MIND THE GAP

Closing the Care Divide for Canadians with Dementia

Insights and Solutions to Strengthen Canada's Path Forward

Brainwell Institute

REPORT

Contents

The Brainwell Institute is an independent think tank that elevates evidence to ignite change and revolutionize thinking about dementia and brain health. Now. Made up of a global team of researchers, journalists, policy analysts and healthcare professionals with a shared goal, the Brainwell Institute mobilizes rigorous research, informed reporting and public engagement.

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Executive Summary: Closing the Gap in Dementia Care in Canada

Turning strategy into action for national wellbeing and economic resilience

Dementia is one of the top 10 causes of death in Canada and one of the fastest-growing health crises facing the country. It's not just a health issue; it's also an economic challenge, a nation building one. Left unaddressed, Alzheimer's disease and related dementias threaten to overwhelm families, strain healthcare systems, and erode productivity at a time when Canada can least afford it. As a nation we are facing unprecedented economic challenges, but with the right investments and coordination, dementia care can become part of the solution to Canada's challenges. We can improve quality of life, support caregivers to remain in the workforce, and drive smarter, more sustainable healthcare spending.

Canada is falling behind—but it doesn't have to stay that way.
Supporting dementia is a growing concern worldwide. While Canada has the potential to be a leader in innovative solutions, we were the last G7 country to release a national dementia strategy. And compared to our peers, we're lagging behind in turning strategy into action. Countries like Austria, Denmark, Germany, and Scotland have shown that with clear implementation plans, measurable targets, and proper funding, progress is not only possible, it's a must. These nations are seeing real system-wide improvements. Canada, by contrast, ranks just 7th out of 12 peer nations.

We've already proven we can do this.
Canada successfully transformed cancer and stroke care by creating strong national coordinating bodies, such as the Canadian Partnership Against Cancer (CPAC) and the Canadian Stroke Network. These models work by aligning provinces and territories around shared goals for coordinating care, funding, and standards. Dementia needs a similar approach, recommended as far back as 2016 by the Senate of Canada [1].

Innovation exists but remains trapped in perpetual pilot mode.
Since launching its national strategy, Canada has supported over 70 pilot projects in dementia care. Many have shown promise, improving access, outcomes, and experience. But without national coordination, pathways, or scale-up plans, these successes remain scattered and short-lived. We are innovating without integrating, which means life-changing solutions remain stuck at the local level with small-scale impacts.

What's missing: leadership, targets, and accountability.
Unlike other leading nations, Canada's strategy has no clear timeline, measurable outcomes, or governance structure. There's no national system for scaling what works, measuring what matters, or holding accountability. The result? Progress is slow, fragmented, and difficult to track.

The public and the system feel it.

Despite the investments, fewer than one in five Canadians believe dementia care has improved. Diagnosis still takes an average of two years, and services remain fragmented. Meanwhile, caregivers, who are most often women, continue to bear immense burdens, contributing to an estimated $25 billion in lost productivity and indirect costs.

1 in 5

Fewer than 1 in 5 Canadians believe dementia care has improved.

2 years

Average time to diagnosis.

$25B

Estimate in lost productivity and indirect costs.

Closing the Gap: A Call to Action

Canada has the knowledge and precedent. Now we need to act. To truly improve dementia care and strengthen our health and economic systems, we must:

1. Establish a National Implementation Plan

» Create a detailed, time-bound roadmap with clear roles, responsibilities, and targets.
» Learn from successful national implementation plans (e.g. Denmark's and Germany's).
» Embed accountability and support cross-jurisdictional collaboration.

2. Create a Canadian Dementia Coordinating Body

» Model on the Canadian Partnership Against Cancer (CPAC) or the Stroke Network with governance and federal and provincial/territorial shared accountability.
» Guide policy implementation, set benchmarks for success, manage data, monitoring and reporting and standards development and facilitate communication across provinces and territories.
» Facilitate and support coordination of care, pathway development and innovation scale up across provinces and territories.

3. Set Measurable Goals and Monitor Progress

» Track key indicators like diagnosis wait times, caregiver distress, and home care access.
» Build real-time data systems to drive improvement and transparency.

4. Commit to Long-Term, Sustainable Funding

» Support infrastructure, workforce development, and proven care models.
» Tie funding to outcomes and impact, not just intent.

Canada cannot afford to delay.

Dementia is not just a illness; it's a test of our systems, our society, our values, and our future. This is our chance to build a more compassionate, coordinated, and productive country. With bold action now, we can ease the burden on families, unlock economic value, and strengthen the foundations of our health system for generations to come.

Acknowledgements

The Mind the Gap report leverages existing data and research from published reports and experts around the country to paint a broader picture of dementia care in Canada. No further analysis of these data were conducted except for Chapter 3 which contains new findings.

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Research, Coordinating and Editing: The team that coordinated the development, research and writing of this report includes Dr. Larry Chambers, Alixe Menard, Kedron Raju, Katie Kondorosi, Bob Neufeld, Shriya Esananda, Alexandra Whate and Saskia Sivananthan.

Report Reviewers and Subject Matter Experts:

Reviewer	Affiliation
Art Eggleton	Former, Senate Committee on Social Affairs, Science and Technology
Bill Tholl	Former, Heart and Stroke Canada & Canadian Medical Association
Charles Alessi	Former, Public Health England
Christine Thelker	Lived experience of dementia
Claire Godard-Sebillotte	McGill University
Eric Smith	University of Calgary
Frances Morton-Chang	University of Toronto
Jennifer Boger	University of Waterloo & University of British Columbia (Okanagan)
Kelly Kay	Provincial Geriatrics Leadership Ontario
Laura García Diaz	World Health Organization
Laura Tambyln Watts	CanAge, University of Toronto
Leah Sandals	Lived experience of dementia
Marianne Sargosa	Science of Care Institute, Sinai Health
Muir Grey	Former, NHS (England) & University of Oxford
Myrna Norman	Lived experience of dementia
Pamela Fralick	Former, Canadian Cancer Society & Innovative Medicines Canada
Phyllis Fehr	Lived experience of dementia
Ron Beleno	Lived experience of dementia
Rose Joudi	Carya
Sanjna Navani	The Research Institute of the McGill University Health Centre
Tamara Moona	Lived experience of dementia
Tony Hakim	Ottawa Hospital Research Institute
Vivian Stamatopoulos	Ontario Tech University

Every effort was made to accurately assess and interpret the available information; however, given the limitations of publicly accessible data, there may be unintentional errors or omissions. We welcome any corrections or additional insights and encourage readers to reach out to us directly.

Foreword

When our Senate committee tabled ***Dementia in Canada: A National Strategy for Dementia-Friendly Communities*** in November 2016, we warned that dementia was poised to become one of the defining social and economic challenges of this century. We heard again and again from families, experts, and health leaders who knew that the system was not ready for what was coming.

We urged federal leadership, measurable targets, and sustained funding, lessons Canada had already learned in cancer care. Some progress followed, including the release of a national dementia strategy, but too much of our advice remains unfinished business. Diagnosis still takes years, promising innovations are caught in "perpetual pilot" mode, and families shoulder an estimated $25 billion a year in lost productivity. The gap between vision and reality is widening, not closing.

That is why this new report, ***Mind the Gap: Closing the Care Divide for Canadians with Dementia***, arrives at exactly the right moment. It translates longstanding Senate recommendations for today's economic reality with a clear, cost-smart action plan: establish a national implementation roadmap, create a dedicated coordinating body with authority, link public spending to outcomes, and build the realtime data systems that drive accountability.

Most importantly, it reminds us that strengthening dementia care is nation building work.

By easing the burden on caregivers, most of whom are women, and keeping them in the labour force by investing in proven community supports, and scaling what already works, we can boost our productivity and our collective wellbeing.

The choices we make now will decide whether dementia becomes an overwhelming cost or a catalyst for smarter, more compassionate care. The Senate set the course; this report shows us how to reach the destination. Let's get moving.

THE HONOURABLE ART EGGLETON, P.C.
Chair / Deputy Chair, Senate Standing Committee on Social Affairs, Science and Technology (2006-2016)

Chapter 1

The Impact of Dementia in Canada is Beyond Ignoring

Dementia is one of the fastest-growing health challenges in Canada. It is in the top ten causes of death and one of the diagnoses people report worrying about the most [2].

Dementia describes a set of progressive brain diseases that cause a decline in thinking, memory, behaviour and physical abilities over time. It affects how someone remembers, makes decisions, communicates, behaves and moves until they can no longer function in their daily lives.

Age is by far the biggest risk factor for the more common Alzheimer and vascular-related dementias; however, dementia is also a growing concern for those under the age of 65. More than 770,000 Canadians are living with some form of dementia today. In five years, that number is expected to rise to nearly 1 million. On average, more than 350 people are diagnosed with dementia every single day in Canada [3].

The real impact is even bigger.

Many people go undiagnosed, and others live with dementia connected to conditions like Parkinson's disease, Huntington's disease, Down syndrome, brain injuries, and brain tumours—cases that aren't always included in official counts [3].

Canada's population is aging. In the next 20 years, the number of people aged 65 and older is expected to grow by 68%, making up 1/4 of the population by 2040 [4]. That increase means there will be more dementia diagnoses, more families affected, and more pressure on our health care systems [5].

> **"The decision was harrowing. Witnessing the gaps in care led me to continue my caregiving role. I moved to be within five minutes of the facility, and only took jobs which would allow for daily visits. I took him out for walks, drives, and visits home daily while continuing to advocate for his needs. As my peers pursued careers and nurtured their social lives, I often felt isolated".**
>
> *Katie Kondorosi, Caregiver*

Dementia doesn't affect everyone equally and for some, the challenges are overwhelming. Income, education, race, and geography all shape who is most at risk and who gets the care they need, when they need it. Indigenous peoples, racialized communities, and newcomers often face barriers to culturally safe services, leading to delays in diagnosis and treatment. Women bear a double burden as they are more likely to develop dementia and more likely to care for someone who has it. For LGBTQ2S+ people, stigma and discrimination in healthcare can add yet another layer of difficulty [6].

Caregiving for people living with dementia is a complex and demanding role.

A caregiver (also called a care partner) of a person living with dementia spends on average 26 hours a week assisting with activities of daily living [7]; this number can increase to 40 hours as the disease progresses [8].

Dementia caregivers—most of whom are women—provide hundreds of millions of unpaid hours each year, a contribution valued in the billions. By 2050, those hours could be worth nearly $1.4 billion annually, the equivalent of more than 690,000 full-time jobs [3]. But the cost isn't just financial. Nearly half of caregivers supporting someone with dementia report feeling distressed, which is almost twice the rate of those caring for older adults without the disease [7].

Economically, the cost of dementia goes beyond caregiving, and is growing rapidly.

In 2020, total direct and indirect estimates in Canada were at $40.1 billion annually, or $110 million every single day [9]. To put that in perspective, it's nearly equivalent to Canada's entire annual military spending, which was approximately $42 billion that same year. These costs come from many places. Direct costs, which are health system costs incurred in hospitals, care homes, and other care settings and the money families pay out of pocket make up $15.1 billion (46%) [9].

One of the hidden tolls of dementia is *indirect costs*. Indirect costs represent the lost income and productivity for both those living with the disease and their caregivers. For example, many people with young-onset dementia (diagnosed under age 65) and caregivers are forced to cut back on work, take leave, retire early, or quit altogether.

These lost hours add up to an estimated $25 billion a year, or 472 million hours [9]. The burden falls hardest on women, who not only provide more care than men but are also far more likely to scale back or leave paid work entirely [10]. To provide a sense of scale, $40.1 billion annually is roughly enough to pay for over 500,000 direct care homecare workers or run approximately 25,000 community-based dementia care clinics across the country.

> **"The cost of caregiving is huge. I lost approximately $50,000 in annual income and went below the poverty line by having to switch from a full-time job to a part-time (remote) job. My dad's disease progressed faster than the healthcare system could keep up, and I wanted to better support my mum so that she could support my dad and reduce her risk of burnout".**
>
> *Jana Schulz,*
> *Caregiver*

Therapeutically, dementia treatment has lagged far behind other serious conditions in the development of diagnostic tools and drug therapies.

Challenges in developing effective drugs continue to persist, even as progress has been made in understanding dementia and improving diagnosis. Most current treatments offer only temporary symptom relief, with few options that actually slow or change the course of the disease. It is only recently that a new class of disease-modifying drugs for Alzheimer's disease has begun to come to the market, along with new approaches to diagnosis that include blood-based biomarkers and recognition of the value of rehabilitative therapy for dementia. With the increasing application of AI to diagnosis and drug development, it is likely many new options are on the horizon. But currently, Canadian health systems are not yet ready to scale access [11].

Research on risk factors related to dementia has progressed significantly, with strong population evidence. We now understand the impact of risk factors that cannot be changed such as aging and genetics, and lifestyle factors that can be changed such as later in life hearing loss, smoking, high blood pressure, obesity, physical inactivity, and social isolation which all play a big role in increasing dementia risk [12].

Many of these risk factors are interconnected and contribute to multiple health conditions, including cardiovascular diseases, diabetes, and other chronic illnesses. It is estimated that addressing 14 common health and lifestyle factors could prevent or delay nearly half (45%) of new dementia diagnoses, highlighting the significant impact of these shared risk factors on overall health [12]. People with lower income or education, along with Indigenous and racialized communities, are more likely to face risk factors for dementia and have less access to care. This increases their chances of developing the disease and adds to existing health inequalities in Canada [6].

The impact of dementia on Canadians can no longer be ignored.

Dementia is now in the top ten leading causes of death in Canada and one of the diagnoses people are most concerned about [2]. As more people are affected, the emotional, financial, and social impact will only grow. Our health systems are already under significant strain. Without action, the pressure has become overwhelming.

There is hope. New treatments and diagnostics are on the horizon along with increased research investment, but they must be paired with coordinated, integrated, and equitable care, strong support for caregivers, and better prevention efforts. Right now, too many brain health risk factors are going unchecked.

Canada needs to act quickly. We need to redouble our efforts to close the gap with smart investments, better coordination, and committed political leadership to build health systems that can truly support people living with dementia and their caregivers. With the right action today, we can create a better tomorrow.

Chapter 2

A Promising National Dementia Strategy That Lacks Accountability

In 2019, Canada introduced its first-ever National Dementia Strategy [13]. Though it was the last G7 country to do so, the move fulfilled Canada's commitment to the World Health Organization's goal of 75% of countries having a national dementia plan in place by 2025 [14].

The strategy received praise around the world for its person-centered, rights-based approach. It laid out three core priorities: prevention, advancing therapies, and improving quality of life and included a set of aspirational goals (see Table 1). The vision and ambition of the strategy matched what Canadians want to see in terms of leadership for dementia care.

But despite this strong vision, the plan lacks measurable, meaningful targets. There are no clear benchmarks or timelines to track progress or to define what success may look like. Despite the national commitment to equity in dementia care, Canada currently lacks a foundational system of coordinated support into which culturally responsive frameworks can be meaningfully and inclusively implemented.

Oversight for the strategy sits with the Public Health Agency of Canada (PHAC) and is supported by a Ministerial Advisory Board on Dementia. So far, the federal approach has largely focused on funding community pilot projects, raising awareness initiatives and investing in research.

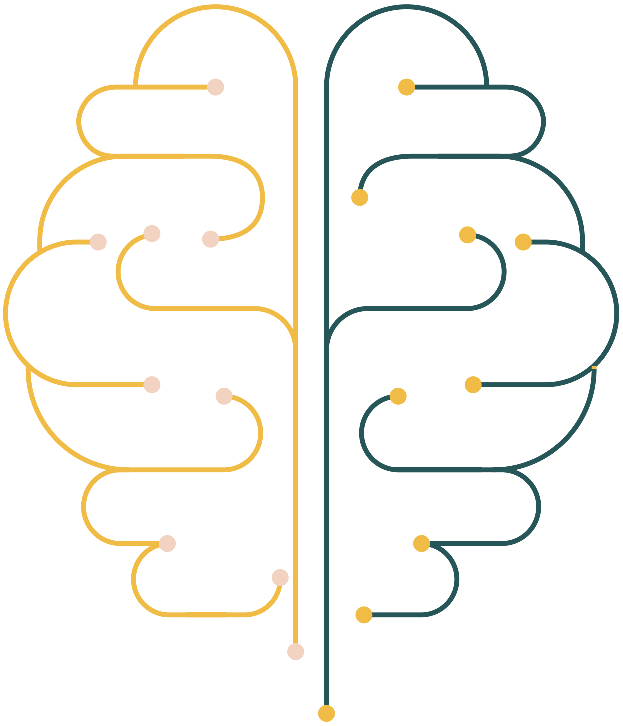


TABLE 1: NATIONAL DEMENTIA STRATEGY PILLARS AND ASPIRATIONAL GOALS [13]

Objectives	Aspirational Goal 1	Aspirational Goal 2	Aspirational Goal 3	Aspirational Goal 4	Aspirational Goal 5
Prevent Dementia	A complete understanding of the risk and protective factors linked to dementia, their impacts and interactions.	Availability of effective prevention resources and interventions, supported by a strong evidence base.	All people living in Canada are aware of actions that prevent dementia.	All people living in Canada have access to built and social environments that support their ability to pursue healthy living in ways that may reduce their risk of developing dementia.	
Advance Therapies and Find a Cure	Research priorities established in an inclusive manner with broad stakeholder input, with the participation of those living with dementia and caregivers.	Annual investment in dementia research in Canada exceeds one percent of dementia care costs.	New evidence-informed person-centred therapies are more readily available.	People living with dementia and caregivers are active participants and partners in research to develop new therapies and find a cure.	Research design always includes efforts that ensure findings can be understood, adopted and quickly put into practice.
Improve the Quality of Life of People Living with Dementia	All people living in Canada understand dementia and stigma no longer exists in Canada.	A timely diagnosis, provided in a compassionate manner, is available to all people living in Canada, along with immediate availability of resources and supports.	Integrated, person-centered quality care based on evidence-informed best practices across all settings and that people feel welcomed and well-cared for when hospitalization or admission to long-term care is necessary.	Care providers have access to the resources and training needed to deliver quality care.	All caregivers have access to the resources and supports required to protect their own wellbeing and to care for someone living with dementia, including being equipped to navigate health care and other support systems.

A Big Investment that Has Ended with Small Reach and No Scale

The federal government initially committed $50 million over five years to support Canada's national dementia strategy. Of this, $40 million was allocated to the Dementia Strategic Fund (DSF) and $10 million to Dementia Surveillance.

In 2018, an additional $20 million over five years was invested in the Dementia Community Investment (DCI) fund. Together, these commitments brought total dementia-related funding to $70 million [15] (Figure 1).

Excluding a separate $50 million allocated for research, the DSF and DCI supported over 70 pilot projects across Canada, delivering services, supports, and public awareness campaigns for people living with dementia and their caregivers.

These funding programs concluded in the 2024–25 fiscal year, with many projects demonstrating a positive impact on participants [16].

But here's the catch: current projections of the overall reach and impact are small.

According to PHAC, between 2019 and 2022, just 8,820 people out of the approximately 770,000 people living with dementia were reached through the DCI funds of $20M –only about 1% of all Canadians living with dementia [17]. Despite the proven success of many of these pilot programs, most people across the country never had access to them, as programs were not given the opportunity to move to scale. Post national awareness campaign surveys similarly show minimal changes in the public's understanding of dementia [17].

Evaluation of PHAC's Aging, Seniors, Dementia Acitvities 2024 [17]

"DCI projects ($20 million) reached 8,820 individuals as well as their family and caregivers [~1% of those with dementia]".

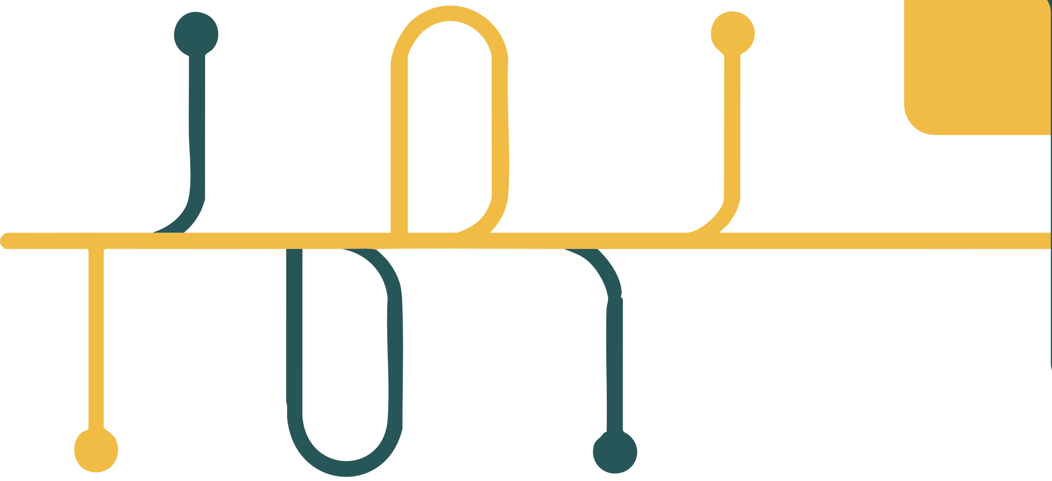


FIGURE 1 - TIMELINE OF FUNDING ANNOUNCEMENTS FOR NATIONAL DEMENTIA STRATEGY

2018

BUDGET ANNOUNCEMENT

February 27, 2018. Federal Government commits $20 million over 5 years – Dementia Community Investment (2018-2023)

February 27, 2018. Federal Government commits $4 million per year ongoing - Dementia Community Investment (2018-->)

2019

BUDGET ANNOUNCEMENT

March 19, 2019. Federal Government commits $50 million over 5 years – Starting 2019/2020 - National Dementia Strategy (2019-2024)

-$10 million will be used to support a better understanding of the impact of dementia in our communities through surveillance

-$40 million for the Dementia Strategic Fund

2022

BUDGET ANNOUNCEMENT

April 7, 2022. Proposes to provide $20 million over five years, for the Canadian Institutes of Health Research to ramp up efforts to learn more about dementia and brain health, to improve treatment and outcomes for persons living with dementia, and to evaluate and address mental health consequences for caregivers and different models of care (2022-2027)

April 7, 2022. Proposes to provide $30 million over three years, starting in 2022-23, to the Public Health Agency of Canada, for the Centre for Aging and Brain Health Innovation (2022-2025)

**Figure adapted from CanAge 2022.*

What Happens When the Funding Runs Out?

Although PHAC has encouraged programs funded through the DCI and DSF funds to build more partnerships and reach more people, there's no current plan to continue funding these projects since funding ended in 2024 [18]. Nor was funding earmarked in the 2025-26 funding estimates tabled in the House of Commons in May 2025 [19].

This lack of long-term support contradicts one of the main recommendations from the World Health Organization's (WHO) Global Dementia Action Plan–which Canada signed on to. The WHO Action Plan called on countries to "allocate *sustainable* financial resources that match the need for services, staff, and tools to carry out national dementia plans" and to "develop a pathway of efficient, coordinated care...that is embedded in the health and social care system" [14].

Without stable, ongoing investment and a plan to scale and integrate the most successful programs into a coordinated pathway of dementia care through our health systems, the original funding committed will sadly have little lasting impact for most Canadians living with dementia and their caregivers.

Five Years In, Still Waiting for Change in Care

Five years after its launch, the National Dementia Strategy remains largely unknown to the public –and its promises of better access to diagnosis, care, and services have yet to be felt by most Canadians. Even PHAC's own polling shows little movement.

Between 2019 and 2024, nearly 60% of Canadians said their views on dementia haven't changed– despite the fact that 82% believe dementia is having a moderate to significant impact on the country [20].

PHAC Dementia Tracking Survey Final Report 2024 [20]

> **"Among those who know someone living with dementia, only 18% believe there is good access to advance care planning and end-of-life care. Only 17% of respondents believe there is good access to quality health care for people living with dementia"**

Among Canadians who personally know someone living with dementia, fewer than 1 in 5 felt that the person has good access to quality health care. A large majority (84%) thought people living with dementia had only a moderate to poor quality of life [20].

Caregivers are also feeling the strain. In 2024, just 47% felt they could provide the care needed, down from 57% in 2020 [20].

Despite this, no formal assessments have been conducted to determine whether the strategy has actually improved access to dementia diagnosis, care planning and other services, or care pathways across Canada (Appendix A).

The Current State of Dementia Care in Canada Is One Without a Coordinated Pathway

Dementia care in Canada has sometimes been described like bushwhacking through the wilderness with no map. Unlike cancer or stroke, which have clear care paths and dedicated systems, people with dementia are left to navigate a confusing maze of waitlists, untrained providers, and scattered services only to hit repeated dead ends. For example, someone might wait two years just to get a diagnosis, then go months without a home care assessment—if they get one at all. In many parts of the country, especially rural or remote areas, families are left to figure things out on their own with little guidance or coordination to help them connect the dots (Figure 2).

Diagnosis Wait Time of Years - Compared to Days for Other Major Diseases

The average wait time for a diagnosis of dementia in Canada is among the longest in the G7, with national averages typically ranging from 21 to 28 months - nearly two years or more from the onset of symptoms to receiving a formal diagnosis [21].

For reference, the average wait time for a diagnosis of cancer, heart disease or diabetes is currently measured in days [22].

> **"This lack of specialist capacity, compounded by family doctors making referrals to specialists due to lack of adequate team-based support for diagnosis, and/or not performing timely initial assessments, accounts for over 90% of the projected wait times to receive a diagnosis."**
>
> *Ontario Dementia Care Alliance (2023)*

Another key metric is the formal diagnosis rate, namely the number of people diagnosed with dementia versus the estimated number of those actually living with it.

This metric is not available for Canada nationally, but broad estimates for high income countries suggest that missed diagnoses are as high as 50% [23], meaning half of all people living with dementia are neither receiving a diagnosis nor receiving appropriate supports and financial benefits nor will they be eligible for future therapeutics. Underdiagnosis is an especially important issue for certain groups of people such as Indigenous peoples, racialized communities and newcomers who already struggle due to social and structural barriers [24].

Most people in Canada find out they have dementia at their family doctor's office or a memory clinic. But here arises another problem: only 41% of Canadian family doctors report feeling well prepared to manage dementia in the community [25]. This is a significantly lower percentage compared to other countries like Norway (69%) and the UK (63%), where doctors feel more confident in managing dementia care [25]. This lack of preparedness means that some people face long wait times just to get diagnosed, which means they might miss out on important early help and support.

In fact, about one-third of Canadians are first diagnosed in the hospital [26]. This scenario usually happens due to a crisis, leading to an ER visit or hospitalization. Hospital environments are very confusing and stressful for someone with dementia, exacerbating disorientation and often leading to longer hospital stays and worse health outcomes in the long run [26].

> **"The biggest challenge has been the lack of urgency. I really have to chase, follow up and advocate for my mother, when I really think that healthcare should be accessible and I should be able to trust my healthcare providers to do things in a timely manner. But I really had to be on top of it to make sure appointments were scheduled as soon as possible."**
>
> *Tamara Moona, Caregiver*

The Brink of a Major Shift for Treatment and Rehabilitation – But We're Not Ready Yet

Drug treatments for dementia are limited and often come with serious side effects. It is only recently that a new class of drugs for Alzheimer's disease – called disease-modifying therapies (DMTs) – are making their way to market [27].

These treatments, already approved in the United States, aim to slow the progression of the disease rather than manage its symptoms. In Canada, both the approval and efficacy of these drugs are still under review, with ongoing evaluation of their long-term benefits and risks. However, when these (or other DMTs) do arrive, our health systems will need serious upgrades to deliver them within the window of opportunity of early stages of the disease—starting with faster, more accurate diagnoses and appropriate access to advanced tools like PET scans, MRIs and cerebrospinal fluid tests.

But medication is only one piece of the puzzle.

A much broader and holistic approach to dementia care is needed – one that includes rehabilitation, better management of related health issues like hearing loss and heart disease, improved caregiver support, and culturally safe care for Indigenous and diverse communities [28]. With the population aging and dementia cases rising, Canada faces an urgent need to get ready for this next chapter in treatment and care management.

Meanwhile, there's growing evidence that non-drug therapies like exercise programs, music therapy, group memory activities, and support for caregivers can greatly improve quality of life for people living with dementia and those who care for them [29]. Some of these programs have received funding through the DCI funds, but no new money or expansion plans have been announced by the Government of Canada. We also don't have national data on how many people benefitted from these services.

Another promising area is rehabilitation. While often overlooked, therapies like occupational therapy, speech therapy, and 'reablement' care help people with dementia stay active, independent, and connected.

In fact, there are now calls for rehabilitation as a guiding philosophy, not just a treatment—similar to how people recover from strokes [30]. This is especially important because people live an average of eight years after a dementia diagnosis. Yet many wrongly assume diagnosis marks the end.

According to the WHO, rehabilitation means "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment" [31]. In the context of dementia, this can include occupational therapy to support daily living skills, speech therapy to address communication difficulties, exercise programs to enhance physical and cognitive function, reablement care to promote autonomy, and cognitive rehabilitation to sustain daily functioning and independence [30] [32]. While often overlooked, such rehabilitation therapies help people with dementia stay active, independent, and connected.

> **"The need for a greater understanding and acceptance of the concept of rehabilitation in dementia is paramount as it plays a crucial role in delivering and accessing rehabilitation services."**
>
> *Jeon et al., 2023.*

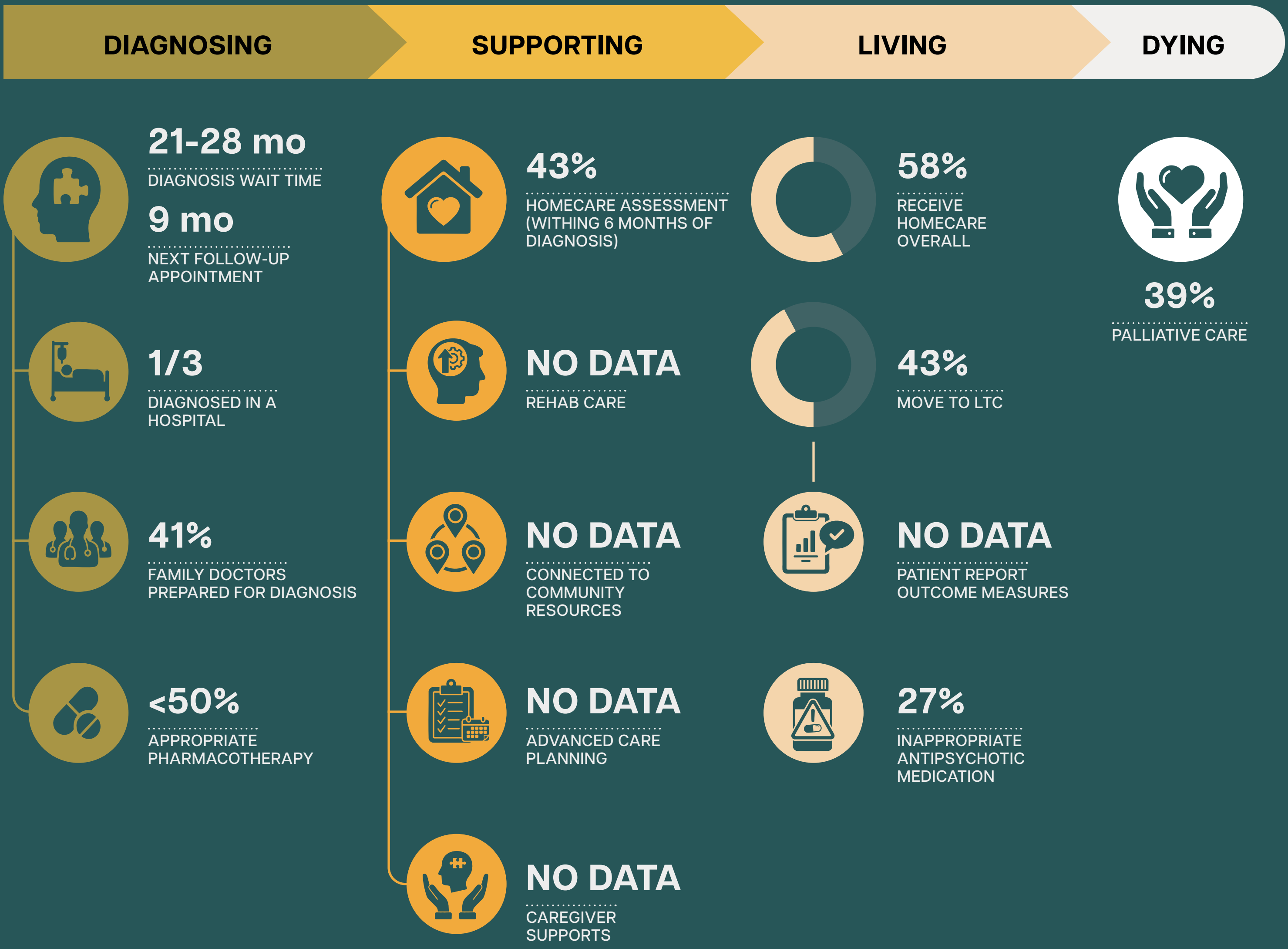
The challenge? Access to publicly funded rehabilitative care in Canada remains extremely limited, (and is even more limited for marginalized groups) and national data on its availability is lacking.

As demand grows, so does the urgency to invest in the full range of care options. This is true not just for new drugs, but services that support well-being, dignity, and independence.

Dr. Barry Campbell, Medical Director of Geriatric Psychiatry at St. Boniface Hospital in Winnipeg

> **"Health systems don't plan to fail people with dementia, but rather fail to plan what to do with them when they reach the inevitable crisis of needing more intense resources and sometimes dealing with acute behavioural issues."**

FIGURE 2: PAIN POINTS ALONG DEMENTIA CARE PATHWAY AND NATIONAL AVERAGES



DIAGNOSING

- 21-28 mo — DIAGNOSIS WAIT TIME
- 9 mo — NEXT FOLLOW-UP APPOINTMENT
- 1/3 — DIAGNOSED IN A HOSPITAL
- 41% — FAMILY DOCTORS PREPARED FOR DIAGNOSIS
- <50% — APPROPRIATE PHARMACOTHERAPY

SUPPORTING

- 43% — HOMECARE ASSESSMENT (WITHING 6 MONTHS OF DIAGNOSIS)
- NO DATA — REHAB CARE
- NO DATA — CONNECTED TO COMMUNITY RESOURCES
- NO DATA — ADVANCED CARE PLANNING
- NO DATA — CAREGIVER SUPPORTS

LIVING

- 58% — RECEIVE HOMECARE OVERALL
- 43% — MOVE TO LTC
- NO DATA — PATIENT REPORT OUTCOME MEASURES
- 27% — INAPPROPRIATE ANTIPSYCHOTIC MEDICATION

DYING

- 39% — PALLIATIVE CARE

> **“It took us about two years to get a diagnosis. We didn’t see this coming, our family was completely devastated.”**
>
> *Tamara Moona,*
> *“Caregiver “*

A Lot of People with Dementia Live at Home—But Many Aren’t Getting the Care They Need

In Canada, about 61% of people living with dementia remain in their homes, relying on help from family, friends, and community services. Even with this blend of formal and informal support, access to home care remains a serious challenge.

Fewer than half—just 43%—receive a home care assessment within six months of their diagnosis. Moreover, only 58% of people living with dementia eventually get home and community care services at all. Of those who do, nearly half are later moved into long-term care, often because they didn’t get enough support at home [26].

The gap between need and support is especially apparent. In 2020 in Ontario, there were 82,000 home care visits for people living with dementia. But the Alzheimer Society of Ontario estimated that 2.5 million visits per year were actually needed. In other words, 30 times more home care visits are needed. This profound deficit illustrates just how far the system is from meeting demand [33].

Caregivers are also feeling the strain.

Family members, particularly women, provide the bulk of dementia care. Respite provides much needed opportunities for rest. Without proper access to a variety of respite options leave many carers burned out and unable to provide care as well as triggering adverse health conditions for the carers themselves [7]. In 2022 only 13% of caregivers accessed formal respite services, such as short-term care stays in a long-term care homes, in-home support, or adult day programs.

The situation is even tougher in rural and northern areas, where waitlists for in-home respite and adult day programs are long and service options are limited. Canada’s National Dementia Strategy has flagged the need for more home care and respite support. While some progress has been made, it is highly dependent on where you live. Most provinces and territories are still struggling with staff shortages and a lack of funding for dementia-specific care.

Without major improvements, too many people with dementia and the families who support them will continue to fall through the cracks.

The Current Reality of Dementia Care

An overwhelming 96% of Canadians say they want to stay in their homes and be cared for in their communities as they age [34]. But for people living with dementia, that goal is often out of reach.

Instead, many end up in long-term care (LTC) homes, where the numbers tell a stark story: about 69% of residents have dementia, and that jumps to 87% when all types of cognitive impairment are included [35].

Getting into LTC is a challenge. Waitlists are long and growing, and families across the country face increasingly lengthy delays.

Inside these facilities, caring for people with dementia is complex, and resources are largely inadequate [36]. More than half of residents show responsive behaviours like pacing and often appear to be upset, frustrated and/or restless. Nearly one in three (31%) show signs of depression. There are other troubling trends. To 'manage' these symptoms, about 27% of residents with dementia are given antipsychotic medications, even if they don't have a diagnosis of psychosis. And the use of physical restraints continues to raise concerns about dignity and safety as well [35].

Many direct care healthcare workers, especially Personal Support Workers (PSWs) and nurses in LTC, are underprepared when it comes to dementia care. PSWs deliver most of the hands-on support for people living with dementia, yet they often receive little formal training on the condition and have few chances for ongoing education. As a result, the quality of care can suffer. PSWs say they need more support in understanding dementia, handling responsive behaviours, using person-centred communication, and spotting conditions like delirium [37].

People With Dementia Often Miss Out on Quality End-of-Life Care

Palliative care is a whole-person approach to treatment that focuses on comfort and quality of life for people facing serious illness at any age and any stage. It aims to ease pain, manage symptoms, and provide emotional, social, and spiritual support for both patients and their families, alongside any other treatments they may be receiving [38].

Unfortunately, for people living with dementia, access to palliative care is far from equal.

Only 39% of eligible people with dementia receive palliative care, compared to 77% of people with cancer [39]. That means most people with dementia aren't getting the support they need during one of the most vulnerable times in their lives. Many barriers make it difficult for people with dementia to access palliative care. These include the mistaken belief that dementia is not a terminal illness, as well as shortcomings in policies and resources that support palliative care. There is also a shortage of healthcare professionals who are trained in both palliative care and dementia [40].

People with dementia are less likely to be referred to palliative care teams, to be prescribed key medications that ease symptoms, or to be admitted to hospice care [39]. These gaps show that end-of-life care for people with dementia is still falling short, even though we know what helps.

MIND THE GAP STUDY FINDINGS

Chapter 3

Lessons for successful dementia implementation from others

What Makes a National Strategy Work?

A strategy is only truly successful if it makes a real difference in people's everyday lives. For dementia, this means achieving meaningful improvements through coordinated care, support, and a better day-to-day experience for people living with the condition and for their caregivers.

To understand what makes a national dementia strategy work, we examined research in business and change management. We found **six key ingredients for successful implementation** (see Table 2). These are especially important in systems like Canada's, where health care is managed by different provinces and territories instead of a single central authority.

These six ingredients of success are based on proven ideas from research about how to lead change in big, complex systems. You can learn more about how we did this review in **Appendix B**.

TABLE 2: IMPORTANT DEFINITIONS AND MEASURES FOR THIS CHAPTER

Ingredients for successful implementation	Definition	Measures
Who makes decisions? **(Governance)**	Strong governance structures and committed leadership are crucial for driving the implementation. Clarity on lines of authority, responsibility and decision-making processes need to be included.	• Implementation led by one ministry coordinated with others • Implementation responsibility across multiple ministries and stakeholders • Ongoing decision-making process exists for funding and implementing with senior ministry personnel assigned
Are there clear goals we can track? **(Measurable goals & initiatives)**	An implementation blueprint which outlines details of initiatives, targeted populations, expected outcomes that are measurable with achievable targets. In some cases, these may be broader goals with explicit, timebound measurable targets.	• Goals with measurable targets (specific quantifiable benchmark with a timeframe) • Goals with measures or indicators of success (metric to evaluate the success of reaching that goal)
How much money and support is provided? **(Resource allocation)**	Adequate funding, staffing, and infrastructure are required to support implementation efforts. While sustainable investments are critical, a competent workforce with capacity to implement is equally critical for system change.	• Overall sustainable funding (multi-year funding allocated and disbursed) • Staffing or infrastructure identified • Funding tracked for initiatives or goals
Are timelines and roles clearly communicated? **(Timeframes & responsibilities)**	Along with strong governance should be a clear roadmap outlining timeframes and responsibilities. This requires partnership and collaboration in federated systems. Key partners should have buy-in to ensure those responsible for implementation have autonomy to execute, tied to having mechanisms in place for monitoring and reporting.	• Specific timelines for goals • Responsible partners identified for goals
How is progress tracked? **(Monitoring)**	Accurate and timely information systems for surveillance and program monitoring are critical. These provide data to track implementation progress and impact against targets. These should ideally be interoperable and standardized across information systems though annual surveys measuring against performance targets can be equally effective.	• Surveillance system or organization for monitoring • Data or surveys regularly deployed
How is progress shared? **(Reporting)**	Regular disclosure and public reporting on implementation progress and impact including on performance targets. Ideally, a mechanism for feedback from people with lived experience of dementia, clinicians, researchers and the general public about the reporting is desirable.	• Public reporting accessible (either reports or website or dataset) • Detailed data accessible (specific data and statistics available through information systems for surveillance and program monitoring) • Mechanism for feedback from public is available

Canada Ranks 7th out of 12. What Can We Learn from Other Countries?

To help guide improvements in Canada, we looked at how other countries have put their dementia strategies into action. As of May 2025, many countries (47 in total) have created and begun carrying out national dementia strategies [41].

Table 3 presents a summary what we found comparing the 11 other countries that are most like Canada (i.e., similar health systems, economies, and government structures) against the six key ingredients of successful implementation.

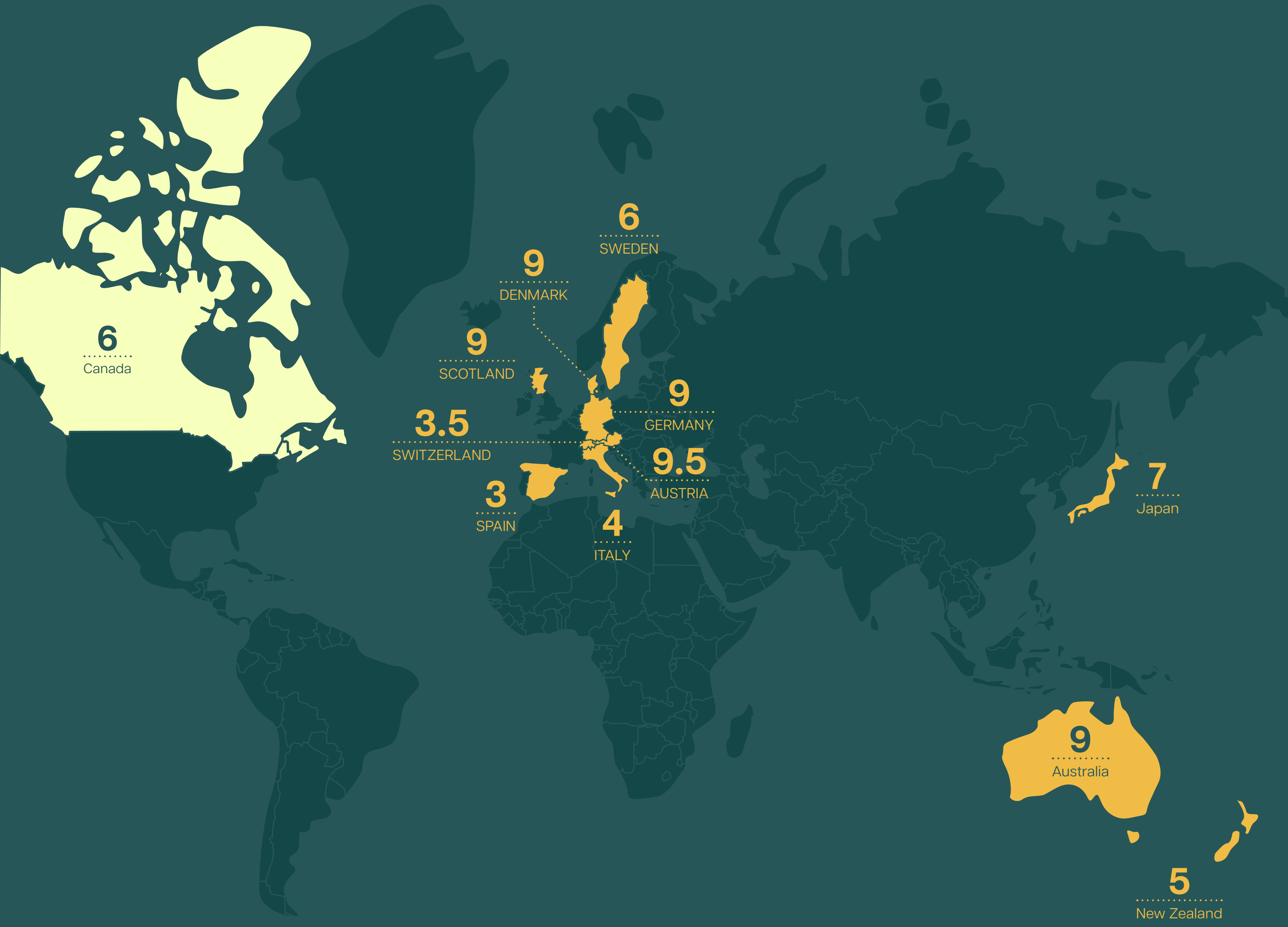
Our review showed a wide range of approaches. Some countries are doing well in several areas, while others still have a long way to go. These global examples give us important lessons on what works—and what doesn't—when it comes to making dementia strategies real and effective.

Five countries in particular stand out for consistently meeting more of the key ingredients of success, resulting in a score of 9 or more (out of a possible 14): Australia, Austria, Denmark, Germany and Scotland (Figure 3).

TABLE 3: DETAILED ANALYSIS OF COUNTRIES IMPLEMENTATION OF DEMENTIA STRATEGIES

		Implementation led by one ministry, coordinated with others	Implementation responsibility across multiple ministries and stakeholders	Ongoing decision making process exist for funding & implementing with senior ministerial personnel assigned	Goals with measurable targets (specific quantifiable benchmark with a timeframe) *ALL/SOME/NONE	Goals with measures or indicators of success (metric to evaluate the success of reaching that goal) *ALL/SOME/NONE	Overall sustainable funding (multi-year funding allocated and disbursed)	Staffing or infrastructure identified	Funding tracked for initiatives or goals	Specific timelines for goals	Responsible partners identified for goals	Surveillance system or org for monitoring	Data or surveys regularly deployed	Public reporting accessible (either reports, website, or dataset)	Detailed data accessible (specific data & statistics available through information systems for surveillance & program monitoring)	Mechanism for feedback from public is available	
🇦🇹	2015		✓	✓	SOME	ALL	✓				✓	✓	✓	✓		✓	9.5
🇦🇺	2024 - 2034		✓	✓	NONE	NONE	✓			✓	✓	✓	✓	✓	✓		9
🇩🇰	2025	✓		✓	ALL	ALL	✓		✓		✓		✓	✓			9
🇩🇪	2020-2026		✓	✓	NONE	ALL	✓			✓	✓		✓	✓		✓	9
🏴󠁧󠁢󠁳󠁣󠁴󠁿	2023 - 2033	✓		✓	NONE	NONE	✓			✓		✓	✓	✓	✓	✓	9
🇯🇵	2019		✓	✓	SOME	SOME	✓			✓		✓		✓			7
🇸🇪	2025 - 2028	✓		✓	NONE	NONE	✓				✓			✓			6
🇨🇦	2019	✓			NONE	NONE	✓		✓			✓	✓	✓			6
🇳🇿	2020		✓		SOME	SOME	✓				✓					✓	5
🇮🇹	2014	✓		✓	NONE	NONE	✓					✓					4
🇨🇭	2014 - 2019		✓	✓	NONE	SOME					✓						3.5
🇪🇸	2019 - 2023	✓			NONE	NONE	✓					✓					3
		Governance			**Measures**		**Resource Allocation (funding & capacity)**			**Timeframes & Responsibilities**		**Monitoring**		**Reporting**			**Overall Score**

FIGURE 3: COUNTRY SCORE FOR DEMENTIA STRATEGY IMPLEMENTATION (MAXIMUM SCORE 14)



Full results available in Sivananthan SN et al. Lessons from Abroad for Canada's National Dementia Strategy: Actions for Implementation. Canadian Health Policy, May 2025.

GOVERNANCE

Who's Making the Decisions? Strong Leadership and Clear Lines of Decision-Making

Strong leadership is a key component of the successful implementation of any strategy. For Canada's dementia strategy to succeed, a Canadian dementia coordinating body with the authority to lead the effort and work with provinces and territories to set shared goals, define responsibilities, and track progress is required. This type of leadership is key to guiding successful policy implementation, capacity planning, standards development and facilitate communication.

What other countries are doing: Countries have taken different approaches to leading their national dementia plans. Some—like Denmark, Italy, Scotland, Spain, and Sweden—use a centralized model, where a single ministry takes the lead. This helps with coordination and staying on track. Other countries—such as Austria, Germany, Japan, New Zealand, and Switzerland—spread the work across several ministries and partners. This can involve more people, but it enables more buy-in and a broader approach that extends beyond health.
Essential to it all are clear lines of decision making and funding. All countries who have successfully moved their strategies forward have engaged senior ministers to lead the charge who have authority to make decisions.

Lessons for Canada: Right now, PHAC is the named lead of the national dementia strategy. But when it comes to putting the strategy into action, there is fragmentation and disorganization.

Different provinces and territories have different dementia initiatives and policies, and it's not always clear who is responsible for what [17]. As a recent government report notes, this confusion slows progress and makes it hard to hold anyone accountable for outcomes.

WHAT NEEDS TO CHANGE

BOX 1: NEXT STEPS IN GOVERNANCE FOR CANADA'S DEMENTIA STRATEGY

- **Clarify provincial and territorial roles** ensuring each region knows exactly what it's responsible for, while still working toward the same national goals and standards.
- **Strengthen national advisory leadership** by giving Canada's Ministerial Advisory Board on Dementia more authority to monitor progress, facilitate shared work and ensure accountability.
- **Improve communication and transparency** by implementing clear, agreed upon ways to report progress, share updates, and engage shareholders for long-term, measurable results.

With clearer leadership and strong coordination - one that utilizes strengths from both federal leadership and provincial/territorial frameworks - Canada can improve consistency, drive implementation, and ultimately deliver better outcomes for people living with dementia and their care partners.

MEASURES

Are There Clear Goals We Can Track? Measurable Progress

An effective strategy needs clear, realistic, measurable goals along with a plan for how to achieve them. These goals should have deadlines and be designed to meet the needs of specific groups. Milestones along the way help track progress and show when adjustments are needed.

What other countries are doing: Denmark is leading the way; it is the only country that includes clear targets and measures of success for each goal in its dementia plan. Others like Austria, Japan, and New Zealand have some goal success measures, but most countries lack strong systems in place to track progress.

An Example from Denmark:
Goal: *Increased timely and accurate diagnosis*
Target: *80% of people living with dementia must have a specific diagnosis by 2025*
Success measure: *National diagnostic rates and integration of memory clinics data*

Lessons for Canada: Canada's National Dementia Strategy articulates a strong vision and objectives and it tracks progress on some key data points through annual reports.

But the strategy doesn't include specific targets or a plan to measure what success looks like. That makes it difficult to know whether the strategy is working or how to improve it. While initiatives like the DCI funds and the Enhanced Dementia Surveillance Initiative have produced innovative projects and some valuable data, there is no plan for the scale and spread of the programs that demonstrate success.

WHAT NEEDS TO CHANGE

BOX 2: NEXT STEPS IN MEASUREMENTS FOR CANADA'S DEMENTIA STRATEGY

Create an action plan that includes:

- **Specific, time-bound targets** for each priority area.
- **Specific performance indicators** to measure progress and success.
- **Milestones** to check if we're on track.
- **Strong data and reporting** tools for shared accountability and transparency.

With better planning and tracking building on the strengths of the PHAC surveillance unit and CIHI, Canada can demonstrate accountability when coupled with strong governance structures.

RESOURCE ALLOCATION

How Much Money and Support is Provided? Sustainable Funding and Resources

A good dementia strategy doesn't just need money —it needs steady investment in people, services, and systems. Federal, provincial and territorial funding should come with clear performance indicators and be tracked to ensure it's being used to achieve outcomes that have been agreed upon.

What other countries are doing: Almost all the countries studied had some form of multi-year funding for their dementia strategies. Our review didn't measure if the funding of these strategies is adequate for its population or outcomes. Denmark and Sweden clearly linked their budgets to specific programs, as does Canada. Most countries' plans didn't include enough details about spending on staff or facilities, which make it hard to measure results or assess accountability.

Lessons for Canada: Canada's dementia strategy has received more than $81 million over five years. But experts note this is not enough to truly change the system of care, especially when compared to other national health strategies like cancer control, which have received substantially higher and ongoing funding. Right now, most of the investment goes to short-term pilot projects or research, making it challenging to move beyond pilot projects and achieve the large-scale, sustainable improvements that are desperately needed.

WHAT NEEDS TO CHANGE

BOX 3: NEXT STEPS IN RESOURCES FOR CANADA'S DEMENTIA STRATEGY

- **Commit to multi-year, sustainable funding in the health budget** that matches the size of the challenge and ambition of the dementia strategy.
- **Dedicated funding to scale successful pilots** to move solutions from small to large scale impact.
- **Link funding to clear performance indicators and outcomes** so it's easier to have shared accountability and celebrate success.
- **Improve funding transparency and reporting** to build public trust and allow clearer evaluation on the return on investment.
- **Invest in staff and infrastructure to support care coordination** so that we leverage the strengths of our health system while addressing local need.

With smart, steady investment and better tracking, Canada can move from promising pilot projects to a fully realized, equitable, and effective national dementia strategy that truly improves life for people living with dementia and their caregivers.

TIMEFRAMES & RESPONSIBILITIES

Are Timelines and Roles Clearly Communicated?

For a national dementia strategy to work, everyone involved—governments, organizations, and communities—must know what they're responsible for and when. A clear plan should include timelines, role assignments, and ways to work together. There also needs to be a balance between accountability and flexibility so that actions are taken while allowing room for local solutions.

What other countries are doing: International Findings: Some countries, like Japan and Switzerland, included clear timelines in their plans. Others, such as Austria, Denmark, New Zealand, and Australia, named specific agencies to lead different aspects of their strategy. Germany excelled in having both clear timelines and being specific about who is responsible for delivery.

🇩🇪 ***An Example from Germany:***
Goal: *Counselling for dementia in public institutions*
Role: *The Federal Ministry of Education, Research, Senior Citizens, Women, and Youth (BMFSFJ), German Alzheimer's Society (DAlzG) and Federal Association of Independent Welfare Organizations (BAGFW) work together to ensure that open meetings or consultation hours on the subject of "dementia" are increasingly offered in publicly accessible institutions and, for example, as part of lunch tables – especially for people living alone.*
Timeline: *By the end of 2024, the relevant stakeholders will establish dementia counseling services in public institutions where needed and publicize these services.*

Lessons for Canada: Canada's strategy recognizes the importance of collaboration among governments, organizations, and communities. But it doesn't communicate who is responsible for carrying out specific parts of the plan or detailed assignments of responsibility for implementation across federal, provincial, territorial, and community partners. Without this, it's hard to measure progress or make sure the strategy leads to real change.

WHAT NEEDS TO CHANGE

BOX 4: NEXT STEPS IN ROLES AND TIMELINES FOR CANADA'S DEMENTIA STRATEGY

- **Create an action plan with clear roles and responsibilities of delivery:** for federal, provincial, territorial and community actors.
- **Set realistic deadlines:** for each priority so that progress can be tracked.
- **Establish measurable targets:** for shared accountability and regular tracking of success.
- **Establish a coordinating committee with authority:** for fostering collaboration, communication and processes for coordination across all levels of government.

By being clearer about roles and timelines, Canada can turn high-level vision into real action, and make life better for people living with dementia and the people who care for them.

MONITORING & REPORTING

How is Progress Tracked and Shared?

To know if a national dementia strategy is working, we need a robust system to monitor progress. This means collecting data in the same way across provinces and territories and checking regularly to see what's working and what's not. It also means sharing updates with the public. Reports should show real results, highlight where things need to improve, and include voices from people living with dementia, caregivers, healthcare workers, and communities. This type of communication supports transparency, program evaluation, and accountability.

What other countries are doing: Australia, Austria, Germany and Scotland have strong systems in place to monitor progress and report on it. In some cases, countries deploy annual surveys, or maintain consistent indicators with central agencies responsible for routine tracking. Others, like Australia and Scotland, commit to sharing public "report cards" to show progress transparently.
Austria, New Zealand, Germany and Scotland also have ways for the public to provide much needed feedback on the strategy.

An Example from Austria:
Monitoring surveillance system: *Outcome Measurement in Health Care framework*
Surveys regularly deployed: *Austrian Dementia Quality Registry (ÖDQR) and annual formal reporting on initiatives made public through https://www.demenzstrategie.at/*

Lessons for Canada: While Canada does have some public reporting, it lacks a national system to collect and track dementia-related data in real-time. Different provinces and territories collect different types of information, which makes it hard to compare results, measure against targets or identify where care is falling short. While annual reports offer some updates, there is no consistent way to measure performance or gather feedback from people living with dementia and their care partners.

WHAT NEEDS TO CHANGE

BOX 5: NEXT STEPS IN MONITORING AND REPORTING FOR CANADA'S DEMENTIA STRATEGY

- **Deploy a centralized monitoring system** that collects the same data across the country and tracks progress in real time against targets.
- **Link monitoring and reporting directly to targets and performance indicators,** making sure the data is tied to clear implementation and used to adjust the strategy when needed.
- **Continue to report publicly and regularly** on what's working and what still needs attention.
- **Create a formal mechanism for feedback** from people with lived experience and shareholders to be responsive to the needs of those most affected by dementia.

These steps would help Canada better understand what's helping people with dementia and what needs to change. A strong monitoring system builds trust, supports smart decisions, and ensures the strategy makes a real difference.

Chapter 4

From strategy to implementation - Canada knows how to tackle major health issues

Transforming a national strategy into real change in complex health systems requires not only funding, but also strong leadership, clear roles, and a system for tracking progress. In Canada, responsibility for our healthcare systems are divided between the federal and provincial and territorial governments, which adds extra layers of complexity.

The federal government sets national standards, funds healthcare, and leads public health initiatives. But provinces and territories control how healthcare is planned, delivered, and regulated.

For dementia care, this division has created a confusing and fractured system. There's no clear path for people to follow from diagnosis to care, partly because dementia touches so many parts of life other than health. It often falls under multiple ministries, including Health, Long-Term Care, Seniors, Accessibility, Municipal Affairs, and Housing.

Canada has already shown that it can tackle major health challenges when the right pieces are in place. Two powerful examples are cancer care and stroke care.

Coordinated and Integrated Dementia Care Across the Country Must be Next

Canada has shown it can build strong, effective systems for complex health conditions like cancer and stroke. These areas now have coordinated networks, clear care pathways, and national plans that help people get better care, faster. But for dementia, the picture looks very different.

Right now, dementia care in Canada is fragmented and inconsistent. Access to services varies from region to region. Many families are left confused, trying to navigate a system that isn't built to support them from diagnosis to end-of-life care.

As the number of people living with dementia continues to grow, the need for action is urgent.

To improve care, Canada needs a national dementia implementation strategy, designed using lessons from the transformation of cancer and stroke services. This strategy should:

Create provincial and regional dementia agencies or networks to lead and coordinate care on the ground.

Set clear responsibilities tied to measures, so everyone knows who is accountable and how.

Use proven methods to put research into action across provinces and territories.

Build standardized care pathways, so people with dementia and their families know what to expect and how to get support.

Improve data collection and sharing, to track progress and make sure services are working well and reaching everyone.

By taking these steps, Canada can scale up what works, better support caregivers, and build a seamless system where people living with dementia get the care they need—when and where they need it.

The success we've seen in cancer and stroke care shows what's possible. It's time to bring that same energy and coordination to dementia.

How Canada Tackled Cancer - What Dementia Care can Learn

In 2006, Canada created the Canadian Partnership Against Cancer (CPAC)—a major turning point in how the country approached cancer.

Moving from a fragmented, unstructured approach to a coordinated and comprehensive system, CPAC was created as an independent, federally funded organization to steward the Canadian Strategy for Cancer Control. CPAC brought over 700 groups together, including doctors, researchers, government bodies, patient groups, and community organizations.

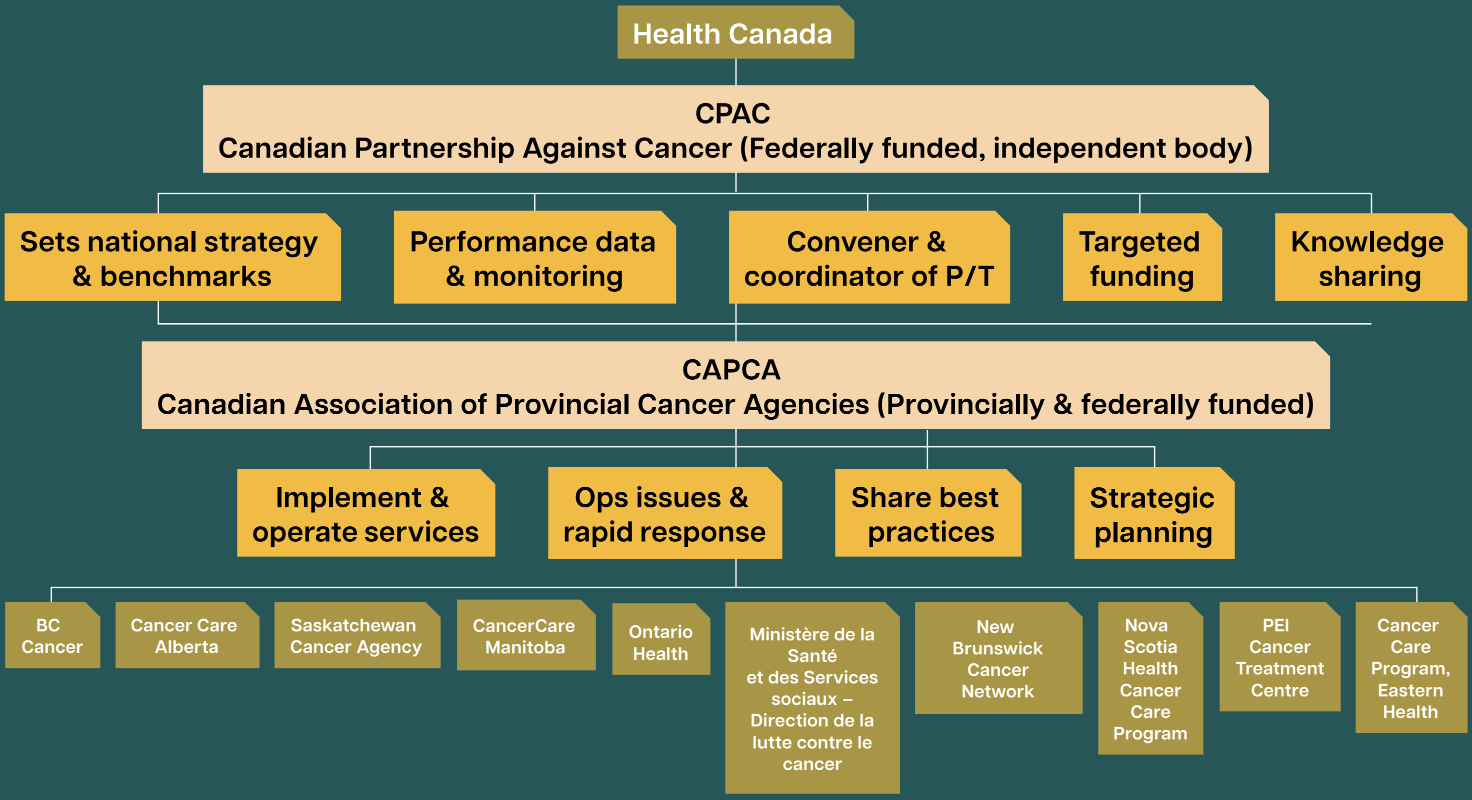
CPAC was given a specific mandate: 1) set as needed and support implementation of a national cancer strategy including setting benchmark for success 2) linked to the benchmarks is collecting and managing performance data, monitoring and reporting regularly 3) convene and support coordinating care across the provinces and territories 4) support knowledge sharing and 5) provided targeted funding to specific initiatives that need scale and spread.

The result? A national strategy that united the country around common goals while respecting provincial and territorial control. To be clear, the model for cancer care is not perfect, and the parallels are not exact, but it does demonstrate how it is possible to mobilize tangible improvements in coordination of care, standards and scaling innovations.

Building Provincial and Territorial Coordination Across Canada

A key element in CPAC's success has been its collaboration with provincially and territorially established cancer agencies and programs (Figure 4).

FIGURE 4 – STRUCTURE OF CPAC IN RELATION TO PROVINCIAL AND TERRITORIAL ORGANIZATIONS



Every province and territory in Canada has its own cancer care agency or program, each responsible for the operations and coordination of cancer prevention, diagnosis, treatment, research, and data collection. Some report directly to their provincial and territorial Ministers of Health, while others report to local health authorities. All receive sustained provincial and territorial funding.

Together, these agencies form CAPCA (the Canadian Association of Provincial Cancer Agencies) which helps coordinate and operationalize shared priorities, joint initiatives, and consistent standards across jurisdictions.

From screening and diagnosis to treatment, survivorship, and palliative care, patients are supported every step of the way. Patient navigation programs, coordinated by oncology nurses and other professionals, proactively help individuals and their families move more smoothly through the healthcare system.

Rapid referral and diagnostic systems reduce wait times and the improve speed and accuracy of cancer diagnoses. Integration with family doctors ensures patients receive comprehensive support throughout their cancer journey.

6

Between CPAC and CAPCA **all six ingredients of successful implementation** are met: strong governance, measurable targets, appropriate resources, clear responsibility, monitoring and public reporting - allowing Canada to develop clear care pathways for people with cancer (Figure 5).

Real Results for Cancer

This model of shared accountability, coordination, and collaboration has delivered significant, measurable improvements.

BOX 6: IMPROVEMENTS IN CANCER CARE

1. **More people survive cancer thanks to earlier detection and population-wide screening.**

   Over 65% of individuals diagnosed with cancer are alive five years post-diagnosis, positioning Canada among countries with the highest cancer survival rates.

2. **Cancer screening and smoking cessation rates have improved.**

   95% of cancer care settings now offer help to quit smoking. Screening participation increased for eligible Canadians for major cancers to almost 70% nationwide with benchmarks of 90% [42].

3. **Care is more consistent** with shared standards and patient reported outcomes being used to improve services.

   Developed and implemented clinical guidelines, ensuring consistent, high-quality cancer treatment across provinces and territories. Integration of Patient-Reported Outcomes into routine cancer care is widely adopted across Canada.

4. **A national data strategy** helps track progress and improve performance and quality.

   The Pan-Canadian Cancer Data Strategy was initiated to mobilize data for improving cancer care access, quality, and outcomes.

5. **Palliative care is easier to access**, with better transitions between cancer care and primary care [39].

   Over 50% of cancer patients now access palliative care earlier in their treatment journeys, improving quality of life.

**Data primarily from the Canadian Partnership Against Cancer, Canadian Institutes for Health Information and Statistics Canada.*

A Blueprint for Dementia from Cancer

The CPAC model shows what's possible when federal leadership and provincial/territorial coordination work together. Dementia is complex, but cancer is too.

Right now, the path forward is unclear. But the cancer strategy proves that, with the political will, long-term investment, and a coordinated national effort, Canada can rise to the challenge.

How Canada Tackled Stroke – What Dementia Care Can Learn

Back in 2005, Canada launched a bold plan to tackle stroke care. The Canadian Stroke Strategy (CSS) was a national effort led by the Canadian Stroke Network (CSN) and the Heart and Stroke Foundation, with support from all levels of government. The goal? To reduce deaths and disability due to stroke and improve care for everyone in Canada—no matter where they lived.

The strategy focused on spreading best practices, improving coordination, and making sure every Canadian had access to fast, high-quality stroke care.

Building Stroke Networks Across Canada

One of the biggest successes of the strategy was the creation of provincial/territorial and regional stroke networks.

Heart and Stroke Canada, with support from industry and the provincial Foundations, worked with academic leaders across Canada to successfully compete for federal funding under the Network of Centres of Excellence program to establish the CSN. Through the CSN, clinical leaders and researchers came together to improve stroke care (e.g. early clot busting interventions); to enhance collaborative research across the country and scale and spread best practices through clinical practice guidelines. Working through and with provincial leadership, the CSN helped bring the national plan to life at the local level. They were tasked with adapting and turning stroke care guidelines into action —making sure hospitals, rehabilitation centers, ambulances, and community organizations worked together.

The CSN provided leadership, accountability, and coordination, ensuring that stroke care was not only standardized but also responsive to local needs (Figure 5). This approach helped create smooth care pathways for people who had a stroke, from emergency care to recovery at home.

The CSS also brought in stronger, integrated data systems and treatment protocols. Provinces built stroke registries to track cases, treatments, and outcomes in real time. This made it easier to spot gaps, develop benchmarks, share successful practices quickly, and keep improving stroke care across the country.

Critical to this success was sustained federal funding of some $80M over 14 years.

Real Results for Stroke

This coordinated approach led to major improvements in stroke care and outcomes.

BOX 7: IMPROVEMENTS IN STROKE CARE

1. **Fewer stroke deaths:** Thanks to earlier diagnosis, dedicated emergency care, and stronger prevention strategies, more people are surviving strokes.

   More than 80% of Canadians who have a stroke and make it to the hospital now survive.

2. **Fewer strokes overall:** Public awareness campaigns and better management of risk factors like high blood pressure helped reduce the number of strokes.

   Awareness of the early signs of stroke doubled from 20% to over 40% in 10 years.

3. **Fairer, more consistent care:** No matter where you live in Canada, stroke care is now more likely to follow best practice guidelines.

   Achievable benchmarks of care (ABC) set and measured nationally. Development and dissemination of Canadian Best Practice Recommendations for Stroke Care.

4. **Faster treatment in emergencies:** Programs like code stroke and telestroke help doctors act quickly enabling timely administration of thrombolysis and endovascular therapy, which can save lives and reduce disability.

5. **Specialized stroke units:** Many hospitals now have dedicated teams and units just for stroke patients, which research shows leads to better outcomes.

   Stroke patient admissions decreased and referrals to stroke prevention clinics increased.

6. **Better access to rehabilitation services:** Stroke survivors are now more likely to get timely, intensive rehabilitation, which improves recovery and quality of life.

Data primarily from the Heart & Stroke Foundation of Canada, and Canadian Institute for Health Information

A Blueprint for Dementia from Stroke

The Canadian Stroke Strategy worked because it had collaborative national leadership, sustained multi-year funding, provincial coordination, industry engagement and a clear plan based on evidence.

As Canada faces rising rates of dementia, the stroke strategy offers a blueprint. With the right leadership and sustained financial support, we can build a similar system—one that ensures people living with dementia and their families get the care they need, when and where they need it.

FIGURE 5 – CANCER AND STROKE CARE IN CANADA MEASURED AGAINST THE 6 INGREDIENTS OF SUCCESS

Ingredients for success	**Cancer Care**	**Stroke Care**
Who makes decisions? (Governance)	✓ CPAC, CAPCA, Provincial Cancer Agencies	✓ Heart & Stroke Foundation, Canadian Stroke Network, Provincial Steering Committees ⊗ No dedicated national agency
Are there clear goals we can track? (Measurable goals & initiatives)	✓ Canadian Strategy for Cancer Control – sets system benchmarks, patient reported outcomes	National Stroke Strategy – set clinical targets ⊗ Variable system benchmarks depending on province
How much money and support is provided? (Resource allocation)	✓ Contribution Agreements - Federal and provincial budgets	✓ Provincial budgets
Are timelines and roles clearly communicated? (Timeframes & responsibilities)	✓ Canadian Strategy for Cancer Control and implementation plans	✓ Stroke Network, Provincial Steering Committees ⊗ No national operational framework
How is progress tracked? (Monitoring)	✓ Cancer system performance reports, independent evaluations	✓ Provincial systems and registries ⊗ No unified national data system
How is progress shared? (Reporting)	✓ Annual reports by CPAC	✓ Provincial reports ⊗ No comprehensive national reporting

CPAC - Canadian Partnership Against Cancer, CAPCA - Canadian Association of Provincial Cancer Agencies

Chapter 5

Getting things done for dementia in Canada

Dementia is one of Canada's biggest public health challenges. More people are being diagnosed, and the healthcare system is struggling to keep up. It's time to move from strategy to action—action that's coordinated, funded, and focused on results.

This international analysis reveals that while Canada's strategy articulates a strong vision, its implementation remains fragmented, underfunded, and inconsistently measured. Most critically, the strategy lacks the core ingredients that have enabled transformative change in other countries and in Canadian domains such as cancer and stroke care: clear governance structures, measurable goals, sustainable funding, defined responsibilities, and ongoing monitoring and evaluation.

> **"Despite the heartbreaking changes, my father showed remarkable grace and courage. We, however, were unprepared for the progression of dementia."**
>
> *Katie Kondorosi, Caregiver*

Key Takeaways

Canada is not alone—but it is lagging. While Canada was the last G7 country to launch a national dementia strategy, many peer nations have advanced further by adopting concrete implementation plans. Countries like Denmark, Germany, and Australia have shown that with health systems similar to ours, they can deliver coordination and progress when governance is clear and funding is tied to measurable outcomes leaving Canada ranked 7 out of 12.

We have models from other major diseases. Canada has already shown, through cancer and stroke care, that we can make significant improvements toward clearly articulated shared goals in collaboration with provinces and territories. Coordinating bodies like CPAC and the Stroke Network were crucial for this and we need to adapt these successful models to dementia as recommended in 2016 by the Senate of Canada.

Pilot projects that need scale and integration into dementia care pathways. Over 70 pilot projects have been funded across Canada since the strategy was launched, many of which have shown promising outcomes. Yet without dementia pathways of care, national coordination or scale-up plans these successes remain isolated and limited, unlikely to make a lasting mark.

Clear targets with governance and accountability. Unlike Denmark or Germany, Canada's strategy does not include time-bound targets to measure impact or strong governance structures to maintain accountability and drive change. This must be the next phase of Canada's strategy.

Canadians don't feel the change. Despite investments, public opinion polling shows that fewer than 1 in 5 Canadians believe there has been improvement in dementia care. Wait times remain extreme, services remain inaccessible to many, and caregivers continue to shoulder the burden with inadequate support.

Closing the Gap: A Call to Action

To meaningfully improve the lives of people living with dementia and their caregiver, Canada must urgently evolve from strategy to action. This will require:

1. Establishing a National Implementation Plan:

- Develop a detailed, time-bound plan that outlines roles, responsibilities, and measurable targets similar to the Danish or German implementation plans.
- Embed mechanisms for accountability and cross-provincial/territorial collaboration.

2. Creating a Canadian Dementia Coordinating Body:

- Modeled on CPAC or the Stroke Network, this body should guide policy implementation, capacity planning, standards development and facilitate communication, supporting provinces and territories in developing care pathways, implementing evidence-based practices, and scaling innovations.

3. Setting Measurable Goals and Monitoring Progress:

- Define indicators tied to each strategic priority (e.g., diagnosis wait times, home care access, caregiver distress rates).
- Build real-time, interoperable data systems to track outcomes and inform quality improvement.

4. Committing to Long-Term, Sustainable Funding:

- Ensure multi-year investments that support workforce development, infrastructure, and the expansion of proven community and clinical supports.
- Tie funding to outcome metrics to promote accountability and transparency.

Canada cannot afford to delay.

Canada has the knowledge, expertise, and precedent to deliver meaningful, national improvements in dementia care. But strategies alone do not deliver change—implementation does. The challenge ahead is not one of awareness or innovation, but one of political will, coordinated leadership, and sustained investment.

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APPENDIX A: STATE OF IMPLEMENTATION OF CANADA'S NATIONAL DEMENTIA STRATEGY BASED ON PUBLIC HEALTH AGENCY OF CANADA REPORTS AND SURVEYS

Prevent Dementia	Current State	Aspiration State	Implementation Status*
Advance research to identify and assess modifiable risk and protective factors	Incomplete understanding of risk and protective factors linked with dementia, with some factors not yet identified and insufficient evidence on the link between factors and dementia.	A complete understanding of the risk and protective factors linked to dementia, their impacts and interactions.	Underway through CIHR-IA and research from other national databases and international research collaboratives
Build the evidence base to inform and promote the adoption of effective interventions	Limited evidence about effective interventions to reduce risk for dementia and insufficient information resources.	Availability of effective prevention resources and interventions, supported by a strong evidence base.	Funded pilot programs do exist with strong outcomes but limited nationally coordinated scaling or broad municipal engagement. Lack of national targets to work toward.
Expand awareness of modifiable risk and protective factors and effective interventions	A lack of awareness among the general public and care providers about actions that may help prevent dementia.	All people living in Canada are aware of actions that prevent dementia.	A public awareness campaign launched in 2023 with good reach. From public opinion poll those taking actions to reduce their risk increased from 22% in 2020 to 34% in 2023. While some factors have lowered or are stable, there is an increase in diabetes, obesity, physical inactivity and social isolation.
Support measures that increase the contribution of social and built environments to healthy living and adoption of healthy living behaviours	Barriers related to built and social environments limit the ability of individuals to pursue healthy living in ways that may reduce the risk of developing dementia.	All people living in Canada have access to built and social environments that support their ability to pursue healthy living in ways that may reduce their risk of developing dementia.	Funded pilot programs but limited nationally coordinated scaling or municipal engagement. Public opinion poll found 75% of respondents hadn't heard of "dementia-inclusive communities".

The implementation status was assessed by Brainwell from annual reports to Parliament by PHAC as of November 2024.

Improve the Quality of Life of People Living with Dementia	Current State	Aspiration State	Implementation Status
Eliminate stigma and promote measures that create supportive and safe dementia-inclusive communities	Widespread stigma within communities and a lack of understanding of dementia.	All people living in Canada understand dementia and stigma no longer exists in Canada.	Public opinion poll 59% reported no changes in their views towards dementia in past five years. 43% feel very comfortable with dementia (down from 50%).
Promote and enable early diagnosis to support planning and action that maximizes quality of life	Individuals are unable to receive an early or timely diagnosis, or feel unsupported when receiving a diagnosis.	A timely diagnosis, provided in a compassionate manner, is available to all, along with immediate access to resources and supports.	Time to diagnosis data (or the diagnosis rate) is limited across the country with no national targets and agree upon measures
Address the importance of access to quality care, from diagnosis through end of life	Lack of access to, awareness or understanding of health and social services that provide integrated and person-centred care.	Integrated, person-centred quality care based on evidence-informed best practices across all settings where people feel welcomed and well-cared for when admission to long-term care or hospitalization is necessary.	Funded pilot programs underway with strong outcomes but limited nationally coordinated scaling, sustainability, no provincial integrated pathway or national targets
Build the capacity of care providers, including through improved access to and adoption of evidence-based, culturally appropriate guidelines for standards of care	Lack of information and resources for care providers, reducing the capacity to provide quality care.	Care providers have access to the resources and training needed to deliver quality care.	Funded pilot programs underway with strong outcomes but limited nationally coordinated scaling, sustainability, and no national targets
Improve support for family/friend caregivers, including through access to resources and supports	Caregivers experiencing burnout, financial hardship, isolation and depression while caring for someone living with dementia.	Caregivers have access to the resources and supports required to protect their own wellbeing and to care for someone living with dementia, including being equipped to navigate health care and other support systems.	2 in 5 caregivers experienced challenges when accessing dementia recommendations. 47% of caregivers were able to provide the care needed, decreased from 57% in 2020.

Advance Therapies and Find a Cure	Current State	Aspiration State	Implementation Status
Establish and review strategic dementia research priorities for Canada	Limited broad stakeholder input when setting research priorities and insufficient engagement of people living with dementia and caregivers.	Research priorities established in an inclusive manner with broad stakeholder input, with the participation of those living with dementia and caregivers.	Underway through CIHR-IA and Dementia Research Funders Alliance
Increase dementia research	Annual investment in dementia research in Canada is less than one percent of dementia care costs.	Annual investment in dementia research in Canada exceeds one percent of dementia care costs.	In 2011 estimate care cost was $8.3 billion. 1% = $83,000,000 annually. CIHR-IA received $4,000,000 annually over 5 years bringing overall amount to $52,000,000 in 2022-23. Additional funding to Brain Canada and CABHI.
Develop innovative and effective therapeutic approaches	Options for evidence-informed therapies remain limited and often are not person-centred.	New evidence-informed person-centred therapies are more readily available.	Funded pilot programs underway with strong outcomes but limited nationally coordinated scaling, sustainability, and no national targets
Engage people living with dementia and caregivers in the development of therapies	People living with dementia and caregivers are predominantly the subject of research to develop new therapies and find a cure.	People living with dementia and caregivers are active participants and partners in research to develop new therapies and find a cure.	Engagement a requirement through CIHR-IA and partners (note limited funding and public awareness)
Increase adoption of research findings that support the strategy, including in clinical practice and through community supports.	Research findings tend to stay within academic settings and journals and are not broadly known, accepted, or brought into clinical practice.	Research design always includes efforts that ensure findings can be understood, adopted and quickly put into practice.	KTE Hubs funded through PHAC and CIHR and incorporated into pilot program funding, but limited public awareness

APPENDIX B: METHODOLOGY FOR INTERNATIONAL REVIEW OF DEMENTIA STRATEGIES

Strategies were identified through the Alzheimer Disease International's (ADI) national plans database, the World Health Organization's (WHO) Global Dementia Observatory, and a manual search of government websites from all 193 WHO member states. All analysis was supplemented with a literature review and cross-referenced with published peer-reviewed publications, and publicly available data from validated grey literature sources. To ensure relevance and contemporary applicability, strategies published more than ten years ago or officially reported as expired were excluded.

For in-depth assessment, inclusion criteria were developed to ensure relevance to the Canadian context. Countries were selected based on the following criteria:

- A federated or decentralized healthcare system (identified using the Commonwealth Fund's 2020 International Profiles of Health Care Systems).
- A high-income or upper-middle-income classification according to the World Bank's 2023 income groupings.
- Insurance structures comparable to Canada's public insurance system (also per the Commonwealth Fund).
- A publicly available, active national dementia strategy.

To validate inclusion, each country's healthcare governance, income classification, and insurance models were cross-referenced using peer-reviewed literature, official policy reports, and validated grey literature (Table 3). Given the lack of a unified global database for dementia strategy implementation, a cross-referencing approach was employed to extract data from official strategy documents, legislative texts, and evaluation frameworks. The strategies of 11 countries that met the inclusion criteria were analyzed in depth. These included: Australia, Austria, Denmark, Germany, Italy, Japan, New Zealand, Scotland, Spain, Sweden, and Switzerland.

The scope of this review of National Dementia Strategies and implementation across different countries was limited to examination of published reports. Thus, only a general overview of each country's approach to achieving effective implementation can be gleaned from public documentation.

For the six criteria, each of the indicators were assigned an equal weighting score. Although there were 15 indicators, the Governance criteria only had two of its three indicators weighted because these were mutually exclusive, allowing for a total maximum score of 14.

For more details on methods and results please refer to Sivananthan SN et al. Lessons from Abroad for Canada's National Dementia Strategy: Actions for Implementation. Canadian Health Policy, May 2025.

> “This report reflects our unwavering commitment to turning evidence into action for people living with dementia and caregivers. Behind every data point is a human story. It’s time for coordinated care to honour them. My deepest hope is that this report sparks the national resolve we need to finally close the gaps. Join us in raising your voice.»
>
> – Dr. Saskia Sivananthan

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