stroke.

3.2 QUALITY OF LIFE AT ALL STAGES OF DEMENTIA

Conference and roundtable participants emphasized that living well is possible throughout all stages of dementia. We heard that the use of a case management approach can provide great improvements to quality of life. This approach provides a medical assessment and care coordination in an individualized way through a case manager. The case manager is assigned at diagnosis and advocates for that individual by coordinating and communicating with a care team on care and treatment (including clinicians and specialists such as speech-language pathologists and audiologists). With a case management approach, individualized care plans are considered to be “living documents” that are revisited and adjusted as care needs increase and become more complex.

DEMENTIA PROGRESSION

Early—Common symptoms include forgetfulness, communication difficulties, and changes in mood and behaviour. Many functional capabilities are retained and minimal assistance is required.

Middle—Greater decline in cognitive and functional abilities, and greater assistance required with many daily tasks, such as shopping, homemaking, dressing, bathing.

Late—Care is likely required 24 hours a day, requiring access to additional services and support.

End-of-life—More specialized care is likely required 24 hours a day.

(2)



We also heard that quality of care has an impact on quality of life. This is especially true in institutional settings where care may not always be specifically tailored to someone with dementia. Introducing systems for monitoring quality of care for people living with dementia was suggested, as was the need to define “quality” to include indicators such as inclusion of meaningful activities and fostering a culture among care workers that is inclusive, respectful, responsive, culturally competent, and safe.

Conference and roundtable participants also advised that, currently, the palliative approach to care is not well integrated into dementia care. The [Framework on Palliative Care in Canada](#), released in December 2018, defines palliative care as “an approach that aims to reduce suffering and improve quality of life for people who are living with life-limiting illnesses through the provision of:

- pain and symptom management;
- psychological, social, emotional, spiritual and practical support; and
- support for caregivers during the illness and after the death of the person they are caring for.”

Instead of trying to estimate life expectancy and setting criteria for when palliative care can be accessed for people living with dementia, we heard that individualized care goals should be established and used as a guide. Consideration of medical assistance in dying for people living with dementia was also raised.

3.3 INCREASED AWARENESS AND REDUCTION OF STIGMA

Awareness campaigns were identified as an opportunity to educate Canadians that it is possible to live well with dementia and to reduce the stigma surrounding the condition. We were told that awareness raising campaigns should include messages that are inclusive, give hope, respect the rights of people living with dementia and support them to live well throughout each and every stage of the condition. Campaigns should be targeted and tailored to different populations and consider cultural diversity.

Conference participants also called for an awareness campaign to educate the population about dementia, including enabling Canadians to identify the signs and symptoms in order to seek early diagnosis and treatment.

8 What We Heard

Informing a dementia strategy for Canada

3.4 REDUCED FINANCIAL HARDSHIP FOR THOSE LIVING WITH DEMENTIA AND THEIR FAMILY/FRIEND CAREGIVERS

Canadians living with dementia and their caregivers spoke about the financial toll of dementia. Financial stresses add a significant strain on an already challenging situation, leading to poorer health outcomes for all involved.

Caregivers described the career challenges they face as a result of providing support. They often experience financial losses from reduced hours of work or from having to leave the workforce early. This is especially challenging for caregivers who may be raising families of their own and who, at the same time, have family members with early onset dementia. Costs of housing, respite care, transportation, medications and other treatments are often overwhelming, and have an impact on quality of life. Tax benefits can be difficult to access, and many don't know what financial support is available or don't seek them out due to stigma. Simplifying processes, reviewing eligibility criteria and providing more accessible information on available financial support (such as compassionate care benefits) would be useful.

In addition, people living with dementia told us that they would like to continue working as long as possible following their diagnosis, would like more information on their possible career trajectories via counselling, and more education for employers on workplace accommodations for employees living with dementia.

Conference and roundtable participants suggested that additional financial support would be most helpful in the areas of:

- Subsidized technological innovations
- Affordable housing
- Financial aid extended to assisted and independent living (not just long-term care)
- Caregiver income support for lost/reduced wages
- Financial support for proven therapies (pharmacological and other)

4.0 FOSTERING IMPROVEMENTS TO HEALTH AND SOCIAL SYSTEMS

4.1 EMPOWER AND VALUE CARE WORKERS

The ability of people to live well with dementia is directly affected by interactions with front-line care providers, such as personal support workers and health care aides.

Consultation participants noted that care workers are often undervalued, underpaid, and over-worked with few opportunities to learn and advance their knowledge. Burnout and workplace injury are common among care workers. The resulting turnover negatively impacts the quality of care and continuity of services received by people living with dementia.

Conference and roundtable participants emphasized the need for care workers to be included in care teams as they are best positioned to provide feedback on care needs and planning. Care workers are often the ones who spend the most time with people living with dementia, and they may be the first to notice changes in an individual's condition.

Improving conditions for care workers and valuing the physical and emotional work that caregiving entails would better enable them to provide quality services while improving quality of life for their patients.

Increasing the number of care workers and providing better compensation were identified as solutions. With an eye to Canada's aging population and the expected increase in needs for dementia care, some Canadians suggested workforce planning will be required to ensure that there is an appropriate supply of workers. Participants at the Centre for Aging and Brain Health Innovation (CABHI) roundtable suggested leveraging innovation and assistive technologies to address potential human resource gaps.

4.2 DEVELOP GUIDELINES AND TRAINING FOR HEALTH CARE PROVIDERS

People living with dementia suggested that their diagnosis experience and general interactions with the health care system would be improved if health care providers had more training in dementia (e.g. in diagnostic tests appropriate for different types of dementia). Conference and roundtable participants indicated that dementia should be a core competency in medical and health care education and that up-to-date guidelines for diagnosis, treatment and care are needed to bring standardized, evidence-based recommendations on dementia more widely into clinical practice. More research is needed on the best way to train health care providers.

While some care and treatment guidelines for family physicians exist, conference and roundtable participants emphasized the need for these guidelines to be updated and communicated. Guidelines must be accessible and easy to understand, include the latest information on available community support, rehabilitation interventions, and home care. Conference and roundtable participants also called for new guidelines to be developed that are culturally appropriate and specific to certain populations, such as Indigenous communities, the LGBTQ community, those living in correctional facilities and people living with intellectual and developmental disabilities.

10 What We Heard

Informing a dementia strategy for Canada

4.3 PROVIDE MORE SUPPORT TO FAMILY/FRIEND CAREGIVERS

The importance of understanding and addressing caregivers' needs cannot be overstated as the caregiver's quality of life and that of the person living with dementia whom they are caring for are completely interdependent. Caring for someone living with dementia is complex. Dementia often exists along with other chronic conditions, such as heart disease, diabetes, high blood pressure, Parkinson's disease and overall frailty, all of which require coordinated treatment and care. Provision of this complex care often falls almost equally to a spouse (46 percent) or adult child (44 percent). Of adult child caregivers, 71 percent are women, whose average age is 54, and 60 percent are employed².

Providing care to loved ones with dementia takes an emotional and physical toll. With many hours in the day dedicated to looking after loved ones with dementia, caregivers often face increased stress and may neglect their own health. To address caregiver fatigue, conference and roundtable participants suggested that more respite support is needed, such as adult day programs and overnight respite. With respite support, family/friend caregivers could take more time to look after their own health and have more time to run errands, attend to other priorities or continue to work. It was noted that support with meals and other day-to-day activities would be of great help. While caregivers appreciated the availability of support groups in their communities, the common challenge voiced was that they were unable to leave their loved one to attend the meetings. Regular check-ins between the care team for the person living with dementia and the family/friend caregiver were suggested as a way to ensure that support is provided to the caregiver in a timely fashion. Conference and roundtable participants called for a high priority to be placed on caregiver support as part of a national strategy.

Many caregivers also identified dementia-specific challenges such as feeling ill-prepared to respond to behavioural symptoms of dementia. Others said that being left out of medical decisions, particularly those to do with changes to prescribed drugs, created stress and sometimes caused negative impacts to the person living with dementia. Caregivers suggested that they be included as active members of the care team, involved in health decisions, and provided with education, decision aids and support for navigating the health care system and future planning to reduce stress. Simply providing a list of services/resources was identified as not enough.

“They changed my mother’s meds without notifying us. She lost her speech and they said it was because she had low iron. She has had low iron her entire life! They just did that without asking us and now her speech is garbled.”

—ANONYMOUS, NEW BRUNSWICK (ASC ROUNDTABLE)

² <https://www150.statcan.gc.ca/n1/pub/82-003-x/2016005/article/14613-eng.htm>

Ethnic and visible minority caregivers face additional challenges due to lack of access to culturally appropriate services and information in their preferred languages. Some may be reluctant to consult health care providers as a result of historical and persistent experiences of colonization and racism. The need for culturally appropriate care and guidelines, and consideration of diversity were identified as essential to ensure equitable access to services.

4.4 SHIFT TOWARD INTEGRATED COMMUNITY-BASED CARE AND INCLUSIVE COMMUNITIES

“With an aging population, we need to change the way that we deliver health care services. The future of health care is in primary care, home care, and self-care. If we can build a more robust and accessible system of home and community care to support older people, we can welcome this demographic shift.”—ANONYMOUS, NEW BRUNSWICK (ASC ROUNDTABLE)

4.4.1 Integrated community-based care

With a rapidly aging population, limited spaces in long-term care facilities, and research findings indicating that home and community-based care can lead to better outcomes, we heard a call for a shift in delivery of dementia care from institutional care to home and community-based care (see box 3). Care should be integrated, meaning that case managers would not only provide guidance for health support but also for related social support, such as financial and housing.

COMMUNITY-BASED CARE

“Community-based care is coordinated, integrated care provided in a range of community settings, such as people’s homes, health care clinics, physicians’ offices, public health units, hospices, and workplaces. It is delivered in a way that is person- and population-centred, and responsive to economic, social, language, cultural, and gender differences.”

www.patientsafetyinstitute.ca/en/Topic/Pages/Community-Based-Care.aspx

(3)

Frequent transitions in care are described as being disruptive, complex, and costly. Transitions in and out of acute care in a hospital setting can be especially stressful for those living with dementia. Conference participants suggested that access to quick and effective home and community-based care could reduce the need for transitions in care.

12 What We Heard

Informing a dementia strategy for Canada

Canadians suggested that establishing local networks of people living with dementia, care partners, care facilities, and others, is critical in providing community-based care. The Dementia Network Calgary was identified as an example of a best practice in this area (see box 4).

DEMENTIA NETWORK CALGARY

Dementia Network Calgary is a growing multi-stakeholder group of knowledgeable, capable, and passionate individuals from across public, private, and non-profit sectors in Calgary and an area that is taking a cross-sector, collaborative approach to tackling the complex challenges of dementia.

www.dementianetworkcalgary.ca

(4)

4.4.2 Inclusive communities

People living with dementia told us that they want to be able to interact with community members with ease and comfort. To do this, they need a range of dementia-specific accommodations to be available in their communities. We also heard that there is a need for education within the community to promote inclusion of people living with dementia. This education would help increase action towards providing accessibility measures specific to those living with dementia, such as signage and other efforts to assist with navigating shops and transportation. We also heard that barriers such as social isolation should be addressed and that those living with dementia should feel safe in their communities. Some conference participants suggested community incentives and partnerships in order to achieve a buy-in for this approach.

5.0 REDUCING CANADIANS' RISK OF DEVELOPING DEMENTIA

5.1 PROMOTE RISK REDUCTION INTERVENTIONS

While the risk of developing dementia increases with age, the research is clear: dementia is not a normal part of aging. In fact, we are learning more and more about the actions that can be taken by individuals to reduce their risk of developing dementia. Exercise, healthy eating, smoking cessation and preventing hearing loss have all been shown to reduce the risk of developing dementia³ as with other chronic diseases. Emerging evidence indicates that good oral hygiene also plays a part in reducing the risk of dementia. Researchers, advocacy groups, and conference and roundtable participants suggested the federal government take a leadership role in promoting healthy living activities to reduce the risk of dementia. Many Canadians called for further research into risk reduction measures and their effectiveness in delaying the onset of symptoms.

³ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)30578-6/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)30578-6/fulltext)

6.0 ADVANCING RESEARCH AND INNOVATION IS ESSENTIAL

6.1 ADDRESS KNOWLEDGE GAPS

There are a number of persistent knowledge gaps when it comes to dementia. These include but are not limited to: the impacts of dementia on caregivers, households and communities; the rates of existing and new cases of dementia by various population groups and type of dementia; the progression of dementia; and interventions to delay the onset of dementia symptoms. Canadians called for more research in these areas, including enhanced data collection. By collecting more and richer information on dementia (such as data on Canadians living with dementia under 65 years of age, ethnicity, sex, gender, income level and geographic factors), we will be better able to understand how dementia is impacting Canadians across the country, which will inform development and implementation of policies and programs. Canadians also identified a gap in knowledge regarding the impacts and scope of dementia for Canadians who are excluded from national surveys, such as the Survey on Living with Neurological Conditions in Canada. Conference participants noted that the voices of those with later stage dementia, specifically those living in long-term care, are not always heard and that research in improving their quality of life is needed.

There are also knowledge gaps related to the way research on dementia is conducted in Canada. As highlighted during the conference and roundtables, these gaps include the need for:

- A balanced approach to the study of dementia that includes prevention, treatment and a cure
- Collaboration with researchers at universities and other research centres in Canada and internationally
- Sharing of research platforms and procedures
- Including women and diverse perspectives throughout the research effort, from most basic to clinical and care aspects
- Addressing the specific needs of Indigenous peoples
- Contributing to the required research capacity in interdisciplinary research to face the challenge of dementia
- Ensuring new knowledge is rapidly and efficiently translated into better preventative/ risk reduction measures, treatments and care
- Considering the ethical, legal and social aspects of research on dementia

6.1.1 Data

Researchers and clinicians told us that there are many barriers which prevent data sharing across provincial and territorial boundaries and in the capturing of “Canada-wide” data. Challenges across jurisdictions include: different database structures, use of various indicators, lack of consistent definitions for types of dementia, and multiple sub-populations. Canadians suggested that the federal government consider implementing data standards to simplify data sharing, including the standardization of diagnostic codes and case definitions.

14 What We Heard

Informing a dementia strategy for Canada

6.2 INCLUDE PEOPLE LIVING WITH DEMENTIA IN DEMENTIA RESEARCH

At all consultations, participants were clear: ongoing involvement of people living with dementia in research and innovation is paramount. We heard this from researchers, advocacy groups, and family/friend caregivers, but we heard this most clearly from those living with dementia. These individuals know what it feels like to have dementia and are acutely aware of the barriers they face in their daily lives, and in their interactions with the health and social care systems and long-term care. They want to be actively involved in all aspects of research, including as participants and in priority setting.

6.3 TRANSLATE AND IMPROVE ACCESS TO RESEARCH FINDINGS

There was a broad consensus that more effort is needed in translating dementia research into action. Researchers, health care professionals and policy makers told us that while considerable research in the field of dementia is being undertaken in Canada, it is often unclear how to translate research into best practices so that effective treatments and therapies can reach a broader audience.

Many of those consulted suggested a dementia information hub as a solution. This hub would include knowledge translation of research results into plain language best practices that are ready to be implemented. Roundtable participants suggested that this hub contain information in a variety of formats, including webinars, videos, infographics, newsletters and journal articles to make it easy for the general public, and especially those living with dementia, to absorb and use this information. We also heard that a hub such as this could connect people living with dementia with researchers and would provide information on how to participate in clinical trials and other research. Going even further, some suggested that such a hub could provide opportunities for people living with dementia and researchers to work collaboratively to produce collective intelligence and improve communication. Other suggestions included investment in research to learn more about how to ensure evidence-based interventions are adopted, and the integration of research translation efforts with education and awareness efforts including the development and use of treatment guidelines. It was also suggested that efforts be focused on the culturally appropriate translation of research findings for Indigenous peoples, different ethnic groups, specific populations (e.g., people who are incarcerated, or those who have mental health issues or Down Syndrome).

6.4 INCREASE INNOVATION

There is excitement among Canadians about the potential for innovation in dementia care and treatment. We heard that while most people first think of technology when they think of innovation (such as assistive robots), social and biomedical innovations are equally important.

Conference participants called for innovations in biomedical research on the causes of dementia, sub-types of dementia, frailty and cognitive stimulation.

The Centre for Aging and Brain Health Innovation (CABHI) roundtable participants encouraged us to consider how the federal government could assist in breaking down barriers to innovation, such as restrictions on how research funds can be used and differing rules for adoption of innovations across regions. Participants emphasized the need for an “experimentation” mindset in health care, where more risk is tolerated to test innovative approaches.

In order to implement innovations in a diverse and geographically dispersed country such as Canada, CABHI roundtable participants told us that the testing of innovations across regions is necessary, as are channels to help information about innovations flow across geographic boundaries to the public.

When roundtable participants talked about innovation they emphasized the need to respect diversity and identified the challenge of innovations that must be scalable across the country, but also personalized. Public-private partnerships were identified as a way to sustain and scale up innovations.

7.0 ENSURING THE STRATEGY IS MEANINGFUL

7.1 APPLYING A HUMAN RIGHTS LENS

The importance of applying a human rights lens to the development of a dementia strategy for Canada and of aligning the strategy with international and domestic rights was raised.

While all Canadians are protected by the *Canadian Charter Rights and Freedoms*⁴, many individuals and organizations believe that work is needed to uphold and protect the human rights of those living with dementia. People living with dementia often face stigma related to others’ assumptions of their capabilities. This stigma can lead to discrimination in the workplace, in the community and in interactions with the health system. Stigma and discrimination can also contribute to fear in seeking diagnosis, resulting in late or missed diagnoses, social isolation and diminished quality of life.

Dementia is considered a disability in Canada. People living with dementia in Canada can apply for disability benefits and their rights are protected by the *UN Convention on the Rights of Persons with Disabilities* (see box 5), to which Canada is a party. The Convention recognizes that persons with disabilities have the right to recognition as persons before the law and can make decisions about their life. It states that appropriate measures must be taken by governments “to provide access by persons with disabilities to the support they may require in exercising their legal capacity⁵.”

⁴ <https://laws-lois.justice.gc.ca/eng/Const/page-15.html>

⁵ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>

16 What We Heard

Informing a dementia strategy for Canada

HIGHLIGHTS FROM THE GENERAL PRINCIPLES OF THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

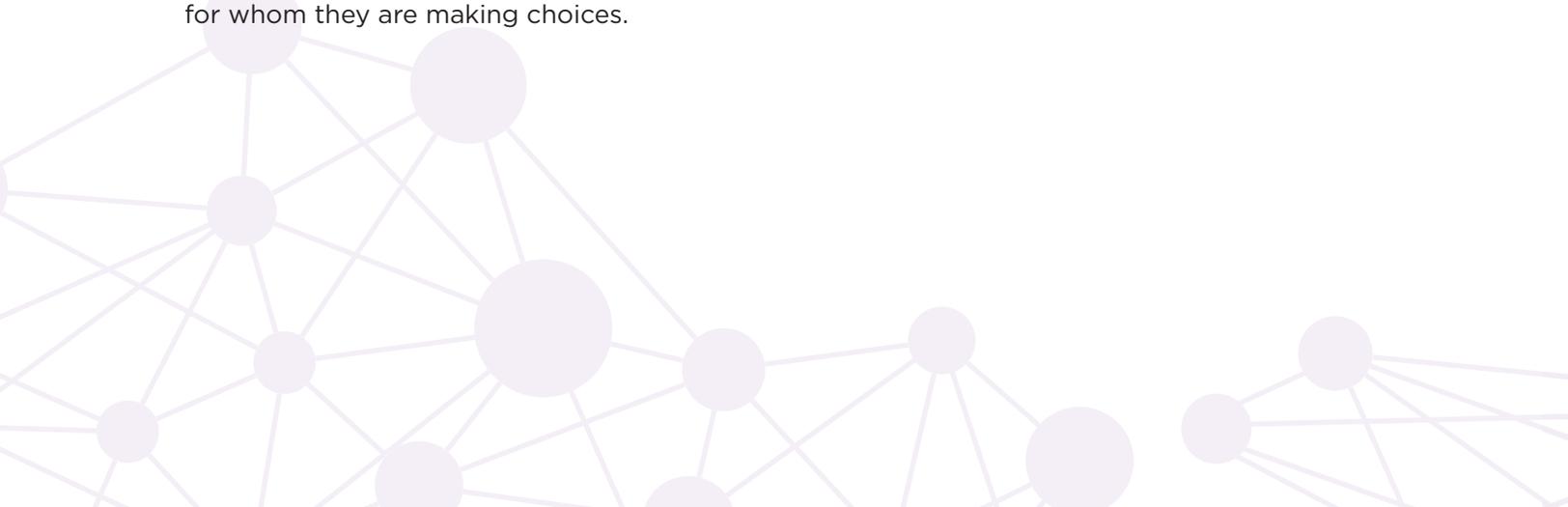
- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society

(5)

For example, recognition of the importance of autonomy and dignity was highlighted as an area for more progress as both have a direct impact on quality of life and foster a sense of hope. People living with dementia told us that they can continue to live their life with purpose and meaning if the right support is in place. Autonomy and dignity can mean continuing to work after diagnosis, living well at home as long as possible, participating in day-to-day community activities, and being involved in decisions that affect them.

Solutions suggested by conference and roundtable participants included more research on how to achieve autonomy and dignity, assistive technologies to help with day-to-day activities and ensure safety (such as mobile apps with a GPS), as well as improved transportation infrastructure to enable participating in community activities, and support to remain at home as long as possible.

Many people living with dementia, especially those at the end stages, have a substitute decision-maker (see box 6). Conference participants suggested that the Substitute Decision-Making Model can be inflexible and may not respect the rights of people living with dementia. The Supported Decision-Making Model was put forward as an alternative. Conference participants suggested that through supported decision-making, choice can be more easily included as part of care pathways and support systems, helping people living with dementia to remain as autonomous as possible. Participants at the conference felt that legislation around health care decision-making should be reviewed to consider the supported decision-making model where this is not available. If a substitute decision-maker is required, conference participants emphasized the importance of advance care planning to ensure that the substitute decision-maker is fully aware of and understands the preferences of the person for whom they are making choices.



SUBSTITUTE DECISION-MAKING MODEL

All decisions relating to the life of the person with disabilities such as financial, residential, and health care decisions are made by a substitute (usually a family member or friend). Often known as a Power of Attorney or Guardian.

SUPPORTED DECISION-MAKING MODEL

A person with disabilities makes their own decisions about their care with the support of a team of people they know and trust.

Note: decision-making regimes fall under provincial and territorial jurisdiction

(6)

Roundtable participants told us that policies around consent, privacy and sexual autonomy for people living with dementia vary from province to province and across long-term care facilities. Roundtable participants signaled a need to develop standardized policies in this area that balance the right to autonomy with personal safety. We also heard of the challenges faced by people living with dementia and the need to understand and improve how they and their families experience the law and the justice system.

7.2 CONSIDERING DIVERSITY AND EQUITY

We heard that Canadians living with dementia and their family/friend caregivers across the country are facing inconsistent access to services and quality of care due to diversity that includes gender, race/ethnicity, sexual orientation, ability, and rural or remote/urban residence. Conference and roundtable participants emphasized the importance of understanding and considering the diversity and varying needs of the Canadian population as essential to the development and implementation of an effective dementia strategy for Canada. Challenges faced by people living with dementia and their family/friend caregivers in rural, remote and Indigenous communities were especially highlighted by conference and roundtable participants. Some suggestions included the development of service standards and culturally appropriate cognitive screening tools in various languages.

18 What We Heard

Informing a dementia strategy for Canada

7.2.1 Rural and remote

Rural and remote areas in Canada have fewer primary health care providers, specialists, and support services available. People who live in these areas often have to travel long distances to see a doctor or specialist, are much further from ongoing support after diagnosis or after a hospital stay, and often have to leave their communities to enter long-term care. In some cases, care services are so far away that they become inaccessible to those living in rural and remote communities. The Rural Dementia Action Research's Rural and Remote Memory Clinic was identified as a best practice for helping to address this issue (see box 7). Other suggestions included the use of a toll-free hotline.

RURAL AND REMOTE MEMORY CLINIC (from Rural Dementia Action Research)

The Rural and Remote Memory Clinic is funded by the Saskatchewan Ministry of Health to provide clinical services to Saskatchewan residents. The clinic streamlines assessment and diagnosis in order to reduce repeated travel over long distances and shortens the time to diagnosis by coordinating an interdisciplinary assessment over one day. Caregivers are required to attend and are assessed for psychological health and level of caregiver burden.

<https://cchsa-ccssma.usask.ca/ruraldementiacare/Rural%20Remote%20Memory%20Clinic.php>
(7)

“The support provided is often inadequate. My phone calls are typically unreturned, and I miss important windows of opportunity to get the care my wife needs.”—ANONYMOUS, RURAL NEW BRUNSWICK (ASC ROUNDTABLE)

7.2.2 Indigenous peoples

Indigenous communities face some challenges that are similar to those in rural and remote communities. Many families face separation as loved ones must travel great distances for care. However, we are seeing some indications of unique challenges related to dementia and Indigenous communities. Some evidence is showing that dementia has only recently become more common in Indigenous populations⁶. Prevalence is higher, and onset may occur as much as 10 years earlier in First Nations people than in non-First Nations People⁷. Access to quality, culturally appropriate care for Indigenous peoples as well as the need to develop culturally sensitive education for health professionals and community members to address stigma, racism and discrimination were raised as important areas of focus for a dementia strategy.

⁶ “What is Dementia? First Nations perspectives and cultural understandings”. Kristen Jacklin. 2015

⁷ “Signs and Symptoms of Dementia: A First Nations Guide”. Kristen Jacklin. 2015

First Nations researchers tell us that factors such as lower socio-economic status, disconnection from protective factors (such as traditional ceremony, singing, language, beading and medicines) as well as higher rates of traumatic childhood experiences from exposure to the residential school system and the Sixties Scoop may contribute to the greater risk and prevalence of dementia. Additional research and consultation around contributing factors are needed to adequately begin to address dementia risk reduction, treatment and care in Indigenous communities.

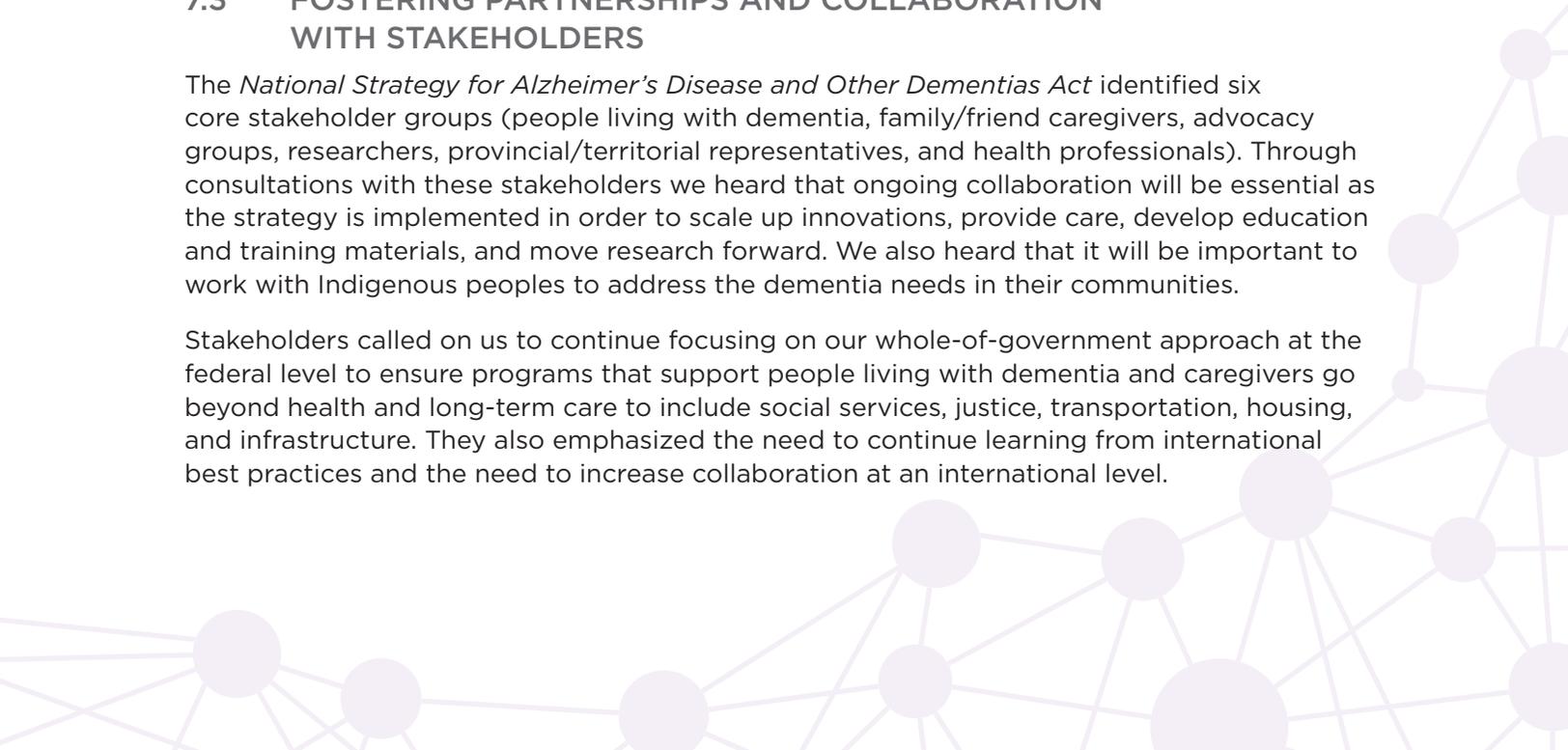
“English is not my mother’s first language, so she scores more poorly on cognitive testing than she otherwise would. It skews the results that she’s unable to have the test in the language she knows best and uses at home. I find that the time of day she is tested also makes a difference. These tests impact the care and services that are provided to my mother and others like her. It is so important that they be administered in the right way and they are not.”—ANONYMOUS, VANCOUVER (ASC ROUNDTABLE)

There is a gap in our understanding of the dementia challenges faced by Indigenous Peoples. Therefore, in order to learn more and to develop a distinctions-based approach for the implementation of the strategy, the Public Health Agency of Canada has reached out to more than 60 Indigenous organizations, communities and governments across Canada. Groups have been invited to engage with federal officials in order to understand the impacts of dementia on their communities with a view to facilitating solutions. While some dialogue has begun, much more is required to inform the implementation of the national dementia strategy.

7.3 FOSTERING PARTNERSHIPS AND COLLABORATION WITH STAKEHOLDERS

The *National Strategy for Alzheimer’s Disease and Other Dementias Act* identified six core stakeholder groups (people living with dementia, family/friend caregivers, advocacy groups, researchers, provincial/territorial representatives, and health professionals). Through consultations with these stakeholders we heard that ongoing collaboration will be essential as the strategy is implemented in order to scale up innovations, provide care, develop education and training materials, and move research forward. We also heard that it will be important to work with Indigenous peoples to address the dementia needs in their communities.

Stakeholders called on us to continue focusing on our whole-of-government approach at the federal level to ensure programs that support people living with dementia and caregivers go beyond health and long-term care to include social services, justice, transportation, housing, and infrastructure. They also emphasized the need to continue learning from international best practices and the need to increase collaboration at an international level.



20 What We Heard

Informing a dementia strategy for Canada

Conference and roundtable participants also noted the specific need to bring researchers together to collaborate and suggested that a dementia strategy could help increase connections between researchers and non-researchers such as people living with dementia. Creating opportunities to bring these groups together will help to identify relevant policy questions, to conduct collaborative research, and to understand and apply emerging evidence so it can be translated into practice.

7.4 CLEAR ACCOUNTABILITY AND QUICK ACTION

We heard that clear accountability across federal, provincial and territorial governments and other partners is necessary as part of the implementation of Canada's dementia strategy and that strong leadership from all stakeholders is critical. The federal government was called on to inspire and lead change especially in translating research findings into policy and best practices.

In speaking with Canadians, there is a sense of urgency that action should be taken quickly to address the challenges, raise awareness and implement best practices relating to dementia. To that end, they suggested that Canada's dementia strategy include an action plan with targets, timelines and tangible steps that will be taken in the short term as well as in the longer term. The importance of the federal government continuing to seek opportunities for ongoing discussions with Canadians on their experiences with dementia was also raised as a priority.

7.5 FUNDING

Conference and roundtable participants were clear that further investment is needed to support the implementation of a dementia strategy for Canada. Many stakeholders identified a lack of adequate funding in dementia research as a barrier to generating new knowledge. Conference and roundtable participants emphasized that the current research funding in Canada for dementia is too low and that dementia funding should be in line with that for other chronic diseases. Conference and roundtable participants supported the recommendation from the Standing Senate Committee on Social Affairs, Science and Technology that dementia research funding be increased to \$100 million per year as this would represent 1 percent of the total direct medical dementia costs in Canada.



Participants suggested that, in addition to research funding, new dementia funding be allocated strategically to support innovation and to help identify projects that are working well in order to implement best practices. Biomedical research priorities were identified at the Weston roundtable and other priorities have been identified by the Canadian Dementia Priority Setting Partnership, a steering committee made up of people living with dementia, advocacy groups and health care providers⁸ and through Sex and Gender-based Analysis (SGBA+). Some of these priorities include research into:

- Impacts of stigma
- Supporting emotional well-being and quality of life
- Impact of early treatment, support and care services
- Dementia-friendly communities
- Use of non-pharmacological treatments
- Health system and connections to meet health and social care needs
- Training for health and social care providers
- Implementing best practices
- Sex and gender impacts
- Biomedical research

⁸ <http://ccna-ccnv.ca/news/canadian-dementia-priority-setting-partnerships-top-10-research-priorities-announced>

22 What We Heard

Informing a dementia strategy for Canada

8.0 FINAL THOUGHTS

The sense of urgency for greater action on dementia has been clearly heard. In these consultations, Canadians spoke honestly of their experiences and were energized and enthusiastic about moving from ideas to action. There is strong support for working together to make change through ongoing, multi-stakeholder engagement and for including the diverse voices of people living with dementia and their caregivers. Canadians feel the time is right for raising awareness and reducing stigma, investing new resources into research and expanded surveillance, and identifying and sharing best practices for dementia care that work across jurisdictions.

There were many examples shared of the challenges that Canadians living with dementia and their caregivers are facing as well as what is working well across the country. Research is providing hope for the future. One example is the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER), which is expanding into a world-wide study⁹ of lifestyle interventions (e.g. physical activity, cognitive training, and social activities) and is showing encouraging results. But new innovations and a stronger evidence base are needed to advance health policies and practices for dementia.

Canadians want a dementia strategy that puts the quality of life of people with dementia and their family/friend caregivers at the forefront; where person-centred, compassionate, integrated care is provided with equity across the country, and the rights of people living with dementia are respected.

⁹ <http://wwfingers.com>



