



Champlain Dementia Network

Réseau de la démence de la région Champlain

Integrated Model of Dementia Care

Champlain 2020: Making Choices that Matter



April 4, 2013

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Executive Summary

Dementia is the leading cause of dependency and disability among older persons and is one of the top three causes of death in Champlain¹.

“The overwhelming number of people whose lives are altered by dementia, combined with the staggering economic burden of families and nations, makes dementia a public health priority.” (WHO)

Community dwelling persons with dementia account for 34% of all hospital alternate level of care days, and a diagnosis of dementia or delirium accounts for more than six times the number of hospitalisation days than diabetes, hypertension and asthma, combined. Despite this reality, dementia remains one of the few chronic conditions not supported by a comprehensive chronic disease management strategy.

There were 18,400 people with dementia living in Champlain in 2012. This population is projected to increase by a further 30% to nearly 24,000 in 2020. The intent of this project is to lay the foundations to develop a Model of Dementia Care for Champlain which incorporates best practices in chronic disease and dementia management with those of integrated continuing care.

4,800 people with dementia in Champlain live in long term care homes, and 13,600 live in the community. The vast majority of their care (94%) is delivered by family and friends. This creates a context in which the consequences of the illnesses that cause dementia are magnified through detrimental effects on those closest to them.

There is therefore a compelling case that the burden of dementia is multiplied many fold across the population of persons with dementia and multiple chronic conditions, their caregivers, and society at large. There is an equally compelling case that earlier diagnosis and assessment, preventive treatments and coordinated care management and caregiver support can significantly reduce the cumulative impact of the burden of dementia. This re-framing of the approach to dementia away from the at times devastating effects of dementia towards the evidence and potential to adapt and improve the quality of life of persons with dementia, is fundamental to this project.

Our Vision: Champlain 2020

“Being the best...for persons with dementia, their families, our health system, and society.”

A strategic framework comprised of six strategies and key results has been proposed to drive the development of a new model of dementia care for Champlain.

Public Awareness	<i>Improved understanding, acceptance and support of dementia as a chronic condition.</i>
Detection, Diagnosis & Assessment	<i>Earlier detection, diagnosis, and intervention to manage the consequences of dementia.</i>
Self-management & Caregiver Support	<i>Promotion of activities and attitudes to ‘live well’ with dementia.</i>
System Navigation	<i>Persons with dementia and their caregivers know what to expect and where to find it.</i>
Coordinated Pathways of Support	<i>Timely and coordinated access to a continuum of dementia care that supports persons with dementia and their caregivers in making choices that matter in their day-to-day lives</i>
System Integration	<i>A system of support that is tailored & targeted to their changing needs.</i>

¹ Towards a Person Centred Health Care System, Integrated Health Services Plan 2013-2016 Champlain LHIN



The effort to re-frame the experience of persons with dementia and their caregivers is ambitious in its reach but realistic in its intent. The scope of change that is required is significant and will require several years of planning, negotiation and implementation. As such, the Project Team has proposed preliminary priorities for development to reflect both feasibility and an understanding of the pre-requisites for change. Subject to further discussion and agreement with the Champlain LHIN, the following priorities are recommended for initial stages of implementation planning:

1. It is recommended that the Champlain LHIN commit to the development of an Integrated Model of Dementia Care for Champlain, and support the following **strategic priorities** for the coming year:

System Integration: Evaluate and propose a system-wide, shared governance structure or mechanism for dementia services across Champlain, and which should include a process for coordinated intake and referral, and explore options for coordinated funding strategies.

Caregiver Support: Develop clear mechanisms for the involvement of persons with dementia and family caregivers in system wide-planning;

Public Awareness: Promote greater public awareness of dementia and inspire a clear commitment to improving the lives of persons with dementia and their caregivers amongst health system leaders.

Pathways of Support: Designate a LHIN staff lead for dementia and consider mechanisms to integrate dementia care with other LHIN-wide chronic disease management strategies, including Health Link, Falls, Diabetes, the Champlain Regional Stroke Network, ED / ALC and Champlain Cardiovascular Disease Prevention Network.

2. It is recommended that, the Champlain LHIN consider funding the following operational priorities as part the first year of operation of its new Integrated Health Services Plan:

A. System Integration:

Implementation Planning: Continue regional implementation planning of Dementia Care Model.

B. Early Detection & Diagnosis:

Primary Care Memory Clinics. Extend Dr. Lee’s model and support training for up to 5 primary care memory teams across Champlain, and to include direct affiliation with First Link.

Memory Disorder Clinic: Support redevelopment of the Bruyere Memory Disorder Clinic to improve access to specialised dementia assessments and enhance support to primary care.

Specialised Dementia Services: Hospital budget pressures have resulted in staffing reductions in several specialised dementia services. Consideration should be given to preserve and protect service levels in light of the critical role of dementia assessment and intervention.

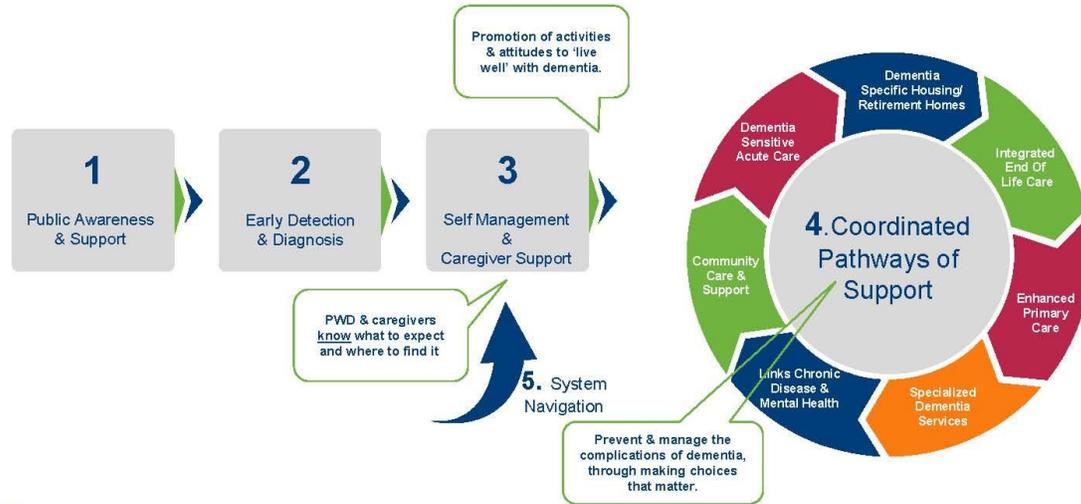
C. Public Awareness:

Regional Coordination of Dementia Education: Coordinate existing educational resources and optimize the resources to include a dementia literacy and marketing strategy to both service providers and the public so they are aware of what is available to live well with dementia.

D. Caregiver Support: Ensure First Link and Adult Day Programs are equitably accessed throughout Champlain, including North Grenville /North Lanark.

These priority actions will lay the foundations for success, move the region toward fulfillment of the six strategic results driving system level change, and prepare Champlain region and its health system for the challenges of 2020 and beyond.

Strategic Framework: Integrated Model of Dementia Care:



6. System Integration



A system of support that is tailored & targeted to the changing needs of persons with dementia and their caregivers.

Project Outline:

Funding was provided in January 2013 to propose an integrated Dementia Model of Care spanning the continuum from primary to long term care by March 31, 2013. Six phases were proposed for project implementation. Given recent provincial and local caregiver consultations, it was determined that the project would focus on proposed solutions for integrated dementia care and that targeted consultations would be conducted only in the final phase.

1. **Project Definition and Scoping:** A Project Advisory Team was selected and convened January 4. Project scoping and substantive discussion on alternative approaches to frame the model around the experience of persons with dementia and their caregivers. Additionally, through the RGPEO, a series of primary care education and engagement sessions were convened on the topic of Primary Care Memory Clinics, with Dr. Linda Lee, a family physician from Waterloo / Wellington LHIN. Given the potential range of approaches, the scope of potential integration strategies for the purposes of project planning, was also defined
2. **Review Frameworks of Dementia Care:** While there is growing international interest in collaborative interdisciplinary models of dementia care, actual implementation of integrated service delivery models is limited. A comprehensive review of seven dementia frameworks and consultation with select chronic disease networks was conducted. Research on interdisciplinary service delivery for persons with dementia, focused principally on primary care, chronic disease management and caregiver support, were also reviewed. A review of existing caregiver consultation needs assessments was also conducted. This was used to identify preliminary outcomes to drive model development.
3. **Environmental Scan:** Given the focus on system design, and the limited information about how persons with dementia and their caregivers use existing services, efforts were undertaken to develop a preliminary profile of persons with dementia and their caregivers in Champlain. This involved integration of data from multiple regional, provincial and national resources and where necessary, an extrapolation of results to the population of Champlain.
4. **Analysis & Solutions:** Subsequent to an analysis of the patterns of service utilisation by persons with dementia, the Project Team undertook to identify and prioritise 37 key activities intended to achieve the six proposed outcomes to be realised by a Champlain Model of Dementia Care.
5. **Integrated Model of Dementia Care:** The Project Team worked with an Integration Toolkit, adapted from Hollander's best practices framework for organising systems of continuing care, to identify and propose elements to facilitate system level change in dementia care in Champlain. An expedited consultation was undertaken in light of project timeframes. This involved four focus groups of providers and caregivers with 23 participants, 7 key informants, as well as an on-line survey distributed through several organisational networks such as OANHSS, Community Support Coalition. To date 45 survey responses have been received for a total of 75 organisations and individuals.
6. **Final Report:** The final report integrating key project findings and recommendations was completed March 28 and finalised April 4th after consultations with Champlain LHIN

Dementia: A Public Health Priority

Dementia is the leading cause of dependency and disability among older persons². Poor understanding of the condition creates barriers to timely diagnosis, which can in turn lead to large gaps in treatment, care and support and a subsequent cascade to dependency. This in turn takes its toll of the resilience of the family unit and increases the likelihood of high costs associated with increased dependence and morbidity. The total economic burden of dementia in Canada has been projected to grow from \$15B in 2008 to \$153B by 2038³.

“The overwhelming number of people whose lives are altered by dementia, combined with the staggering economic burden of families and nations, makes dementia a public health priority.”⁴

Growing recognition of this burden has led a select number of jurisdictions to develop strategic plans or policy frameworks intended to reduce the social and economic burden of dementia.

Seven such frameworks were reviewed to inform the development of a more integrated Champlain Model of Dementia Care. These included strategies developed in the Quebec, European Union, Ireland, United Kingdom, Norway, Australia, as well as the United States which launched its national strategy in 2012. Few of these policy frameworks proposed specific models of service delivery, the objective of this project. However, a review of goals, strategies was undertaken to inform the strategic foundation of the proposed Champlain Model of Dementia Care.

The Alzheimer Society of Canada has also recommended five broad recommendations for a national dementia strategy:

1. Accelerated investment in dementia research.
2. Recognition and support of the role of caregivers.
3. A focus on prevention & early intervention.
4. Greater integration of care and increased use of ‘best practice’ frameworks in chronic disease management, community care and support.
5. Strengthening Canada’s workforce.

Despite the reality that dementia is the leading cause of dependency and disability amongst older Canadians⁵, and that both Canadian and Ontario Alzheimer Societies have promoted action plans to respond to the personal and societal burdens of dementia, dementia remains one of the few chronic conditions not supported by a comprehensive chronic disease management strategy.

The intent of this project is to develop an integrated Model of Care for Champlain which integrates best practices in chronic disease and dementia management with those of integrated continuing care. This will allow for a more effective response to the changing needs of the more than 36,000 people with dementia and their caregivers in Champlain, who are directly affected by dementia, and at the same time, alleviate a significant burden on our regional health system.

² Dementia A Public Health Priority, World Health Organisation, 2012.

³ Rising Tide: The Impact of Dementia on Canadian Society, Alzheimer Society of Canada, 2010.

⁴ Dementia A Public Health Priority, World Health Organisation, 2012.

⁵ Rising Tide: The Impact of Dementia in Canada, Alzheimer Society of Canada, 2010,

Understanding Dementia:

Dementia is an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgment and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person's ability to function at work, in relationships or in everyday activities.

Several conditions produce symptoms similar to dementia. These can include depression, thyroid disease, infections or drug interactions. Early diagnosis is essential to make sure that people with these conditions get the right treatment.

If the symptoms are caused by dementia, an early diagnosis will mean early access to support, information, and medications currently available.⁶

While a diagnosis of dementia may often be viewed as traumatic or shocking, many people with dementia are able to maintain a satisfactory lifestyle within their community, with appropriate support. The table below, adapted from the South Australia Dementia Action Plan, explains the impact of dementia on memory and personal care.

STAGES OF DEMENTIA (Adapted from: South Australia's Dementia Action Plan 2009-2012.)				
IMPACT	Early Onset	Mild	Moderate	Advanced
	Estimated % of people with dementia			
	55%		30%	15%
MEMORY	Slight forgetfulness that happens regularly e.g. gets lost on familiar route	Noticeable short term memory loss that affects everyday life e.g. has false memories, forgets layout of home.	Substantial memory loss when old information can be recalled and new information is rapidly lost.	Severe memory loss when only parts of old memories remain.
PERSONAL CARE	Manages own self care	May need prompting	Requires assistance	Full Assistance required.

⁶ Alzheimer Society of Canada, <http://www.alzheimer.ca/en/About-dementia/Dementias/What-is-dementia>

A Profile of Persons with Dementia in Champlain:

It is important to understand where people with dementia live and how they use services in order to develop meaningful strategies for more coordinated care and support. There were 18,400 people with dementia living in Champlain in 2012⁷. Of these, 13,588⁸ are living in the community, inclusive of retirement home settings. Champlain region has the fourth highest number of persons with dementia amongst the 14 LHIN regions in Ontario⁹. This population is projected to increase by a further 30% to nearly 24,000 in 2020.

Language:

The population of persons with dementia in Champlain presents unique challenges in terms of diagnosis and access to services in their first language. As it is common for persons with dementia to revert to their first language¹⁰, special consideration must be given to ensure access to diagnostic and assessment services in one's first language. Additionally, consideration should be given to ensure the needs of family caregivers are adequately addressed as there is evidence they may be more likely to lack information on dementia and delay help-seeking¹¹.

Applying the prevalence of francophone older adults to the dementia population, it is estimated there are 3,312 francophone older adults with dementia in Champlain, of whom 2,446 live in the community. A recent working document of the Regional Geriatric Program of Eastern Ontario suggests we are not currently prepared or resourced to meet the needs of francophone persons with dementia. Access to language specific diagnostic and assessment must therefore be a major consideration in dementia services planning across the region.

Similar planning linguistic and cultural considerations will also be required with respect to the aboriginal population of almost 32,000, and other linguistic minorities who represent 16% of the total population in the region¹².

Health Service Utilisation:

Community dwelling older adults with dementia accounted for almost 176,000 primary care visits in Champlain in 2012. Almost one half of them visited the emergency department in 2012, and one in four (25.1%) were admitted to hospital.¹³ It is significant to note that, although only one third of hospital admissions for persons with dementia resulted in alternate level of care days, their average length of stay (40 days) was significantly longer than those for other chronic conditions. As a result, community dwelling persons with dementia account for **34%**¹⁴ of all hospital alternate level of care days, reflecting a significant societal impact of dementia. (A more in-depth analysis of hospitalized persons with dementia is offered later in this report).

There are 8,400 older adults living in retirement homes in Champlain in 2012¹⁵. Given the diversity and limited regulation of the retirement home industry in general, it is not possible to specify the exact number of persons with dementia in retirement homes in Champlain. However we have the benefit of having conducted some of the largest research studies on the prevalence of dementia in retirement homes in Canada, in which Comprehensive Geriatric Assessments were conducted on large segments of

⁷ Dementia Evidence Brief: Champlain LHIN, Alzheimer Society of Ontario 2012.

⁸ Health System Use by Frail Ontario Seniors, ICES, 2011 (extrapolated to 2012 pop'n)

⁹ Health System Use by Frail Ontario Seniors, ICES, 2011

¹⁰ Alzheimer Society of Canada, <http://www.alzheimer.ca/en/Living-with-dementia/Ways-to-communicate>

¹¹ Faits saillants démence, Réseau des services de santé en français, 2013.

¹² Towards a Person Centred Health Care System, Integrated Health Services Plan 2013-2016 Champlain LHIN

¹³ Health System Use by Frail Ontario Seniors, ICES, 2011

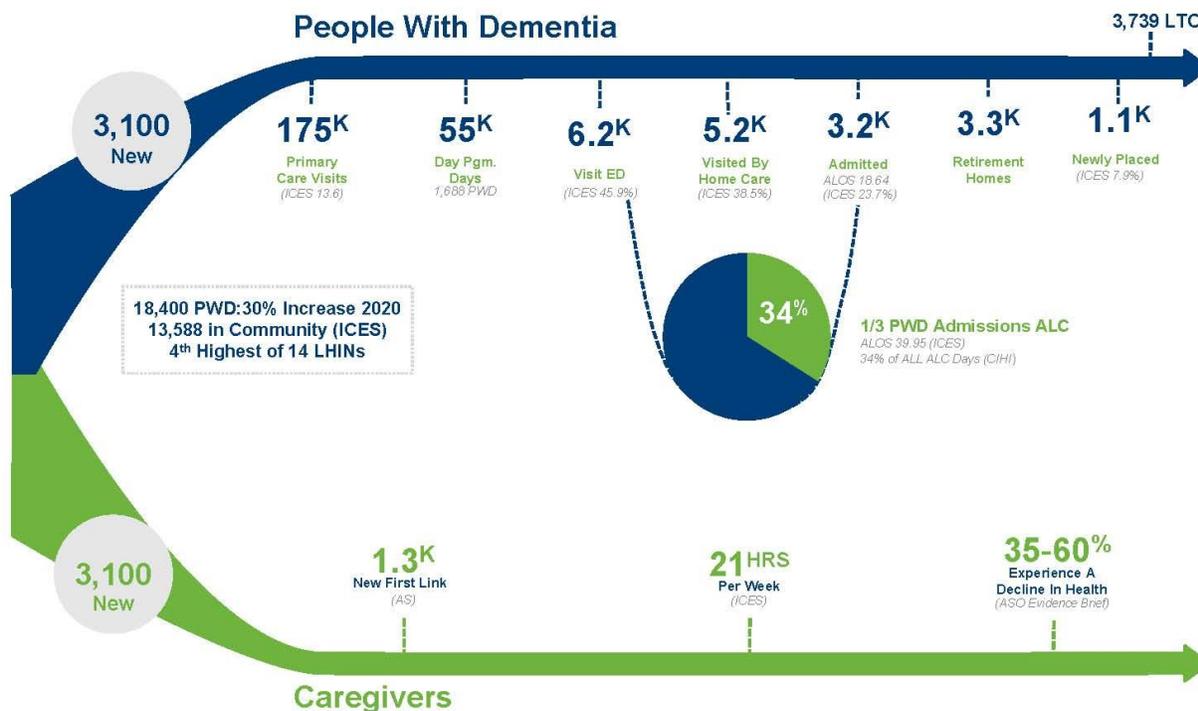
¹⁴ Analysis in Brief: Alternate Level of Care in Canada, Canadian Institute for Health Information, 2009

¹⁵ Seniors Housing Report – Ontario, Canada Mortgage and Housing Corporation, 2012.

retirement home residents. The findings suggest 43% of the resident population having mild to severe cognitive impairment¹⁶. Applying these findings to the 8,400 residents suggests a significant population of up to 3,600 persons with cognitive impairment in retirement homes. (Refer to CCAC data).

Almost 1,100 community dwelling persons with dementia transitioned to long term facility care in 2012, for a total of 4,812 residents with dementia in long term care. This reflects 63.5% of the total 7,576 long term care beds in Champlain as of January 2013¹⁷. While a majority of persons with dementia in Champlain remain living in their own homes, 46% are living in residential and long term care. This and other patterns of health care utilisation should be considered in the development of a Champlain Model of Dementia Care.

Figure 1 Profile of Persons with Dementia: Champlain 2012



16 Aminzadeh, F., Dalziel, W.B., Molnar, F., Alie, J., & Firth, C. (2003). An examination of health profile, service use and care needs of older adults in residential care facilities in the City of Ottawa. Ottawa: Regional Geriatric Assessment Program of Ottawa-Carleton.

17 Correspondence from Champlain CCAC February 13, 2013.

Hospitalised Older Adults with Dementia:

Dementia is associated with significant costs to health care, and hospital costs in particular. A comprehensive analysis of Medicare claims in the United States indicated dementia accounted for three times the overall expenditures and risk of hospitalisation compared to non-demented older adults¹⁸. This study further attributed a high proportion of costs associated with hospitalised dementia patients to those with co-morbid conditions. This distinction is important in order to understand how to reduce costs and morbidity associated with dementia. Dementia is not usually identified as the reason for a hospital admission¹⁹. However, as noted previously, the Canadian Institute for Health Information recognises dementia as a key diagnosis related to ALC, indicating **34%** of all Alternate Level of Care (ALC) days in hospitals are attributable to persons with dementia. The impact of dementia therefore contributes to a systemic impact on access to hospital and health services, including paramedical services, emergency department wait times, and surgical cancellations²⁰ affecting our entire population.

Persons with dementia and multiple chronic conditions account for 88% of total hospitalisations for persons with dementia²¹. This has significant implications for the development of strategies to alleviate ALC pressures in regional hospital systems.

Studies being undertaken on behalf of the Waterloo Wellington LHIN confirm the burden of chronic disease as a key driver in health care costs, but notes ‘*not all chronic conditions are equivalent with respect to their impact on patient outcomes and health service utilisation*’²². This review indicated that a diagnosis of dementia or delirium accounted for more than six times the number of hospitalisation days than diabetes, hypertension and asthma, combined. The cost per episode of hospitalisation for dementia is also significantly greater.

Table 1: Estimated average cost of inpatient hospital services provided to the average patient (CIHI Cost Estimator for Ontario 2008-09)

Condition	Average cost per hospitalization
Dementia	\$19,302
Heart failure	\$6,633
COPD	\$6,561
Fractured femur	\$6,219
Type 2 Diabetes mellitus	\$5,306
Hypertension	\$3,419
Asthma	\$2,470

These findings also attributed a high proportion of hospital and ALC days to four major chronic conditions: dementia, heart failure, hip fractures due to falls, and COPD. Heckman’s analysis further indicates this cluster of these four chronic conditions is not random, and reflects a correlation between dementia, heart failure, falls and COPD.

¹⁸ Bynum JP, et al. The Relationship Between a Dementia Diagnosis a, Chronic Illness, Medicare Expenditures and Hospital Use, Journal of the American Geriatrics Society 52: 187-194, 2004.

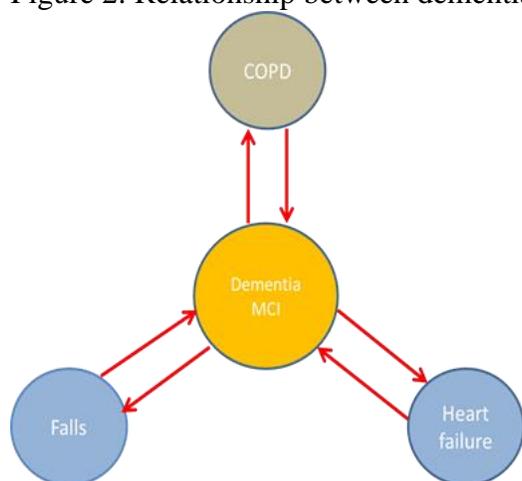
¹⁹ Wait Times Alliance, Report Card on Wait Times in Canada, 2012.

²⁰ Wait Times Alliance, Report Card on Wait Times in Canada, 2012.

²¹ Analysis in Brief: Alternate Level of Care in Canada, Canadian Institute for Health Information, 2009

²² Draft Report – Recommendations for the Development of a Community-Based System of Care for Frail Seniors in WWLHIN, George Heckman et al, January 2013.

Figure 2: Relationship between dementia, heart failure, falls and COPD (Heckman)



The effect of dementia on the management of other chronic conditions is increasingly recognised. It has been characterised as the “Keystone Diagnosis”²³, the Dementia Domino Effect²⁴ and the “Godfather”²⁵ of chronic diseases. Regardless of one’s preferred analogy, the impact of dementia on the management of chronic disease, and its consequent impact on persons with dementia, their caregivers and society as a whole, is significant.

This suggests the need for an integrated strategy across primary and acute care, which aligns chronic disease management interventions across these patient populations. This can be achieved by creating care strategies for Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD) and other chronic conditions that work for people with dementia. These should include the identification of cognitive impairment by physicians caring for people with CHF, COPD and other chronic conditions, resulting in early referral and intervention by dementia specialists.

²³ Draft Report – Recommendations for the Development of a Community-Based System of Care for Frail Seniors in WWLHIN, George Heckman et al, January 2013.

²⁴ Wait Times Alliance, Report Card on Wait Times in Canada, 2012.

²⁵ Chronic Diseases related to Aging and Health Promotion and Disease Prevention, Report of the Standing Committee on Health, House of Commons, May 2012.

Use of Home Care and Related Services:

Extrapolating provincial home care utilisation rates to the population of community dwelling older adults with dementia suggests approximately 5,231(38.5%)²⁶ older adults with dementia in Champlain received CCAC services in 2012.

Table 2: Champlain Community Care Access Centre: Profile of Clients with Cognitive Impairment 2012 (Source: CCAC Decision Support)

	Private Dwelling	Retirement Home
Total PWD	3,364	1,704
Avg RAI Score	14.0	14.2
Avg MAPLE score	9.3 (High)	9.5 (High)
Avg CPS	2.5	2.5
Select Services		
# with Personal Care	2,700	1,360
Hrs. / 30 days	53.2	38.5
# with Nursing	1,039	428
# with OT	1,057	377

Actual utilisation of CCAC services in 2012 confirms almost **5,200** people with mild-severe cognitive impairment were served. This closely mirrors the provincial utilisation profile developed by the Institute for the Clinical Evaluative Sciences (ICES). Additionally, both methodologies indicate that 30% of all community dwelling older adults with dementia received personal care services to assist with activities of daily living.

This would suggest that efforts to enhance care and support for persons with dementia should consider the extent to which they rely on personal care, in addition to traditional case management support offered through the Champlain CCAC.

The CCAC also coordinates access to other key resources for persons with dementia and their families, including adult day programs which provide a combination of activation and respite, and long term care, as a housing alternative for those whose needs can no longer be met in their own homes.

There were almost 1,700 people using Adult Day Programs in Champlain 2011/12, served through 55,168 days of care²⁷. Not all clients in adult day programs have dementia. There were 559 people with dementia referred to Adult Day Programs in Champlain in 2012. Their average Cognitive Performance Score of 2.5 suggests that they function, on average, in the mild-moderate level of cognitive impairment. Older adults referred to day programs were assessed as being eligible for and at high risk for placement, suggesting adult day programs are effectively targeting clients with high needs, of whom the majority have mild-moderate dementia²⁸.

During the same period, Champlain CCAC opened 1,924 new referrals for persons with dementia, for long term care. Approximately 1,100 transitioned to long term care²⁹ in 2012, resulting in a total of 4,812

²⁶ Health System Use by Frail Ontario Seniors, ICES, 2011

²⁷ The Champlain Adult Day Program Project: Coordinated Access - Final Report & Framework for Action, Martell Consulting 2011 (Prepared for Champlain Dementia Network)

²⁸ Champlain CCAC Dementia Client Report, 2012 Custom Tabulation, CCAC Decision Support.

²⁹ Health System Use by Frail Ontario Seniors, ICES, 2011

people with dementia in long term care in the region. As might be expected, those referred to long term care demonstrated a somewhat higher level of cognitive impairment than those referred to adult day programs (CPS of 2.9 compared to 2.6).

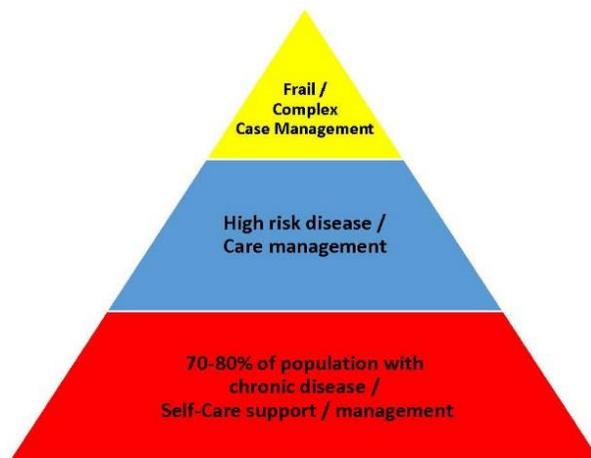
Primary Dementia Care

Community dwelling older adults with dementia account for an average of 13.6 visits with the primary care physicians and 10.3 with other medical specialists³⁰ annually. This reflects an estimated 176,000 primary care visits in Champlain in 2012. This reflects the tremendous extent to which persons with dementia and their caregivers rely on primary care. Strategies to either prevent or more effectively manage the consequences of dementia must therefore rely, to a great extent, on more integrated approaches to community based dementia care centred on primary care³¹. Yet, due in part to both the complexity of dementia and capacity, a majority of primary care providers (80%) delegate the diagnosis and assessment of dementia to specialists.

In light of the growing population of persons with dementia and the health burden they present for themselves, their caregivers and society at large, new models of primary dementia care practice must be considered.

The concept of stratifying risk in order to more effectively target regular care and specialised interventions is central to specialised geriatric services and chronic disease management alike³². The Kaiser Permanente Triangle has been adopted in a variety of jurisdictions to distinguish the need for more targeted interventions.

Figure 3: Kaiser Permanente Triangle³³



Such an approach would suggest the potential for primary care to be able to support the majority of persons with dementia and their families, and partner with secondary and tertiary services for the remaining 20-25%. While dementia presents added complexities for early diagnosis and assessment, various models to further develop capacity for earlier diagnosis and intervention in primary care are emerging.

Building upon chronic disease management frameworks, several approaches have been evaluated to improve the assessment and management of dementia in primary care³⁴ through the development of more

30 Health System Use by Frail Ontario Seniors, ICES, 2011

31 Aminzadeh et al A Scoping Interpretative Review of Perceptions and practices of Primary Care physicians, 2012.

32 Hollander MJ, Prince MJ, Organising Care Delivery for Persons with Continuing Care Needs, Health Care Quarterly, Vol 11, No 1, 2008.

33 Source: Paul Williams, University of Toronto UK Department of Health (2005)

34 Lee I, et al. Developing Memory Clinics in Primary Care: An Evidence-based Interprofessional Program of Continuing Professional Development, Journal of Continuing Education in the Health Professions, 33(1): 24-32, 2013.

integrated and systematic³⁵ approaches to care. Studies have demonstrated a range of outcomes including improved caregiver satisfaction³⁶, patient outcomes, overall quality of care³⁷, system navigation, and health service utilisation³⁸. As for any chronic disease management strategy, these must be targeted to the changing needs of persons with dementia and their families in order to be both effective and efficient in the use of primary care and specialised resources.

A review of the patterns of health care use by persons with dementia reinforces the applicability of such a model of stratification for dementia care. As noted previously, 76% of persons with dementia are stable to the point of not requiring hospitalisation³⁹. Patterns of primary care utilisation in the same study, are also revealing. There is a significant difference in the number of primary care visits amongst hospitalised and non-hospitalised persons with dementia. Those who were not hospitalised visited their family physician a total of 10.2 times over the course of a year. Those who were hospitalised and designated ALC, visited a family physician an average of 34.4 times during the same period. As mentioned previously, this same group of patients account for 34% of all Alternate Level of Care days in acute hospitals. The potential benefit of a more integrated and comprehensive approach for patients, family caregivers and society at large, is most evident.

The Ministry of Health and Long Term Care has recently launched a new initiative intended to support primary care in responding to the needs of high-risk patient populations with multiple chronic conditions. Health Link is being proposed as a new way of organizing health care services for people with the highest, most complex needs⁴⁰. Given the significant burden and complexity associated with caring for persons with dementia and multiple chronic conditions, the development of Health Links provides a relatively immediate opportunity to begin aligning dementia care with other chronic disease management strategies.

...And Their Caregivers

The combination of shifts in care to the community, and population changes resulting in increased prevalence of chronic conditions in general, and dementia specifically have placed an increased burden on informal support networks of families and friends. In 2010, families and friends spent 87,100,000 unpaid hours caring for people with dementia⁴¹ in Ontario. The vast majority of care (94%)⁴² for the 13,600 persons with dementia in living in the community Champlain is delivered by family and friends.

This creates a context in which the illnesses that cause dementia are multiplied through the detrimental effects on those closest to them. Caring for a person with dementia can be one of the most difficult, frustrating and distressing of all caregiving roles.⁴³ Some surveys of dementia caregivers identify 70% as having stress, and 40% depression⁴⁴, which can exacerbate other illnesses. Comparable results were identified in a comprehensive dementia caregiver study involving more than 2,400 caregivers in Ontario⁴⁵.

35 Iliffe S, et al Dementia Diagnosis in primary care: thinking outside the educational box, *Aging health*, 5.1 p.51, 2009.

36 Cherry DL, Interventions to Improve Quality of Care: The Kaiser Permanente –Alzheimer’s Association Dementia Care Project, *The American Journal of Managed Care* Vol 10, No 8, 553-560 (2004)

37 Venohr I, et al Improving Dementia Care Through Community linkages: A Multi-Site demonstration Project, *Home health Care Services Quarterly*, Vol 19(4) 2001.

38 Draft Report – Recommendations for the Development of a Community-Based System of Care for Frail Seniors in WWLHIN, George Heckman et al, January 2013.

39 Health System Use by Frail Ontario Seniors, ICES, 2011

40 *Champlain LHIN*, 2013.

41 10 by 20: Ontario Action Plan for Dementia, Alzheimer Society of Ontario, 2010.

42 Canadian Study on Health and Aging, 1994.

43 In Their Own Voices: A Profile of Dementia Caregivers in Ontario, Smayle & Dupuis, Murray Alzheimer Research and Education Program, University of Waterloo, 2004.

44 Huckle, P.L. (1994). Families and Dementia. *International journal of geriatric psychiatry*, 9(9), 735-741.

45 In Their Own Voices: A Profile of Dementia Caregivers in Ontario, Smayle & Dupuis, MAREP, 2004



Table 3: 'In Their Own Voices' - Feelings of Dementia Caregivers

“Since I began caregiving I feel increasingly....”	
Frustrated	59.7%
Worried	58%
Emotionally Drained	57.2%
Sad	49.1%
Depressed	35.9%
Helpless	33.7%
Fulfilled	14.5%
Joyful	11.3%

While a significant proportion of caregiver burden can be attributed to the consequences of dementia⁴⁶, dementia caregivers also attribute a significant proportion of frustration and burden to the manner in which dementia services are provided.

Table 4: "In Their Own Voices": Problems with access and use of community services

“% identifying barriers and problems related to access / use of community services...”	
Hours of help inadequate to caregiver needs	55%
Too difficult to navigate system	48.7%
Caregivers have little input into what is offered	43.1%
Bureaucratic procedures	34.3%
Services are too expensive	33%

While this was a provincial survey conducted in 2004, results from a caregiver survey conducted as part of the Ottawa Dementia Needs Assessment, 2012, mirror these findings.

- Communication Problems with different service providers
- Complex system
- Difficult communicating with Agency
- Waiting Time to get help, to return calls, and waiting lists too long
- Amount of respite insufficient and little follow up*

Cost of services, and difficulty in accessing services in French were also identified in focus group discussions.

⁴⁶ Final Report of the Dementia Caregiver Help Line Feasibility Project, Martell Consulting for the Ontario Dementia Network, 2012.

The consequences of caregiver burden are significant. 35 – 60% report declines in their own health and 71% report disruptions to employment.⁴⁷ Such costs, both direct and indirect, underline the tremendous importance of bridging between the needs of persons with dementia and their caregivers, and the manner in which services are organised and delivered.

One in five dementia caregivers report high level of distress, anger or depression and inability to carry on. The consequences of caregiver breakdown present significant risk for premature hospitalisation, and / or placement. Increasingly, the need to recognise family caregivers as active members of the health care team and provide them with the necessary information, tools and support is being acknowledged (Nichols 2011). Integrated caregiver support programs have proven effective in both reducing caregiver stress and delaying institutional care⁴⁸.

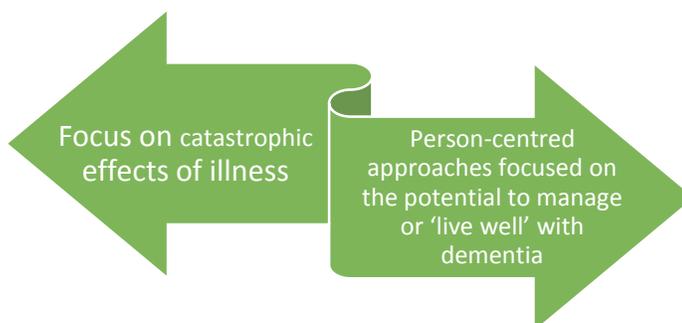
⁴⁷ Champlain Dementia Evidence Brief, Alzheimer Society of Ontario, 2012.

⁴⁸ Mittelman, M.S., Roth, D.L., Clay, O.J., & Haley, W.E. (2007). Preserving Health of Alzheimer Caregivers: Impact of a Spouse Caregiver Intervention. *American Journal of Geriatric Psychiatry*, 15(9), 780-789.

Re-Framing Our Experience of Dementia:

The Strategic Framework

There is no doubt a compelling case that the burden of dementia is multiplied many fold across the population of persons with dementia and multiple chronic conditions, their caregivers. Society at large is also impacted through the unnecessary use of acute care services represented by disproportionate ALC rates. There is an equally compelling case that earlier diagnosis and assessment, preventive treatments and coordinated care management and caregiver support can significantly reduce the cumulative impact of the burden of dementia. This re-framing of the approach to dementia away from the at times devastating effects of dementia towards the evidence and potential to adapt and improve the quality of life of persons with dementia is fundamental to this project.



Consistent with the rationale of the Champlain Integrated Model of Dementia Care, six of the seven national dementia strategies that were reviewed explicitly commit to the development of more coordinated, integrated models of service delivery. The seventh, the United States, refers more generally to optimising care, quality and efficiency.

In this regard, a key recommendation of the Alzheimer Society of Canada is relevant to consider again, in which they reference the need for...

“Greater integration of care and increased use of ‘best practice’ frameworks in chronic disease management, community care and support.”

At the outset of this effort, the Project Team was asked to identify key outcomes that should be achieved through successful implementation of an Integrated Model of Dementia Care for Champlain. Subsequent to a brief review of the literature and the preliminary profile of persons in Champlain that was developed, these were reviewed and re-grouped to guide the development of the Integrated Model of Dementia Care. These integrate to some extent, approaches across other jurisdictions with knowledge of the region and its potential, and have been adapted to form the strategic framework for this project. They integrate elements of practice from both chronic disease management and dementia management strategies.

Table 5: Strategic Framework: Champlain Integrated Model of Dementia Care

Strategy	Result
Public Awareness	<i>Improved understanding & acceptance of dementia as a chronic condition</i>
Detection, Diagnosis & Assessment	<i>Earlier detection, diagnosis, and intervention to manage the consequences of dementia.</i>
Self-management & Caregiver Support	<i>Promotion of activities and attitudes to 'live well' with dementia.</i>
System Navigation	<i>Persons with dementia and their caregivers know what to expect and where to find it.</i>
Coordinated Pathways of Support	<i>Timely and coordinated access to a continuum of dementia care that supports persons with dementia and their caregivers in making choices that matter in their day-to-day lives</i>
System Integration	<i>A system of support that is tailored & targeted to their changing needs.</i>

Proposed Priority Activities:

The Project Team then identified and prioritised specific activities intended to achieve the key results for each of the six strategies intended to guide the development and implementation of an Integrated Model of Dementia Care for Champlain.

Public Awareness	<i>Improved understanding & acceptance of dementia as a chronic condition</i>
<p>Discussion of the benefits of enhanced dementia literacy focused on two dimensions. Firstly, it is recognised that meaningful change in a societal approach to dementia must begin with the communities in which people with dementia and their families live.</p> <p>Secondly, from the perspective of chronic disease management, as equally important as it is to enhance earlier detection and diagnosis of dementia, it is critical that people who will acquire dementia, and their families, have a better understanding of the condition and the alternatives that are available to help them manage their lives on a day to day basis. Health literacy, in this context, can be viewed as a risk factor that influences health outcomes at three critical points: access to health care, the interaction between patients and their health care providers, and self-management⁴⁹.</p> <p>Towards these ends, three activities have been proposed:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Promote public awareness of brain health. Many of the risk reduction strategies for dementia align with those for other chronic conditions such as stroke, diabetes, and heart failure. <input type="checkbox"/> Enhance dementia literacy amongst the general population. <input type="checkbox"/> Enhance the role of communities and neighbourhoods in promoting resilience and healthy living for persons with dementia and their caregivers, including the development of alternative housing and transportation services. 	

⁴⁹ Nutbeam D, The Evolving Concept of Health Literacy, Social Science and Medicine 67(2008) 2072-2078.

Detection, Diagnosis & Assessment

Earlier detection, diagnosis, and intervention to manage the consequences of dementia.

Primary care physicians diagnose as few as 50 – 64% of dementia cases^{50,51}. Given the improvements in treatments which have been effective in slowing the progression of Alzheimer's Disease, delays in diagnose can translate into delays in treatment, avoidable use of emergency departments, hospital and long term care. Their families are also less likely to access community care and support.

Given the critical role of primary care for persons with dementia and their families noted previously, a significant emphasis has been placed upon enhanced capacity to detect and diagnose dementia. It is recognised that a broad range of primary, secondary and tertiary interventions will be required to fully develop this capacity. Key partnerships with specialised assessment resources are seen as critical as both an educational and consultative resource to primary care, but also, for more complex or unstable conditions, to temporarily intervene. Promising models of Primary Care Memory Clinics, developed in Waterloo-Wellington, have demonstrated significant potential to improve primary dementia care and reduce reliance on scarce specialised resources⁵². Shared care models of primary care partnering with more specialised clinical resources have also demonstrated positive outcomes⁵³. Additionally, Health Links presents a relatively immediate opportunity to alleviate the tremendous burden of dementia through the integration of dementia care within a broader chronic disease framework.

It should be re-emphasized that early detection of dementia should also be extended to other chronic disease specialists to reduce the effects of dementia on the management of other chronic conditions such as diabetes, heart failure, and stroke noted previously. Early detection and referral to dementia specialists to develop an approach adapted to the needs of persons with dementia would alleviate the so-called domino effect across other chronic conditions.

At the same time, the importance of broader community surveillance in detection of persons at risk of developing dementia is acknowledged.

Four priority activities are proposed to promote earlier diagnosis and intervention:

- Collaborate with partners in primary care to develop a range of strategies to enhance capacity in primary care. (e.g. Primary Care Memory Clinics, Dementia Advance Practice Nurses, co-location of First Link etc...)
- Explore the role of, and partnerships affiliated with the Bruyere Memory Disorder Clinic.
- Train Personal Support Workers (PSWs) in the community to detect cognitive problems and be able to effectively support persons with dementia and their caregivers.
- Optimise the use of technology for system wide assessments, electronic medical records (EMRs) and electronic consults to support community surveillance and referral.

50– Alzheimer's Association Dementia Care Project, The American Journal of Managed Care, Vol 10 No 8(2004) 553-560. Cherry D, et al Interventions to Improve Quality of Care: The Kaiser Permanente

⁵¹ Lee L, et al. Developing Memory Clinics in Primary Care: An Evidence-based Interprofessional Program of Continuing Professional Development, Journal of Continuing Education in the Health Professions., 33(1): 24-32, 2013.

⁵² Lee L, et al. Developing Memory Clinics in Primary Care: An Evidence-based Interprofessional Program of Continuing Professional Development, Journal of Continuing Education in the Health Professions., 33(1): 24-32, 2013.

⁵³ Callahan CM, Boustani MA, et al Implementing Dementia Care Models in Primary Care Settings: The Aging Brain Care Medical Home, Aging & Mental Health, Vol 15, No 1 January 2011. 5-12

Self-Management & Caregiver Support *Promotion of activities and attitudes to 'live well' with dementia.*

As noted previously, the concept of health, in this case, dementia literacy has implications for both the development of the public awareness strategy and the self-management and caregiver support strategy. In terms of self-management (for both persons with dementia and their caregivers) the knowledge acquired through health literacy is intended to develop skills that allow people “to participate more fully in society, and to exert a higher degree of control over everyday events.”⁵⁴ Research in dementia literacy is in its formative stages and Champlain region, through current research, is well positioned to adapt and develop dementia literacy initiatives.

However, the majority of care for community dwelling persons with dementia is provided by family caregivers and friends. The cumulative impact of the consequences of dementia, combined with a service delivery model that is fragmented and does not recognise the needs of family caregivers in their own right, takes a tremendous toll. While it is recognised that innovative approaches to involve and engage persons with dementia in their own care can alleviate this burden to some extent, comprehensive caregiver strategies are seen as central to the Champlain Integrated Model of Dementia Care.

Seven activities are proposed to improve the capacity of persons with dementia and their caregivers to live well with dementia:

- Establish a Caregiver Help Line for off-hours support.
- Develop a Comprehensive Caregiver Strategy for Champlain, including enhanced access to First Link.
- Promote acceptance and self-management for persons with dementia.
- Develop CCAC pathways linked to the needs of caregivers.
- Provide education on living with dementia.
- Develop an integrated web-repository for on-line dementia resources.
- Provide pre-orientation to long term care to facilitate planning and adaptation.

⁵⁴ Nutbeam et al.

System Navigation

Persons with dementia and their caregivers know what to expect and where to find it.

Central to being able to access the range of care and support services required for persons with dementia and their families, are resources to facilitate system navigation. People with dementia, particularly those with multiple chronic conditions often require the support of 3-5 organisations, and being able to select the appropriate resources from the many providers across Champlain is not without challenges. Previous studies in the region on service access indicated older adults or families members would need to make 8-10 phone calls to find the appropriate resources, if they did not give up in frustration. While this remains the reality for many, the potential to use technology and web-based resources can provide tremendous benefit for those who are able.

Although much can be undertaken to improve system navigation for persons with dementia, five activities are proposed to achieve the goal of informing persons with dementia and their caregivers what they might expect from the service system and where it could be found:

- Promote the use of the on-line resource directory of the Champlain Dementia Network*.
- Develop a coordinated intake and referral system consistent with other chronic conditions.
- Adapt and promote the use of 211 and 310 CCAC telephone and on-line resources.
- Develop electronic patient tracking systems in order that partners in care are aware of the status of clients with dementia in order to facilitate effective care planning.

*This excellent referral resource is unfortunately at risk due to funding constraints for the Champlain Dementia Network.

Coordinated Pathways of Support

Provide timely and coordinated access to a continuum of dementia care and support that supports persons with dementia and their caregivers in making choices that matter in their day-to-day lives.

As referenced in the profile, people with dementia and their caregivers account for a disproportionate utilisation of our regional health system. Yet, as might be expected, the addition of more care increases risks of duplication, problems with communication, quality and cost. These are all evidenced in our current experience with dementia care in the region. The majority of dementia caregivers cite the lack of an organised and systematic approach to dementia care and support as a major concern, and the one in four persons with dementia who are admitted to hospital, account for 34% of all ALC hospital days.

For the purposes of this framework, activities related to the continuum of dementia programs and services that must work together to respond to the changing needs of people with dementia are captured under the strategy of Coordinated Pathways of Support. A case sample developed previously through the Champlain Dementia Network, describing how the needs of someone with dementia changes over the trajectory of their condition, and the range of services they require at critical moments, will serve as a useful planning resource in this regard. The Project Team has further identified eleven activities intended to collectively alleviate and better manage the direct and indirect consequences of dementia, and allow persons with dementia and their caregivers to make choices that matter to the quality of their lives.

- Partner with other chronic disease networks such as Seniors Mental Health, Health Links, Diabetes Regional Coordinating Centre, the Champlain Regional Stroke Network and the Champlain Cardiovascular Disease Prevention Network. These would be intended to develop reciprocal screening and referral relationships to adapt these services to the needs of people with dementia and other chronic conditions.
- Explore the evolving role of the Memory Disorder Clinic at Bruyere to broaden the scope and accessibility of specialised memory assessments in the region.
- Co-locate dedicated CCAC Case Managers with select community partners including primary care.
- Enhance partnerships between CCAC and Community Support Services in the planning and delivery of dementia care and support.
- Optimise the role and scope of CCAC rural Geriatric Assessors with respect to dementia care and assessment.
- Promote dementia-sensitive acute care including implementation of the Senior Friendly Hospital Strategy and enhanced access to geriatric psychiatry. (e.g. treatment of delirium, responsive behaviours etc.)
- Enhance the role of pharmacy throughout the region in cognitive screening and referral, as well as medication review. (e.g. medications that impair cognition or cause falls)
- Consider a more targeted approach to the needs of the more than 3,600 people with dementia in Retirement homes, including increased education requirements for Personal Support Workers.
- Develop dementia-specific housing choices, including a more diversified role for long term facility care.
- Enhance alignment with BSO services.
- Better education and training for professionals working across the health sector is paramount to the quality of dementia care. This should be accomplished through both colleges and universities, as well as continuing education.

System Integration

Enable a system of support that is tailored and targeted to the changing needs of persons with dementia.

For various reasons, unlike other major chronic conditions, there is not yet any organised or coordinated approach to dementia service delivery. A range of chronic disease management strategies and best practices for continuing care have been reviewed and proposed for adaptation across Champlain dementia services. Hollanders' Best Practices Framework for Continuing Care⁵⁵, in particular, was reviewed for its scope in addressing both clinical and administrative best practices. The Framework is outlined in Appendix (). While it is important to consider the extent to which relevant dementia services are available, the extent to which **how** programs are organised around the changing needs of persons with dementia and their caregivers, is fundamental to their quality of life, as well as that of their caregivers and other members of society who share the burden of dementia.

The following evidence-based administrative practices, in principle, were accepted as a basis for further planning and adaptation into a more integrated approach to dementia service delivery:

- A **coordinated administrative structure**, such as a board, steering committee or planning group for shared decision-making / governance;
- Service or **participation agreements** confirming the scope of commitment from partner organisations
- Involvement of persons with dementia** and family and caregivers in system wide-planning;
- A clear **commitment to improving the lives of persons with dementia** and their caregivers (as an organisational principle.)
- A coordinated funding envelope.

The following clinical best practices were prioritised and affirmed for the purpose of preliminary planning:

- Coordinated access** or entry mechanisms and processes
- Adoption of consistent evidence-based clinical practice guidelines.
- System-wide case management, and
- Involvement of persons with dementia and their families in decisions about their care.
- Broader application of **system-wide client assessment and classification** systems such as the Inter-RAI, which it was noted, is now being extended to the CSS sector, complemented by **specialised evidence-based diagnostic and assessment** tools.

⁵⁵ Hollander MJ, Prince MJ, Organising Care Delivery for Persons with Continuing Care Needs, Health Care Quarterly, Vol 11, No 1, 2008.

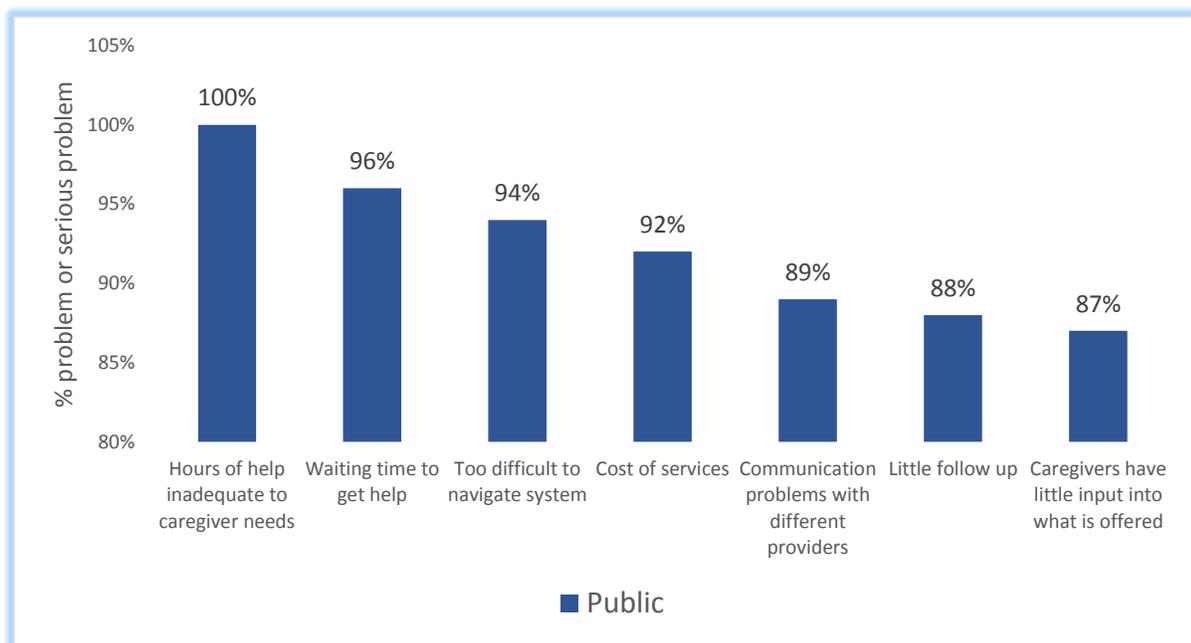
What They Said.....

An expedited consultation process was used to clarify primarily, the extent to which stakeholders in dementia care felt the six proposed strategies would be appropriate to guide the development of an integrated system of care, and respond to the real needs of persons with dementia and their caregivers. Once the Project Team had developed a broad framework an expedited consultation process was conducted between March 14 -29, 2013. It comprised 5 focus groups with 23 participants, including both caregivers and providers, and seven key informants. Additionally an on-line survey was developed to solicit agency level feedback through a number of regional networks. These included the Ontario Association of Non-Profit Homes and Services for Seniors (OANHSS) Region 7, the Champlain Community Support Services Coalition, the Eastern Counties Specialised Geriatric Services Network, as well as several agencies participating in the Carleton Place Focus Group. 47 organisations responded to the on-line survey, providing a sample of 77 organisations and individual responses.

100% of the 77 respondents agreed that an organised provider network was required for dementia care in the region, and 98% agreed the proposed strategies, if implemented, would respond to the real needs of persons with dementia and their caregivers.

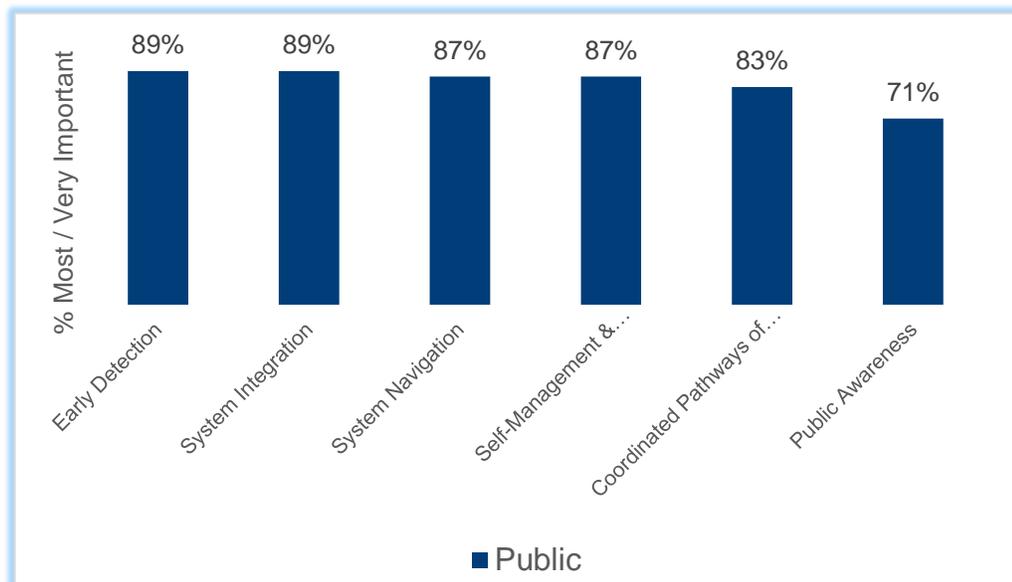
Survey respondents were asked to indicate the extent to which system barriers previously identified in caregiver surveys, were problematic.

Figure 4: Agency Survey Response: What do you currently see as the major roadblocks to accessing care & support for persons with dementia and their caregivers? N=47



Survey respondents were also asked to rate the relative priority for implementation of each strategy:

Figure 5: Agency Survey Response - Please rate the relative importance of each of the proposed strategies to be associated with an integrated Model of Dementia Care for Champlain?



Survey Respondents were also given the option of commenting on each of the 34 proposed activities associated with the framework. A majority (67%) exercised this option for a more detailed review of the proposals. This reflects the perspectives of approximately 31 organisations across the region, and along with that from the face to face focus groups and interviews, was considered by the Project Team in their recommendations. A summary of responses is included in Appendix 5.

Strategy	Priorities for Action*
Public Awareness	<ul style="list-style-type: none"> Enhance the role of communities and neighbourhoods
Early Detection & Diagnosis	<ul style="list-style-type: none"> Enhance capacity for Primary Care
Self-Management & Caregiver Support	<ul style="list-style-type: none"> Develop comprehensive caregiver strategy Develop CCAC pathways to caregiver support. Pre-orientation to long term care.
System Navigation	<ul style="list-style-type: none"> Coordinate intake and referrals Electronic patient tracking system
Coordinated Pathways of Support	<ul style="list-style-type: none"> Promote dementia-sensitive acute care Develop dementia-specific housing options, including diversified role for LTC. Explore role and supports required for persons with dementia in retirement homes Enhanced partnership between CCACs and Community Support Services. Enhanced role for pharmacy
System Integration	<ul style="list-style-type: none"> Apply common screening tools System-wide case management Align Dementia Care with CLHIN Integrated Health Services Plan

*= 80% or more rated as Most / Very Important (4, 5 on scale of 1-5)

In order to support implementation planning, survey respondents, key informants and focus group participants were also asked to identify ‘Quick Wins’ that might build momentum for change in dementia care in the region. Supplementary comments were generated by 40 respondents. Comments which reinforced strategic priorities or activities were not repeated for the purposes of clarity.

What would you suggest as 'quick wins' to build momentum for change in dementia care across the region?

- Designate one coordinating agency, Co-locate for ‘one-stop’ dementia services
- Don’t reinvent the wheel
- Identify Champions for change, engage those who know what needs to be done
- Re-development of Memory Disorder Clinic
- Simplify processes.
- Expand First Link
- Align with Good Neighbours / Healthy Neighbourhoods
- Humanise care for persons with dementia.
- On-call dementia APN
- More affordable supportive housing.
- Increase respite for caregivers, in any way possible!
- Joint education campaign adopted and used by all CSS and CCAC.

The Context for Change

‘Living Longer, Living Well’⁵⁶:

Prior to identifying recommended next steps to move the development of an Integrated Model of Dementia Care forward, the recently released provincial strategy for seniors health was reviewed. There are several provisions related to dementia care and caregiver support which are strongly aligned with our proposed approach.

The need for a focus on dementia care is acknowledged with a specific section on dementia. The need for services to be ‘tailored’ to the changing needs of persons with dementia and their caregivers is specifically referenced, and the expansion and standardisation of First Link is recommended. The report indicates that 65% of the residents of long term care homes have dementia, and recommends a diversification of the role of long term care, including the development of dementia-specific housing options.

Additionally, the important role of caregivers is acknowledged and proposes a range of options for consideration, including tax credits, as well as consideration of direct funding options which have proven successful in reducing reliance on both acute and long term care.

The need for more coordinated approaches to care for certain populations is also recognised in recommendation # 71:

⁵⁶ Living Longer, Living Well, Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on recommendations to Inform a Seniors Strategy for Ontario. Dr. Samir K. Sinha, Provincial Lead, Ontario’s Seniors Strategy, 2012

“The Ministry of Health and Long-Term Care should encourage the further expansion and testing of hospital-led care coordination and home care models for select populations. These models need to complement existing community-based care coordination structures and patients’ primary care providers.”

The further integration of primary and community care is also recognised as a goal.

One concern regarding the provincial report is that while it recommends the implementation of universal risk screening for older adults’ health promotion, cognition is not included as a risk factor.

Champlain LHIN Integrated Service Plan 2013-2016:

The Integrated Health Services Plan recently published by the Champlain LHIN provides the context for all health services planning in the region. As the third such plan developed through the Champlain LHIN it is remarkable both for its expressed commitment to person-centred care, but also in its recognition of the challenges of dementia and the need for more integrated systems of care for our most vulnerable populations.

There are three Key Results and three Strategies as elements of the IHSP which are particularly aligned with the proposed direction for an Integrated Model of Dementia Care for the region.

Key Result 1: *More people are involved in planning their health services.*

While the proposed dementia framework is committed to supporting persons with dementia and their caregivers in making choices that matter to them, a strategic priority to develop mechanisms for engaging people with dementia and caregivers in implementation planning for the new model has been identified as a priority as well.

Key Result 4: *More seniors are cared for in their communities.*

The LHIN strategy is explicit in its recognition of the needs of persons with dementia. Additionally the proposed dementia framework and its own strategies regarding caregiver support, system navigation and coordinated pathways to care are tightly aligned with similar commitments in the IHSP.

Key Result 5: *More people with complex health conditions are able to manage their conditions*

People with dementia, particularly those with multiple chronic conditions are amongst the most complex to diagnose and support and as a result contribute to high levels of hospital utilisation. The IHSP commitments to a coordinated care plan, support for system navigation, and access to linguistically appropriate diagnostic and assessment services, are consistent with the proposed elements of the Dementia Model of Care.

Strategy 1: *Build a strong foundation of integrated primary, home and community care.*

Proposed actions to create integrated health networks, promote early identification and management of risk, and system navigation are also aligned with the proposed Model of Dementia Care.

Strategy 2: *Improve coordination and transitions of care.*

Proposed actions related to continuity of care, information sharing, intensive case management and promotion of evidence-based clinical practice are all consistent with both the proposed strategies and activities which are proposed within the Dementia Model of Care.

Strategy 3: *Increase coordination and integration of services among hospitals.*

Although the Integrated Model of Dementia Care comprises the full continuum from hospital to home, the proposed actions of the LHIN regarding improve approaches to regional program development, central intake and referrals as well as emergency room initiatives are all reflected in the proposed model. Additionally, the proposed changes in funding could be leveraged to enhance system level planning.

Pulling it all Together:

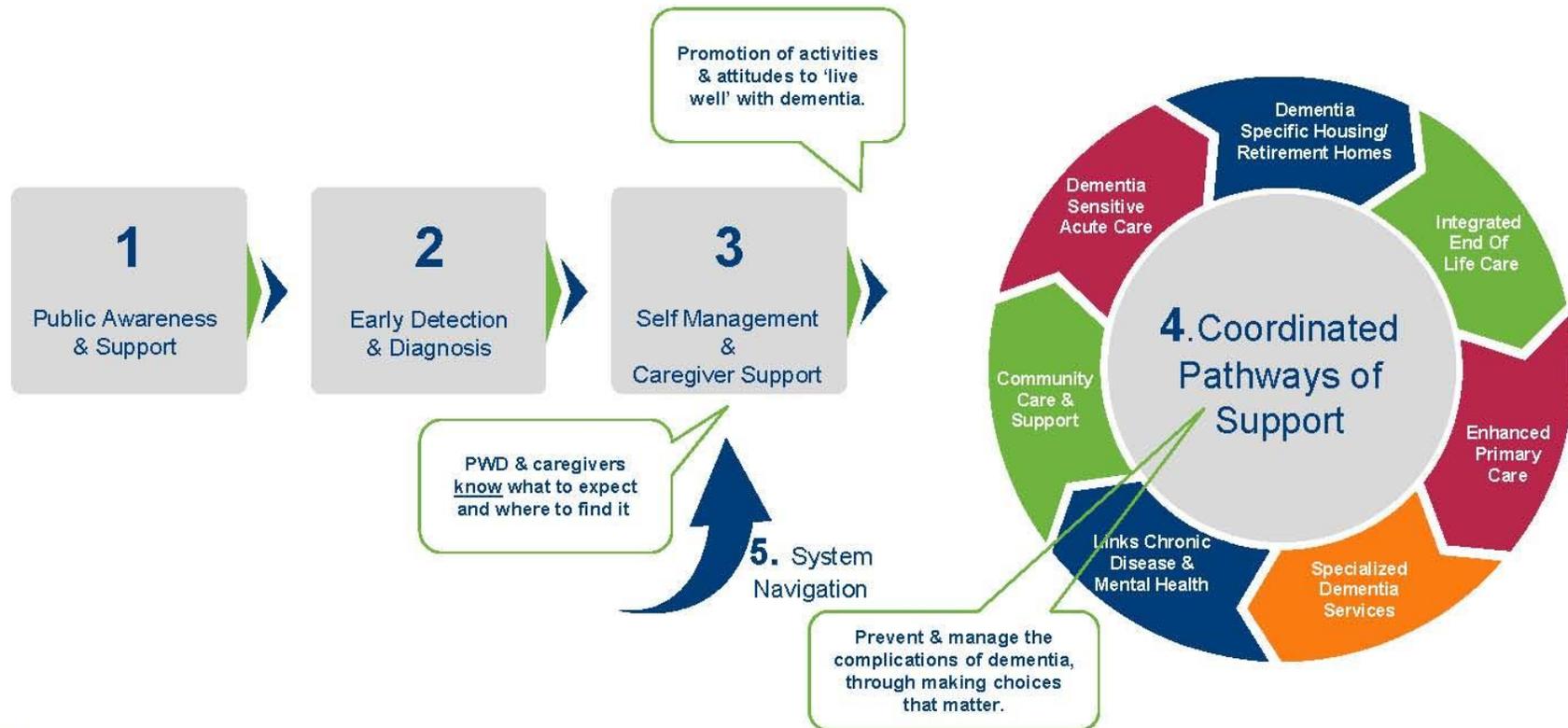
Champlain 2020: Our Vision:

“Being the best...for persons with dementia, their families, our health system, and society.”

Our Principles:

- ❖ People with dementia and their caregivers are valued, respected, and supported in their right to make well informed choices that matter to them.
- ❖ The important role of caregivers and the consequences of their commitment, must be recognised and supported.
- ❖ A person’s first language should be taken into account in the diagnosis and assessment of dementia.
- ❖ People with dementia, and their caregivers will receive integrated, coordinated services that respond to their social, cultural or economic background, location and needs.
- ❖ A full range of dementia services should be available in both official languages.
- ❖ A well-trained work force is required to deliver quality care.
- ❖ Communities play an important role in the quality of life and resilience of people with dementia and their caregivers.
- ❖ An organisational culture characterised by empowering people, ensuring accountability, and continuously improving quality.

Figure 6: Strategic Framework for an Integrated Model of Dementia Care



6. System Integration



Shared Decision-Making Process



Coordinated Funding



Incentives For Evidence-Based Practice



Common Screening & Assessment



System Wide Case Management



Education & Training

A system of support that is tailored & targeted to the changing needs of persons with dementia and their caregivers.

Making it Happen:

The effort to re-frame the experience of persons with dementia and their caregivers in Champlain is ambitious in its reach but realistic in its intent and desperately needed. The scope of change that is required is significant and will require several years of planning, negotiation and implementation. Even many of the caregivers we have consulted recognise much of the benefit will come to those that follow in their paths. As such, the Project Team has proposed preliminary priorities for development to reflect both feasibility and an understanding of the pre-requisites for change. Subject to further discussion and agreement with the Champlain LHIN, the following priorities are recommended for initial stages of implementation planning:

1. It is recommended that the Champlain LHIN commit to the development of an Integrated Model of Dementia Care for Champlain, and to support the following **strategic priorities** for the coming year:

1. **System Integration:** Evaluate and propose a system-wide, shared governance structure or mechanism for dementia services across Champlain, and which should include a process for coordinated intake and referral, and explore options for coordinated funding strategies.
2. **Caregiver Support:** Develop clear mechanisms for the involvement of persons with dementia and family caregivers in system wide-planning;
3. **Public Awareness:** Promote greater public awareness of dementia and inspire a clear commitment to improving the lives of persons with dementia and their caregivers amongst health system leaders.
4. **Pathways of Support:** Designate a LHIN staff dementia lead and consider mechanisms to integrate dementia planning with other LHIN-wide chronic disease management strategies, including Health Link, Falls, Diabetes, Champlain Cardiovascular Disease Prevention Network, ED/ALC, Champlain Stroke Network.

2. It is recommended that the Champlain LHIN consider funding the following **operational priorities** as part the first year of operation of its new Integrated Health Services Plan:

- A. System Integration:**
Implementation Planning: Continue regional implementation planning of Dementia Care Model.
- B. Early Detection & Diagnosis:**
Primary Care Memory Clinics. Extend Dr. Lee's model and build up to 5 primary care memory teams across Champlain, and to include direct affiliation with First Link.
Memory Disorder Clinic: Support redevelopment of the Bruyere Memory Disorder Clinic to improve access to specialised dementia assessments and enhance support to primary care.
Specialised Dementia Assessment Services: Hospital budget pressures have resulted in staffing reductions in several specialised dementia services. Consideration should be given to preserve and protect service levels in light of the critical role of dementia assessment and intervention.
- C. Public Awareness:**
Regional Coordination of Dementia Education: Coordinate existing educational resources and optimize the resources to include a dementia literacy and marketing strategy to both service providers and the public so they are aware of what is available to live well with dementia.
- D. Caregiver Support:** Ensure First Link and Adult Day Programs are equitably accessed throughout Champlain, including North Grenville /North Lanark.

It is believed that these priority actions will lay the foundations for success and move the region towards fulfillment of the six strategic results driving system level change, and prepare Champlain region and its health system for the challenges of 2020 and beyond.



Appendix 1: An Integration Tool Kit (Hollander)

Best Practices for Organising a System of Continuing Care⁵⁷

Philosophical & Policy Prerequisites
1. Belief in the benefits of systems of care
2. Commitment to a full range of services & sustainable funding
3. Commitment to a psychosocial model of care
4. Commitment to client-centred care
5. Commitment to evidence-based decision-making.

Best Practices for Organising a System of Continuing / Community Care
Administrative Best Practices
1. A clear statement of philosophy, enshrined in policy
2. A single or highly coordinated administrative structure
3. A single funding envelope
4. Integrated information systems
5. Incentives for evidence-based management
Clinical Best Practices:
6. A single or coordinated entry system
7. Standardised system-level assessment & care authorisation
8. A single system-level client classification system
9. Ongoing system-level case management
10. Involvement of clients & families

Linkage Mechanisms across Population Groups
1. Administrative integration
2. Boundary spanning linkage mechanisms
3. Co-location of staff

Linkages with Hospitals
1. Purchase of services from speciality services
2. Hospital in reach approach
3. Physician consultants in community
4. Greater medical integration of care
5. Boundary spanning linkage mechanisms
6. A mandate for coordination

Linkages with Primary Care
1. Boundary spanning linkage mechanism
2. Co-location of staff
3. Review of physician remuneration
4. Mixed models of continuing / community care and primary healthcare

Linkages with Other Social & Human Resources
1. Purchase of service for specialty services
2. Boundary spanning linkage mechanisms
3. High-level cross sectoral committees.

⁵⁷ Hollander MJ, Prince MJ, Organising Care Delivery for Persons with Continuing Care Needs, Health Care Quarterly, Vol 11, No 1, 2008.

Appendix 2 – Project Team

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Appendix 3: Summary of Select Dementia Strategies

	Quebec	Ireland	European Union	United Kingdom	Norway	Australia	United States
Strategy / Goals	<ul style="list-style-type: none"> • Raise Awareness, inform, mobilise • Treat caregivers as partners who need support • Access personalized ,coordinated assessment & treatment • Promote high quality life through access to home support and alternative living facilities • Promote therapeutically appropriate end-of-life care • Develop & support training programs • Mobilise universities, public and private sectors for research. <p>Proposed a service delivery structure based upon chronic care and collaborative practice model</p>	<ul style="list-style-type: none"> • Early intervention, education & training (information & advice centres) • Enhanced community-based services to allow PWD to make choices that matter for them. (refers to Challis’ care management model) • Coordination and integration of multidisciplinary care. • Quality residential care. <p>Suggests no two individuals affected by the disease in the same way, arguing for individualized approaches.</p>	<p>Calls for member states to adopt national strategies along four themes:</p> <ul style="list-style-type: none"> • Exchange of best practices in prevention, diagnosis, treatment, rehabilitation and integrated care. • Improvement in epidemiological information • Exchange of best practices in protection of patients’ rights, and ethical issues associated with aging with dignity • Research 	<ul style="list-style-type: none"> • Improved awareness • Earlier diagnosis and intervention • Care pathways to living well with dementia <p>Identifies 17 objectives including:</p> <ul style="list-style-type: none"> - Enabling easy access to care, support & advice (dementia advisors) - Structured peer support & learning networks - A caregiver strategy - Assessment & regulating of health care services for PWD - Joint commissioning (integration) 	<ul style="list-style-type: none"> • Capacity growth, raising skills & knowledge • Partnership with families and local communities. • Improving collaboration among professions & medical follow up • Quality development, research and planning • Active care (day programs) 	<ul style="list-style-type: none"> • Information and education (incl dementia literacy) • Care and Support • Coordinated, flexible pathways to respond to peoples changing needs • Access to dementia-sensitive mainstream services • Priorities for primary care • Evidence-based service models & funding arrangements. • Workforce Training • Access and Equity • Research 	<ul style="list-style-type: none"> • Enhance public awareness and engagement. • Expand support for People with Alzheimer’s Disease and their families • Prevent & effectively treat Alzheimer’s disease by 2025. • Optimise care quality and efficiency • Track progress and drive improvement.



Appendix 4: Consultation Summary: On-Line Survey

N=47

Do you agree an organised dementia provider network is important?	
Yes	100%
No	0

Do you agree the six proposed strategies have the potential to meet the real needs of PWD and their caregivers?	
Yes	96%
No	4%

Figure 7: Relative importance of Public Awareness activities

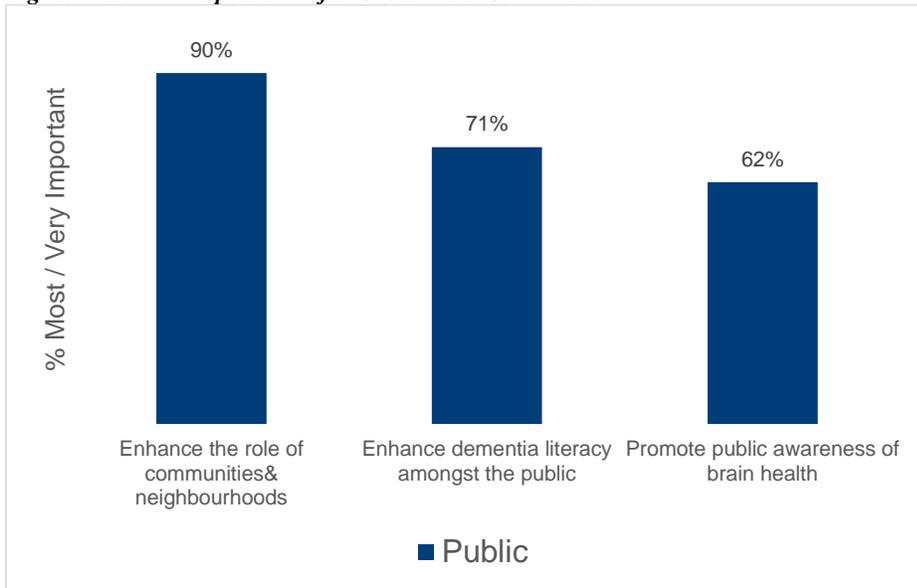


Figure 8: Relative Priority of Detection & Diagnosis activities

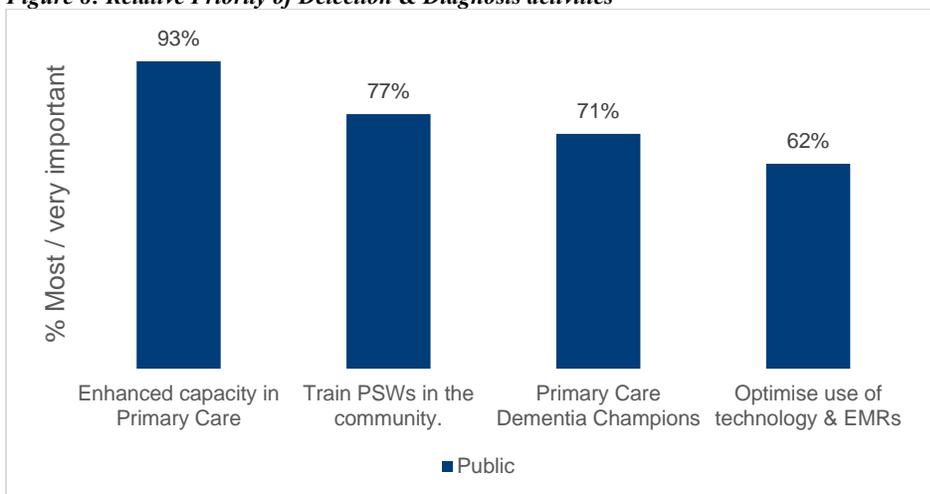


Figure 9: Relative priority of proposed Self-management and Caregiver Support activities

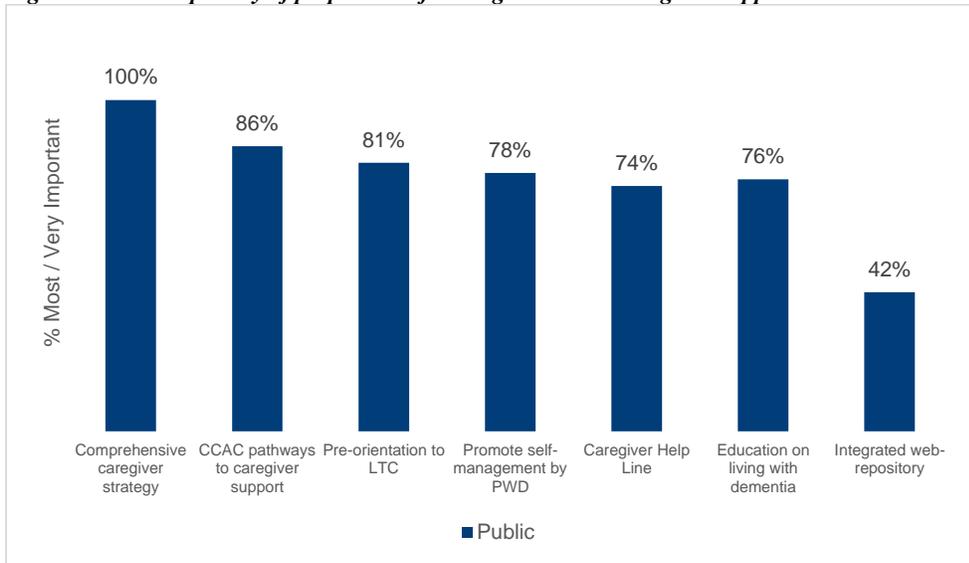


Figure 10: Relative Priority of proposed System Navigation activities

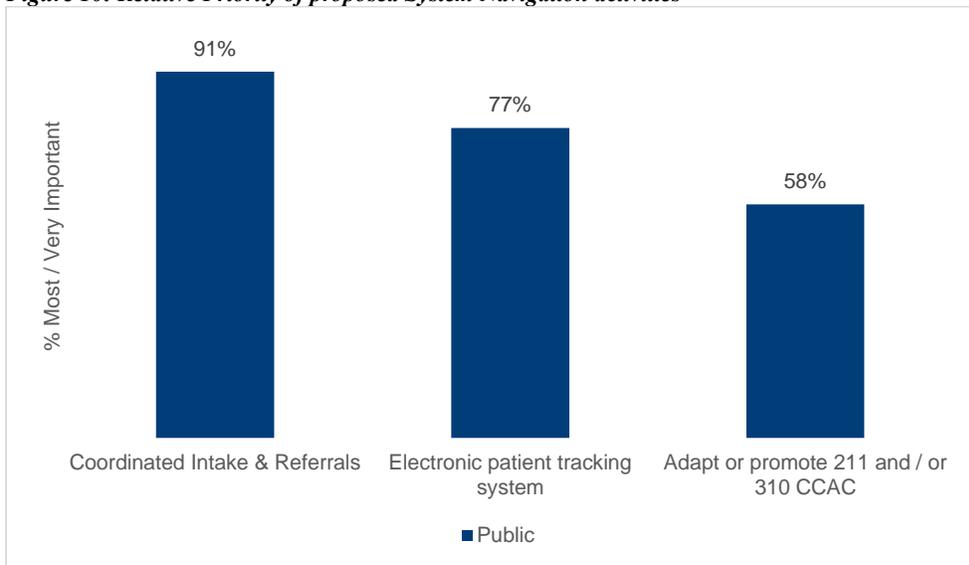


Figure 11: Relative priority of proposed Coordinated Pathways of Support activities

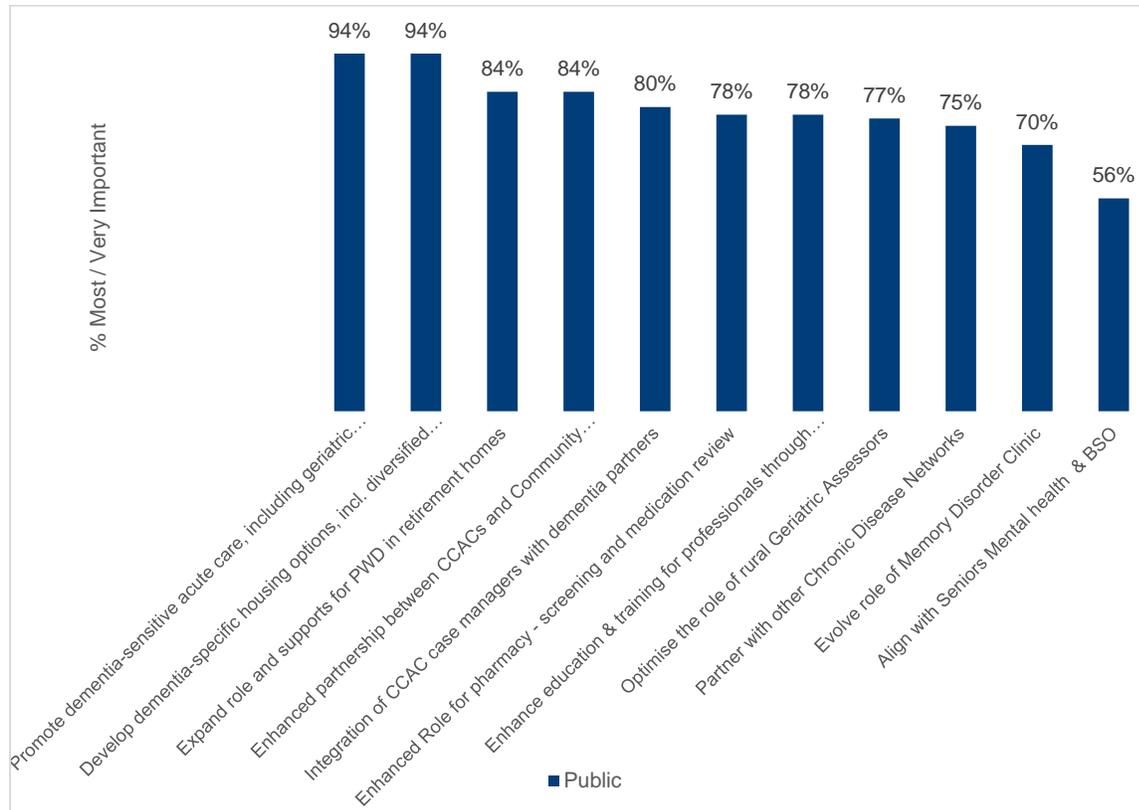
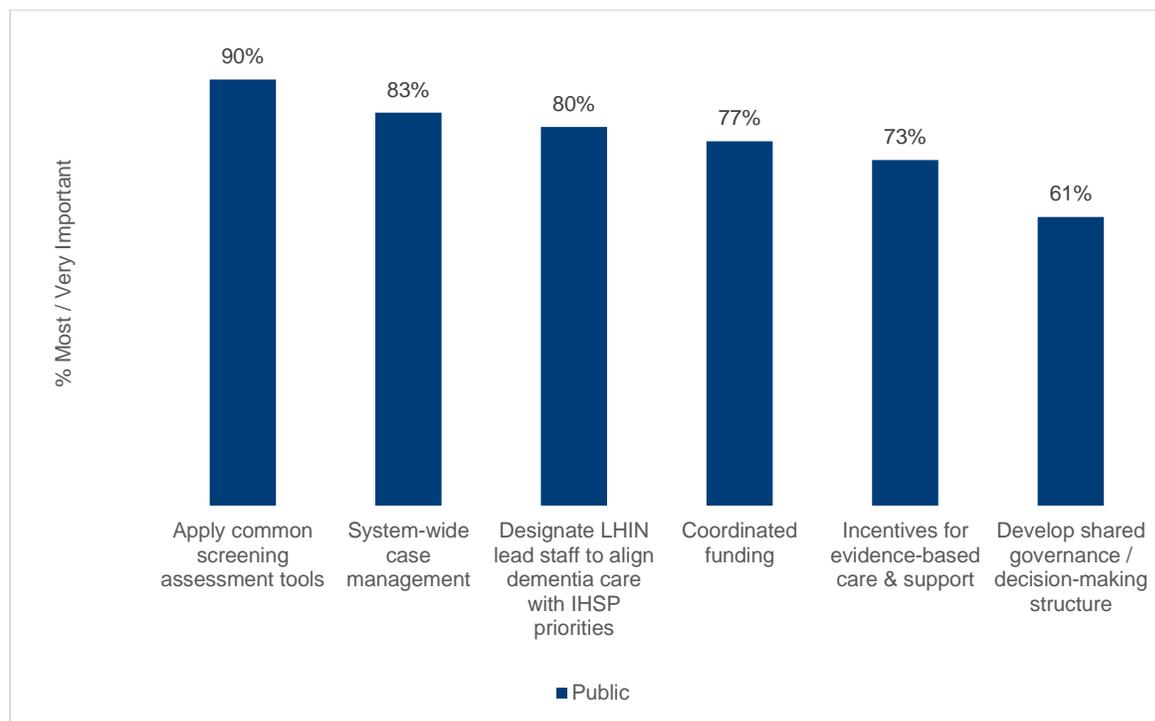


Figure 12: Relative priority of proposed System Integration activities



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