



# Alberta Dementia STRATEGY AND ACTION PLAN

## **Alberta Dementia Strategy and Action Plan**

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We are indebted to the many Albertans living with dementia (like the gentleman featured on the cover) and their caregivers, family and friends who shared their stories so Albertans can better understand the impact of dementia.

Also important to the success of this strategy were the valuable contributions of community partners that include, but are not limited to:

- Alzheimer Society of Alberta and Northwest Territories;
- Alzheimer Society of Calgary;
- Early Onset Dementia Alberta;
- Caregivers Alberta; and
- many clinicians, health care providers, seniors' services providers and researchers.

For a list of contributors, please refer to Appendix B.

Throughout this document you will see key terms **bolded and underlined**. Please refer to Appendix A for definitions.

***“Quotes, highlighted green and italicized, are provided by individuals living with dementia and their caregivers.”***

# Executive Summary

Dementia is a devastating, costly chronic disease that has become a health priority worldwide. As of 2016, just over 42,000 Albertans have been diagnosed and are living with dementia. If nothing changes, this number is expected to increase to more than 155,000 within 30 years (*source: the Population Estimates of Dementia in Alberta Working Group*).

Dementia affects far more Albertans than those living with the disease. It impacts us in our homes, communities, care facilities, hospitals and society as a whole. Dementia does not have one face - it affects men and women, the elderly and those under the age of 65. It affects individuals from every culture and background. As such, it is important to address dementia as both a health and societal issue.

The time has come for Alberta to commit to raising awareness of dementia and to better support Albertans living with dementia, their **caregivers** and the communities in which they live.

The Government of Alberta is committed to working with our partners to increase public understanding of dementia and provide the support needed by Albertans living with and affected by dementia. While many supports and services are already available in Alberta to improve the lives of individuals living with dementia and their caregivers, more can and must be done.

The Alberta Dementia Strategy and Action Plan is composed of two parts: the Strategy and the Action Plan. The Alberta Dementia Strategy (the Strategy) outlines how, through collaboration with persons living with dementia and their caregivers, community organizations and **care providers**, the Government of Alberta can raise awareness of dementia and support all Albertans living with and impacted by dementia. The Strategy outlines the steps needed to achieve our vision.

**Our vision is to see a future where: Albertans are committed to optimizing brain health and valuing and supporting individuals impacted by dementia from its onset through to end-of-life.**

During the development of this strategy, we heard from many individuals and groups, including Albertans living with dementia, their caregivers and families, care providers and community members. They told us that our approach to dementia care and support must be person- and family-centred. It must also be a collaborative, integrated, flexible and adaptable approach that meets the needs of each Albertan living with or affected by dementia.

The Strategy recommends four outcomes that support our stated vision:

### **Outcome 1**

Albertans understand the impact of dementia and actively work towards optimal **brain health**

### **Outcome 2**

Albertans living with dementia and their caregivers are supported in communities

### **Outcome 3**

Albertans living with dementia and their caregivers receive timely recognition, diagnosis and clinical management through **primary health care**, supported by specialized services

### **Outcome 4**

Albertans living with dementia and their caregivers experience timely, accessible, integrated and high quality care and services

The Strategy also recommends three enablers that address the system changes needed to ensure high quality dementia care and services:

### **Enabler A**

Position Alberta as a leader in dementia research, the development of supportive technologies and translating research into practice

### **Enabler B**

Ensure Alberta has a trained and supported workforce to provide dementia care and services

### **Enabler C**

Implement a comprehensive measurement, monitoring and reporting framework to guide implementation of the Strategy

The Alberta Dementia Action Plan (the Action Plan) provides further detail on actions, timelines, priorities and accountability. Success will rely on the collaborative efforts of many individuals and organizations, including persons living with dementia and their caregivers, government, health and social care providers, local authorities and communities.

Alberta Health will work closely with Alberta Health Services, relevant government ministries, local authorities, community organizations, other key partners and stakeholders, and most importantly, persons living with dementia to implement this strategy. Progress will be evaluated and reported to the public on a regular basis.

# What is Dementia?

Dementia may be suspected when noticeable changes are observed in an individual's thinking and/or their ability to manage daily activities or behaviour. As the changes associated with dementia are subtle and progress gradually, it may be years after the onset of symptoms before an individual first seeks medical attention. Changes in memory are usually the first sign, but individuals living with progressive dementias develop more symptoms over time and may eventually lose the ability to undertake essential tasks of daily living, such as the physical ability to walk or swallow.

Observation of these changes ideally results in an early assessment to determine if dementia is the cause and to allow for timely diagnosis and treatment, which can reduce the negative impacts of the disease.

During the initial stages of most types of dementia, individuals will typically experience memory changes that may be accommodated through changes in behaviours, patterns and lifestyle, such as using a notebook or calendar to keep track of names and dates. At this stage, the impacts are primarily on the individual and their close family and friends, with little need for outside support for daily tasks or care, though medical and social supports can be highly beneficial. The early stages of dementia are also an important time to plan for the future, including updating a will and obtaining a Personal Directive and Enduring Power of Attorney.

## **It is believed that one in three seniors die with a dementia.**

As dementia progresses, participating in family and community activities, work and hobbies becomes more and more challenging. Daily activities, such as driving safely, making sound financial decisions and reliably taking medication, can become difficult or even impossible without support. The reduced ability to communicate with friends and family, combined with other behavioural and cognitive changes, can lead to voluntary or involuntary isolation.

With these changes to the brain, behavioural changes may also emerge that prove challenging to the individuals with dementia or their caregivers. Behaviours may range from apathy to unrest and aggression, and can indicate unmet needs. When these behaviours arise, there is a need for an accurate assessment of the behaviour and any related situational factors. In these circumstances the creation of individualized plans, as well as caregiver training and supports, may be needed to respond to changes in behaviour. This typically marks the time when increased support from health and social systems is needed.

***“He was good at trying to manage his thinking trouble...he would do things like always pay for everything with a \$20.00 bill as he couldn't calculate the change.”***



During later stages of the disease, individuals may need help with most basic activities of daily living, such as dressing, toileting and bathing. They and their caregivers often become increasingly isolated. The person living with dementia may require constant supervision and care, which can be provided through extensive home, family and community supports or transition to a continuing care residence.

***“He is having a harder time navigating the house – he goes into the kitchen and cannot remember how to leave the kitchen so he calls me. His world is getting smaller and smaller...he cannot watch TV.”***

At this stage, caregivers and care providers work closely together to provide the care and supports needed for the individual living with dementia. It is important that the individual who is living with dementia continue life as meaningfully as possible for as long as possible, even as care needs increase and become more complex over time. Finally, dementia is a terminal illness and quality end-of-life care is an important component of supporting individuals throughout the dementia journey.

## Types of Dementia

The most common type of dementia is Alzheimer’s disease, which accounts for approximately 60 per cent of all cases. Other common types of dementia include vascular, mixed (where there is more than one brain disease leading to the dementia), Lewy Body and frontotemporal. The medical evaluation of a person living with dementia should include determining the type of dementia in order to determine the best possible treatment and plan for future needs.

The major risk factor for the development of Alzheimer’s disease and other dementias is age. Other dementia risk factors include family history, developmental disabilities and modifiable risk factors that can be managed or otherwise mitigated, such as diabetes, high blood pressure, obesity, smoking, depression, cognitive inactivity and low physical activity. Recent research suggests that managing modifiable risk factors may help to decrease the future likelihood of dementia.

### **Risk of dementia doubles every five years past the age of 65.**

Having one or more of the risk factors associated with dementia means that there is an increased chance, but not a certainty, that a dementia will develop. Likewise, the absence of known risk factors does not mean that a person will not develop the condition.

***“I did not realize that Alzheimer’s disease was a type of dementia, there are so many types. We need more education.”***



## Impact of dementia

There are a number of obstacles that can hinder the timely diagnosis of dementia. These obstacles include a lack of awareness regarding dementia, ageism (as some people believe that dementia is a part of normal aging and do not seek help), the stigma and worry associated with dementia and a belief that there is little to offer the person living with dementia.

Furthermore, when dementia is recognized, it may not always be documented in an individual's health record. As a result, the number of individuals living with dementia and the impact of the condition on Alberta's health and social systems and on our communities is underestimated. As our population ages, the prevalence and impact of dementia will significantly increase.

The important contributions of caregivers should not be underestimated or go unrecognized. Support from caregivers enables Albertans living with dementia to remain in their homes and communities as long as possible. Without these caregivers, this care would need to be provided through our health and social systems. Supporting caregivers and addressing their needs is vital to the success of this strategy.

**In 2008, caregivers provided more than 18 million hours of unpaid care to Albertans living with dementia. This is expected to increase to 68 million hours of unpaid care by 2038. (source: *Rising Tide: The Impact of Dementia on Canadian Society, Alzheimer Society of Canada, 2010*).**

Dementia also impacts the social fabric of communities and society. Communities need to challenge themselves to become more inclusive, welcoming and supportive of individuals living with dementia and their caregivers.

Age-Friendly Alberta emphasizes the reduction of isolation and meeting the needs of Albertans of all ages and abilities, including those living with dementia. By becoming more dementia friendly, Alberta can be a province where individuals living with dementia remain connected and contributing members of society, living full and meaningful lives.

Although associated with age, dementia does not only impact seniors. Individuals with early or young onset dementia (diagnosed before age 65), and their families and caregivers, face complex and sometimes unique challenges due to the earlier life stage during which their symptoms begin. These challenges can go unrecognized because of the common perception that the disease only affects seniors.

**While dementia is most commonly seen in older adults, it can develop at younger ages. Dementia in individuals under the age of 65 is referred to as early or young onset dementia.**

The loss of employment income, as symptoms progress to the point where retirement is the only alternative for the person living with dementia, often results in significant financial challenges and frequently undermines a person's sense of worth. In addition, many of the programs and services offered to Albertans living with dementia are not designed to meet the needs of younger people, such as supporting a desire to remain physically active.

Additional challenges may also be faced by Albertans living with dementia who have unique needs, including, but not limited to:

- members of Indigenous populations;
- Albertans for whom English is a second language and those who don't speak English;
- lesbian, gay, bisexual and transgender Albertans;
- those who live in rural and remote areas;
- Albertans living in poverty or experiencing homelessness; and
- those who have mental illnesses and/or developmental disabilities.

As our population grows and ages, the already high costs of dementia will continue to increase. The cost of dementia is not solely health-linked. It includes direct financial impacts as well as the indirect impacts on individuals living with dementia, caregivers, society and the economy. Dementia is, however, a major cost driver across our health care system, including primary care, continuing care and acute care.

**In 2008, the direct health care costs related to dementia in Alberta were almost \$650 million. When social support costs and employment impacts on caregivers were included, the cost exceeded \$1.2 billion.**

Albertans living with dementia need ongoing medical and practical supports. They often have multiple chronic conditions and experience longer stays in hospitals. The direct costs of providing health care and social supports in the community and continuing care residences, as well as the significant indirect costs of unpaid care and supports provided by caregivers, may increase as much as three times over the next 35 years as baby boomers increase the proportion of Albertans who are seniors and are proportionately affected by dementia.

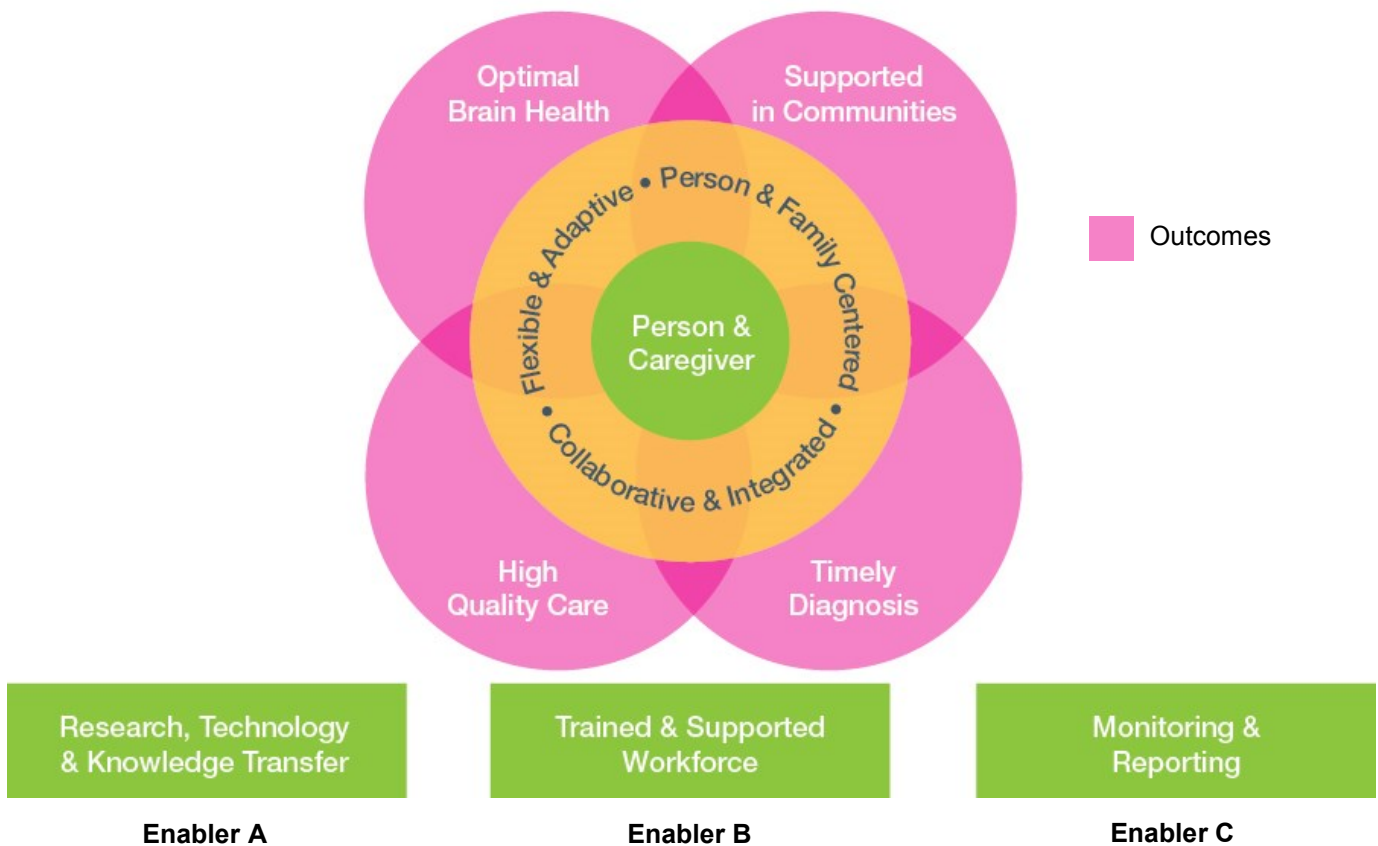
The challenge is, and will continue to be, providing quality care and supports as the total direct and indirect costs of the disease increase due to the growing number of Albertans impacted by dementia.

## Alberta's Approach to Dementia

It's been 15 years since Alberta released its last dementia strategy - *Alzheimer Disease and Other Dementias: Strategic Directions in Healthy Aging and Continuing Care*. Many of the recommendations from the report were implemented and provide a foundation for this new strategy. The intent of the 2002 report was to provide information and advice to key stakeholders in the planning of continuing care services for individuals with Alzheimer's disease and other dementias. In particular, the document was to act as a reference for the former regional health authorities to assist with preparations of their ten year continuing care strategic service plans.

Since that time, dementia's impact on society as a whole, not just on the health system, has become increasingly evident. The number of Albertans living with dementia has increased along with the desire of individuals to receive the care and support they need in their communities. A broader strategy is now needed to address these new realities as well as gaps in services and program delivery across the health and social systems. New initiatives that are already improving supports for Albertans living with dementia and their caregivers include Dementia Advice through Health Link 811, First Link®, ASANT Café, the Appropriate Use of Antipsychotics initiative and the addition of specialized dementia spaces in care facilities.

The Alberta Dementia Strategy consists of four outcomes that outline the desired future state for Albertans, supported by three enablers that address the system changes needed to ensure high quality dementia care and services. Although these outcomes and enablers are addressed separately, integration of them all is essential for maximum impact.



# Why Have a Dementia Strategy?

Dementia affects all Albertans directly or indirectly. It is *our* problem.

Dementia is a syndrome, usually of a chronic or progressive nature, where the decline in cognitive function is severe enough to affect independence in everyday activities. While people usually think of dementia as a condition that affects memory, it is much more than that. Dementia may also affect a person's ability to speak, recognize people or places and, ultimately, the ability to live safely without the assistance of others.

**In 2016, just over 42,000 Albertans were living with dementia, almost 1% of the total population.**

**If nothing changes, this number is expected to increase to more than 155,000 within 30 years.**

*(source: the Population Estimates of Dementia in Alberta Working Group)*

Subtle changes to brain function are a part of normal aging. When these changes are more than one would expect given an individual's age and education, while they remain mostly independent for everyday activities, this condition is referred to as mild cognitive impairment or MCI.

MCI may only be noticeable to the individuals themselves or to the people close to them. Individuals with MCI may need to expend more effort or make adjustments to perform daily activities. Individuals with MCI are at an increased risk of developing dementia.

In Canada, dementia is one of the leading causes of disability and death in older adults. Although each individual's experience with dementia is unique and depends on the disease cause, the condition typically progresses from early through late stages. Most types of dementia are progressive and irreversible.

Dementia is not a normal or inevitable part of aging, even though the probability of it occurring increases with age. It is important to remember that with the right health and social care supports, Albertans living with dementia can continue to live full and active lives for many years.

Dementia has been identified as a major public health issue, resulting in the development of dementia strategies in many jurisdictions around the world. Dementia is becoming one of the most costly chronic disease and the second largest cause of disability in people over the age of 70.

As populations age, the situation becomes critical - action is necessary. Collectively, we need to acknowledge and address the growing impact of dementia.

Because dementia robs individuals of their ability to live independently, it also affects their caregivers, families, communities and society as a whole.

*“I don’t know what is wrong with me, my brain is not working.”*

As symptoms progress and the number of individuals affected increases, so too does the cost of care. Increased knowledge of risk reduction strategies (what people can do to reduce individual and population rates of dementia), earlier diagnosis and the early provision of medical and social interventions can reduce the negative impact of dementia on those affected and improve the quality of life of individuals living with dementia, as well as their caregivers.

## What will the Alberta Dementia Strategy accomplish and how?

The Alberta Dementia Strategy outlines the steps that government, in collaboration with community organizations, care providers and individuals living with dementia and their caregivers, can take to raise awareness of dementia and support all Albertans living with dementia. It includes the vision, principles, enablers and recommendations required to make Alberta a place where individuals living with dementia are valued, understood and included so that they can continue to experience meaningful lives.

The Alberta Dementia Strategy complements and builds on other initiatives underway in Alberta, and the Action Plan outlines specific steps that will be taken to achieve the recommendations in this strategy.

**Brain health is the ability of a person to perform all the mental processes that are collectively known as cognition, including the ability to learn new things, intuition and judgment. Optimized brain health can reduce the impact of dementia on an individual’s life.**

Public health efforts to promote brain health and thereby reduce the risk of dementia and its impact on individuals and society will only be successful through education and increased public awareness of behaviours that can reduce the risk of dementia. Known risk reduction strategies include exercise, healthy eating, social engagement and the avoidance of head injuries. These strategies are most effective when practiced early in life, though they can still have an impact when started later.

Individuals with symptoms of dementia require timely access to diagnostic services. Once a diagnosis is received, appropriate and adequate primary health care is needed to coordinate and provide health services, and connect individuals with community resources and supports.

Though no cure for dementia has been found yet, research has shown that access to an appropriate range of community-based services and supports can improve quality of life, **mental health** and the overall wellbeing of individuals living with dementia and their caregivers. It is imperative that these services and supports are available and accessible, regardless of an individual's living situation, age or cultural background.

Individuals living with dementia frequently experience **transitions** between their home, hospitals and continuing care facilities. These transitions are disruptive and sometimes cause irreversible decline in condition. We need to explore innovative models of care to integrate services, reduce and improve transitions, and avoid unnecessary hospitalizations.

***“Not only do I want to live well with dementia, I want to live with purpose...and with help I can.”***

Research is also beginning to reveal new evidence across all aspects of brain health and dementia, including steps that individuals can take to reduce their risk of dementia. The search for new treatments, services and eventually a cure for dementia is ongoing, but it requires support. A comprehensive approach to dementia-related research, including a plan to translate research into practice, will address the knowledge gap around dementia and increase our understanding of how to reduce its impact on Albertans and improve their lived experience.

Dementia impacts every aspect of the lives of individuals, their caregivers and close family members. To address the needs of individuals living with dementia and their caregivers, we require an integrated response that incorporates both health care services and supports, as well as community-based supports, including socialization opportunities, transportation options and home support services.

Partnerships across government, health providers, local authorities, community organizations, educational institutions and individuals living with dementia and their caregivers are essential to successfully deliver on the recommendations outlined in the Alberta Dementia Strategy.

# Vision and Principles

## Vision

**Albertans are committed to optimizing brain health and valuing and supporting people impacted by dementia from its onset through to end-of-life**

## Guiding Principles

The guiding principles provide overall direction and indicate the key components of a framework to guide the work of decision-makers, health care providers and policy makers involved in dementia care.

### **Person- and Family-Centred**

Dementia care and services centre on meeting the needs of each individual and honouring their values, beliefs, cultural traditions, identities, autonomy, preferences and relationships.

### **Collaborative and Integrated**

Providers of dementia care and services collaborate with individuals and caregivers to provide integrated and seamless supports throughout the dementia journey.

### **Flexible and Adaptive**

Dementia care and services are adaptable to meet the changing and unique needs of each Albertan living with dementia and their caregivers - regardless of living situation, age or location in Alberta.



# Moving Forward: Outcomes

## Outcome 1: Albertans understand the impact of dementia and actively work towards optimal brain health.

Dementia has historically been seen as something to ignore or hide. While this stigma has begun to lessen, more needs to be done to raise awareness - what dementia is, its risk factors, how it affects individuals and their caregivers, and what steps all Albertans can take to reduce their own risk of developing dementia.

Without proper access to information about dementia and how to support those affected by it, people may avoid individuals living with dementia. As a result, individuals and their caregivers can feel isolated and cut off from their communities. Individuals who have received a diagnosis, as well as their family and friends, may sometimes pretend that dementia is not a part of their lives and may not seek care or support. This can make things more difficult for everyone in the long run, as some preparations that can be done early in the dementia process are impossible later on (e.g., writing personal directives or wills), and supports that would make life better are missed at the time when they would be most helpful.

A greater understanding of dementia will help improve quality of life, as it will lead to a society where individuals living with dementia and their caregivers are accepted and supported by services that anticipate and meet their needs, and where they will not be afraid to ask for and accept the help available.

***“It’s like a book, and every day you rip out one page. And the cover looks the same, but the person inside is gone.”***

### ***How we will achieve this:***

#### **Elevate public consciousness and understanding of dementia.**

A strong and coordinated effort to share information regarding dementia is needed to expand Albertans’ understanding of the disease, what it means for people’s daily experiences, and how to relate to individuals living with dementia.

Public awareness activities, with messages targeted to reach Albertans at each life stage from childhood through retirement, will enhance Albertans’ understanding of dementia and ultimately increase societal acceptance of individuals living with and impacted by dementia.

***“She knows how to interact with him and is not afraid. She knows, she understands.”***

## **Promote steps Albertans can take to optimize their brain health and reduce the risk of dementia.**

Although research on risk reduction is still in the early stages, physical exercise, socialization and a diet rich in vegetables and fruits are related to improved brain health. Albertans can take action to proactively protect themselves from the impact of declining brain health and reduce the risk of dementia. Sharing this information, through public awareness activities about dementia, will increase understanding of the importance of brain health and provide Albertans with the information they need to practice healthy life choices.

## **Outcome 2: Albertans living with dementia and their caregivers are supported in communities.**

Albertans living with dementia, as well as their caregivers, want to remain active and engaged members of their communities, but the required supports to do so are often absent. Many communities are unaware of the steps they can take to make their communities inclusive, welcoming and appropriate. Programs and services have been established in some communities to support Albertans with dementia and their caregivers, enabling them to remain connected and engaged. Availability is limited, however, and knowledge has not spread consistently across the province. Information about programs and supports must be effectively shared with Albertans living with dementia, their caregivers and community members.

### ***How we will achieve this:***

#### **Increase access to flexible and available respite options that meet the needs of Albertans living with dementia and their caregivers.**

Respite options are supports that provide caregivers with the breaks they need to support their own personal health and wellbeing. A range of respite options offer flexibility to meet caregivers' needs, including respite that is available as needed, without the need to plan in advance.

The location and length of respite also needs to be addressed to meet the needs of caregivers, including in-home and facility-based options, multi-day and overnight respite, and community-based adult day programs. A greater understanding of respite availability and needs in Alberta is required along with a commitment to enhance the availability of respite options.

***“If I could describe my wish list, I would ask for 5 days of the adult day program every week because when he is there he is with a group of men, he watches and he knows he is with other men. They say good morning to him; otherwise it is just us in our home.”***

### **Increase the capacity of health and social organizations to establish and provide meaningful services for persons living with dementia and their caregivers.**

Many of the programs that support Albertans living with dementia are run by community organizations while others are provided by the health system. These varied opportunities make it easier for Albertans to get the health and social supports they need while remaining connected to their friends and communities. It is important that we increase the capacity of these community-based health and social organizations to provide services, such as adult day programs.

### **Develop and support local age- and dementia-friendly communities.**

**Age-Friendly Communities** are communities that are intentionally inclusive of all members, including children, adults, seniors, persons with disabilities and those living with dementia. Supporting and encouraging Alberta communities to become more age-friendly and dementia-friendly by highlighting the specific needs of Albertans living with dementia will lead to more inclusive and supportive communities for all Albertans.

The Ministry of Seniors and Housing is leading the work to promote Age-Friendly Communities and has developed resources and tools to encourage local action, including supporting businesses to become more accessible and welcoming to all members of a community.

***“Education for families and caregivers is of utmost importance because you simply do not realize how the disease will affect your loved one as well as yourself!”***

### **Develop a central access point for trusted, user-friendly brain health and dementia information and resources.**

Individuals diagnosed with dementia, their caregivers, care providers and Albertans interested in learning need a trusted, reliable and easily accessible source of information on brain health and dementia.

Establishing a central access point, available both online and in other formats, would allow people to more easily find the information they need. This resource would include listings of dementia resources, as well as available community programs and services.

## **Review public policy options that reduce the negative financial impacts experienced by persons living with dementia and their caregivers.**

Caregivers of Albertans living with dementia may experience financial stress due to the demands associated with caregiving, including high out-of-pocket costs. Employed caregivers may have to reduce hours of work or leave the workforce entirely. Providing supports that address the financial issues caregivers experience can reduce stress, improve mental and physical health and enable caregivers to continue providing care and support for a longer period of time.

## **Outcome 3: Albertans living with dementia and their caregivers receive timely recognition, diagnosis and clinical management through primary health care, supported by specialized services.**

Currently, Albertans who suspect they or a family member might have dementia are often uncertain about where to go for assistance. When they do decide to ask for help, they can experience delays in getting the health care supports they need. In addition, many primary health care practitioners are uncertain of their role in providing dementia diagnosis and clinical management. They may experience a lack of confidence in their knowledge and understanding of dementia.

Primary health care should be the foundation of dementia recognition, diagnosis and clinical management through end-of-life. Action is needed to make primary health care the first destination for all and to ensure that primary health care providers and teams have the required capacity and knowledge to respond.

### ***How we will achieve this:***

#### **Support case finding to ensure accurate and timely diagnosis of dementia.**

When the individuals themselves, caregivers or care providers feel significant cognitive decline has occurred in a person, these observations should lead to a careful assessment for possible dementia. There is currently insufficient evidence to justify universal screening for dementia in middle-aged or older adults who do not have cognitive concerns. However, case finding is one way to identify individuals at higher risk of dementia.

***“We both felt relieved after the diagnosis – it was like an elastic band that finally snapped. The relief was like a little ‘gush’ for me, for him, it was a ‘flood.’ He felt – ‘here I am; I do not need to hide anymore.’”***

Developing the tools, resources and education required to support care providers in the recognition and diagnosis of cognitive impairment will enable timely identification of individuals living with dementia. Timely identification will lead to the wider implementation of advance planning and earlier use of interventions that may mitigate troublesome symptoms (where treatments exist).

### **Build capacity, and spread evidence-informed best practices in recognizing, diagnosing and clinically managing dementia among primary health care teams.**

As the foundation of dementia care, primary health care providers must be supported to increase their ability to recognize, diagnose, and clinically manage dementia. Models for dementia service delivery should be developed or adapted, shared and integrated across primary health care. Sharing best practices in dementia care needs to occur across community based primary health care teams and Primary Care Networks to build on the good work already occurring in Alberta.

Enhancing the ability of primary health care teams to provide this care will result in earlier and more accurate recognition and diagnosis and more cohesive clinical management throughout the progression of dementia. Timely diagnosis will greatly improve the experience of Albertans living with dementia and their caregivers as it allows for planning and medical interventions to be put in place earlier and decreases the likelihood of making decisions in times of crisis.

***“I wanted the doctor to be the one to pick up on the issue. I did not want to be the one to take my husband’s sense of control away, so he did not see a doctor specifically for this problem.”***

### **Ensure that primary health care teams have timely access to specialist consultation for dementia diagnosis and advice on clinical management.**

While most Albertans living with dementia can receive the clinical care they need through primary care, some individuals need care from a specialist or team with enhanced knowledge in geriatrics, neurology, psychology, mental health or another specialty. Many persons living with dementia experience several other chronic illnesses concurrently. During an acute illness, or following a fall or injury, individuals may experience loss of key functional abilities (e.g., the ability to walk or eat) that are necessary for them to retain their independence and to return to their homes after hospitalization.

It is important that specialized services, which provide consultation and advice to help minimize functional losses, are available in the community and in hospitals for individuals when and where they need them. Expanding the availability of consultations, particularly for individuals in rural and remote areas of the province, will improve the health system’s ability to serve all Albertans living with dementia.

Standardizing referral criteria and processes for specialist consultation will help to minimize delays. This will ensure everyone receives services from the most appropriate practitioner in a timely manner.

***“We waited months for (an) appointment (with a specialist for extensive cognitive testing) and he changed drastically during that time.”***

## **Outcome 4: Albertans living with dementia and their caregivers experience timely, accessible, integrated and high quality care and services.**

Albertans living with dementia, as well as their caregivers, require care and services to meet their needs and support their continued independence and quality of life. Although exemplary care and services are now provided, they may be difficult to access and the available options may be difficult to understand. In addition, care and services may be available in one part of the province but not in another.

In order to improve the lives of individuals living with dementia, as well as their caregivers, we must work toward improving access to health care and social supports throughout the province. Enhancing the coordination and integration of care and services will reduce the burden on Albertans living with dementia, as well as their caregivers, and increase the efficiency of the health and social systems.

### ***How we will achieve this:***

#### **Ensure everyone with a diagnosis of dementia receives assistance to navigate the health and social systems and coordinate services.**

Albertans living with dementia and their caregivers have told us that they need one person to help them access and organize the services and supports they require over time. This coordinator could be any care provider involved in the care of an individual, from a primary care physician to a community organization representative or case manager. The care and services coordinator’s role would be to support the individual and their caregiver, ensure early planning to reduce negative impacts of dementia, and take a leading role in the planning, coordination and provision of care and supports.

#### **Involve persons living with dementia, caregivers, as well as the care team, in developing and updating individual care and service plans.**

An individualized care and service plan that addresses needs as they change over time can greatly increase the integration of care and services and ensure that everyone is aware of the needs of individuals and their caregivers. Involving individuals with dementia and their caregivers in the development of care and service plans ensures that plans will be person- and family-centred and focused on what is needed to support individual quality of life as well as quality of care.

Developing individualized **care plans** provides an opportunity to discuss with individuals and their caregivers the balancing of risks and freedoms. It also allows for a more proactive approach to care planning, encouraging individuals to consider their long-term goals, including future decision making and end-of-life care.

### **Reduce the number of health care transitions experienced by Albertans with dementia and ensure transitions are only undertaken when in the best interests of the individual.**

Health care transitions often have significant negative impacts on the experience of individuals living with dementia and their caregivers, especially those transitions that involve changing care providers and locations. Transitions adversely affect health status and increase stress and worry for the individual and their caregivers.

All efforts should be made to minimize the number of transitions and make them as smooth as possible. Reducing the number of required transitions can be achieved by:

- supporting individuals to receive the care they need in their home rather than in an emergency department;
- developing continuing care residences that enable individuals to age in place rather than having to move to receive more care; and
- ensuring that all care providers understand the needs of individuals living with dementia and adapt accordingly.

Enhancing timely access to restorative and rehabilitative care can also reduce transitions by providing more time and support to assess needs, develop individualized care and service plans and improve individual function.

### **Improve the prevention, early identification and management of delirium, depression and frailty in all care settings.**

**Delirium**, depression and **frailty** are often experienced by persons living with dementia and, if not addressed, have major impacts on health and quality of life. It is essential to prevent, identify and manage these conditions whenever possible.

Education can enhance caregiver and care providers' ability to prevent, recognize and manage these conditions and ultimately reduce their impact on individuals' lives. Education regarding the use of medications and other therapeutic interventions is needed, in addition to regular and comprehensive medication reviews, to ensure individuals living with dementia are taking medication appropriate to their needs. Completing the work underway to develop and implement care pathways for delirium, depression and frailty will enhance the care of persons living with dementia.



## **Expand access to mental health supports for individuals living with dementia and their caregivers.**

In 2016, the Government of Alberta released the report *Valuing Mental Health*, which recognizes the wide array of mental health challenges facing Albertans, including dementia.

Mental health is greater than the absence of mental illness, it also includes the need for mental and social wellbeing. The importance of mental health care and supports has been recognized throughout our health and social systems as a way to support high quality of life for individuals. More work is required to understand the mental health supports needed by Albertans living with dementia and their caregivers. Identifying and addressing gaps in currently available supports will expand access and improve the overall mental and social wellbeing of individuals with dementia and their caregivers.

## **Create dementia-friendly health and care settings.**

Individuals living with dementia, as well as their caregivers, may live in and interact with a range of environments, including individual homes, community organizations, continuing care residences, hospitals and social centres. Environment is much more than the physical buildings and spaces that surround us. Environment includes the people we interact with, social structures, the services we receive and cultural characteristics. These are all aspects that can either support or inhibit functioning and engagement, and can be shaped to be more supportive of the needs of individuals living with dementia. Making all environments more dementia friendly, which includes the concept of age-friendly but adds components specific to the needs of individuals living with dementia, can result in better quality of life for Albertans.

## **Support development of a single electronic health record.**

Currently, care and services provided to individuals living with dementia are often disjointed, which is further aggravated by the lack of a single electronic way to track individual experiences across the health and social systems. Albertans often have to tell their story multiple times, and information regarding an individual's background, symptoms and treatments does not travel with them across different services and sites. Individuals may stop telling their story or may recount an incomplete version (sometimes due to dementia-related memory impacts). As a result, important information may be lost that could make a difference in developing an effective plan of care for the person living with dementia.

The development of a single **electronic health record**, accessible across health and social systems, will benefit all Albertans, especially those living with dementia who need additional assistance with keeping track of their care and supports over time. Making this single care record available to community organizations, with appropriate privacy safeguards in place, will also help to integrate health and social services and establish more informed and responsive supports.

# Moving Forward: Enablers

Enablers are the necessary components of the Alberta Dementia Strategy that will support achievement of the outcomes and vision. The three identified enablers will ensure that research, technology and knowledge transfer; a trained and supported workforce; and monitoring and reporting assist in achieving the outcomes and vision that have been identified.

## Enabler A: Research, Technology and Knowledge Transfer

***Position Alberta as a leader in dementia research, the development of supportive technologies and translating research into practice.***

Innovations in dementia prevention, risk reduction, treatment and care delivery are being developed in Alberta, across Canada and throughout the world. Implementing the necessary actions to make Alberta a leader in research, development of supportive technologies and translating research and innovations into practice will result in improved quality of life for Albertans living with dementia, as well as their caregivers.

### ***How we will achieve this:***

#### **Develop and implement a dementia research framework for Alberta.**

Dementia research includes research into the causes, impacts and treatments of dementia, the most effective care and services for individuals living with dementia and their caregivers, and pursuing the ultimate goal of a cure or way to prevent dementia. Dementia-related research in Alberta and across Canada is promising, but can be uncoordinated, lack sufficient funding and does not always result in timely sharing or effective application of research outcomes.

The development of a cohesive dementia research framework for Alberta, in collaboration with research and funding bodies and under the leadership of a group responsible for overseeing the Strategy, is needed. Enhancing resources to support research in targeted areas will accelerate the development and translation of new knowledge and Alberta's ability to implement a dementia research framework.

#### **Implement promising innovations in care.**

Research and innovation will not improve the lives of individuals living with dementia unless there are mechanisms in place to allow for the smooth and efficient translation of knowledge and evaluation results into practice.

A process is needed to identify effective innovations in dementia diagnosis, care and management, including technologies that support individuals living with dementia. This process must also be able to transform innovation into standard practices across the province. In addition to identifying these innovations, seed funding, partnerships and other resources will be required for implementation and ongoing evaluation.

## Enabler B: Trained and Supported Workforce

### ***Ensure Alberta has a trained and supported workforce to provide dementia care and services.***

Care providers of all levels and disciplines and members of the broader community workforce have a major impact on the lives and experiences of Albertans living with dementia, as well as their caregivers. Currently, dementia education for care providers is inconsistent or insufficient, and little education is available to the broader workforce.

Improving our workforce training and ensuring the availability of other supportive tools and resources will enhance the quality of care and services provided to Albertans and contribute to attracting workers to dementia related careers now and in the future.

#### ***How we will achieve this:***

#### **Work with stakeholders to develop core competencies in dementia care and embed these into educational programs.**

Developing core competencies for care providers who provide dementia care and services will help identify the knowledge and experience needed to provide high quality care. Standard sets of core competencies also enhance employers' abilities to assess their staff's knowledge and ability to care for Albertans living with dementia.

Core competencies will also enable educational programs and employers to develop appropriate continuing education programs and performance expectations. This will ultimately result in a workforce that is better prepared to meet the needs of Albertans living with dementia.

#### **Expand access to education and training programs for all members of the workforce.**

All members of Alberta's workforce can benefit from a better understanding of what dementia is and how to interact positively with individuals living with dementia. Basic awareness and education programs should be made available in formats that support easy access. Education and training should include appropriate ways to interact with individuals living with dementia and offer more in-depth training for care providers who have direct, day-to-day roles.

Ensuring all training is based on a person-centred care philosophy will encourage a more inclusive approach to the care and support of individuals living with dementia. Education and training will also help reduce stigma associated with dementia.

### **Better understand Alberta’s health workforce, considering the current and future needs of persons living with dementia.**

As the expected number of individuals living with dementia increases, the strain on the workforce that provides dementia care and services will also increase. Alberta Health is currently working on understanding the supply and demand of its health workforce to ensure we meet the needs of Albertans. Contributing a dementia care and services perspective to this development process will ensure that our future workforce is adequate in numbers, training and support in order to provide the care that Albertans living with dementia will require. Dementia care and services extend beyond the health care workforce, so it will also be necessary to contribute to the understanding of other workforces outside of the health system.

## **Enabler C: Monitoring and Reporting**

### ***Implement a comprehensive measurement, monitoring and reporting framework to guide implementation of the Alberta Dementia Strategy.***

The Action Plan is critical to effectively achieve the Strategy’s vision and outcomes, including evaluating outcomes, measuring and monitoring progress and sharing information with the public.

#### ***How we will achieve this:***

### **Implement the Alberta Dementia Action Plan, which details the process for achieving the recommendations of the Alberta Dementia Strategy.**

The Action Plan is an essential aspect of achieving the outcomes and recommendations outlined in the Strategy. The Action Plan includes a step-by-step approach to successfully achieve the Strategy’s vision and desired outcomes and enablers while outlining the proposed timeline.

As the Action Plan is implemented, the responsible stakeholder organizations or departments for each recommendation will be designated along with the resources required.

As part of the Action Plan, a monitoring and evaluation framework will ensure that the outcomes of the Strategy are achieved and the impact of initiatives on the lives of Albertans living with dementia and their caregivers is monitored. Ongoing evaluation of the overall strategy and individual actions or initiatives will also ensure that the Strategy is continuously adapted based on what is learned during the implementation process. An effective evaluation and monitoring framework will support a focus on the outcomes that matter most to Albertans.

The development of a mechanism to publicly share the ongoing results of monitoring and evaluation will serve two purposes: keeping Albertans informed and ensuring that the vision, principles and actions continue to be a priority. Public reporting will be completed on a regular basis throughout implementation, enabling Albertans to stay connected, celebrate successes and understand any challenges that may be encountered and how they can be addressed.

## Next Steps

The Alberta Dementia Strategy lays out the future direction for dementia risk reduction, research, diagnosis, care and support in our province. It builds on existing strengths across our health and social systems and identifies opportunities for improvement. Implementation of the Strategy, through the associated action plan, will result in a society that is better prepared to take steps to reduce the risk of dementia and support fellow Albertans living with dementia now and in the years to come.

To implement this strategy, Alberta Health will work closely with Alberta Health Services, other government ministries, local authorities, community organizations, other key partners and stakeholders and, most importantly, persons living with dementia and their caregivers. Progress will be evaluated and reported to the public on a regular basis.

The four outcomes below outline the desired future state for Albertans.

OUTCOMES	16/17	17/18	18/19	19/20	20/21
<b>Actions</b>	(→ indicates when work will <i>begin</i> )				
<b>Outcome 1 - Albertans understand the impact of dementia and actively work towards optimal brain health</b>					
Develop and implement public awareness activities to address dementia, brain health awareness and risk reduction strategies		→			
Develop a dementia awareness program for Albertan employers				→	
<b>Outcome 2 – Albertans living with dementia and their caregivers are supported in communities</b>					
Enhance and expand the variety of health and social support options available, including respite and self-managed care	→				
Promote an age- and dementia-friendly Alberta	→				
Ensure available mental health and behavioural supports for persons living with dementia	→				
Conduct a review of provincial policies affecting persons living with dementia and their caregivers considering the financial impact and needs related to those with an earlier diagnosis			→		
<b>Outcome 3 – Albertans living with dementia and their caregivers receive timely recognition, diagnosis and clinical management through primary health care, supported by specialized services</b>					
Identify and share accessible, evidence informed, understandable dementia care information	→				
Engage with primary care teams, specifically physicians, to review needs related to enhancing the recognition, diagnosis and management of dementia across the care continuum through to end-of-life	→				
Develop resources and service delivery models for primary health care teams that support timely recognition and diagnosis		→			
Implement best practices in primary care, acute care and continuing care settings	→				
Promote Advance Care Planning upon a diagnosis of dementia	→				
Expand availability of specialist consultation services, especially to rural communities, when caring for Albertans with complex needs		→			
<b>Outcome 4 – Albertans living with dementia and their caregivers experience timely, accessible, integrated and high quality care and services.</b>					
Ensure Albertans have access to programs and a knowledgeable key contact to assist them with navigation across the health and social system continuums	→				
Improve transitions between the community and care settings	→				
Improve access to restorative and rehabilitative care across the community, acute and continuing care systems		→			
Promote evidence-informed care and service planning for all Albertans that emphasizes living well with dementia		→			
Encourage the appropriate use of medication for seniors, including the Appropriate Use of Antipsychotics initiative	→				

The three enablers below support the desired future state for Albertans and address the system changes needed to ensure high quality dementia care and services.

ENABLERS	16/17	17/18	18/19	19/20	20/21
Actions	(→ indicates when work will <i>begin</i> )				
<b>Enabler A – Research, Technology and Knowledge Transfer</b>					
Position Alberta as a leader in dementia research, development of supportive technologies, and translating research into practice					
Develop a dementia research framework for Alberta and support knowledge translation and transfer	→				
Develop a process to identify innovations and technologies to enable dementia diagnosis, care, management and caregiver support			→		
Support expansion of the provincial Electronic Health Record, and other information sharing platforms, to improve access to and information sharing among Albertans living with dementia, caregivers, community agencies, care providers and social support organizations			→		
<b>Enabler B – Trained and Supported Workforce</b>					
Ensure Alberta has a trained and supported workforce to provide dementia care and services					
Support the development and integration of dementia care core competencies into educational programs for those who work in dementia care		→			
Collect and disseminate information about dementia and best practices to Alberta's workforce		→			
Work to understand the supply and demand of the health workforce to ensure that the needs of Albertans, including those living with dementia, are met			→		
Establish and support learning collaboratives and innovations to encourage person-centred approaches to dementia care	→				
<b>Enabler C – Monitoring and Reporting</b>					
Implement a comprehensive measurement, monitoring and reporting framework to guide implementation of the Alberta Dementia Strategy and Action Plan					
Identify and/or develop measures specific to person-centred care and utilize them in planning and monitoring activities	→				
Develop and implement a public reporting structure and process to support the implementation of the Alberta Dementia Strategy and Action Plan	→				



# Appendix A: Key Terms

**Age-Friendly Communities:** Age-friendly communities promote healthy and active aging. People in age-friendly communities are supported in maintaining their independence and have access to the community supports and services they require. Age-Friendly Alberta was inspired by the World Health Organization Age-Friendly Cities Project. Age-Friendly is an international effort to help cities and communities prepare for the aging of populations and urbanization.

**Brain Health:** Brain Health, much like physical health, can be viewed along a continuum - from optimal functioning, to mild cognitive impairment, to severe dementia. It is not simply the absence of diseases such as Alzheimer's disease. It is multidimensional in nature and many of the changes that take place over the life span are a natural part of the aging process. It's never too soon, or too late to make changes that will maintain or improve your brain health. These changes may also help reduce your risk of developing dementia. Evidence suggests that healthy lifestyles help the brain maintain connections and even build new ones.

**Caregiver:** A caregiver is a family member or friend who provides unpaid care for someone who is living with a disability, illness, or is aging.

**Care Plan:** A care plan (also known as a service plan), plan of care, or treatment plan, is developed in collaboration with the individual and their family and caregivers. The care plan provides details on the person's history as well as the plan for services including treatments, interventions, personal goals, and anticipated outcomes. The care plan provides a complete picture of the individual and their care, and includes the clinical care path and information that is important to providing person-centred care (e.g., individual wishes, ability/desire to partner in their care, the an individual's family or support network). The care plan is accessible to the team and used when providing care.

**Care Provider:** A care provider provides paid support, diagnostic services and/or care to persons living with dementia and their caregivers.

**Core Competencies:** Core competencies for staff that provide care to persons living with dementia include specialized knowledge about the condition, specialized skill in assessing, planning and providing optimum care, and an attitude of respect for the person living with dementia and their caregiver. The knowledge, skill and attitudes required to provide person-centred dementia care are known as core competencies. These competencies are usually addressed in dementia education and through mentoring.

**Continuing Care:** Continuing care is an integrated range of services supporting the health and wellbeing of individuals living in their own home, a supportive living or long-term care setting. Continuing care clients are not defined by age, diagnosis or the length of time they may require service, but by their need for care. In Alberta, the current continuing care system is comprised of the following subsectors: home living/home care, supportive living, and facility based long-term care.

**Delirium:** Delirium is a clinical syndrome characterized by an altered level of consciousness and cognitive changes that develop over a short period of time (usually over hours or days). The causes of delirium include, but are not limited to, certain medications and infections. If treated, lasting effects can be avoided or minimized.

**Electronic Health Record:** The Alberta Electronic Health Record (Alberta EHR) is the integrated provincial electronic health information network that provides shared access to health information, by authorized custodians, in a secure environment.

**Frailty:** Frailty is a state of increased vulnerability, with reduced physical reserve and loss of function across multiple body systems. This reduces ability to cope with normal or minor stresses, which can cause rapid and dramatic changes in health.

**Mental Health:** A state of wellbeing where individuals realize their potential, can cope with normal stresses of life, work productively, and contribute to their community.

**Mild Cognitive Impairment:** Mild cognitive impairment (MCI) is a general term most commonly defined as a subtle but measurable memory disorder. A person with MCI experiences memory problems greater than normally expected with aging but does not show other symptoms of dementia, such as impaired judgment or reasoning. Because the changes caused by MCI are not severe enough to affect daily life, a person with MCI does not meet diagnostic guidelines for dementia.

**Primary Care Networks:** Groups of family doctors who work with Alberta Health Services and other health professionals to coordinate the delivery of primary care services for their patients.

**Primary Health Care:** The first place people go for health care or wellness advice and programs, treatment of a health issue or injury, or to diagnose or manage physical and mental health conditions. In Alberta, primary health care includes a wide range of services delivered by teams of providers that can include physicians, nurses, psychologists, pharmacists, dietitians, counsellors, rehabilitation therapists, and social workers, among others, depending on the needs of the people with whom they are working. Social and community initiatives such as housing, employment, and income supports are part of the programming people can draw on to support their overall health and wellbeing.

**Transitions:** Transitions in care are changes individuals experience in health status, care needs, health-care providers or locations (within, between, or across settings). Persons living with dementia also experience many transitions in their social roles and abilities as the dementia journey continues.

## Appendix B: Strategy Participants

The following individuals contributed greatly to the development of the Alberta Dementia Strategy and Action Plan through their participation on the Steering Committee, Advisory Committee, Working Groups or Project Management Team. Many more individuals have contributed their perspective as this work was undertaken and we thank everyone who participated in the process.

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