



Champlain Dementia Network

Réseau de la démence de la région Champlain

Integrated Model of Dementia Care

Champlain 2020: Making Choices that Matter

Progress Report & Workplan (2014/15)



May 2, 2014

Acknowledgements

Our deepest appreciation is extended to the following people and organisations for their contribution to our shared goal of improving support for people with dementia and their caregivers in Champlain.

- *The Champlain Local Health Integration Network for their funding support for this project, and the express commitment to new approaches to dementia care in the region identified in their Integrated Health Services Plan.*
- *All the members of the new Champlain Dementia Network Steering Committee, of the Regional Geriatric Advisory Committee, whose individual and collective efforts have laid the foundation for what will become a truly integrated service delivery network.*



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Background

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

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 in Canada.

There is 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 program.

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. In recognition of this reality, the Champlain LHIN commissioned the development of an integrated model of care for dementia in 2013, and has committed to enhanced dementia care in both its strategic and business plans. Following the endorsement of the emerging model by the community, the Champlain LHIN invested an initial \$320,000 in 2013/14 to support the implementation of the Champlain Model of Dementia Care. This report summarises the preliminary planning and implementation which has been undertaken in this first year, to lay the foundation for future developments in dementia care in the region.

Strategic Framework:

Preliminary implementation planning has been guided by six strategic directions and outcomes that serve as the strategic foundation for the model of care. They are referenced below:

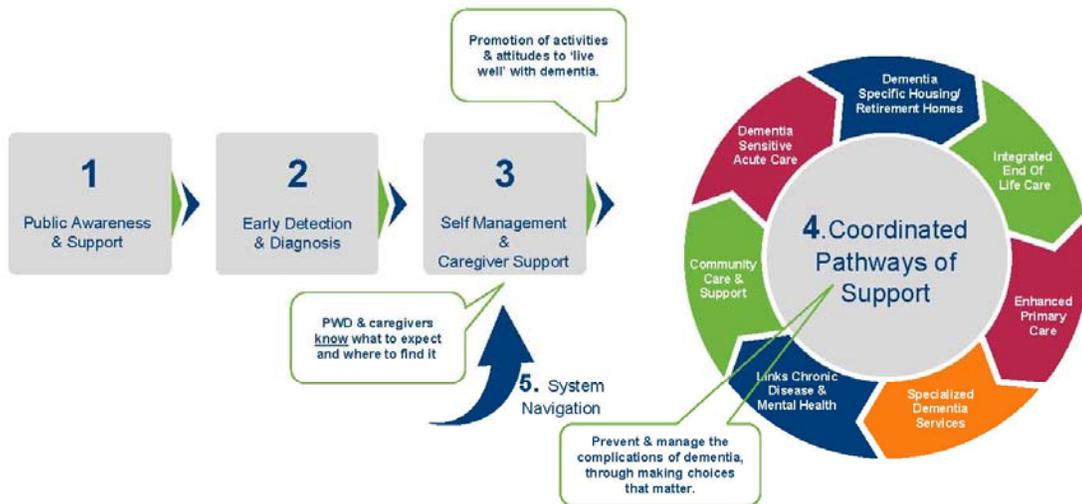
Our Vision: Champlain 2020

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

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



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>



6. System Integration



Shared Decision-Making Process



Coordinated Funding



Incentives For Evidence-Based Practice



Common Screening & Assessment



System Wide Case Management



Education & Training

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.

Preliminary priorities for development, prioritised through community consultations, were used to guide initial implementation 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.
- 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.

Caregiver Support:

- Develop clear mechanisms for the involvement of persons with dementia and family caregivers in system wide-planning;
- Ensure First Link and Adult Day Programs are equitably accessed throughout Champlain, including North Grenville /North Lanark.

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 Program 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 assessment services. Consideration should be given to preserve and protect service levels in light of the critical role of dementia assessment and intervention.

System Integration:

- Invest in further implementation planning and designate a LHIN staff lead for dementia
- 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.

A Project Lead was hired at the end of October 2013. This report summarises the achievements that were supported between then and March 31, 2014, aligned with four of the six strategies of the strategic framework. It reflects the efforts of the entire Champlain Dementia Steering Committee and its community partners, through a combination of new and existing resources.



Program Implementation:

System Integration (Governance & Shared Decision-making):

The Champlain Dementia Network was first established in 2005 to promote collaboration in service delivery, education, research and policy development. As the first dementia network in Ontario, it had a strong record of achievement including the development of new models of support, such as First Link, a physician education program, and a variety of dynamic educational resources including a web site.

Terms of Reference: A retreat, facilitated by Health Quality Ontario representatives, was convened in October 2013 to explore how the mandate and governance might need to evolve to reflect its broadened scope as an emerging 'integrated service delivery network'. A revised Terms of Reference and membership for the new Champlain Dementia Network Steering Committee was drafted and used as the basis of recruiting new membership. The newly recruited members, including 3 caregiver representatives, refined and approved their new Terms of Reference (Appendix 2) in December 2013. To ensure overall coordination of dementia planning within the seniors planning framework of Champlain, the Steering Committee was situated as a sub-committee of the Regional Geriatric Advisory Committee.

LHIN Liaison: The Champlain LHIN identified a representative to serve as liaison between the LHIN and to promote linkages with other chronic disease management initiatives supported through the LHIN.

Participation Agreements: In order to facilitate the development of administrative and clinical best practices implied in the Champlain Model of Dementia Care, participation agreements were negotiated to reflect members shared commitment to the development of the model, and signed by organisational leaders who were able to commit their respective agencies to support the implementation of the model as proposed. A number of regional networks were consulted and shared examples of their respective agreements. These ranged from provincial groups such as the Ontario Renal Network and the Better Outcomes Registry and Network to the Champlain Complex Care Program, the Child and Youth Network of Eastern Ontario, and numerous others. Additionally, previous work on the development of an Integration Toolkit, adapted from the work of Dr. Marcus Hollander was reviewed to identify key integrating functions to be considered by the Steering Committee. Seven elements were incorporated into the Participation agreements signed by all members of the Champlain Dementia Steering Committee. It was acknowledged however, that such commitments should be sensitive to the different roles of members. As a result, three types of Participation agreements were finalised:

- 1) **Statement of Relationship with the Champlain LHIN**, committing to support the principles and strategic framework of the model and seek the advice of the Steering Committee for all dementia and related services. (Appendix 4)

- 2) **Agency Members** reflecting their shared commitment on all seven elements. (Appendix 2)
 - Our Vision*
 - Our Purpose*
 - Our Principles*
 - Resource Development*
 - Quality & Performance Improvement*
 - Consumer Engagement, and*
 - Operational Changes.*

It should be noted that the Steering Committee became particularly energised at the potential to use quality improvement initiatives to leverage system level change.

Overall, it is felt that Steering Committee members have formalised substantive commitments to each other and the region, towards supporting the development of an integrated service delivery system for dementia care and support.

Early Detection & Diagnosis

Given that as many as 64% of people with dementia are not assessed early enough to take full advantage of treatment, management and caregiver support, the engagement with, and development of increased capacity for dementia screening and assessment was seen as fundamental to the implementation of the model from its earliest inception. Primary Care engagement sessions, focused on the development of Primary Care Memory Clinics², were convened as early as January 2013 as part of the initial planning for the model.

The additional LHIN funding approved in October 2013, will be devoted to training and educating 15 Family Health Teams across the region to implement their own Primary Care Memory Clinics. To date 5 teams have been trained, and will be expected to adopt the new model by May 2014, with 10 more are planned for later in 2014.

Several other models of primary care assessment are being tested and evaluated, in order to respond to the varied needs of primary care practice models across the region. A Geriatric Outreach Assessment Clinics, has been tested in two practices to date, and will be extended to several others during the remainder of the year. Additionally, as part of an

² 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

interprovincial research initiative headed by Dr. Howard Bergman, a model of nurse-led dementia clinics will also be evaluated.

However, the complexity of dementia will continue to require family physician have ready access to specialty clinics and assessments to support them in their care and treatment of people with dementia, as well as their caregivers. An operational review of the former memory Disorder Clinic at Bruyere continuing care was undertaken last year. Subsequent to this review, the range of specialties has expanded to include to geriatricians, and together with existing personnel, the wait list for specialised dementia assessment at the clinic were reduced from 9 to three months this year. The clinic is being re-named the Bruyere Memory Program to reflect both the more interdisciplinary nature of the new service, as well as their intent to extend outreach capacity in the region.

It is expected that the continued efforts of the Physician Education Working Group will support changes in practice, in addition to the above program interventions.

Self-Management & Caregiver Support:

People with dementia and their caregivers have consistently identified the lack of communication and input into what is being offered in terms of education, care and support, as a major barrier to their being able to 'live well' with dementia. Additionally, there is a growing body of research, over the past 50 years, which recognises the need for health consumer involvement to improve service delivery, the quality of the patient experience, and outcomes³. A provincial planning framework for people with dementia and their partners in care also promoted a relationship-based approach to planning, and embedded three pillars fundamental to effective consumer engagement⁴:

- Promoting an informed society;
- Creating enabling and supportive environments; and
- Sustaining personal, social, and system connectedness.

Exploration of consumer and caregiver engagement has therefore been a major focus of the early stages of implementation planning for the Champlain Dementia Model of Care. A targeted review of the literature on health consumer engagement was conducted. Thirteen studies, including a number of meta-analyses were reviewed. Five dealt with the broad spectrum of health consumer involvement, four were dementia specific, and four were related to other chronic conditions. These have been added to the project bibliography, and are highlighted in this report for ease of reference.

*"We have observed that in a growing number of instances where truly **stunning levels of improvement** have been achieved, organizations have asked patients and families to be directly involved in the process. And those organizations' leaders often cite this change—putting patients in a position of **real power and influence**, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history." (AHRQ, 2012)*

³ *Consumer and Community Engagement: A review of the literature, Australian Institute of Health Information, University of New South Wales, 2012*

⁴ *An ADRD Planning Framework, 1st Edition, Alzheimer Strategy Transition Project, Alzheimer Society of Ontario, September 2006*



Evidence-based Outcomes

A select summary of the range of engagements strategies and evidence-based outcomes⁵ is provided below to inform the potential scope of dementia consumer strategies to be considered by the Steering Committee as it moves forward.

Level of Engagement	Type of Engagement	Population	Evidence-based outcomes
Individual Care	Pt. access to EMR (Howard Univ. Hospital)	Diabetes	↓ A1C
	Pt. Training (Ryhov Hospital- Sweden)	Dialysis	↓ Infection rates ↓ side effects
	Peer Support ((Maticka-Tyndale 2010)	HIV	↑ Knowledge and behaviour
	Peer Support (Lassi, 2011)	Maternity	↓ morbidity
	Pt. Decision-Aid (O'Connor,2011)		↑ communication ↓ length of consultation
Care Team	Pt. advisors (Emory Health care AHA)	Nursing protocols/ staff education	↑ satisfaction ↑ pressure ulcers ↑ falls
	Pt. centred primary care (Geisinger Health System)		↑ access, care ↓ costs
Organisation	Pt. family advisors (Georgia Health Sciences)	Pt. safety / service design	↑ satisfaction ↓ medical errors
	\$ incentives (Saint Elizabeth,Bellin,& Sentara HC)	Staff	↑ Health ↓ Costs
Community / System	Pt. education / nursing protocols (Griffin Hospital)	Nursing home & community care	↓ readmissions
	Pt. education / nursing protocols (Cambridge Health Alliance)	Youth /Asthma	↓ Hospital admissions (45%) ↓ ER Visits (50%) ROI: \$4/\$1

Internationally, Canada, through the Patient Decision Aids Research Group here in Ottawa, has been recognised for its leadership in developing tools to integrate knowledge transfer into the shared decision-making process between patients and providers. At the level of individual care this is seen as having tremendous potential to shift the balance of power that is perceived between patients and professionals.

Lessons Learned:

While there is a longstanding, and growing body of evidence on the benefits of actively engaged consumers at all levels of decision-making, from individual care to system-level planning, it should be recognised that, similar to other research in seniors' health and home and community care, caution must be exercised in considering how to adapt interventions from one community or population to another. A summary of some key findings are presented below for consideration by the Steering Committee.

⁵ American Hospital; Association. (2013). *Engaging Health Care Users: A Framework for Healthy Individuals and Communities*, Chicago, 2012 Committee on Research



- ❑ Principles are strong, evidence is mixed, and primarily supports local, context-specific interventions⁶.
- ❑ It should not be assumed older adults prefer to participateindividual variations should be assessed⁷.
- ❑ Some engagement strategies risk marginalising vulnerable populations, suggesting the need to use a variety of approaches⁸.
- ❑ Presents challenges to the methods of communicating and consulting with Persons with Dementia⁹.

Dementia Consumer Engagement:

Given the need for a diversity of approaches, a range of techniques for engaging persons with dementia have been adopted across a number of jurisdictions, in an effort to be sensitive to the varied interests and capacities of persons with dementia and their caregivers, while recognizing that they have important things to say, when enabled. These may include:

- ❑ **Dementia Literacy: The By Us For Us© Guides (BUFU guides)** developed through the Murray Alzheimer Research and Evaluation Program, are a series of information guides that they are created **by** persons with dementia and/or partners in care, **for** persons with dementia and/or partners in care.
- ❑ **Advisory Board of People with Early Dementia:** The Alzheimer's Association USA has established a National Advisory Board comprised of representatives nominated by their respective chapters. Nominations are for a one-year term and their roles include media liaison, advocacy and project review. A number of local chapters have also convened conferences organised for and by people with dementia as a means to strengthen the dialogue between people with dementia and other advocates.
- ❑ **Town Hall Meetings:** All local chapters in the United States also organise publicly advertised town hall meetings. The purpose of the meetings is to invite people with dementia to share their opinions about how they can improve care and support. Attention is given to presenting questions in plain language, and cover a broad scope from participation in research to changing relationships¹⁰.

⁶ *Consumer and Community Engagement: A review of the literature*, Australian Institute of Health Information, University of New South Wales, 2012

⁷ Lyttle, D.J. and A. Ryan, *Factors influencing older patients' participation in care: a review of the literature*. *International journal of older people nursing*, 2010. 5(4): p. 274-82

⁸ NHHRC 2009. *Consumer Peak Bodies Position Paper: National Health and Hospitals Reform Commission Final Report*, available <https://www.chf.org.au/pdfs/pos/pos-549-nhhrc-joint-pos-paper.pdf>

⁹ Bryan, K and Lorentzon, M (2007) *Respect for the person with dementia: fostering greater user involvement in service planning*. *Quality in Ageing - Policy, practice and research*, 8 (1). 23 - 29

¹⁰ Doyle C, *Consumer Involvement in Dementia Care Research, Policy and Program Evaluation*, Australian Institute for Primary Care, 2008.



- ❑ **Care Services Improvement Project:** An approach to involving people with dementia and their caregivers in service development and evaluation was developed as an element of the national dementia strategy in the UK in 2007. An effective, but informal approach which has been used in some jurisdictions, is through **Dementia Cafes**, using structured questions, similar to the Town Hall meetings in the United States, but in a less structured format at local cafes.

Principle of Dementia Consumer Engagement

The review of evidence in consumer engagement culminated in Champlain Dementia Steering Committee unanimously approving the following statement of principle and four policies on dementia consumer engagement in February 2014. These are expected to influence and guide the work of the Steering Committee and their partners in involving people with dementia and their partners in care, throughout the implementation process. A commitment to support and adopt this principle has been integrated into the Participation Agreements signed by each member.

1.0 Principle:

'The individual with dementia and his or her partners in care¹ are in a unique position to reflect on the effectiveness and value of services and policies developed to meet their needs.

They must be seen as crucial partners actively involved alongside service providers in the planning, policy development, delivery and evaluation of programs and policies that are intended for their benefit.'

Policies:

- 1.1 Current and / or experienced partners in care will be directly represented as members of the Steering Committee
- 1.2 Given that decision-making capacity in the person with dementia may influence their role in evaluations and decisions about their care, a range of communication strategies, including the involvement of caregivers as partners in care, should be considered to determine their needs and preferences for service.
- 1.3 Caregivers of people with dementia should be defined as clients who are entitled to receive services in their own right.
- 1.4 A range of communication mechanisms will be adopted to engage people with dementia and their partners in care in organisational decision-making, in order to reflect the diversity of needs and preferences of people with dementia and their caregivers

¹ Defined to include both family and friends in dementia caregiver roles.

Public Awareness & Education:

Improved awareness and community support for people with dementia and their caregivers is an important outcome which the Champlain Model of Dementia Care is working towards. Consequently the Steering Committee addressed three important elements of their work in this area.

Re-Alignment of Physician Education Work Group:

There was a need to re-consider the support and alignment of the Physician Work Group established previously under the Champlain Dementia Network. A collaborative effort was undertaken and resulted in the re-alignment of the work group under the auspices of the Primary Care Working Group of the Regional Geriatric Advisory Committee, to promote a more coordinated approach to primary care. Additionally, scheduling and linkages with First Link will be maintained by the Alzheimer Society, with administrative support provided through Geriatric Psychiatry Community Services of Ottawa. It should be noted that the physician education newsletter, developed initially in Champlain, is now distributed provincially.

Web-site

One of the major accomplishment of the Champlain Dementia Network, in its earlier form, had been the development of a comprehensive educational and referral resource integrated into their web-site. As a reflection of the broader information and referral role of the Champlain Health line hosted by the Champlain Community Care Access Centre, and to address the need for sustainability of on-line resources, dementia resources used for education and referral, are in the process of being integrated into the Champlain Health Line. This work has been completed, and is consistent with approaches for other chronic diseases such as diabetes.

Public Awareness Strategy

The Champlain LHIN provided annualised funding to develop a three year Public Awareness Strategy under the auspices of the Steering Committee. A marketing firm has been retained and they have undertaken preliminary consultations with people with dementia (25) across the region, family caregivers and key informant experts. Although the strategy is still under development, the Steering Committee has prioritised the general public and providers as the primary target audiences at this point.

Key messages for the general public, which have been proposed include:

- Year 1: Strategies to promote brain health
- Year 2: Know the warning signs, and
- Year 3: Creating dementia friendly communities.

Full details of the plan will be finalised this spring, and are expected to include a comprehensive, multi-media marketing campaign.



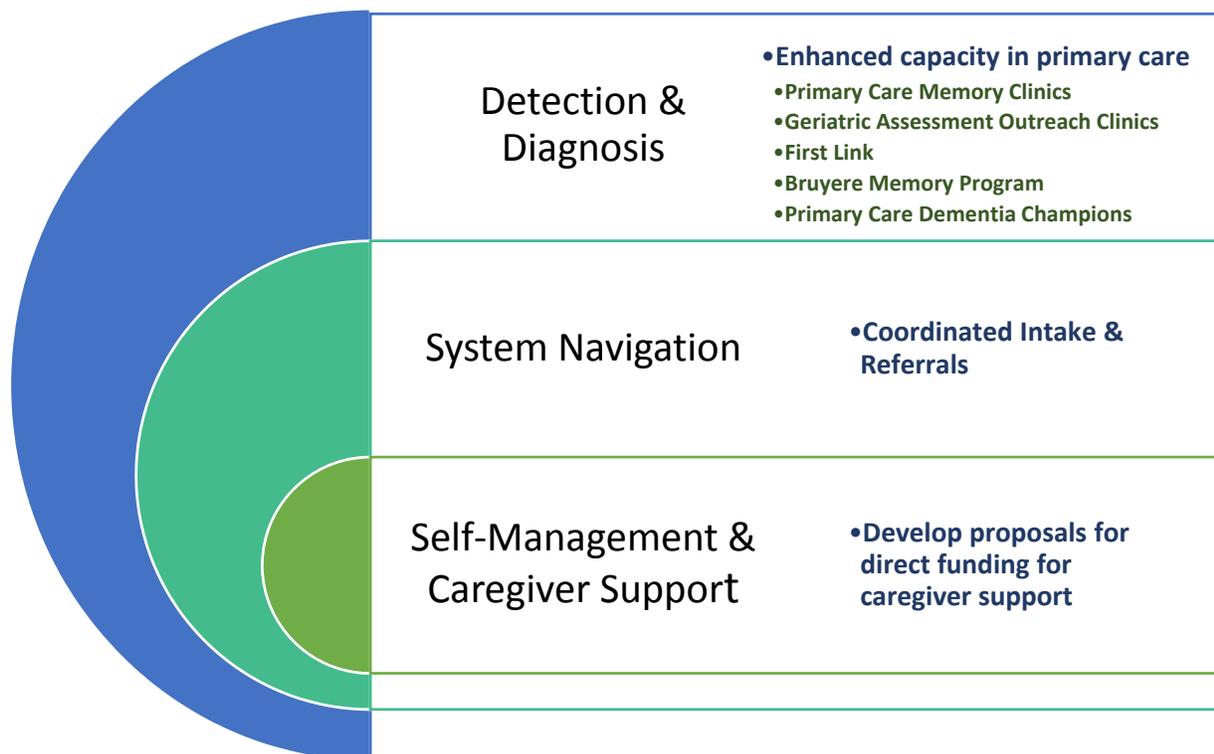
Implementation Priorities 2014/15:

34 activities aligned with the six strategies were identified and prioritised as part of the initial consultations on the Champlain Dementia Model of Care. These priorities, as summarised in this report, were used to guide the initial development of the Steering committee in its first five months from November 2013 to March 2014.

The Steering Committee undertook a further prioritisation in April 2014, to guide its work for the following year. The same activities identified by the community were considered. Members were asked to consider three criteria in identifying their respective priorities:

- Impact on strategic outcomes*
- Timeliness in relation to other opportunities, pre-requisites etc.*
- Feasibility (can be accomplished within available resources and timelines).*

Members individually 'scored' their priorities and the results were discussed and compiled. The following were identified as the most important priorities by the Steering Committee:



Additionally, members identified five other priorities to be considered in the development of their work plan:

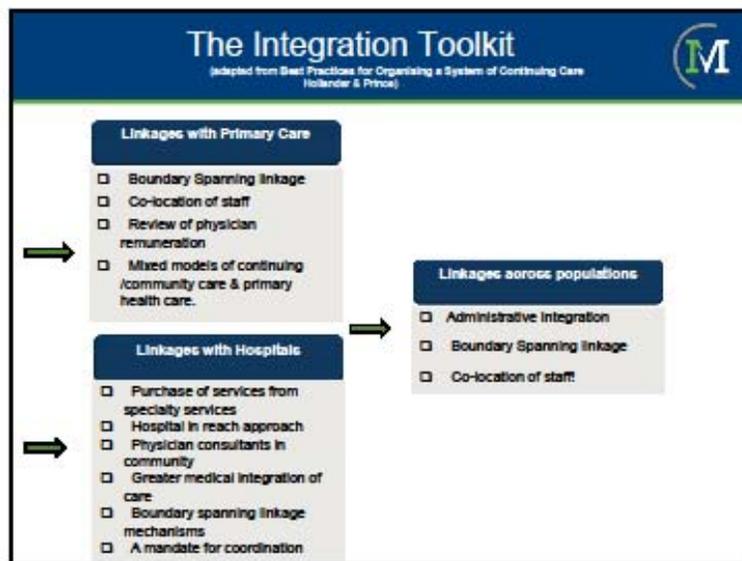
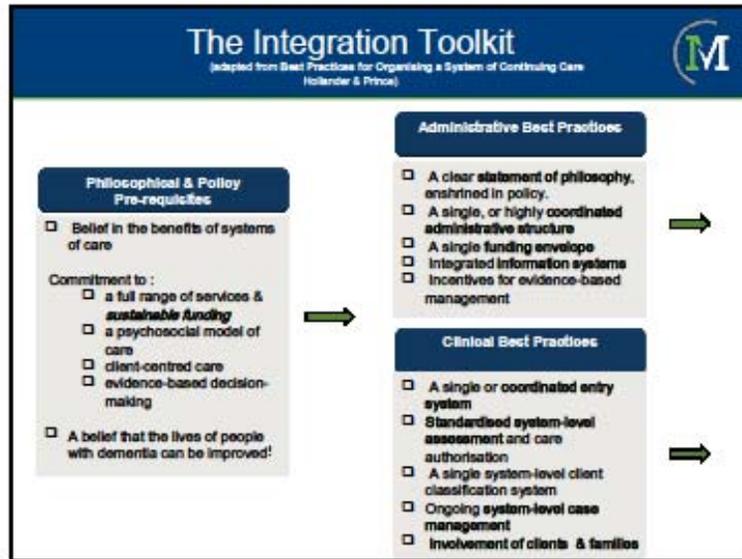
- Supports for People with Dementia in Retirement Homes*
- System-wide case management*
- Integrated web-repository*
- Partner with other chronic disease networks*
- Protect and enhance the role of rural Geriatric Assessors.*

Proposed Workplan: 2014/15

The following work plan priorities, integrating those identified by the Steering Committee during the priority-setting exercise, as well as those they had adopted previously, is proposed for consideration:

Strategy	Outcome	Activity	Organisational Lead
Detection & Diagnosis	<i>Earlier detection & diagnosis</i>	Enhanced capacity in primary care <ul style="list-style-type: none"> ▪ <i>Primary Care Memory Clinics</i> ▪ <i>Geriatric Assessment Outreach Clinics</i> ▪ <i>First Link</i> ▪ <i>Bruyere Memory Program</i> ▪ <i>Primary Care Dementia Champions</i> ▪ <i>Promote dementia care as an element of the regional Health Links strategy.</i> ▪ <i>Review funding mechanisms to protect access to speciality dementia assessment services in hospitals.</i> 	RGPEO ASORC Bruyere RGAC / CLHIN CLHIN
System Navigation	<i>Persons with dementia and their caregivers know what to expect and where to find it.</i>	<ul style="list-style-type: none"> ▪ <i>Continue and assess partnership with Champlain health line.</i> ▪ <i>Review & assess alternative approaches to intake & referral for existing regional services and recommend options for dementia services</i> 	ASORC Project Mgr + All
Self-Management & Caregiver Support	<i>Promotion of activities and attitudes to 'live well' with dementia</i>	<ul style="list-style-type: none"> ▪ <i>Review and assess current direct funding programs in Champlain and make recommendations for investment to the Champlain LHIN.</i> ▪ <i>Promote uptake and adoption of principles of consumer engagement amongst partners through dementia consumer experts.</i> 	Project Mgr + Caregivers All
System Integration	<i>Enable a system of supports that is tailored and targeted to their changing needs</i>	<ul style="list-style-type: none"> ▪ <i>Develop system-wide program management and quality reporting mechanisms, beginning with volumes and access (wait list, wait times).</i> ▪ <i>Review and determine appropriate models of system-wide case/care management for people with dementia.</i> ▪ <i>Ensure all new funding requests for dementia and related services are reviewed by the Steering Committee.</i> 	Project Mgr + All Project Mgr + CCAC CLHIN
Coordinated Pathways of support	<i>Prevent and manage the complications of dementia by providing choices that matter</i>	<ul style="list-style-type: none"> ▪ <i>Partner with other chronic disease networks, such as CHF, COPD, and Diabetes, including seniors' mental health, BSO and the Champlain BSS.</i> ▪ <i>Protect and enhance the role of rural geriatric assessors in dementia services.</i> 	TBD CCAC
Public Awareness & Education	<i>Improved awareness and community support</i>	<ul style="list-style-type: none"> ▪ <i>Develop and implement a multi-year public awareness campaign</i> ▪ <i>Coordinate access to dementia education and information.</i> ▪ <i>Continue the physician education program aligned with activities in primary care.</i> 	ASORC ASORC GPCSO + ASORC + RGAC

Appendix 1 – The “Integration Toolkit”



Appendix 2: Terms of Reference

Role	To inform the Regional Geriatric Advisory Committee and provide the leadership and support required to implement an Integrated Model of Dementia Care for Champlain that will ensure <i>a system of support that is tailored & targeted to the changing needs of persons with dementia and their families.</i>
Responsibilities	<ul style="list-style-type: none"><input type="checkbox"/> <i>Provide direction and support to the project manager on the planning and development of the Integrated Model of Dementia Care.</i><input type="checkbox"/> <i>Develop an annual work plan aligned with funding agreements with the Champlain LHIN.</i><input type="checkbox"/> <i>To ensure the perspective of persons with dementia and their families are specifically recognised within the governance structure and mechanisms.</i><input type="checkbox"/> <i>Conduct community consultation and engagement to define the future direction of the Integrated Model of Dementia Care.</i><input type="checkbox"/> <i>Communicate actively with stakeholders and the public through mechanisms such as the Annual Dementia Forum.</i><input type="checkbox"/> <i>Make recommendations regarding new investments within the designated funding envelope.</i><input type="checkbox"/> <i>Support the development of, and make recommendations regarding the adoption of evidence-based practices in dementia care across IMDC organisations.</i><input type="checkbox"/> <i>Evaluate the effectiveness of governance structures, processes and recommend changes as required.</i>

Membership and Voting 12-15 members representative of senior clinical and administrative leaders of organisations involved with dementia care across the region, persons with dementia and their family caregivers, community leaders.

- Dr. Carrier / Nicole Robert (Community Geriatric Psychiatry)
- Kathy Wright (ASORC)
- Frank Knoefel (Bruyere Memory Clinic)
- Akos Hoffer (PRVHC)
- Andrew Wiens (BSO)
- Rose Ann Hoffenburg (Caregiver)
- Gweneth Gowanlock (Caregiver)
- Eleanor Ryan (LTC Family Councils)
- Shelley Vaillancourt (Eastern Counties)
- Bonny Johnson (Renfrew County)
- Frank Molnar (Geriatric Medicine)
- Kelly Milne (RGP)
- Cristina DiTomaso (CSS)
- Kim Peterson (CCAC)
- Linda Garcia (Research)
- Christine Gagne-Rodger (CLHIN)

Non-voting member:
• *Project Manager.*

Chair
Interim Co-Chairs: Kathy Wright, Akos Hoffer

Chairpersons will be confirmed by the Regional Geriatric Advisory Committee and will be deemed members of the RGAC Executive Committee.

Frequency of Meetings and Manner of Call
Monthly to at least 10 times a year.

Term
Up to three years or until final scope of governance is agreed upon.

Approved: December 6 2013.



Appendix 3: Participation Agreements

The Champlain Dementia Network Steering Committee of the Regional Geriatric Advisory Committee and The Regional Geriatric Program of Eastern Ontario

formally acknowledge their shared commitment to develop a system of care and support that is tailored & targeted to the changing needs of people with dementia and their caregivers, and that is founded on the following **shared 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 collaboration, accountability, and continuously improving quality*

We endorse the **principle of consumer engagement** adopted by the network, and will work towards implementing the policies on caregiver engagement, as appropriate.

Any and all **new requests for funding** for dementia care and support will be brought to the Steering Committee for transparency and ideas for collaboration.

We will work towards developing a system-wide approach to **quality and performance improvement**, including shared reporting, and collaborating in the development of appropriate system-wide decision-support tools and processes.

Any upcoming **operational changes** that may affect access to, or the nature of dementia services in our organisation, will be shared with the Steering Committee.

We embrace our **shared vision** of striving to “*Being the best...for persons with dementia, their families, our health system, and society*” and the strategic framework around which the Champlain Model of Dementia Care is founded.

Appendix 4: Statement of Relationship

The Champlain Dementia Network Steering Committee of the Regional Geriatric Advisory Committee and the Champlain Local Health Integration Network

formally acknowledge their shared commitment to develop a system of care and support that is tailored & targeted to the changing needs of people with dementia and their caregivers, and that is founded on the following *shared 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 collaboration, accountability, and continuously improving quality*

We endorse the **Principle of Consumer Engagement** adopted by the Steering Committee, and will work towards integrating the policies on caregiver engagement as appropriate.

The Champlain LHIN will seek input and advice from the Steering Committee on **requests for funding** from health service providers for dementia related health services.

Déclaration de relation

Le Comité directeur du Réseau de la démence de la région de Champlain (RDRC) du Conseil consultatif régional gériatrique et le Réseau local d'intégration des services de santé de Champlain

reconnaissent officiellement leur engagement partagé au développement d'un système de soins et d'appui qui est personnalisé et ciblé en fonction des besoins changeants des personnes atteintes de démence et de leurs soignants, et qui est fondé sur les *principes partagés* suivants :

- ❖ *Les personnes atteintes de démence et leurs soignants sont valorisés, respectés et appuyés en ce qui a trait à leur droit de faire des choix éclairés qui leur sont importants.*
- ❖ *Le rôle important des soignants et les conséquences de leur engagement doit être reconnu et appuyé.*
- ❖ *Il faut tenir compte de la langue maternelle d'une personne lorsqu'on l'évalue et pose un diagnostic de démence.*
- ❖ *Les personnes atteintes de démence et leurs soignants recevront des services intégrés et coordonnés qui répondent à leurs besoins sociaux et culturels et qui tiennent compte de leur situation financière et de leur emplacement.*
- ❖ *Une vaste gamme de services relatifs à la démence devrait être offerte dans les deux langues officielles.*
- ❖ *Une main-d'œuvre bien formée est essentielle afin d'assurer la prestation de soins de qualité.*
- ❖ *Les communautés jouent un rôle important dans la qualité de la vie et la résilience des personnes atteintes de démence et celles de leurs soignants.*
- ❖ *Une culture organisationnelle se distinguant par sa capacité à donner des moyens d'agir aux personnes, à assurer la collaboration et la responsabilisation et à améliorer la qualité de façon continue.*

Nous appuyons le **principe de mobilisation des consommateurs** adopté par le RDRC, et travaillerons à intégrer les politiques relatives à la mobilisation des soignants comme il convient.

Le RLISS de Champlain obtiendra les commentaires et les conseils du Comité directeur du RDRC relativement aux demandes de financement pour des services de santé relatifs à la démence reçues de fournisseurs de services de santé.



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