



TOWARDS UNDERSTANDING

Final Report and Recommendations of the Dementia Strategy Project, May 28, 2015

[Abstract](#)

The 2014-2015 Department of Health and Wellness (DHW) Statement of Mandate identified a provincial dementia strategy and action plan will be released in the spring of 2015. This is the final report of the dementia strategy project.

Dementia Strategy Advisory Committee and Project Team

Acknowledgements

Completion of the Nova Scotia Dementia Strategy project would not have been possible without the participation and involvement of multiple stakeholders across the province in addition to others both nationally and internationally. Their thoughtful insights and perspectives are greatly appreciated and have shaped the development of the information contained in this report.

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- Chairs and members of the Advisory Committee and 6 working groups (detailed in Appendix A and B)
- Nova Scotia subject matter experts:
 - Dr. Paul Brown, Professor Emeritus, School of Public Administration, Dalhousie University.
 - Dr. Janice Keefe, Professor and Director, Nova Scotia Centre on Aging, Lena Jodrey Chair in Gerontology, Mount Saint Vincent University.
 - Dr. Kenneth Rockwood, Geriatrician, Professor of Geriatric Medicine and Neurology, Kathryn Allen Weldon Professor of Alzheimer Research, Dalhousie University.
- Best Brains panel members and moderator:
 - Dr. June Andrews, Professor and Director of Dementia Services, University of Stirling, Scotland.
 - Dr. Howard Bergman, Chair of the Department of Family Medicine, Professor of Family Medicine, Medicine and Oncology, McGill University, Quebec.
 - Dr. Duncan Robertson, Senior Medical Director of the Strategic Clinical Network: Seniors' Health, Alberta Health Services, Alberta.
 - Dr. Samir Sinha, Director of Geriatrics, Mount Sinai Hospital, Toronto, Ontario.
 - Dr. Gail Tomblin Murphy, Professor, School of Nursing and Director of WHO/PAHO Collaborating Centre on Health Workforce Planning and Research, Dalhousie University (moderator).
 - Dr. Isabelle Vedel, Assistant Professor, Department of Family Medicine and Division of Geriatrics, McGill University, Quebec.
- Nova Scotia Health Research Foundation for gathering and analysing the consultation data, producing an asset map and literature review and for coordinating the Best Brains/REAL results event.
- Canadian Institute of Health Research (CIHR) for coordinating the Best Brains event.
- Centre on Aging for conducting the public consultation sessions, providing project management support and developing the evaluation framework.

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Executive Summary

Dementia is an umbrella term used to describe a group of diseases that affect the brain and cause a progressive decline in the ability to think, remember and carry out day to day activities. It affects people, their families and caregivers differently. It is not a normal part of aging.

While most people who develop dementia are older adults, it is important to note that the disease can present at a younger age and is identified as ‘early onset dementia’. About 1 person in every 1,000 under the age of 65 develops dementia.¹

The number of people living with dementia (prevalence) in Nova Scotia is increasing; estimates show that by 2038, 2.5 % of the population will be living with Alzheimer disease and related dementias. The social and economic implications are substantial for those who experience dementia, for their families and caregivers and for the health and social system.²

Nova Scotia needs to address dementia care and supports sooner rather than later. The intent of this strategy is to address the needs of people living with dementia, their families and caregivers regardless of type of dementia or age of onset.

In January 2014 the Nova Scotia government announced that the Department of Health and Wellness and the Alzheimer Society of Nova Scotia would co-lead an advisory committee to guide the development of a provincial dementia strategy. The strategy was mandated³ as a key action to ensure that the health system places Nova Scotia’s patients, families and individuals first.

The advisory committee was established in the spring of 2014 and background information was gathered over the summer. A public consultation process occurred during the fall with over 700 respondents (either through public sessions, online surveys or support group interviews). Working groups conducted analysis of opportunities, gaps, and challenges related to six themes: public awareness, supports for families and caregivers, diagnosis and management of dementia, coordination of care, education of health care providers

¹ Alzheimer Society of Nova Scotia website, <http://www.alzheimer.ca/en/ns/About-dementia/Dementias/early-onset-dementia>

² Information adapted from P. Moise, et.al, Dementia Care in 9 OECD Countries: A comparative analysis, 2004.

³ Annual Statement of Mandate for the Fiscal Year 2014-2015, NS Department of Health and Wellness.

and research. A Best Brains panel⁴ with national and international representation was held in the fall of 2014 to obtain advice and guidance on best practice for implementation of a dementia strategy. Throughout the course of the project, Nova Scotia content experts provided input on key deliverables.

Based on the work of the advisory committee, working groups and consultations, a framework for action was developed to create positive change for people living with dementia, their families/caregivers, for health care providers and the health system.

The vision of a future desired state aims for a better quality of life for people living with dementia, their families and caregivers through an accessible, welcoming and inclusive system that is responsive, innovative and culturally specific. Three strategic goals to attain this vision focus on:

- care and support;
- access and delivery of care; and,
- information and education.

Sixteen corresponding priority actions are nested under the relevant strategic goals. The vision and guiding principles establish a foundation for the strategy and are meant to be reflected in the implementation of all priority actions.

Best practices for implementation of the strategy have been identified. An evaluation framework has been developed to support the implementation of priority actions and to provide a process for measuring progress and ensuring accountability. The strategy will need to be flexible based on information gathered from implementation of priority actions and informed through ongoing health system planning.

⁴ Best Brain Exchanges are one-day, in-camera meetings for decision makers, and researchers with expertise on a topic that has been identified as a high priority by provincial/territorial ministries of health and the Health Portfolio. For more details go to the Canadian Institutes of Health Research (CIHR) website: <http://www.cihr-irsc.gc.ca/e/43978.html>

Background

The need for a dementia strategy

Dementia is an umbrella term used to describe a group of diseases that affect the brain (including Alzheimer disease) and cause a progressive decline in the ability to think, remember and carry out day to day activities. It affects people, their families and caregivers differently. Often there are significant changes to behaviour, personality and function that can be distressing for the individual and for those who care for them. Dementia is not a normal part of aging.

New cases of dementia are on the rise in Nova Scotia. Over the next 30 years the number of newly diagnosed cases (incidence) is expected to double from the 2008 estimate of 3,240 per year, reaching to over 6,800 new cases per year.⁵ The number of people living with dementia (prevalence) in Nova Scotia is also increasing; estimates show that by 2038, 2.5 % of the population will be living with Alzheimer disease and related dementias. The social and economic implications are substantial for those who experience dementia, for their families and caregivers and for the health and social system.⁶

The economic impact of dementia and dementia care in Nova Scotia will be significant. Cumulatively, over the years from 2008-2038, it is estimated that dementia will cost Nova Scotia society over \$24.5 billion dollars in total direct health costs, unpaid caregiver costs and indirect costs.⁷

Nova Scotia needs to address dementia care and supports sooner rather than later. The ultimate goal of developing a strategy is to improve the quality of life for people living with dementia, their families and caregivers regardless of type of dementia or age of onset.

Impact at multiple levels

A lack of information and understanding about dementia in society contributes to stigma and heavier health burdens for those living with dementia and their family/caregivers and can cause an ineffective health care provider and health system response for care and support. People need to be aware and informed about the types of dementia and corresponding symptoms, healthy living activities that may reduce risk of developing dementia, the importance of a timely diagnosis, and relevant services and supports that are available. Health

⁵ Rising Tide: The Impact of Dementia in Nova Scotia: 2008 to 2038. Risk Analytica, October 2009, page 7.

⁶ Information adapted from P. Moise, et.al, Dementia Care in 9 OECD Countries: A comparative analysis, 2004.

⁷ Rising Tide: The Impact of Dementia in Nova Scotia: 2008 to 2038. Risk Analytica, October 2009, page 8.

care providers and the health system need to recognize the impact of dementia and ensure that they are able to effectively respond to people with dementia and to family/caregiver needs.

People living with dementia

Dementia impacts a significant proportion of the older population and causes many to require long term support and care. Like other provinces, a large segment of Nova Scotians are part of the “baby boomer” generation. The aging of this segment, coupled with out-migration of working age citizens, among other reasons, has resulted in Nova Scotia having one of the highest proportions of people aged 65 years and older in Canada (18.3% as of July 1, 2014).⁸ In addition, the aging of the Canadian (and Nova Scotian) population has led to an epidemiological shift in disease profile, with many older people living to an advanced age with multiple chronic health conditions.⁹ With aging there is a higher risk of social vulnerability and frailty, both of which can increase the risk for development of dementia.

Women are disproportionately affected by dementia; they are at a higher risk of developing the disease due to gender, they live longer, and are more likely than men to be living alone as they age.

While most people who develop dementia are older adults, it is important to note that the disease can present at a younger age and is identified as ‘early onset dementia’. About 1 person in every 1,000 under the age of 65 develops dementia.¹⁰ The impact on these individuals and their families can be quite distinct from older adults living with dementia. Many younger people may still be working with significant financial commitments and have dependent children or parents living at home.

Diverse populations

There are differences in prevalence and incidence of dementia for specific Nova Scotian populations (e.g. First Nations, African Nova Scotians and new immigrants). Part of the reason is related to differences in the proportion of younger people in these populations. A recent study conducted in Alberta shows that dementia is an emerging health concern for First Nation people (the age-standardized prevalence of

⁸ Nova Scotia Department of Health and Wellness: Business Intelligence and Analytics, Privacy Branch, 2014. Note: This is in the context of NS birth and death rates, mobility of population with out-migration of younger people and older people moving into the province. These lead to constant changes in the average age and age group distributions. As of July 2014 Stats Canada data, NS is currently tied with NB.

⁹ Future Care for Canadian Seniors-Why it Matters, Briefing October 2013, The Conference Board of Canada and the Canadian Alliance for Sustainable Health Care, page 3.

¹⁰ Alzheimer Society of Nova Scotia website, <http://www.alzheimer.ca/en/ns/About-dementia/Dementias/early-onset-dementia>

dementia in First Nations in Alberta was 7.5 per 1,000 compared to non-First Nations, at 5.6 per 1,000). The data also suggest that dementia disproportionately affects younger age groups and males in First Nations populations compared to non-First Nations.¹¹

In the United Kingdom (UK) and the United States (US), there is indication that the prevalence of dementia among minority populations (including Black African-Caribbean and African-American) is greater than the white population and that it affects younger people in these age groups as well.^{12 13}

In recognition of the diversity of populations in Nova Scotia the implementation of the strategy needs to build in accountability for demonstration of meeting their needs. The collection of relevant data from underrepresented populations will be required. The need for culturally specific dementia care cannot be overstated.

Families and Caregivers

Families and caregivers have a significant role in dementia care and require appropriate information, care and support to meet their needs. Caregivers are diverse (e.g. relationship to the care recipient, income, health status, etc.) and often require a range of supports to assist them in their role and to meet their needs.

The Health Council of Canada notes that in 2012 2.7 million Canadian family caregivers over the age of 45 were helping seniors with long term health conditions. Three quarters of caregivers were aged 45-64, while one quarter were seniors themselves. Nearly 60% of these family caregivers were women, and 57% of caregivers were employed. If an individual does not have a spouse, he or she is most likely to be cared for by their adult children.¹⁴

The Canadian Institute for Health Information (CIHI) notes that caregivers of people living with dementia provide 75% more care than other caregivers and experience nearly 20% higher levels of stress. The demands on these caregivers tend to increase as the disease progresses often due to changes in behaviour,

¹¹ K. Jacklin, J. Walker, M. Shawande. The Emergence of Dementia as a Health Concern among First Nation people living in Alberta, Canada. Canadian Journal of Public Health, Jan/Feb 2013.

¹² D. Truswell, Black, Asian and Minority Ethnic Communities and Dementia: Where are we now? A Race Equality Foundation Briefing Paper, November 2013, page 3.

¹³ A. Chin, S. Negash, R. Hamilton. Diversity and Disparity in Dementia: The Impact of Ethno-racial Differences in Alzheimer's disease. Alzheimer Dis Assoc Discord. 2011 25(3), 187-195.

¹⁴ Health Council of Canada (HCC), Seniors in Need, Caregivers in Distress, 2012, page 27.

personality or function.¹⁵ Studies show that if caregiver needs are appropriately addressed their own health can be improved and long term care placement of the care recipient can be significantly delayed.¹⁶

Definition of family and caregiver

The terms 'family' and 'caregiver' encompass a diverse range of meaning. What an individual might define as family may include family of origin, family of choice, friends, or members of the same cultural community.

There are a number of terms that describe those that give unpaid support and/or care (e.g. caregiver, carer, and care partner¹⁷) to someone living with dementia. These terms include a family member as defined above, significant other or friend who work in partnership with the person living with dementia and give unpaid support and/or care. It must be recognized that caregivers are not volunteers and they do not work in shifts as many paid care providers do; many who live with the care recipient often give care around the clock. In addition, the majority of caregivers have not received training to manage the complex needs the care recipient may have.

While the term caregiver is used in Nova Scotia it is recognized that there is a shift in terminology used to describe caregivers of people living with dementia. In parts of Canada and the US the term care partner is being utilized instead of caregiver to reflect a more equal relationship between care recipients and those giving care. The care partner relationship recognizes the contributions of both parties in giving and receiving care, empowering the person with dementia to continue to contribute as much as possible while acknowledging and responding to the distinct needs of care partners.

Recognition of these broader definitions of family and caregiver among health care providers and across health settings can begin to address real or perceived barriers in the health system and can also ensure inclusion of families and caregivers in the circle of care, as partners in care.

¹⁵ Caring for Seniors with Alzheimer Disease and Other Forms of Dementia, Analysis in Brief, Canadian Institute for Health Information (CIHI), August 2010.

¹⁶Mittleman, M. et.al. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease, *Neurology* 2006; 67; 1592-1599.

¹⁷ While the term care partner was used at the onset of the project (as reflected in the public consultation data), the term caregiver is being used for the final project report.

The health system

Given the demographic and funding challenges that face most jurisdictions (both in Canada and internationally) momentum is building to fundamentally shift care that is coordinated around an individual's needs that prioritizes prevention and support for maintaining independence. Currently, many health settings in Nova Scotia vary greatly in their understanding of dementia and how to meet the needs of people living with the disease.

A number of models of care (across health settings including community, primary health, acute and emergency departments) are being piloted and evaluated in Canada and internationally. These models recognize that older adults living with chronic conditions have become the core business of health care and if improvements can be made in care for this population, this can positively impact care for others. For example, care for older adults living with frailty that focuses on recognition of a person living with a long term condition (e.g. frailty, dementia) and not on a specific disease label allows for a more person centered approach. Timely, accurate diagnosis, coupled with proactive coordinated care and individualized care planning and support of self-management can make a significant difference in people's lives.

A growing body of evidence indicates that when health care and support services are targeted, case managed, and integrated, outcomes are better for the individuals receiving care, for their family caregivers, and for the health care system.¹⁸ This is very different from the current approach of hospital based, episodic, and disjointed care which creates many problems for older adults (e.g. delirium, falls, decreased mobility) and leads to a reduction in health system effectiveness (e.g. the main cause of long stay patients in acute care is ineffective management of dementia).^{19 20 21 22 23}

Dementia is a chronic, long term and progressive disease and the needs and supports for those living with it and their families/caregivers will change over time. Health care, social support systems and corresponding

¹⁸ A.P. Williams et al. Balancing Institutional and Community Based Care: Why some older persons can age successfully at home while others require residential long term care. *Longwood's Review*, Vol. 7(1), pp.95-105.

¹⁹ Commission on Hospital Care for Frail Older People, HSJ, Serco, November 2014.

²⁰ T. Epp, Person-centre Dementia Care: A Vision to be Refined. *The Canadian Alzheimer Disease Review*, April 2003.

²¹ J. Goldhar, et. Al. Integrated Client Care for Frail Older Adults in the Community: Preliminary Report on a System Wide Approach, *Healthcare Quarterly*, vol. 17, No.3, 2014.

²² R. McCloskey et.al, Alternate Level of Care Patients in Hospitals: What does Dementia have to do with this? *Canadian Geriatrics Journal*, Volume 17, Issue 3, September 2014.

²³ J. McElhane, et.al, Prevention in Acute Care for Seniors, *BC Medical Journal*, Vol. 53, No. 2, March 2011, www.bcmj.org

providers of care in Nova Scotia must be able to respond effectively to these diverse and changing needs in a culturally specific manner and organize care and support with a goal to improve health and quality of life.

Government priority to address dementia

In January 2014, the Nova Scotia government announced that the Department of Health and Wellness and the Alzheimer Society of Nova Scotia would co-lead an advisory committee to guide the development of a provincial dementia strategy. The Continuing Care Branch became the project lead for the Department.

The strategy was mandated²⁴ as a key action to ensure that the health system places Nova Scotia's patients, families and individuals first. The goal of the strategy aims to enhance the delivery of dementia care and treatment ensuring people living with dementia, as well as their families or caregivers are well supported.

The 2015-2016 DHW Statement of Mandate identifies that the implementation of the dementia strategy will support the strategic priority to improve and increase the use of community focused care for seniors and patients with chronic conditions.²⁵

The Project

The dementia strategy project utilized an approach that focused on obtaining relevant information and evidence in a timely manner to inform discussions and support decision making. The following sources were essential for providing insights to this process:

- jurisdictional review of dementia strategy development and implementation
- literature review
- analysis of public consultations and,
- reports from 6 working groups on key themes.

In addition, the following participatory approach established a foundation for developing a comprehensive report to government on the development of the dementia strategy:

- Purposeful and committed relationships between the Department of Health and Wellness, the Alzheimer Society of NS, and the Advisory Committee.

²⁴ Annual Statement of Mandate for 2014-2015, NS Department of Health and Wellness.

²⁵ Annual Statement of Mandate for 2015-2016, NS Department of Health and Wellness.

<http://novascotia.ca/dhw/corporate-reports.asp>

- Ongoing feedback from subject matter experts and key stakeholders in the Department of Health and Wellness and the Nova Scotia Health Authority.
- Focused engagement of people with dementia, their families and caregivers.

Advisory Committee

An advisory committee was established to provide advice and suggest recommendations to the Minister of Health and Wellness regarding the development of a provincial dementia strategy (Appendix A). The committee contributed to the final report of the dementia strategy project. Six meetings were held between April 2014 and April 2015. The advisory committee was co-chaired by the Department of Health and Wellness and the Alzheimer Society of Nova Scotia. Membership on the committee provided a variety of perspectives including the personal experience of living with dementia, family caregivers of people living with dementia, the health and social systems, and non-government agencies supporting people and their families.

Consultation and Engagement

Consultation with the public

Over 700 people provided feedback through: public consultations, online surveys (DHW and Alzheimer Society), Alzheimer Society and Caregivers NS support group meetings and online submissions via the dementia strategy project email (Appendix B). People living with dementia, their families and caregivers along with health care providers were all targeted for consultation. Analysis of feedback from all of the consultations identified the following predominant themes:

- Improving access to information;
- Importance of education
- Improving access to early diagnosis
- Reducing stigma and fear
- Importance of the family physician
- Increasing supports for people living with dementia and their families/caregivers
- Improving home support services
- Enhancing care coordination and system navigation
- Importance of including the caregiver in the dementia journey
- Improving the quality of care.

Underrepresented populations were also consulted including Acadian Nova Scotians, Lesbian, Bisexual, Gay, Transgender and Intersex (LGBTI) communities and African Nova Scotians. A focus group on diversity was held that included representation from the above populations in addition to Mi'kmaq and Nova Scotia Immigrant populations. Specific engagement with Mi'kmaq and Immigrant communities was not able to be completed during the consultation timeline and turnout for the LGBTI and African Nova Scotian sessions was low. A few members of these populations attended the public sessions. It is recognized that more work will need to be done to engage with Mi'kmaq, Immigrant, LGBTI and African Nova Scotian populations to ensure that cultural and linguistic needs in relation to dementia care and support are understood and responded to. While underrepresented groups had similar themes to those noted in the public consultations, several distinct themes emerged:

- The importance of diversity and culturally specific approaches to care for individuals, families and caregivers receipt of information, care and support and,
- The significance of family and community as vital to supporting people with dementia and the high expectations of caregiver roles.

Consultation with subject matter experts

Several Nova Scotia experts were consulted on a regular basis throughout the course of the project and provided valuable input on key deliverables from the following perspectives:

- Policy coherence-Dr. Paul Brown, Professor Emeritus, School of Public Administration, Dalhousie University, Halifax, Nova Scotia.
- Families and caregivers-Dr. Janice Keefe, Professor and Director, Nova Scotia Centre on Aging, Lena Jodrey Chair in Gerontology, Mount Saint Vincent University, Halifax, Nova Scotia.
- Clinical care and the Nova Scotia health system-Dr. Kenneth Rockwood, Geriatrician, Professor of Geriatric Medicine and Neurology, Kathryn Allen Weldon Professor of Alzheimer Research, Dalhousie University, Halifax, Nova Scotia.

A Best Brains session was conducted in the fall of 2014 and 5 panel members presented information and gave advice on considerations to ensure successful implementation of a dementia strategy. The session was moderated by Dr. Gail Tomblin-Murphy, Director, WHO/PAHO Collaborating Centre & Professor, Dalhousie University School of Nursing, and panel members included national and international representation:

- Dr. June Andrews, Professor and Director of Dementia Services, University of Stirling, Scotland
- Dr. Howard Bergman, Chair of the Department of Family Medicine, Professor of Family Medicine, Medicine and Oncology, McGill University, Quebec

- Dr. Duncan Robertson, Senior Medical Director of the Strategic Clinical Network: Seniors' Health, Alberta Health Services, Alberta
- Dr. Samir Sinha, Director of Geriatrics, Mount Sinai Hospital, Toronto, Ontario
- Dr. Isabelle Vedel, Assistant Professor, Department of Family Medicine and Division of Geriatrics, McGill University, Quebec

In addition, panel members provided useful feedback on the development of the framework for action, strategic goals and priority actions.

Working Groups

Over sixty people participated in six working groups that were created to provide input to the advisory committee, based on stakeholder subject matter expertise, regarding the strengths, capacity and gaps in the system. Each group focused on one of the following themes which emerged from the review of Canadian and international dementia strategies, results from a Department of Health and Wellness survey, a literature review and discussions with Nova Scotia researchers:

- Public Awareness
- Supports for Families and Caregivers
- Early Diagnosis and Management of Care
- Coordination of Care
- Education for Health Care Professionals
- Research

Working groups met between September and December of 2014 and each group developed a report that included draft recommendations for action to address key issues under the above themes. The reports were presented to the Advisory Committee in January for their review and this body of work is reflected in the final report.

Framework for Action

Overview

Based on the work of the advisory committee, working groups, consultations and guidance from content experts, a framework for action was developed with the intent to create positive change for people living with dementia, their families and caregivers, health care providers and the health system. The framework

for action identifies the vision, guiding principles, key tenets, strategic goals, current situation, priority actions to support a future desired state.

Foundational components

Strategy Vision

People living with dementia, their families and caregivers will have a better quality of life through an accessible, welcoming and inclusive system that is responsive, innovative and culturally specific.

Guiding Principles

The guiding principles are intended to ensure that the framework for action is grounded in a common set of values and philosophy. They are meant to establish a foundation for the strategy and are to be reflected in the implementation of all priority actions.

- **Person Directed and Relationship Focused:** The person and their family/caregiver are valued, empowered and engaged to make decisions and choices enabled by respectful and trusting relationships.
- **Inclusive, Culturally Competent, Safe and Equitable²⁶:** The different needs of Nova Scotia's diverse populations are valued and integrated to support equitable access in a responsive and inclusive system.
- **Integrated and Coordinated:** The existing system promotes collaboration and is enhanced to provide access to a range of relevant, flexible and coordinated services and supports.
- **Enhancing Capacity:** Informed and knowledgeable individuals, families and caregivers, and health care providers have the skills and abilities that are essential to effectively understanding and supporting needs of people living with dementia, their families and caregivers.
- **Accountability and Quality Care:** Continuous quality improvement and sustainability are achieved through leadership that enables evidence based decision making, monitoring, evaluation and leading practice.

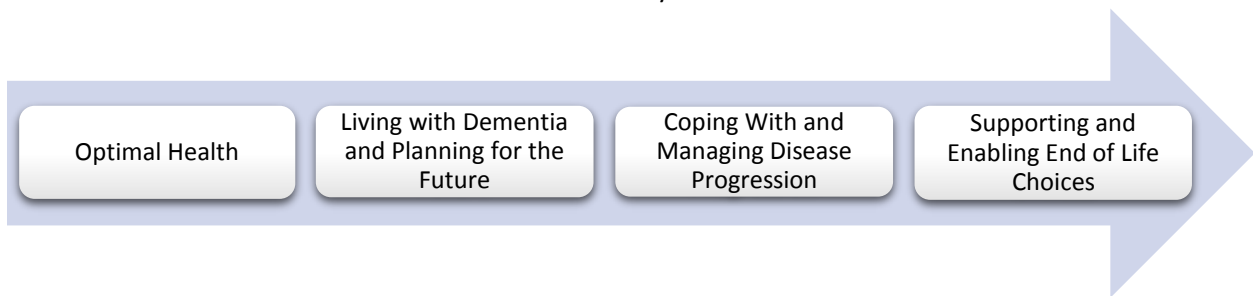
Key Tenets

In order to improve health care culture and response for those living with dementia consideration will need to be given to adopting the following tenets in the approach to care and establishing policy to enable this to occur.

²⁶ Health inequities are health differences between population groups-defined in social, economic, demographic, or geographic terms-that are systemic, unfair, and avoidable (National Collaborating Centre for Determinants of Health). Quoted from Nova Scotia Public Health; Health Equity Protocol.

The personal journey: Experiencing dementia is a personal journey which differs for each individual and their family/caregiver. Given the chronic and progressive nature of the disease, individuals with dementia, their families and caregivers will have diverse needs which will impact them in different ways. In addition, families and caregivers will also experience another aspect along the journey, that of active grieving and the need for bereavement support. It is critical that health care providers and the health system response takes into account the personal journey of dementia when interacting with individuals, their families and caregivers.

The Personal Journey of Dementia²⁷



A person centered approach: A person centered approach to care needs to be part of the culture of care in the health system. Person centered care can have a positive impact on the individual with dementia and their families.²⁸ The continuum of person directed culture incorporates being person centered. Health care providers and the health system need to make the shift further along this continuum to reflect the practice of a person centered approach to care and support so that individuals with dementia, their families/caregivers are well supported. Currently the health system in Nova Scotia is very much provider directed or staff centered instead of being person centered or person directed. Identification of relevant care settings, barriers to change and required policy development or revision must occur in order to move to a more person centered approach.

Continuum of Person Directed Culture²⁹



²⁷ Adapted from the British Columbia Dementia Service Framework. Provincial Dementia Service Framework Working Group, September 2007.

²⁸ Chenoweth, L., King, M., et.al, Caring for Aged Dementia Care Resident Study (CADRES) of person centered care, dementia care mapping, and usual care in dementia: a cluster-randomised trial, Australian Health Ministers' Advisory Council, The Lancet, Volume 8, April 2009.

²⁹ Copied from M. Crotty, Genesis HealthCare Corp., based on the model by S. Misiorski and J. Rader, distributed at the Pioneer Institutes, 2005.

Transforming care for an older population: Responding to the needs of an older population requires a fundamental shift towards care that is coordinated around the full range of an individual's needs and care that prioritizes prevention and support for maintaining independence. Achieving this will require much more integration to ensure that the right mix of services is available in the right place at the right time.³⁰ Effective delivery of dementia related care and supports depends upon this transformation of care for an older population.

Supportive communities: It is recognized that communities and society as a whole play an important role to support individuals with dementia and their families/caregivers and that there needs to be a strong linkage between the health system and community so that people with dementia, their families/caregivers are well supported. This includes neighbours and friends, volunteer, faith based, and service organizations, the built environment and strategies for age friendly communities. While the framework for action falls within the broader context of community it focuses on improving access to responsive community and facility based health care and social supports.

Strategic Goals

Three strategic goals have been identified in the framework for action. They have evolved from the key themes that the consultation and working groups focused on (public awareness, supports for families/caregivers, diagnosis and management of dementia, coordination of care, education for health care providers and research). The strategic goals describe what needs to be addressed, why these areas need to be addressed (current situation) and what will change for people living with dementia and their families/caregivers, health care providers and the health system (desired future state).

The strategic goals are meant to effectively support people, their families and caregivers across the personal journey of dementia focusing on:

1. Ensuring access to timely, accurate diagnosis and appropriate care and support for people living with dementia, their families and caregivers.
2. Enhancing health system capacity to provide coordinated dementia care and support that is person centered and culturally specific.
3. Increasing awareness and understanding through evidence informed information and education.

³⁰ D. Oliver, C. Foot, R. Humphries, Making our health and care systems fit for an aging population. The Kings Fund, 2014, page vi.

Priority actions have been identified in order to meet the strategic goals. These actions are meant to address current gaps, challenges, barriers and aim for the vision of enhanced delivery of dementia care and treatment to ensure people living with dementia, as well as their families or caregivers are well supported (see Appendix D for details on the priority actions).

There are several priority actions that are overarching and will enable successful implementation of the strategy across the 3 strategic goals. They include:

- Evaluate the dementia strategy. There will be a variety of activities identified across all priority actions that will include monitoring of some initiatives and more formal evaluation of others.
- Determine appropriate data to collect across the health system to support individual care, system planning for services, evaluation and research. This work needs to begin in Year 1 and will continue over the course of the strategy.
- Establish dementia related research priorities in Nova Scotia. There needs to be a focus on dementia related research and its impact on successful implementation of the strategy. Alignment with policy questions and with local research strengths can guide investment of scarce resources.

The overarching priority actions focus on information and knowledge. It is challenging to set priorities and plan for dementia related care and supports due to limited knowledge about what programs and services are effectively meeting the needs of people with dementia, their families and caregivers. The lack of dementia related data further impacts program planning, monitoring and evaluation. In addition, useful dementia related research is not being fully utilized to support application in care practices and there are gaps in dementia related research to support evidenced informed dementia care and support.

Strategic Goal-Care and Support

Ensure access to timely, accurate diagnosis and appropriate care and support for people living with dementia, their families and caregivers.

Current Situation

The number of people who have dementia and actually obtain a diagnosis and receive appropriate treatment, care and support is relatively low. There is limited understanding of the benefits of having a diagnosis; many people think “if I have the disease, there is nothing to be done anyway.” Given the stigma of dementia, individuals may choose not to seek out information or may choose to hide their symptoms. In addition, the value of a dementia diagnosis may not be recognized among some health care providers and this can create barriers for those seeking a diagnosis.

Without timely and accurate information and diagnosis it is very difficult to plan for the future. This can have a significant impact on daily life, leading to distress. People may not identify their personal wishes for care (e.g. personal directives, choices for management of co-morbidities and end of life care) or may not be attending to financial and legal considerations.

People with dementia, and their families and caregivers are often not aware of the progressive nature of the disease and that their needs will change. They are not always linked to the necessary information, supports and service they may require. Those who do decide to seek out advice and information may have challenges accessing good information and appropriate support.

Nova Scotians across the province and across diverse populations identified primary health care providers as having a critical role in helping them to access accurate information, get a diagnosis and connect to appropriate care and support.

Priority Actions

- ✓ Strengthen the ability of primary health care providers to diagnose and manage the complex care needs of people living with dementia, and better support families and caregivers.
- ✓ Develop an ongoing assessment approach focusing on the distinct needs of families and caregivers.
- ✓ Enhance existing programs and services for people living with dementia, families and caregivers that are accessible, appropriate, timely, affordable and sustainable.
- ✓ Enhance end of life care for people living with dementia, their families and caregivers.

What will be different?

There will be increased rates of diagnosis and improved management of ongoing care needs for people living with dementia through a responsive primary health care system.

People with dementia will have timely, accurate diagnosis of dementia and will be enabled to plan for the future while they still have capacity. They, along with their families and caregivers will be effectively connected to appropriate information, supports and services and have access to relevant programs and services as their needs change. Early detection of dementia is critical to ensuring that people with dementia, their families/caregivers have access to treatment, education, counseling and other services that can delay decline, prevent crisis, ease caregiver burden and delay transition to long term care.

Strategic Goal-Health Care System Coordination

Enhance health system capacity to provide accessible, coordinated dementia care and support that is person centered and culturally specific.

Current Situation

There is lack of coordination and communication of dementia related care across the health system and between different health settings and services which creates barriers for people accessing programs, service and supports. Care planning becomes piecemeal and transitions in care from one health care setting to another, or to community, can be ineffective.

Not all primary health care providers are linked to community based multi-disciplinary teams (e.g. seniors' teams, geriatricians, psychiatrists or primary care physicians with specific skills in health care of the elderly). This lack of linkage and coordination across health settings impacts accessibility to a timely, accurate diagnosis, treatment and effective ongoing management of the person through their health care journey.

Feedback obtained through the consultations indicated that people living with dementia, their families and caregivers are not recognized as partners in the planning of care. There is also a lack of culturally specific care and support and people feel that even if programs and services are offered they may not be responsive to their specific needs.

In addition, there is minimal involvement of individuals with dementia and their families/caregivers in the development of dementia care program policy and planning across all health settings.

Priority Actions

- ✓ Advance effective coordination of ongoing care and support across the health system to provide a seamless response including a person centered and relationship focused approach for people living with dementia and their families and caregivers.
- ✓ Determine an integrated primary health care approach to improve communication and coordination among health care providers and across the continuum to best support people living with dementia, their families and caregivers.
- ✓ Examine the need and function of a community based role to best support the needs of people living with dementia and their family and caregiver in navigating the dementia journey.
- ✓ Advance the delivery of high quality dementia care through the identification of core competencies for relevant health care providers working with people living with dementia.
- ✓ Recognizing the diversity of the NS population, understand the needs of people with dementia, their families and caregivers from under represented populations in Nova Scotia to inform the implementation of priority actions.

What will be different?

People living with dementia, their families and caregivers indicate that they are engaged in their own care and are recognized as partners in care. Dementia care programs and policies are accessible, equitable and reflect a person centered, culturally specific approach to care.

Care and services are delivered by competent health care providers who are skilled at meeting the needs of people living with dementia, and their families/caregivers.

There is effective coordination of care across health settings (e.g. primary health care, home and long term care settings, emergency health and acute and tertiary care) and at transitions in care. Primary health care providers are supported by and linked to multi-disciplinary specialized services such as geriatric medicine, psychiatry, memory clinics, and mental health providers when required. There is a more effective community based dementia care response where hospital admission is avoided when appropriate, and if admission is required, further functional decline is minimized where possible.

Strategic Goal-Knowledge and Capacity Building

Strengthen awareness and understanding for people with dementia, their families/caregivers and health care providers through the provision of accessible, evidence informed dementia related information, education and training.

Current Situation:

People living with dementia and their families and caregivers are not sure what information on dementia is reliable or relevant. Many Nova Scotians are not aware and informed about dementia; the potential to lower the risk of developing dementia through healthy lifestyle; signs and symptoms of the disease; importance of timely diagnosis; the impact of regular physical activity in improving quality of life and well-being; advance care planning; or of available services and supports.

Many family members and caregivers want more information on how to support the person with dementia and may be seeking out education and practical skills for care.

Not all health care providers across all health settings have the necessary skills to deliver care that recognizes the specific needs and care requirements of people living with dementia, their families and caregivers. They may not be effectively connected to credible information on best practice for dementia care and support.

Priority Actions

- ✓ Develop and implement targeted dementia related awareness activities (e.g. what is dementia, risk reduction associated with healthy lifestyle and physical activity, where to go for information and support, the importance of a timely and accurate diagnosis).
- ✓ Provide education and training on dementia and dementia care to families and caregivers.
- ✓ Ensure dementia education for relevant health care settings and health care providers to support people living with dementia and their families and caregivers is available and accessible.
- ✓ Promote and build on credible knowledge translation resources for health care providers and the public.

What will be different?

People and their families and caregivers have access to valid, reliable information that is understandable. There will be an increase in knowledge of preventative and protective factors associated with dementia particularly the importance of good cardio vascular health and regular physical activity. Families and caregivers have appropriate education and training on caring for people with dementia. Health care

providers are supported to deliver care and services to people living with dementia that is evidence informed. Health care leadership recognizes the importance of education for health care providers and enables them to obtain necessary education and training.

Implementation of the Dementia Strategy

Linkage to Other Strategies and Initiatives

It will be important to promote alignment and collaborative efforts with other government strategies and program initiatives that are currently underway. Collaboration with the palliative care strategy implementation team and advisory committee will be critical for the consideration of awareness and information regarding advance care planning (personal directives, care and treatment considerations at end of life). The Mental Health and Addictions Strategy has been working on building a culturally specific approach to care and lessons learned from this work can support the implementation of culturally specific priority actions of the dementia strategy. In addition, mental health education for long term care settings and providers is a priority action that the dementia strategy can leverage. There is linkage to the Continuing Care Strategy Refresh given the focus on programs and services to support people to remain at home longer.

A number of program initiatives will also be key for the success of implementing the priority actions. It will be timely to link the work currently underway in primary health care (e.g. demonstration projects of different models for primary health care) with several of the priority actions to strengthen the health system response for diagnosis and management of dementia. Active Living programs encourage physical activity and these could be utilized to promote risk reduction and management of the progression of dementia. The ongoing work of the Disability Support Program transformation project (Department of Community Services) will help to assess residential community capacity to support people with dementia.

Best Practices for Implementation

The intent of the strategy is to provide foundational work that will lead to improved care and support for people with dementia, their families and caregivers. It will support the building of capacity for an effective health system response.

A three year plan to begin the work is realistic, acknowledges the complexity and commitment of implementing the priority actions and recognizes that establishing change in dementia care and support will occur over a longer period of time. It allows for the strategy to be informed through ongoing health system

planning and be flexible yet sustainable over the long term. Year 1 priority actions have been chosen based on those that are necessary to begin with. Actions identified in Years 2 and 3 will build upon the consolidation of the new Nova Scotia Health Authority structure currently underway. It is important that addressing the needs of people with dementia, their families and caregivers across the personal journey-from awareness, diagnosis, through to supporting needs and end of life care-is reflected in each year of the strategy.

Purposeful and committed relationships between the Department of Health and Wellness, the Nova Scotia Health Authority, the Alzheimer Society of Nova Scotia and the Department of Community Services, along with ongoing engagement of stakeholders will be key to the success of implementing the dementia strategy.

The establishment of an Implementation Steering Committee, with membership including, the Department of Health and Wellness, the Nova Scotia Health Authority, the Alzheimer Society of Nova Scotia, subject matter experts in dementia care, and supported by a small operational team, can help to ensure ongoing leadership, commitment and accountability for the work of the strategy. The committee would oversee implementation of actions, monitor progress and impact of priority actions and provide input on resource allocation requirements.

In addition, successful implementation of the strategy will depend upon ongoing committed funding, effective monitoring, evaluation and update³¹. There will need to be engagement and commitment from a variety of stakeholders to identify and carry out:

- a shared vision for change
- shared measurement to track progress and ensure efforts remain aligned and participants can hold each other accountable
- consistent and open communication to assure mutual objectives, mutually reinforcing activities among all participants
- differentiation of the work to be done while being coordinated through a mutually reinforcing plan of action

³¹ Ideas and Advice on Developing and Implementing a National Dementia Plan, Alzheimer's Disease International, October 2013, Chapter 6.

- identification of a backbone team (e.g. separate staff with project management skills) to support the implementation of the strategy and coordinate participating organizations and agencies.³²

Evaluation Framework

There is a compelling need to commit to evaluation and monitoring of the Strategy and begin this process at the outset of implementation. Information gathered from monitoring and evaluation activities early in the implementation process can help to answer questions about progress, support knowledge production and dissemination and provide information for decisions regarding resource allocation and ongoing relevancy of the Strategy. In addition, reliable results are essential for communicating about the Strategy with various stakeholders.

An evaluation framework and logic model (see Appendix E) identify what the strategy is meant to achieve and its expected short, medium and long term outcomes. The evaluation framework serves as a guide for those responsible to implement the strategy and provides an overview of accountability and monitoring of implementation of the priority actions.

Different approaches can be taken to evaluating the Strategy; areas of interest may include ongoing relevance, implementation performance, process implementation, and overall impact. It is recommended that an implementation performance evaluation be done beginning late in Year 2 of the Strategy to assess the progress of the strategy in relation to what it was intended to do and its ongoing relevance. This can help to inform future implementation projects. In addition, targeted evaluation of key projects under each strategic goal is also recommended to begin in Year 3. This will help to assess the impact of implementation activities; are the desired outcomes being realized? This can allow for reflection and purposeful changes in direction if required. If outcomes are being achieved this can allow for sharing knowledge and scaling up of successful changes.

Potential indicators and measurement considerations:

Critical to evaluating the success of the strategy is the positive impact that implementation is having on:

- People living with dementia
- Families and caregivers

³² Based on, J. Kania, M. Kramer, Collective Impact, Stanford Social Innovation Review, Winter 2011, page 38.

- Health care providers
- The health system.

While a detailed evaluation plan is not appropriate at this time, the following have been identified as key indicators that could be used to demonstrate that long term outcomes are being realized:

Number of Nova Scotians accessing information and services related to dementia

- Given the focus on enhancing access to information and supports by persons with dementia and their families/caregivers, an indicator to show progress in this area could be obtained through 811, Alzheimer Society of Nova Scotia and Caregivers Nova Scotia.

Incidence rate of dementia

- Tracking the rates of dementia overall as well as by key demographic groups will provide valuable information about the Strategy's impact. The Canadian Longitudinal Study on Aging could be a possible data source for this indicator and baseline information for the Nova Scotia population groups of interest could be captured prior to the Strategy activities being implemented.

Quality of care

- A number of activities are aimed at improving the experience of receiving care include advancing coordination of care, enhancing end of life care, ensuring dementia education for health care providers, and evidence informed best practices. To what extent these activities impact the experience of receiving care and support should be an area of interest. While some service providers may have "satisfaction surveys" or "comment boxes" from which user feedback could be collected, there is currently no common process that asks consistent questions about service experience/quality of care at the point of service across the system. The experience of dementia care may be best captured through qualitative approaches where respondents can convey meaning. Possible methods to address existing data deficiencies could include: a common portal (online and toll free line option) that is promoted by providers across the system to gather stories about experiences and focus groups with select user groups.

The evaluation framework will inform those responsible for planning evaluation and monitoring activities by providing important context and offering possible directions for the ensuing evaluation work. It is

recommended that a collaborative approach with relevant stakeholders be employed for the planning and development of the evaluation plan.

In tandem with the implementation of priority actions, more work will need to be done to develop a comprehensive evaluation plan for monitoring and evaluation. Core elements to develop the plan should include:

- Decision about evaluation approach/scope and delineation of roles and responsibilities related to implementing evaluation plans versus monitoring plans;
- Identification of key evaluation questions, indicators, and sources of data to measure indicators;
- Development of detailed logic models for strategic goals and key actions.

Recommended Timeline for Implementation of Priority Actions

Dementia Strategy Priority Actions	Year to Begin		
	One	Two	Three (+)
Establish dementia related research priorities in Nova Scotia.	✓		
Determine appropriate data to collect across the health system to support individual care, system planning for services, evaluation and research.	✓		
Strengthen the ability of primary health care providers to diagnose and manage the complex care needs of people living with dementia, and better support families/caregivers.	✓		
Enhance existing programs and services for people living with dementia, families and caregivers that are affordable, accessible, appropriate, and timely.	✓		
Enhance end of life care for people living with dementia, their families and caregivers.	✓		
Recognizing the diversity of the NS population, understand the needs of people with dementia, their families and caregivers from under represented populations in Nova Scotia to inform the implementation of priority actions.	✓		
Develop and implement targeted dementia related awareness activities.	✓		
Provide education and training on dementia and dementia care to families/caregivers.	✓		
Develop an ongoing assessment approach focusing on the distinct needs of families/caregivers.		✓	
Advance effective coordination of ongoing care and support across the health system to provide a seamless response including a person centered and relationship focused approach for people living with dementia and their families/caregivers.		✓	
Determine an integrated primary health care approach to improve communication and coordination among health care providers and across the continuum to best support people living with dementia and their families/caregivers.		✓	
Ensure dementia education for relevant health care settings and health care providers to support people living with dementia and their families/caregivers is available and accessible.		✓	
Promote and build on credible knowledge translation resources for health care providers and the public.		✓	
Evaluate the dementia strategy.		✓	
Examine the need and function of a community based role to best support the needs of people living with dementia and their family/caregivers in navigating the dementia journey.			✓
Advance the delivery of high quality dementia care through the identification of core competencies for relevant health care providers working with people living with dementia.			✓

Appendix A

Dementia Strategy Advisory Committee

Purpose: Provide advice and recommendations to the Minister of Health and Wellness regarding the development of a provincial dementia strategy. The committee supports the development of the strategy by contributing to the development of a background report, making recommendations regarding the public consultation process, receiving and providing feedback on the recommendations of the working groups and contributing to the overall recommendations of the dementia strategy and associated action plan.

Timeframe: 6 Advisory meetings were held between April 2014 and April 2015.

Name	Organization
Dr. Melissa Andrew	Staff Geriatrician, Nova Scotia Health Authority (NSHA) and Associate Professor of Geriatric Medicine, Dalhousie University
Lloyd Brown (co-chair)	Executive Director Alzheimer Society of Nova Scotia
Angus Campbell	Executive Director Caregivers Nova Scotia
Dr. Keri-Leigh Cassidy	Clinical Academic Director, Geriatric Psychiatry/ Seniors' Mental Health Program, NSHA, and Associate Professor of Psychiatry, Dalhousie University
Janice Chalmers	Staff Educator Northwood Homecare
Krista Connell	Chief Executive Officer Nova Scotia Health Research Foundation
Heather Fifield	Family caregiver
Reverend Faye Forbes	Person living with dementia
Patricia Harrington	District Manager, Seniors' Health NSHA
Ruby Knowles (co-chair)	Executive Director, Continuing Care Department of Health and Wellness
Lorna MacPherson	Director, Services for Persons with Disabilities Department of Community Services
Sharon Davis-Murdoch	Special Advisor to the Associate Deputy Minister on Diversity and Social Inclusion Department of Health and Wellness
Brenda Nicholson	Director of Resident Care Alderwood Nursing Home, Baddeck
Tony Prime	Coordinator, Adult Mental Health Department of Health and Wellness
Faizal Nanji	Director Corporate Strategy and Policy Department of Seniors
Dr. Merv Shaw	Group of IX Seniors' Advisory Council of Nova Scotia, Senior and Retired Doctors section of Doctors Nova Scotia
Dr. Celina White	Doctors Nova Scotia, family physician

Appendix B

Dementia Strategy Working Groups

Working Groups	
Improved Public Awareness	
Members	Organization
Chair: Linda Bird	Alzheimer Society of Nova Scotia
Work Lead: Kim Clarke	Continuing Care, Department of Health and Wellness (DHW)
Dr. Keri-Leigh Cassidy	Geriatric Psychiatry, Nova Scotia Health Authority (NSHA)
Patricia Harrington	Continuing Care, NSHA
Lynn Langille	Public Health, DHW
Phyllis Marsh-Jarvis	Health Association of African Canadians
Michele McKinnon	Strategic Project Executive, DHW
Gayle Ogilvie	Seniors' Community Health Team, NSHA
Joan Parks-Hubley	Alzheimer Society of Nova Scotia
Tony Prime	Mental Health & Addictions, DHW
Support for Families/Caregivers	
Members	Organization
Chair: Dr. Janice Keefe	Mount Saint Vincent University, Centre on Aging
Work Lead: Susan Baikie	Continuing Care, DHW
Derrick Babin	Victorian Order of Nurses
Rajean Boudreau	Association of Black Social Workers
Angus Campbell	Caregivers Nova Scotia
Janice Chalmers	Northwood Homecare Ltd.
Crissy Doucette	Continuing Care, NSHA
Heather Fifield	Family Caregiver
Dr. Wenda MacDonald	Alzheimer Society of Nova Scotia
Pat Miller	Alzheimer Society of Nova Scotia
Early Diagnosis and Management	
Members	Organization
Chair: Dr. MacKnight	Geriatric Medicine, NSHA
Work Lead: Sam Aiton	Continuing Care, DHW
Dianne Ardern	Alzheimer Society of Nova Scotia
Dr. Ajantha Jayabarathan	Family Physician
Tom MacNeil	Senior LINC Program, NSHA
Carmen Celina Moncayo	Immigrant Services Association of Nova Scotia
Mary Jo Monk	Primary Health Care, DHW
Cheryl Smith	Primary Health Care Nurse Practitioner, NSHA
Dr. Brian Steeves	Family Physician and Continuing Care Medical Director, NSHA
Dr. Celina White	Doctors Nova Scotia

Improved Education for Health Care Providers	
Members	Organization
Chair: Marlene MacLellan	Nova Scotia Community College, Health Studies
Work Lead: Louise Boudreau	Department of Seniors
Rhonda Atwell	African Diaspora Association of the Maritimes (ADAM)
Trish Bilski	Veterans Services, QEII Health Sciences Centre
Yvonne Briggs	Continuing Care, NSHA
Dr. Jeannie Ferguson	Psychiatrist, NSHA
Jody MacDonald	Alzheimer Disease and Other Dementia Care Course
Christie Nickerson-Rac	Collaborative Learning Centre, Maplestone (Shannex) in collaboration with Dalhousie University
Ruth Slack	Seniors' Clinic, NSHA
Dr. William Webster	Dalhousie University, Health Professions
Better Coordination of Care	
Members	Organization
Chair: John Campbell	Mental Health and Addictions, NSHA
Work Lead: Sam Aiton	Continuing Care, DHW
Lewis Bedford	Acute and Tertiary Care, DHW
Darlene Boliver	Family Caregiver
Mary Anne Johnston	Mental Health and Addictions NSHA
Beverley Madill	Union of Nova Scotia Indians
Shauna Maltby Doane	Mental Health and Addictions, NSHA
Marie McPhee	Long Term Care, NSHA
Wendy McVeigh	Access and Flow, NSHA
Mark Scales	Seniors' Clinic NSHA
Research	
Members	Organization
Co-Chair: Dr. Melissa Andrew	Geriatric Medicine, NSHA
Co-Chair: Krista Connell	Nova Scotia Health Research Foundation
Work Lead: Susan Baikie	Continuing Care, DHW
Dr. Sultan Darvesh	Geriatric Medicine, Dalhousie University
Dr. Mary Gorman	Geriatric Assessment Unit, NSHA
Glen Hougan	Nova Scotia College of Art and Design
Dr. Janice Keefe/Pam Fancey	Mount Saint Vincent University, Nova Scotia Centre on Aging
Susan Stevens	Continuing Care, DHW

Appendix C

Consolidated Summary of Consultations

Community Consultations (Sept.-Nov. 2014)				
No.	Date	Group	No. of attendees	Location
1	Sept 26, 2014	Health Care Providers	25	Bridgewater
2	Sept 26, 2014	People with dementia & family/caregivers	0/8/6 ³³	Bridgewater
3	Oct 2, 2014	Health Care Providers	25	Sydney
4	Oct 2, 2014	People with dementia & family/caregivers	1/6/4 ³⁴	Sydney
5	Oct 9, 2014	Health Care Providers	23	Truro
6	Oct 9, 2014	People with dementia & family/caregivers	2/16/5 ³⁵	Truro
7	Oct 23, 2014	Health Care Providers	26	Cornwallis
8	Oct 23, 2014	People with dementia & family/caregivers	0/6/3 ³⁶	Cornwallis
9	Oct 30, 2014	Health Care Providers	64	Dartmouth
10	Oct 30, 2014	People with dementia & family/caregivers	2/22/11 ³⁷	Dartmouth
11	Nov 6, 2014	Health Care Providers – Geriatrics	18	Halifax
			Total = 273	

Nova Scotia Department of Health and Wellness Online Surveys (Oct.-Nov. 2014)		
Date	Group	Responses
Oct 1 – Nov 14, 2014	Health Care Providers	17
Oct 1 – Nov 14, 2014	People with dementia & family/caregivers	36
Oct 1 – Nov 14, 2014	French-speaking	3
		Total = 56

Alzheimer Society of Nova Scotia Online Survey (October 1-November 21, 2014)	
Group	No. of participants
Health Care Providers ³⁸	40
People living with dementia & family/caregivers*	22
Total = 62³⁹	

**This group includes people living with dementia, family members, caregivers, neighbours, and friends.*

³³ This group included 0 self-identified people living with dementia, 8 caregivers and 6 health care providers.

³⁴ This group included 1 self-identified person living with dementia, 6 caregivers and 4 health care providers.

³⁵ This group included 2 self-identified people living with dementia, 16 caregivers and 5 health care providers.

³⁶ This group included 0 self-identified people living with dementia, 6 caregivers and 3 health care providers.

³⁷ This group included 2 self-identified people living with dementia, 22 caregivers and 11 health care providers.

³⁸ Health care provider includes health care professionals and service providers working across all health care settings, non-profit organizations, and community service groups and organizations.

³⁹ Some respondents only provided demographic information and did not answer the questions; they are not included in totals.

Alzheimer Society of Nova Scotia Conference Participants	# in attendance
Health care providers	125
People living with dementia/caregivers	28
Service providers	11
Educators	2
Chief Executive Officers	1
Government workers	1
Lawyers	1
Students	1
Other	11
	Total = 181

Consultation with underrepresented populations				
No.	Date	Group	No. of attendees	Location
1	Oct 7, 2014	Acadian	21	Halifax & Telehealth (Pointe de l'Eglise, Tusket, Petit de Grat, Pomquet)
2	Dec 2, 2014	Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI)	8	Halifax
3	Dec 5, 2014	African Nova Scotian	2	East Preston
			Total = 31	

Dementia Support Group Discussions	
Group	No. of groups
Alzheimer Society of Nova Scotia	8
Caregivers Nova Scotia	9
	Total = 17

Appendix D

Priority Action Details

Priority Action Details	Year to Begin		
	1	2	3
Overarching Actions			
<ul style="list-style-type: none"> • Evaluate the dementia strategy <ul style="list-style-type: none"> • Develop an evaluation framework for the implementation of the strategy that will outline monitoring and reporting activities and specific initiatives that will be formally evaluated. Carry out monitoring and evaluation activities. 		✓	
<ul style="list-style-type: none"> • Determine appropriate data to collect across the health care system to better support individual care, planning for services, evaluation and research. <ul style="list-style-type: none"> • Identify data requirements (including data from underrepresented groups in NS), existing data, and gaps in data along with the necessary processes to ensure improved data collection and analysis. • Determine what is required to address gaps in data and to link current health (administrative and care related) databases for dementia related data mining purposes. 	✓		
<ul style="list-style-type: none"> • Establish dementia related research priorities in Nova Scotia. <ul style="list-style-type: none"> • Develop an ongoing process to ensure a thorough scan of dementia and related research activity and knowledge needs to support decision making in health care. • Engage in a consultation process that incorporates input from the public, health care providers and the research community to identify dementia related research priorities. • Direct the engagement of current research and knowledge translation activities to support priority areas of the dementia strategy wherever possible. • Establish an annual research forum connecting researchers in dementia, aging and caregiving, policy makers and related organizations to build partnerships, identify synergy for emerging research work, and relevant linkage to the strategy. 	✓		
Strategic Goal #1 Actions			
<ul style="list-style-type: none"> • Strengthen the ability of primary health care to diagnose and manage the complex care needs of people living with dementia, and better support families/caregivers. <ul style="list-style-type: none"> • Build a best practice toolkit targeting prevention, risk reduction for dementia, dementia diagnosis, treatment, long term management (including management of responsive behaviours) and care planning. • Develop a plan for implementation including: identification of education modules required to support use of the toolkit, methods of delivery of education (including links to existing educational resources, e.g. CME), recommendations regarding web accessibility of the toolkit, a communication plan and change management plan. • Enhance First Link program (Alzheimer Society) to assist primary health care clinicians in connecting newly diagnosed people with dementia and 	✓		

Priority Action Details	Year to Begin		
<p>their families to information, services and supports at the time of diagnosis and throughout the duration of the disease.</p> <ul style="list-style-type: none"> Enhance existing electronic pathways relevant to dementia care to support primary health care practice. 			
<ul style="list-style-type: none"> Develop an ongoing assessment approach focusing on the distinct needs of families/caregivers. <ul style="list-style-type: none"> Conduct analysis to identify current practice, determine existing tools and processes to assess family/caregiver needs. Determine necessary tools and processes required to support family/caregiver assessment. Where existing tools are identified that can meet the needs, build education/information to support users in enhanced application. If additional tools are required, obtain approvals for use and necessary education/information. Identify who will be conducting assessment/reassessment. Plan for implementation of process and tool. 		✓	
<ul style="list-style-type: none"> Enhance existing programs and services for people living with dementia, families and caregivers that are affordable, accessible, appropriate, and timely. <ul style="list-style-type: none"> Implement enhancements to the 811 service (24 hour resource) for those impacted by dementia to provide support and linkage to information, programs and services. <ul style="list-style-type: none"> Review and introduce dementia protocols Provision of information and education to 811 nurses Create linkage with Alzheimer Society of NS Increase capacity of the Alzheimer Society to respond to needs of people with dementia, their families and caregivers. Change continuing care program eligibility criteria: <ul style="list-style-type: none"> Revise Supportive Care Program eligibility criteria to allow people with a diagnosis of dementia and under the age of 65 to be considered for the program. Revise Caregiver Benefit Program eligibility criteria so that caregivers of people with a diagnosis of dementia have increased opportunity to be considered for the program. Increase access to in home and facility based respite. Review existing DHW and DCS programs and services for people with dementia to enhance accessibility and improve coordination of care. Develop and implement an active living capacity building plan for the Continuing Care Home Care Program. Review current adult day programs to determine the accessibility of programs for those living with dementia: <ul style="list-style-type: none"> Review of eligibility criteria, target populations, referral patterns Identification of trends, enablers and barriers to access Recommendations regarding increasing access to and delivery of these programs. Implement required changes. Align initiatives with relevant mental health priorities. 	✓		

Priority Action Details	Year to Begin		
<ul style="list-style-type: none"> • Enhance end of life care for people living with dementia, their families/caregivers. <ul style="list-style-type: none"> • Work with palliative care strategy team to incorporate consideration of dementia in their initiatives. 	✓		
Strategic Goal #2 Actions			
<ul style="list-style-type: none"> • Advance effective coordination of ongoing care and support across the health system to provide a seamless multi-disciplinary response including a person centered and relationship focused approach for people living with dementia and their families/caregivers. <ul style="list-style-type: none"> • Review and revise current DHW/NSHA policies, processes and practices so that they are flexible, respond to the changing needs of people with dementia, incorporate person centred approaches to care, and provide seamless transitions between different types of care. • NSHA to identify existing health care services and supports that can benefit people living with dementia and their families and ensure accessibility and coordination. • Review current case management roles across the health system and where indicated, enhance to better support the person with dementia and their family/caregiver. • Build and implement a dementia care pathway across the health care system that incorporates: <ul style="list-style-type: none"> ○ Accessible and coordinated delivery of identified health care services and supports, ○ Roles, responsibility, and accountability, ○ Mechanisms for planning collaboratively, ○ Linkage of people to appropriate care and resources, and ○ Equitable, culturally competent, safe, and specific access. 		✓	
<ul style="list-style-type: none"> • Determine an integrated primary health care approach to improve communication and coordination among health care providers and across the continuum of care to best support people living with dementia and their families/caregivers. <ul style="list-style-type: none"> • Establish demonstration sites (one urban and one rural) that focus on utilizing existing sustainable resources, models and best practice. Incorporate linkages between: <ul style="list-style-type: none"> ○ Primary health care teams (e.g. family physician practice utilizing collaborative interdisciplinary team approach) ○ Community based seniors’ health clinics ○ Linkages to multi-disciplinary geriatric specialty services, psychogeriatric services or seniors’ mental health services and continuing care. • Evaluate demonstration sites to determine outcomes with the possibility of scale up and spread. 		✓	
<ul style="list-style-type: none"> • Examine the need and function of a community based role to best support the needs of people living with dementia and their family/caregivers in navigating the dementia journey. <ul style="list-style-type: none"> • Examine current roles within the system of care for effectiveness and gaps in supporting people with dementia and their families/caregiver 			✓

Priority Action Details	Year to Begin		
<ul style="list-style-type: none"> Identify the required function, competencies and educational requirements, along with placement in the system for a potential role(s) to provide support when needed. 			
<ul style="list-style-type: none"> Advance the delivery of high quality dementia care through the identification of core competencies for relevant health care providers working with people living with dementia and their families/caregivers. <ul style="list-style-type: none"> The DHW will work with organizations involved in professional, vocational training and continuing professional development to identify core competencies for dementia care. Organizations will consider how to adapt curricula to include identified core competencies across the continuum of care. 			✓
<ul style="list-style-type: none"> Recognizing the diversity of the NS population, understand the needs of people with dementia, their families/caregivers from under represented populations in Nova Scotia to inform the implementation of priority actions. <ul style="list-style-type: none"> Engage those populations who were under represented in the strategy consultation process including, First Nation, Immigrant Canadian, LGBTI, and African Nova Scotian to identify needs specific to dementia information, care and support. Utilize existing tools and frameworks (NS Public Health “Health Equity” Protocol and the Cultural Competency Guidelines for the delivery of Primary Health Care in NS and accompanying guide) to inform priority actions regarding the development of equitable and culturally specific programs and supports for people living with dementia and their families/caregivers. 	✓		
Strategic Goal #3			
<ul style="list-style-type: none"> Develop and implement targeted dementia related awareness activities. <ul style="list-style-type: none"> Through Department of Health and Wellness involvement in the Health Care Innovations Working Group, influence content and promote participation in a series of Pan-Canadian webinars and a National Dementia Symposium. Work of developing and implementing a public awareness campaign will be carried out by an external organization that has expertise, necessary content and existing delivery mechanisms with oversight provided by the DHW. <ul style="list-style-type: none"> The awareness campaign will focus on the following: <ul style="list-style-type: none"> Increasing awareness about dementia risk factors and possible prevention factors (e.g. healthy lifestyle, regular physical activity), and where to go for information and support. This includes promoting the services of ASNS (Alzheimer Society of NS) and CNS (Caregivers NS). Help inform the needs of diverse populations in NS and include ‘first voice’ accounts from people with dementia and their families/caregivers. Existing resources that are evidenced based and accurate will be utilized (e.g. toolkits) and enhanced where needed. Key target audiences, messages and multi-media to be used will be identified. 	✓		

Priority Action Details	Year to Begin		
<p>Note: Year 2 and 3 will focus on:</p> <ul style="list-style-type: none"> public awareness focussing on the importance of a timely diagnosis and ability to live well with dementia and endorse and align key messages to support the Dementia Friends program implemented by the Government of Canada and the Alzheimer Society of Canada <p>The public awareness campaign needs to be an ongoing process over the course of the strategy and have messages aligned with strategy implementation projects (e.g. enhancing early diagnosis and management).</p>			
<ul style="list-style-type: none"> Provide education and training on dementia and dementia care to families/caregivers. <ul style="list-style-type: none"> Evaluate existing education/information content being provided to ascertain comprehensiveness, effectiveness and accessibility specific to concrete examples, how to have difficult conversations, relationship loss and active grieving and identification/management of responsive behaviours, information to inform decision making, activities of daily living (e.g. personal care, body mechanics, transfer/lifts). Will also assess feasibility of delivery of practical skill training. Develop necessary education and training content including ‘train the trainer’ materials. Develop an implementation plan to deliver education to families and caregivers through established mechanisms across the province. 	✓		
<ul style="list-style-type: none"> Ensure dementia related education for relevant health care settings and health care providers to support people living with dementia and their families/caregivers is available and accessible. <ul style="list-style-type: none"> Develop the necessary education and training content (e.g. assessment for dementia vs. delirium vs. depression, skills for working with people with responsive behaviors) for; <ul style="list-style-type: none"> Primary health care providers Acute and tertiary care staff (e.g. begin with emergency department staff to recognize and provide appropriate care to meet the needs of people with dementia) Continuing care staff working in long term care and home care. 		✓	
<ul style="list-style-type: none"> Promote and build on credible knowledge translation resources for health care providers and the public. <ul style="list-style-type: none"> Identify, through partnership with the provincial health authority, Alzheimer Society of Nova Scotia, NSHRF, academic partners, and community partners, knowledge translation mechanisms to address knowledge needs. Mobilize existing provincial and national resources to ensure accessible, coordinated and efficient use of knowledge translation. 		✓	

Appendix E

Dementia Strategy Logic Model

