Cognitive Health Initiative for Francophone Seniors in the GTA

Options for Service Models

January 2017

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Introduction

As Canada's population ages, it is becoming increasingly important to ensure services are in place to support healthy aging, for those whose cognitive health is diminishing, and for their families and caregivers – for the population as a whole and for Francophones, a population whose unique characteristics and needs must be considered in any plan to improve dementia services. The matter is all the more urgent as the Alzheimer Society of Canada[1] estimates that the incidence of dementia will increase at a faster rate than the population ages. According to Alzheimer Society estimates, by 2038 some 1.1 million Canadians (or 2.8% of the total population) are expected to have some form of dementia, compared with 1.5% in 2008. Unless action is taken proactively, the increase in the number of people with dementia will have a serious impact not only on the health care system but on families, caregivers and communities as well as on the economy and society as a whole.

What is dementia

Dementia refers to a class of disorders characterized by the progressive deterioration of thinking ability and memory as the brain becomes damaged. Although some dementias are reversible, the focus in this report is on irreversible dementias that are associated with progressive neuro-degenerative diseases including Alzheimer's disease and vascular dementia (the two most common) along with other dementias such as frontotemporal dementia, Lewy body dementia and Creutzfeldt-Jakob disease.

Symptoms commonly include loss of short-term and long-term memory, judgment and reasoning along with changes in mood, behaviour and the ability to communicate (including reversion to mother tongue). These symptoms affect a person's ability to function at work, in social relationships and in the activities of daily living[2].

People with dementia require increasing levels of care and support as their disease progresses, care and support most often provided by family and other informal caregivers, with additional help from community care agencies, but also relying on institutional options such as long-term care. Frequently, people with dementia also suffer from other chronic illnesses like diabetes, heart disease and COPD. Overall, dementia places a long-term progressive emotional, psychological and financial burden on those who care for people with dementia as well as on health service providers, the health care system

[1] Alzheimer Society of Canada. *Rising Tide: The Impact of Dementia on Canadian Society*, 2010.

[2] Activities of daily living (ADLs) include basic self-care tasks, akin to the kinds of skills that people usually learn in early childhood, like feeding, toileting, selecting proper attire, grooming, maintaining continence, putting on clothes, bathing, walking and transferring (such as moving from bed to wheelchair) as well as instrumental activities of daily living (IADLs), more complex skills needed to successfully live independently. These skills are usually learned during the teenage years and include the following: managing finances, handling transportation (driving or navigating public transit), shopping, preparing meals, using the telephone and other communication devices, managing medications, housework and basic home maintenance. Together, ADLs and IADLs represent the skills that people usually need to be able to manage in order to live as independent adults. (Source: https://www.caring.com/articles/activities-of-daily-living-what-are-adls-and-iadls, retrieved on 2016-08-29)

and society in general[3]. Indeed, as one family physician phrased it, "When I have a patient with dementia, I have not one patient but two, the individual concerned and his/her caregiver".

Dementia and Francophones: Rationale for initiative

Like the general population, the Francophone population is aging and at a faster rate than the population as a whole. While the median age for the Ontario population is 40.1 years, it is 44 for Francophones, and the largest age categories among Francophones are 45-54 and 65 and over: almost one out of five Francophones is included in these age groups. Although the population of the Central Region, including the Greater Toronto Area (GTA), is somewhat younger, the median age of Francophones is still higher than that of the Central Region population as a whole (41.1 vs 39.4)[4]. Yet services for people with cognitive disorders and their families and caregivers are fragmented and do not necessarily meet their needs or the demand for service. The situation for those seeking services in French is even worse.

Language and culture are key factors in providing quality, safe care. Language barriers constitute a major obstacle for people with dementia and their caregivers and families. Many Francophones lose their second language and revert to their mother tongue as they age, particularly when they are under stress; this is especially true for people coping with dementia.

It is essential that Francophones with dementia and their caregivers have equitable access to a continuum of culturally sensitive quality care in French at every stage of the dementia journey.

To meet the growing needs of the GTA's aging Francophone population, the two French language health planning entities, Reflet Salvéo and Entité 4, have partnered on a feasibility study on cognitive health together with the five GTA LHINs (Central West, Mississauga Halton, Toronto Central, Central and Central East), Centres d'Accueil Héritage (CAH) and the Glendon Centre for Cognitive Health. The purpose of the study is to develop options for service models for memory services, including a memory clinic, focussing on very early detection and intervention for mild cognitive impairment but also addressing the need for referrals and supports for those farther along on the dementia journey, and their caregivers. The initiative will build on work previously done on memory centre services in French and on initiatives developed and implemented in the five GTA LHINs. The models proposed will align with LHIN and provincial strategic priorities for dementia and services for seniors and focus on helping people experiencing cognitive decline to remain active participants in their communities for as long as possible.

Methodology

The first step was a brief analysis of a previous literature review along with a number of studies, reports and plans dealing with the impact of dementia and current service models as well as provincial and LHIN

[3] Alzheimer Society of Canada, op. cit.

[4] Source: Office of Francophone Affairs, http://www.ofa.gov.on.ca.3pdns.korax.net/en/franco-stats.html. Retrieved on 2016-09-12.

strategic priorities and initiatives for the next several years. Research was also conducted into the availability of services for people with dementia and their caregivers both overall and in French.

The next steps involved gaining an overview of existing models and opportunities. As a second stage, interviews were held with LHIN representatives to develop a picture of LHIN priorities and approaches to dementia services in a context of profound system transformation affecting home and community care, primary care and putting the focus on patients, including seniors.

Subsequently, following development of a discussion guide, interviews were conducted with health service providers, both those serving the population as a whole and those identified to provide services in French, to:

- learn more about their approach and vision;
- learn more about their programs and services for both patients and their caregivers/families along the continuum from healthy aging memories to mild cognitive impairment/memory loss to more advanced stages of dementia;
- explore how they can help the Francophone community, including their capacity to provide dementia services in French; and
- explore potential synergies.

Another important step was seeking the voice of the Francophone community through a mixture of focus groups and online surveys to:

- learn from their experience;
- gather their ideas on how to improve services; and
- examine their needs and priorities.

Once options are developed, we will go back to providers and the community to seek their input and validate our recommendations.

Work on the project as a whole was overseen and supported by a steering committee that included representatives of the two French language health planning entities and the five GTA LHINs as well as the Glendon Centre for Cognitive Health and Centres d'Accueil Héritage (CAH). A complete list of steering committee members may be found in Appendix A.

Background

Provincial Context: Transforming the Health Care System

Patients First

The Ontario health system is undergoing a profound transformation that will have an impact on all aspects of health care including primary and specialist care as well as home and community care. In 2015, the Ministry of Health and Long-Term Care released *Patients First: Action Plan for Health Care.* This plan focused on four key objectives:

- to improve access to the right care, including more comprehensive **support for seniors** and improved **dementia supports**;
- to connect services and deliver more coordinated and integrated care in the community with an **enhanced focus on seniors and chronic disease management** as well as transformation of home and community care;
- to inform and support people by providing the education and information needed for informed decision-making, and maintaining the emphasis on health promotion and illness prevention; and
- to protect the health care system by ensuring its sustainability and improving its performance in the context of an aging population with increasingly complex needs.[5]

Published in May 2015, *Patients First: A Roadmap to Strengthen Home and Community Care* represented a first step in giving concrete form to the objectives set out in the action plan. Proposed actions include:

- creating a levels of care framework to ensure consistent services and assessments across the province;
- increased funding for home and community care;
- implementing a bundled care approach, in which a group of providers will be given a single payment to cover all the needs of an individual patient;
- self-directed care; and
- expanded caregiver supports along with greater choice in palliative and end-of-life care and capacity planning that will include standards for access and quality.[6]

> ***"Franco-Ontarians face challenges obtaining health services in French. To meet their needs, and improve their patient experience and health outcomes, we must ensure that the health care system is culturally sensitive and readily accessible in French."***
>
> *Patients First Discussion Paper*, December 2015

To further its work and seek input from providers, users and care partners, the Ministry of Health and Long-Term Care issued discussion papers, including the *Patients First Discussion Paper: A Proposal to Strengthen Patient-Centred Health Care in Ontario* in December 2015, the *Levels of Care Framework: Discussion Paper* in July 2016 and *Developing Ontario's Dementia Strategy: A Discussion Paper* in September 2016.

In the *Patients First Discussion Paper*, the focus is on ways to improve access to consistent, accountable and integrated primary care and home and community care; population health; and public health services. Major concerns include **improving health equity and reducing health disparities** for diverse groups, such as seniors, people with disabilities, Indigenous peoples, **Franco-Ontarians**, members of cultural groups (especially newcomers), and people with mental health and addiction challenges as well

[5] Ministry of Health and Long-Term Care. *Patients First: Action Plan for Health Care*. Toronto, February 2015.
[6] Ministry of Health and Long-Term Care. *Patients First: A Roadmap to Strengthen Home and Community Care*. Toronto, May 2015.

as highlighting the importance of the social determinants of health, such as income level and geography.[7]

Some groups, including Francophones, face special challenges in accessing the health care system. As the paper points out, "Franco-Ontarians face challenges obtaining health services in French. To meet their needs, and improve their patient experience and health outcomes, **we must ensure that the health care system is culturally sensitive and readily accessible in French**".

It will be up to the LHINs to understand the unique needs of these groups, including Francophones, and provide accessible, culturally appropriate services.

The Ministry's proposal to reduce gaps and strengthen patient-centred care has four components:

- more effective integration of services and greater equity,
- timely access to primary care, and seamless links between primary care and other services,
- more consistent and accessible home and community care, and
- stronger links between population and public health and other health services.

The Patients First Act:

Highlights the importance of providing health services in French and considering French language services in planning.

Recognizes the importance of French language services to Ontarians and emphasizes LHINs' responsibility for promoting health equity and diversity, including respect for the diversity of French-speaking communities.

Ensures that LHIN planning includes priorities and directions that foster health services according to the French Language Services Act

A major proposed shift in system management is the transfer of accountability for the planning and performance of primary care and delivery of home and community care services to the LHINs.

The paper included a number of other propositions and provided more detailed information on expansion of the LHINs' mandate in relation to planning and performance of all health services, including primary care, management and delivery of home and community care, and development of linkages with public health. The focus on LHIN sub-regions as focal points for local planning and service management and delivery, the enhanced role of the primary care provider as the gateway to all other services, and a continued emphasis on improved home and community care as set out in the *Roadmap* will all have an impact on how people with dementia and their care partners will experience the health care system.

The proposals put forward by the Ministry in its series of *Patients First* documents came to legislative fruition with

[7] Ministry of Health and Long-Term Care. *Patients First Discussion Paper: A Proposal to Strengthen Patient-Centred Health Care in Ontario*. Toronto, December 2015.

the adoption of the *Patients First Act, 2016* in December. In addition to transferring Community Care Access Centres (CCACs) and the home and community care services they provide to the LHINs, the *Act* expanded the mandate of the LHINs along the lines proposed in the *Roadmap* and *Discussion Paper*. It also amended their objects to include promotion of **health equity** and reduction/elimination of health disparities and highlighted **respect for the requirements of the *French Language Services Act* in the planning, design, delivery and evaluation of health services**. It further added the requirement that LHINs include **priorities and directions that foster health services according to that *Act***. One of the 16 work streams set up to plan for successful implementation of *Patients First* is French language services, identified as a key issue[8]. This creates an opportunity for enhancing delivery of health services to Ontario's Francophones including the most vulnerable groups like people with dementia.

Levels of Care Framework

	Care Needs	Care Services	Dimensions
5	Very high	♦♦♦♦♦	Clients will be stratified across levels based on three dimensions: 1. **Functional capacity**: e.g. difficulties with activities of daily living; 2. **Clinical characteristics**: e.g. disease, condition, or cognition level; 3. **Social supports**: e.g. caregiver capacity and community supports
4	High	♦♦♦♦	
3	Moderate	♦♦♦	
2	Mild	♦♦	
1	Light	♦	
Supported Self-Management			

Levels of Care Framework

The policies developed in response to the July 2016 *Levels of Care Framework: Discussion Paper (Draft)*[9], with its four goals and five initiatives, will have a profound effect on the home and community supports available to people with dementia and their care partners. The goals are:

1. Patients First (services centred on the needs of the patient and his/her caregivers);
2. Equitable Care (similar needs will receive similar services all across the province);
3. High Quality Care (care based on best practices and evidence-informed care standards);
4. Confidence and Trust (building patient and caregiver confidence in the sector's ability to deliver high quality care).

These goals are to be realized through five initiatives that will include:

- a **levels of care framework** whereby services are allocated on the basis of patient needs;
- a **functional support tool** under which clients will be stratified into distinct levels from light to very high needs with a **care plan** to be developed on this basis;
- **home care quality standards** to be developed by Health Quality Ontario;
- a home and community **assessment policy** requiring the use of InterRAI assessment tools in development of a comprehensive care plan; and

[8] Ministry of Health and Long-Term Care, *The Patients First Act, 2016: Strengthening Patient-Centred Care in Ontario*, December 2016 (Technical Briefing), provided by TC LHIN.
[9] Ministry of Health and Long-Term Care, *Levels of Care Framework: Discussion Paper (Draft).* Toronto, July 2016.

- **home care performance indicators** to show how well the system is performing and to drive quality improvement.

These initiatives will give patients, including people with dementia, and their caregivers, a good idea of how their needs will be assessed and what they can expect in the way of services and supports. **Supported self-management** by patients and caregivers is an important component of this approach while communication among care coordinator, patient and caregivers, primary care provider and other social and health service providers will be one of its cornerstones.

Dementia Strategy

The final piece in the provincial puzzle is *Developing Ontario's Dementia Strategy: A Discussion Paper*, issued in September 2016. With its aim of creating supportive and inclusive communities for people living with dementia and their caregivers, the discussion paper recognizes the diversity of experience and needs, including the different types of dementia and the diversity of Ontario's population – indigenous peoples, **Francophones**, ethno-cultural groups and LGBTQ – and the challenges they face, as well as the variations in support service availability, including transportation, housing and health care[10]. Organized around six key themes:

- Supports for people with dementia,
- Accessing dementia services,
- Coordinated care,
- Supports for care partners,
- Well trained dementia work force, and
- Awareness, stigma and brain health,

the paper sets out the current situation and raises issues to consider as the province seeks to develop a comprehensive strategy to ensure that people living with dementia have the supports they need and are treated with dignity and respect, and that Ontario has a dementia capacity planning model in place that will allow for the development of multiple service delivery options, including innovative models of care.

> ***"Ontario's population is diverse – Indigenous peoples, Francophone populations, ethno-cultural groups and LGBTQ2S communities all face different challenges and have different needs for culturally-appropriate care."***
>
> *Ontario's Dementia Strategy: A Discussion Paper,* September 2015

Regional Context: Actualizing *Patients First* at the Local Level

Building on the priorities set out in *Patients First: Action Plan for Health Care*, the GTA's five LHINs – Central West, Mississauga Halton, Toronto Central, Central and Central East – developed integrated health services plans (IHSP) or strategic plans outlining how each LHIN will work toward achieving provincial objectives in a way that reflects local concerns and meets local needs. **All LHINs have identified two priority populations, Francophones and Indigenous people**, and, as stated in Central

[10] Ministry of Health and Long-Term Care. *Developing Ontario's Dementia Strategy: A Discussion Paper*. Toronto, September 2016.

LHIN's 2016-2019 IHSP, they are "**committed to improve access to equitable and accessible programs and services to both Aboriginal and Francophone residents**. This will support the improvement of quality, safe care while providing a better patient experience and reducing the impact of linguistic and cultural barriers on health system performance"[11]. They have further committed "to incorporate the directions of Quality, Equity, Sustainability and Integration into all of the IHSPs across the province"[12].

All LHINs have identified two priority populations, Francophones and Indigenous people … and* are *"committed to improve access to equitable and accessible programs and services to both Aboriginal and Francophone residents"

Improving the patient and caregiver experience is a recurring theme in all of the IHSPs and one that aligns well with the goals of this report. **All of the GTA LHINs identified as a priority, providing better care to seniors, including those with dementia and other complex conditions, and better supports for their care partners**. There is a consistent focus on:

- primary and home and community care;
- coordinated and integrated quality care; and
- population health in a context of offering **timely and equitable access to culturally appropriate care that meets patient and caregiver needs**;
- evaluating, planning and building system capacity to meet the increasingly complex needs of an aging and diverse population;
- ensuring the system is more effective and efficient by:
    - introducing innovative models of care,
    - promoting a greater role for patients and caregivers in care management,
    - changing funding models ("bundled care" or "basket of services") and
    - leveraging technology, as well as
    - encouraging partnerships both within the health system and with municipal and other external partners.

In addition, in line with the common thread of keeping people out of institutions to the greatest extent possible, whether in anticipation of the upcoming provincial dementia strategy or in response to emerging local needs, **many of the GTA LHINs highlighted improvement of services and supports for people living with dementia and their care partners so as to enable them to remain in the community as contributing members of society as long as possible; timely and easily navigated access to such services and supports; and appropriate long-term care when the time comes**.

[11] Central Local Health Integration Network. *Caring Communities, Healthier People Integrated Health Service Plan (IHSP4) for the Central Local Health Integration Network 2016-2019*. Aurora, April 2016.
[12] Ibid.

Age is the most significant and easily identifiable risk factor for dementia.

The Central East LHIN in particular has moved forward with development of an action plan for dementia services, an action plan that specifically addresses the needs of Francophones: diagnosis, assessment and support in French, including in-home support, culturally appropriate resources, education and communication and a data base of health service providers able to provide services in French.

The initiatives proposed here to improve services for Francophone seniors living with cognitive impairments and their care partners are well aligned with the focus in LHIN IHSPs on enhancing French language services, especially for seniors and other vulnerable groups, and the emphasis in the *Patients First Act* on health equity, reduction of health disparities and LHIN responsibility for improving French language services.

Appendix B provides an overview of the strategic directions, priorities and initiatives of the Central West, Mississauga Halton, Toronto Central, Central and Central East LHINs as set out in their IHSPs and strategic plans.

Dementia and its Impacts

Dementia is a group of conditions that affect the brain and cause problems with memory, thinking, speaking and carrying out one's normal daily activities. An individual suffering from dementia may exhibit changes in mood or behaviour that seem out of character. These problems get worse over time and interfere with a person's ability to live independently and maintain relationships[13]. The changes may come very slowly or quite quickly and, although most people with dementia are older adults, younger people can also be affected. Women are more likely than men to get dementia; they represent about 62% of dementia cases and around 70% of new Alzheimer's disease cases. They are also almost twice as likely to die from dementia and over twice as likely to be the informal caregivers of people with dementia[14].

Prevalence

Alzheimer's Disease, accounting for about 63% of cases, and vascular dementia are the most common forms of dementia[15] but there are many other types (see Appendix C for definitions of some types of dementia). Often an individual may have more than one type of dementia, for example, Alzheimer's and

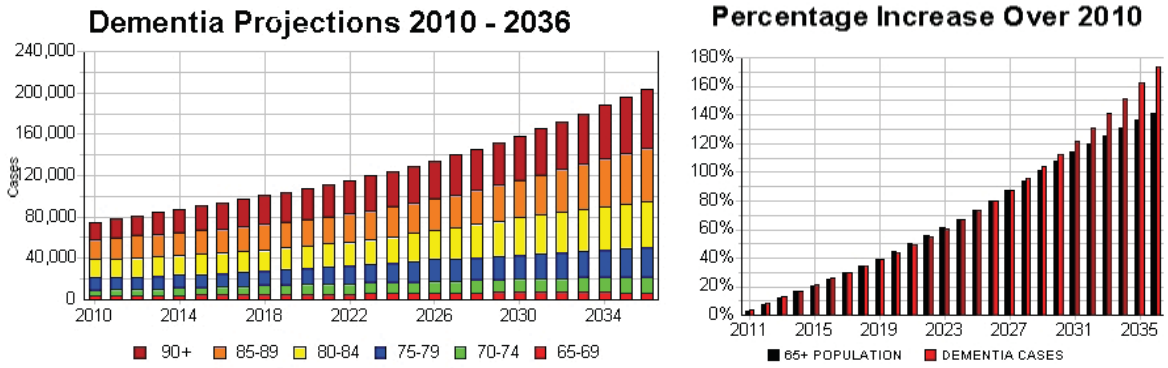
[13] Ministry of Health and Long-Term Care. *Developing Ontario's Dementia Strategy: A Discussion Paper*. Toronto, September 2016.
[14] Reported in *Comparative Study: Early-Stage Dementia Care Model.* Report prepared for Centres d'Accueil Héritage and the Toronto Central LHIN by Santis Health, April 2016.
[15] Alzheimer Society of Canada. *Rising Tide: The Impact of Dementia on Canadian Society.* Toronto, 2010.

vascular, along with other health conditions like diabetes, heart disease or COPD. There is no cure for most types of dementia and the condition is normally progressive.

Currently there are roughly 221,000 people with Alzheimer's or other dementias in Ontario; that is nearly 10% of Ontarians 65 years of age and older. In 2011, the first "baby boomers" reached age 65. **Age is the most significant and easily identifiable risk factor for dementia**. It is thus expected that from 2011 until about 2040, as the number of people aged 65 and over continues to increase greatly (by over 41% over 2010 levels by 2020 and by 125% by 2036), there will be a large increase in all age related medical disorders. Dementia rates in particular will continue to rise substantially, doubling to about 466,000 cases by 2036; only very marked advances in preventative treatment could alter these projections. The increases in dementia cases are caused by the fact that not only is the number of elderly rising, but the oldest age groups ("85 - 89", and "90+") are growing even more rapidly, and they have the highest rates of dementia (e.g. over 50% in the 90+ age group)[16].

Increases will be particularly significant in municipalities like those of the GTA that have grown quickly as "baby boomers" and working-age immigrants moved out to the new suburbs. This has produced a number of large and relatively "young" communities with relatively few elderly people. As these communities age, they will experience exceptionally large increases in both the elderly population and cases of dementia. For example, York will experience almost a 280% increase. These huge increases will put considerable strain on local health care facilities, especially if no effective steps are taken.

Dementia projections for the GTA



Source: *Dementia Projections for the Counties, Regional Municipalities and Census Divisions of Ontario*

Dementia projections by LHIN 2012-2020

LHIN Region	2012	2016	2020	% Increase 2012-2016	% Increase 2012-2020
Central West	7,950	9,880	12,060	24%	**52%**

[16] Robert W. Hopkins. *Dementia Projections for the Counties, Regional Municipalities and Census Divisions of Ontario*. Geriatric Psychiatry Programme Clinical/Research Bulletin, No. 16, June 2010. Retrieved from http://www.providencecare.ca/clinical-tools/Documents/Ontario-Dementia-Projections-2010.pdf. Accessed on September 6, 2016.

Mississauga Halton	13,340	16,210	19,350	22%	**45%**
Toronto Central	17,550	19,010	20,100	8%	15%
Central	23,320	**28,220**	33,330	21%	**43%**
Central East	24,590	**28,590**	32,740	16%	33%

Source: *Alzheimer Society of York Region Evidence Brief*

More than half the people with dementia in GTA LHINs live in Central East and Central LHINs and until 2020 the fastest growth rates will be in Central West, Mississauga Halton and Central LHINs while Toronto Central LHIN will have the slowest growth rate[17]. In 2011 dementia and Alzheimer's disease were the second highest cause of death after ischaemic heart disease both provincially (52.9 deaths per 100,000 population) and generally in the GTA. However, death rates from dementia in the GTA were much lower than the provincial average, given the relative youth of the population, though, as longer-term projections indicate, this will change drastically as the population ages.

Deaths from dementia per 100,000 population in GTA LHINs in 2011

LHIN Region	Dementia deaths per 100,000 pop.	Ranking among causes of death	Comments
Central West	31.3	#2	Lowest in province
Mississauga Halton	39.3	#2	2nd lowest in province
Toronto Central	43.4	#2	Lower than Ontario average
Central	42.7	#2	Lower than Ontario average
Central East	46.2	#3	Lower than Ontario average
Source: *Environmental Scan, 2016-2019 Integrated Health Service Plans*			

Impacts of Dementia

Individuals and Caregivers

Dementia has very significant consequences for the individual, family and caregivers, the health and social service systems, the economy and society as a whole. People with dementia face many challenges in managing their lives and dealing with the changes they are experiencing. Stigma and denial and the assumption that little can be done to help people with dementia may lead to reluctance to ask for help. Dementia is also a leading cause of dependency among seniors while people with dementia tend to have two or more chronic health conditions. Medications commonly subscribed to seniors can complicate dementia symptoms[18].

[17] Santis Health. *Op. cit.*
[18] Santis Health. *Op. cit.*

People with dementia require assistance with the activities of daily living to remain safe and independent. Such help is often provided by family members or other informal caregivers whose mental and physical health may be strongly impacted by their caregiving responsibilities. Caregivers often report high levels of stress, loss of sleep, depression and feeling worried or frustrated. Caregiving demands may also lead to difficulties at work, reduced participation in social activities and isolation from friends. As dementia progresses, the demands on care partners also increase. In Ontario, care partners of seniors with dementia provide up to 75 per cent more hours of care than care partners of seniors without dementia[19].

Language and culture

All too often, too little attention is paid to the important role of language and culture in the recognition, diagnosis, treatment and management of dementia and other chronic diseases for both patients and their care partners. People belonging to minority ethno-linguistic-cultural groups who have dementia, and their care partners, face particular challenges in accessing timely and effective dementia care. They often have less knowledge and awareness about dementia and there may be greater stigma within the community around cognitive decline. This may result in marginalization, delays in diagnosis, less access to services and caregiver supports and less availability of linguistically and culturally appropriate services. In addition, cognitive impairment assessments are generally not conducted in the individual's mother tongue and this can lead to overestimation of the degree of cognitive impairment and inappropriate treatment plans. Yet there is strong evidence that **care and support in one's own language are crucial for people with dementia**, many of whom lose their ability to communicate in their second language over time[20].

Francophones face particular challenges in accessing timely and effective dementia care. Yet care and support in one's own language is crucial for people with dementia.

In Ontario, as will be discussed later, the French-speaking linguistic minority has only very limited access to health services in French. Yet Canadian studies of minority Francophone populations stress the importance of communication in the individual's own language for timely and accurate diagnosis and ongoing management of the illness – and not only this illness, but chronic diseases in general, with a particular emphasis on the notion of "active offer" of services in French by all involved with the patient's care[21].

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[19] Ministry of Health and Long-Term Care. *Developing Ontario's Dementia Strategy: A Discussion Paper*. Toronto, September 2016.

[20] Santis Health. *Op. cit.* See also Farooq Ahmed Khan and Martin Curtice. Cultural barriers and assessment of dementia: a case report. AP J Psychol Med 2012; 13(1):40-3.

[21] See for example, Linda Garcia et al. The Pathway to Diagnosis of Dementia for Francophones Living in a Minority Situation. The Gerontologist doi:10.1093/geront/gnt121. And Manon Lemonde et al. Rapport de recherche. Impact de la situation linguistique minoritaire sur les soins de santé pour des personnes âgées francophones de l'Ontario souffrant de maladies chroniques : partage des connaissances et rétroaction. Oshawa, 2012. http://www.rrasfo.ca/images/docs/publications/2012/RAPPORT_PA_TORONTO_2012-.pdf

According to one study, being French-speaking in Ontario delays cognitive assessment by a specialist by three to six months[22].

> ***Dementia is now one of the leading causes of death and one of the most costly medical conditions in terms of care and housing.***
>
> Standing Senate Committee on Social Affairs, Science and Technology

Health Care System

According to the Standing Senate Committee on Social Affairs, Science and Technology, dementia is now one of the leading causes of death and one of the most costly medical conditions in terms of care and housing.[23]

The increase in the number of dementia cases will impact all aspects of the health care system. Increased reliance on home and community care will substantially increase the burden on community-based services and caregivers. As efforts are made to maintain individuals with dementia in their own homes as long as possible, there will also be increased reliance on informal caregivers. The number of informal care hours is expected to triple across Canada between 2008 and 2038[24]. In addition to the impacts on the mental and physical health of informal care partners mentioned above, this means an increase in the financial burden on care partners in the form of both purchased additional support services, foregone wages and other opportunity costs.

People with dementia also tend to make greater use of health care services; they visit a doctor more often, have a higher number of prescriptions, and are twice as likely to visit an emergency department or be hospitalized for preventable issues[25]. Many patients occupying alternate level of care (ALC) beds in hospitals have some form of dementia as do the majority of long-term care residents. As people with dementia can no longer live safely at home, even in a retirement home, even with supports, there will be an increased need for long-term care facilities. Yet the number of long-term care beds is already limited, wait times are long and people spend months in ALC beds in hospitals while they wait for an appropriate placement. Even with an increase in the number of long-term care beds, the Alzheimer Society of Canada foresees a shortfall of over 157,000 beds across Canada by 2038[26].

Economy and Society

In *Rising Tide,* the Alzheimer Society of Canada estimated that, unless proactive action is taken, dementia will cost the Canadian economy over $872 billion in direct health costs, informal care partner

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[22] Linda Garcia et al. Abstract: Access to dementia services in a Minority Situation: the case of francophones in Ontario, Canada. https://cag.conference-services.net/reports/template/onetextabstract.xml?xsl=template/onetextabstract.xsl&conferenceID=3888&abstractID=869780

[23] Standing Senate Committee on Social Affairs, Science and Technology. *Dementia in Canada: A National Strategy for Dementia Friendly Communities*, Ottawa, February 2016.

[24] Alzheimer Society Canada. *Op. cit.*

[25] Ministry of Health and Long-Term Care. Developing Ontario's Dementia Strategy: A Discussion Paper. Toronto, September 2016.

[26] Alzheimer Society of Canada. *Op. cit.*

opportunity costs and indirect costs related to the provision of unpaid care between 2008 and 2038. For Ontario, that figure is close to $325 billion, including direct health costs, opportunity costs and indirect costs[27].

Direct health costs for dementia include costs for prescription medication, long-term care staff and physicians and hospitals as well as over-the-counter medication, long-term care accommodation and out-of-pocket expenses. Opportunity costs of informal care partners are the wages they could have earned if they were able to take part in the work force. Indirect costs are costs that are not directly connected to dementia but are a result of it, including lost wages and corporate profits resulting from the reduction in labour productivity for both persons with dementia and their informal care partners. Additional elements of the total economic burden of dementia, not calculated here, include reduced domestic demand and tax revenue. It can thus be seen that the impacts of dementia have the potential to pervade every aspect of the economy.

The Alzheimer Society of Canada[28] also calculated the economic and societal benefits of instituting proactive interventions that will delay/prevent the onset of dementia, delay/prevent institutionalization and lessen the burden on care partners. The potential initiatives focus on prevention and support: prevention by increasing physical activity, prevention through brain health, healthy lifestyle and other programs, improved care partner development and support, and support from a system navigator.

Prevention: increased physical activity

There is evidence that increased physical activity can reduce the incidence of dementia. Increasing physical activity for active people over 65 without dementia by 50% would reduce the number of people diagnosed with dementia, which would reduce pressure on long-term care facilities, community care services and informal care partners. This in turn would produce significant savings in direct health costs, care partner opportunity costs and indirect costs, on the order of $31 billion in direct health costs and $52 billion in total economic burden over a thirty-year period.

Prevention: healthy lifestyle and other programs

Such prevention programs, which could be part of a broad public education program to eliminate stigma, foster supportive communities, encourage early diagnosis and promote brain-healthy lifestyles, would target the entire adult population. They could delay the onset of dementia by two years, which would reduce the number of people living with dementia (by up to 410,000 over a thirty-year period) and thus reduce the pressure on health care resources, with a resulting potential reduction in total economic burden of $219 billion. It has also been shown that maintaining a healthy lifestyle (being physically active, eating a healthy diet, staying involved in the community and seeking intellectual stimulation) can slow down the progress of the illness, reduce care partner stress and delay institutionalization, all of which also help to reduce the economic burden of the disease.

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[27] Smetanin, et al. Rising Tide: The Impact of Dementia in Ontario 2008 to 2038. Alzheimer Society of Ontario & RiskAnalytica: Toronto, 2009. Quoted in Ministry of Health and Long-Term Care. *Developing Ontario's Dementia Strategy: A Discussion Paper*. Toronto, September 2016.

[28] Alzheimer Society of Canada. *Op. cit.*

Support: care partner development and support programs

Skill-building and support programs for informal care partners and people with dementia, helping them develop coping skills and build competencies, could reduce the amount of time informal care partners spend on caregiving and thus the economic and health burden placed on them, for a potential thirty-year reduction in opportunity costs of $63 billion. There are other benefits as well, especially for the person with dementia – delayed admission to long-term care, a considerable advantage given the shortage of long-term care beds, along with emotional and quality-of-life benefits.

Support: system navigator

Assigning a system navigator or case manager to newly diagnosed dementia patients to provide care coordination to patients and support to their care partners would both reduce caregiving time and delay admission to long-term care, with a resulting thirty-year savings in health costs of $114 billion, in addition to the emotional and quality-of-life benefits mentioned above.

French Language Services

The Alzheimer Society scenarios do not address the impact of culturally and linguistically appropriate services (or lack thereof) on health care costs. It has been shown that language barriers have a negative impact on access to health service, quality of care, patient satisfaction and experience as well as disparities in receipt of care between English-speaking and other patients. Language barriers may also affect health care costs through their impact on service utilization, health outcomes and other factors such as increased risk to patient safety, including medication errors, misdiagnosis and recourse to more expensive treatments and additional testing. For example, language barriers have been associated with increased risk of hospital admission, less adequate management of chronic diseases, increased risk of intubation. Language barriers may also lead to less participation in health promotion/ education and

To sum up

30-year costs to Canadian society economy if nothing is done: $872 billion 1.1 million cases

Savings from prevention programs:

Increased physical activity:	**$52 billion**	**96,400 fewer cases**
Brain-healthy lifestyle programs (delayed onset)	**$219 billion**	**410,000 fewer cases**

Savings from support programs (delayed institutionalization):

Care partner supports:	**$63 billion**
System navigator/care coordinator	**$114 billion**

French language services: prevention programs, early diagnosis and intervention, patient and caregiver support ⇨lower health care system utilization, improved patient/care partner satisfaction and compliance, delayed institutionalization⇨ savings to health care system and economy as a whole

illness prevention programs, delays in seeking care, reduced comprehension of patients' conditions and compliance with treatment plans, all of which have the potential both to increase health care costs and negatively affect the dementia journey of patients and their care partners[29]. However, as information on language is not systematically collected as part of health care utilization or outcomes data, it is not possible to quantify the negative effects of language barriers or the positive effects of their elimination.

The Francophone Population of the Greater Toronto Area

Age is the single biggest risk factor for dementia. In Ontario Francophones are over-represented in the 65+ age categories and all across the province, the median age for Francophones is generally higher than that for the population as a whole, even in the GTA with its younger population. Dementia is thus of special concern to the Francophone community as is the need for linguistically and culturally appropriate services and programs that consider that community's unique characteristics and needs.

Overview

The Francophone population of the Greater Toronto Area (GTA) is characterized by its great diversity as well as its dispersion across the entire region with no community focal point. There are about 112,000 Francophones in the GTA, representing 18.4% of Ontario's French-speaking population (Inclusive definition of Francophone)[30]. The following table shows their distribution by LHIN in the GTA.[31]

LHIN	Count or estimate*	Total population	Total Francophone population (IDF)	Francophones as % of total population
Central West	Estimate	835,443	14,021	1.7%
Mississauga Halton	Estimate	1,103,643	24,751	2.2%
Toronto Central	Estimate	1,138,570	26,005	2.3%
Central	Estimate	1,690,464	32,725	1.9%
Central East	Estimate	1,484,996	30,221	2.0%

* IDF data were available by Census Subdivision (CSD). For LHINs that are wholly composed of CSDs, IDF totals are true counts. For LHINs where CSDs are split by LHIN boundaries, data were proportionally allocated by the percentage of a CSD's population within each LHIN. In these cases, the IDF values are estimates only.

[29] Sarah Bowen. Language Barriers in Access to Health Care. Health Canada, Ottawa, 2001. Retrieved from http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2001-lang-acces/2001-lang-acces-eng.pdf. Accessed on January 27, 2017. Sarah Bowen. Impact of Language Barriers on Quality and Safety of Health Care. Société Santé en français, Ottawa, 2015. Retrieved from https://santefrancais.ca/wp-content/uploads/SSF-Bowen-S.-Language-Barriers-Study.pdf. Accessed on January 27, 2017.

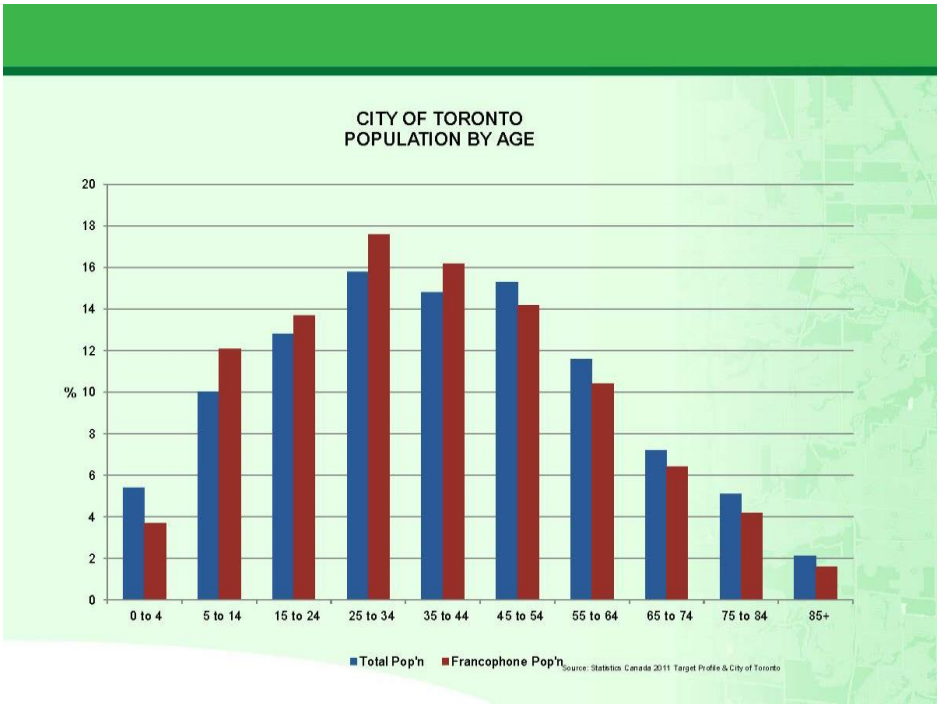
[30] Under the Inclusive Definition of Francophone (IDF), Francophones are defined as "Those persons whose mother tongue is French, plus those whose mother tongue is neither French nor English but have a particular knowledge of French as an Official Language and use French at home". Office of Francophone Affairs. Retrieved from http://www.ofa.gov.on.ca.3pdns.korax.net/en/franco-definition.html. Accessed on October 18, 2016.

[31] Table adapted from Santis Health, *op. cit.* Source data used by Santis Health are no longer available on the Office of Francophone Affairs site. Full table showing IDF and French mother tongue counts by LHIN is available at http://www.hopitalmontfort.com/sites/default/files/Images/Recherche/trousse-information-pack-fr-en-2015-04-16.pdf. Retrieved on October 18, 2016.

The GTA's Francophone population (IDF) is increasingly diverse. In Toronto, for example, almost half of Francophones were born outside of Canada and nearly 75% were born outside of Ontario. In 2006, nearly one in three Francophones was a member of a racialized community. Among Francophone immigrants, one in four arrived between 2001 and 2006; increasingly, immigrants come from countries in Africa, Asia and the Middle East, a change from the historical pattern of external migration mainly from Europe[32].

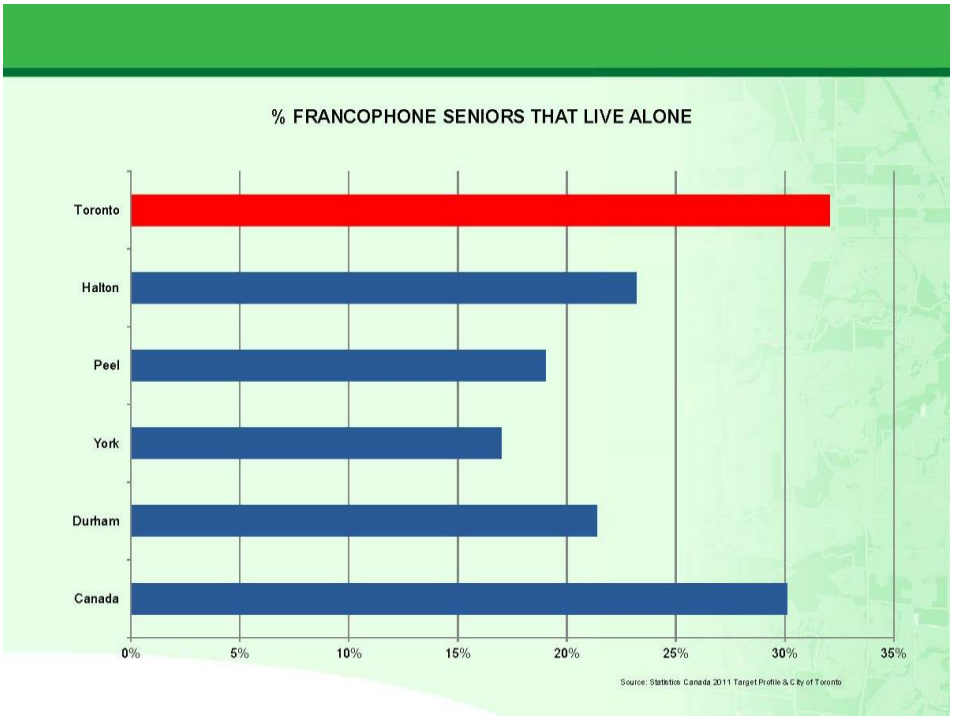
The GTA's Francophone Seniors in all their Diversity

In contrast to the province as a whole, where the median age for Francophones is higher and rising faster than for the general population, the median age of Toronto's Francophone population is younger and rising more slowly. As shown in the following table, compared with the general population of Toronto, a slightly lower proportion of Francophones are aged 65 and over[33]. However, while the proportion of seniors is slightly smaller than for the general population, the number of Francophone seniors in Toronto continues to grow.



Income and housing security are among the challenges faced by Francophone seniors. Like Toronto Francophones as a whole, Francophone seniors in Toronto are twice as likely to live below the low income cut-off as their provincial counterparts (11.9% versus 5.6%). They are also more likely to live alone. This means that they will have less family and caregiver support as their health declines.

[32] Joyce Irvine. *French Language Services in Toronto Central LHIN: Environmental Scan and Future Directions.* Report prepared for Toronto Central LHIN, October 2010. Statistical data taken from Profile of the Francophone Community in Toronto in 2010. Ontario Trillium Foundation, Toronto, 2010 (2006 Census data).
[33] City of Toronto, Social Development Finance and Administration Division. *Changes in the Toronto and Francophone Community Demographics*.



Seniors are more likely to speak French as their only official language than Francophones as a whole. They are thus more vulnerable when health services in French are not available. As the population ages, the number of Francophone seniors who need help with the activities of daily living, who have chronic illnesses and who require a higher level of more specialized care is increasing. In addition, it is common for people with dementia to revert to their first language. All of these factors indicate that the need to serve Francophone seniors in French can only grow in coming years.

The population of Francophone seniors in the GTA is also becoming more diverse. Immigrants who arrived in Toronto years ago are reaching retirement age and younger immigrant and refugee families are bringing their aging parents to join them in Toronto. Francophone seniors from ethno-cultural groups face some special challenges in adapting to Canada and are among the last to integrate. This has an impact on their health, including their mental health.

Their challenges include loss of social and support networks, isolation, racism and discrimination, poverty and non-recognition of their skills and experience. In integrating into Canadian society and accessing the Canadian health care system, immigrant seniors must deal with differing concepts of illness, health and well-being and different values and traditions. In addition, many come from cultures where seniors are valued as elders and transmitters of the culture; they find that Canadian attitudes toward the elderly devalue their contribution to society. Often asked to look after their grandchildren while the parents are working, these seniors also face heavy workloads and sometimes inter-generational conflicts. And finally, it should not be forgotten that immigrants and refugees themselves are a very diverse group who bring with them very different experiences, values, cultures, traditions and

languages. Health service providers will need to understand this diversity and adapt their programs and services to the needs of this increasingly heterogeneous clientele.

The GTA is also home to a population of French-speaking Lesbian, gay, bisexual, transgendered, questioning and two-spirited people, including seniors. This is a highly diversified community, exhibiting a range of sexual orientations and behaviours and health behaviours, whose members may come from ethnic and cultural minorities and who may be native-born or immigrants. Francophone LGBTQ people face barriers in accessing health services that may include racism, discrimination and stigmatization. They are relatively ignored in health promotion programs. In seeking services and displaying an identity, for instance, they may be called upon to choose between being Francophone and following their sexual orientation. **Very few LGBTQ-friendly services are available for them from mainstream Francophone organizations; very few services are available for them in French from mainstream LGBTQ organizations**. In addition, little research has been done on Francophone LGBTQ people in in Ontario. [34]

Like the general population, LGBTQ seniors have concerns about aging and their future living conditions, including long-term care: a desire to maintain their independence and autonomy; reluctance to leave home when they need more specialized care; interest in obtaining assistance with the activities of daily living. It is important for them to have a support network that acknowledges their experience as gays and lesbians. They want to live in a retirement home or community that targets the specific needs of gay and lesbian seniors. They are afraid of or do not trust residential institutions for the general public.

Life-long experience with homophobia and heterosexism can have an impact on the willingness of Francophone LGBTQ seniors to turn to mainstream health services for help in meeting their needs at a stage in life when they are becoming more dependent on professional support, especially as many of them do not have access to an informal family network. The need for adapted services for LGBTQ seniors has been highlighted in some recent studies.[35]

Health Status and Access to Health Care in French

The health status of GTA Francophones is generally the same as that of the general population of Ontario. It is estimated that there are over 1500 Francophones with dementia (about 8% of the population aged 65 and over) in the GTA and the increase in dementia cases among Francophones can be expected to track the increase among the population as a whole, with GTA municipalities likely to experience exceptionally large increases (up to 280%) in the next twenty years[36]. Working from Alzheimer Society projections of the number of dementia cases per LHIN and the percentage of Francophones in each LHIN, the following table provides an approximate idea of the number of Francophones that can be expected to be diagnosed with dementia over the next few years.

[34] Joyce Irvine. *Op. cit.*
[35] FrancoQueer. Analyse des besoins en santé des francophones LGBTQ de Toronto. Rapport préparé pour le compte de Reflet Salvéo. Toronto, mars 2013.
[36] Robert W. Hopkins. *Op. cit.*

Approximate dementia projections for Francophones by LHIN 2012-2020

LHIN Region	% Francos	Cases 2012	Francos 2012	Cases 2016	Francos 2016	Cases 2020	Francos 2020
Central West	1.7	7,950	135	9,880	168	12,060	205
Mississauga Halton	2.2	13,340	294	16,210	357	19,350	426
Toronto Central	2.3	17,550	404	19,010	437	20,100	462
Central	1.9	23,320	**443**	**28,220**	536	33,330	633
Central East	2.0	24,590	**492**	**28,590**	572	32,740	653

Francophones have long been faced with persistent inequities in access to health care in French and access to health services in French continues to be a challenge for Francophones in the GTA.

However, all of the LHINs have made "a commitment to equity, access and universality and decision making where patients come first"[37]. As a result, several priority populations have been identified, including Francophones and new immigrants and the 2016-2019 IHSPs explicitly address some of their needs.

Central East LHIN, for example, has placed a certain emphasis on achieving health equity through:

- Recognition of diversity and development of cultural competency for all populations;
- Providing an "equal opportunity" for good health for all by increasing access to health care for vulnerable and marginalized populations;
- Mitigating impacts due to inequitable access to health care services, social and economic environment, unhealthy living conditions and language barriers; and,
- Developing and monitoring health equity data.

Improving access for Francophones was an objective in IHSP 3 and collaboration with planning partners to enhance and strengthen health care services that are culturally and linguistically adapted to the Francophone community continues in IHSP 4. Making the health system more culturally competent so that it appropriately serves new immigrants and mitigates significant health inequities is also an objective. **Activities will focus on enhancing French language services in assisted living, home and community care, falls prevention, mental health first aid, and supports for seniors with memory impairment; and on improving the capacity of HSPs to develop and offer services in French.**

Nevertheless, although the future holds promise, and despite recent improvements, only a limited number of health services are currently available in French in the GTA.

[37] Central East LHIN. *Living Healthier at Home. Integrated Health Service Plan 2016-2019.* Ajax, 2016.

According to a report from the Office of the French Language Services Commissioner, only 31% of Ontario's Francophone adults report that they speak French with their family physician and 20% report that they use French when accessing other health services[38]. The proportion in the GTA is even lower. Immigrant, refugee and LGBTQ seniors face particular challenges and barriers in accessing culturally and linguistically appropriate health care.

In general, there are no clearly defined care pathways for those seeking health care in French and system navigation remains problematic. At the moment, apart from some solo health care providers, there are only a few organizations providing service in French on a proactive and systematic basis. More detail and especially information related to dementia care will be provided in the next section.

Dementia Care in the Greater Toronto Area

Overview

Dementia care is a labour-intensive and time-consuming responsibility. We all know the expression, "It takes a village to raise a child". We might equally well say, "It takes a village to support a person on her dementia journey". By far the greatest proportion of care and support for people with dementia (94% in Champlain LHIN, for example) is provided on an informal basis by the person herself and her family, friends and broader circle of care including networks like seniors and faith groups.

Access to language specific diagnosis and assessment must be a major consideration in dementia services planning.

Champlain Dementia Network

Along with the person with dementia and his family and informal care partners, many service providers and agencies play a role at different stages of the journey, from prevention and education, through assessment, diagnosis, support and clinical care to end-of-life care. However, there are no clear and coordinated care pathways. Services are fragmented, the system is complex and difficult to navigate and the care and supports received often depend on factors such as where people live, their knowledge of the system and their ability to pay for extra supports. The addition of linguistic and cultural barriers compounds the problem.

Work is, however, going forward on developing a more coordinated and comprehensive approach to dementia. In addition to the development of a dementia strategy at the provincial and national levels, efforts are being made at the regional level to put action plans in place. Both Central East and Champlain LHINs, for example, have developed dementia action plans or strategies that attempt to address the broad spectrum of dementia needs including a patient-centred approach, brain health,

[38] Office of The French Language Services Commissioner. Special Report on French Language Health Services Planning in Ontario. Toronto, 2009. Retrieved from http://csfontario.ca/wp-content/uploads/2009/05/FLSC_report_french_health_planning_2009.pdf. Accessed on October 19, 2016.

education and awareness, diagnosis and assessment, self-management and caregiver and patient supports, work force development and system capacity, system navigation and coordinated care pathways, and system sustainability and accountability.

Language and culture play a crucial role in assessment, diagnosis, care and supports as well as in an individual's willingness to seek help. A number of studies have shown that **use of an English language assessment tool with a person from another language or culture can lead to over-diagnosis and inappropriate treatment plans because of linguistic and cultural differences and the individual's reverting to his/her mother tongue**. These studies show the need to use culturally sensitive assessment tools for people belonging to ethnic minorities (which will encourage ethnic minorities to seek help when needed) and to train professionals to understand these linguistic and cultural issues. [39] As indicated in the Champlain Dementia Network's integrated model of dementia care, access to language specific diagnosis and assessment must be a major consideration in dementia services planning.[40]

Basic premises in dementia care planning include involving the person with dementia in all aspects of care and decision-making to the greatest extent possible and helping the person (and his/her care partners) to live well with dementia as active participants in the community for as long as possible. Ideally there should also be a continuum of services from prevention to palliation for both the patient and his/her care partner with the person with dementia at the centre.

[39] Farooq Ahmed Khan, Martin Curtice. Cultural barriers and assessment of dementia: a case report.. AP J Psychol Med 2012; 13(1):40-3.
[40] Champlain Dementia Network. Integrated Model of Dementia Care Champlain 2020: Making Choices that Matter. Ottawa, April 2013.

Information on dementia care options in the GTA was gathered through interviews with key informants at 23 providers of health and social services across the five GTA LHINs as well as with the five GTA LHINs themselves along with research on the Internet. A full list of the interviews can be found in Appendix E. Of the 23 provider agencies interviewed, 13 are designated, identified or funded to provide all or selected services in French or are subject to the *French Language Services Act* by their legislation. However, there is considerable variation in both the organizational capacity and actual FLS delivery of the agencies, ranging from full capacity and service to no capacity or service.

What follows is a brief survey of cognitive health care options in the GTA.

Primary Care

When they suspect that they or a family member or friend may have memory or cognitive issues, most people turn first to their primary care provider. Primary care providers play the key role in the provision of timely diagnosis, on-going responsive treatment, comprehensive care management, and support to persons with dementia and their care partners.

Yet primary care providers, especially solo practitioners, face a number of challenges and barriers in providing dementia care to their patients. There is evidence that many physicians feel they lack confidence in their ability to recognize and diagnose dementia, especially in the early stages, to manage treatment of dementia disorders, particularly the broader quality of life and psychosocial needs of patients and their caregivers, and that they do not have sufficient knowledge of available support services. Physicians' own attitudes to dementia can also influence how they interact with patients and their care partners. In addition, as dementia care is complex and takes a lot of time, compensation and service models based on short office visits can also impact the quality of care and support provided. This may lead physicians to refer patients to specialist services more often than strictly necessary, with the attendant costs and wait times. Early diagnosis and intervention is the ideal but too often there are substantial delays[41].

A number of reports and studies have indicated that, with appropriate supports and care models, primary care providers can look after the great majority people with dementia living in the community. Around 76% of people with dementia are stable and able to remain at home[42]. The task is easier for physicians working in interdisciplinary care settings like community health centres, family health teams and nurse practitioner led clinics where they have access to other health professionals like dietitians, physiotherapists and social workers who can help develop and implement a care plan.

[41] Faranak Aminzadeh, Frank J. Molnar, William B. Dalziel, Debbie Ayotte. A Review of Barriers and Enablers to Diagnosis and Management of Persons with Dementia in Primary Care. Canadian Geriatrics Journal, Volume 15, Issue 3, September 2012.
[42] Champlain Dementia Network. *Op. cit.*

Only a small minority of Francophone patients have access to primary care services in French. Although there are some French-speaking physicians in standalone practices, the best known sources of primary care in French in the GTA are the Credit Valley Family Health Team, the Centre francophone CHC and TAIBU Community Health Centre. Primary care providers rely heavily on other community resources to provide a range of supports to people with dementia and their care partners. However, practitioners at both the Credit Valley FHT and TAIBU pointed out that one of the challenges they face is the lack of local community-based supports in French to which they can refer their patients while the Centre francophone tends to rely extensively on Centres d'Accueil Héritage, a downtown community support services and supportive housing provider.

For most people it is important to maintain a link with their primary care provider, the person most familiar with them and their circumstances. But it is clear that primary care providers need supports in providing better assessment, diagnosis and intervention services to their patients with dementia and their caregivers. Two service models that can help them deal with these challenges are Health Links and Primary Care Memory Services.

Health Links

At present the role of Health Links in dementia care is not clearly defined. However, with its neighbourhood-based structure, its focus on interdisciplinary coordinated care planning for patients with multiple chronic conditions, planning that includes their informal care networks, and its goal of keeping people in the community with a good quality of life, the Health Links model gives primary care providers an opportunity to help their patients with dementia and other chronic conditions access needed supports and continue to live well in their own homes.

The role of French language health service providers within Health Links is also not yet clearly defined in all LHINs. However, given the small number of available resources and the need to optimize the use of these resources, as well as the dispersal of the French-speaking population across LHINs, it seems likely that a more regional approach will be necessary. Nevertheless, in some LHINs, it may be possible to identify LHIN sub-regions with greater concentrations of Francophones, for example, Scarborough and South Durham in Central East LHIN.

Primary Care Memory Services

There are a number of successful Primary Care Memory Services models. There are the Kawartha Memory Clinics in which nursing assessments are reported back to the referring primary care provider with suggestions for action items to be taken. In the model developed by Dr. Linda Lee, a family physician led group of inter-professional care providers does both assessment and treatment of dementia. This model has been successfully reproduced as the Regional Geriatric Program of Eastern Ontario in Ottawa and is fully functional in French. Under the Primary Care – Dementia Assessment and Treatment Algorithm model from the Department of Psychiatry, Queen's University, Dementia Care

Managers from Providence Care Geriatric Psychiatry Outreach Program facilitate the application of dementia management tools, provide support to the primary care providers, and review complex cases with a Geriatric Psychiatrist. The Central East LHIN is implementing a regional system of primary care based memory services integrated with existing Alzheimer Society programs and specialized geriatric services[43]. There are over 75 such clinics across Ontario, including a language and culture specific program at Yee Hong Centre for Geriatric Care.

This model is very effective at reducing the time needed for assessment and diagnosis and greatly reduces the number of referrals to specialized memory clinics. It works best in inter-professional settings like CHCs, FHOs and FHTs. The model is still quite labour-intensive and one family physician interviewed for this project expressed some caveats about the sustainability of this approach in a setting with major time and patient load constraints.

There are currently no primary care memory services available in French in the GTA although the Central East proposal did include a French language services component and would be most interested in setting up such services.

Community Supports for Persons with Dementia and their Care Partners

Community Care Access Centres

Community Care Access Centres (CCACs) coordinate care for eligible clients with a variety of needs. CCAC care coordinators conduct in-home assessments usually using a standardized assessment tool. Although they serve clients of all ages, the bulk of their clients are older adults with chronic conditions including dementia. In collaboration with the client and family or caregiver, care coordinators develop care plans to meet client needs for personal care, home supports, clinical services and community services like adult day programs. The nature, quantity and duration of the services provided are determined on the basis of client needs. Clients may be referred by hospitals, primary care or other health care provider, friends and family or may self-refer. Care coordinators work with primary care providers and other health professionals like physiotherapists and occupational therapists to support clients at home/in the community and help with the transition to supportive housing and long-term care. People with dementia who are not eligible for CCAC services (they may have only mild cognitive impairment) experience considerable variability with regard to care planning and coordination.

CCACs do not provide direct services beyond care coordination/case management. Frontline services are provided by third party agencies under contract to the CCAC. The result is often significant variability in the quality, consistency and reliability of care.

Development of a provincial Levels of Care Framework is under way that will make it easier for clients and their families to know what to expect from the CCAC. Under *Patients First* legislation and roadmap, the entire sector is being transformed and the CCACs are being transferred to the LHINs, which will thus

[43] Central East LHIN Primary Care-Based Memory Services Project Proposal Submitted to Central East Local Health Integration Network. Initial Submission August 14, 2015. Updated September 18, 2015.

take on responsibility for direct service delivery for the first time. CCAC services are also being integrated into the Health Links model mentioned above.

As scheduled agencies, CCACs are subject to the *French Language Services Act*. The GTA CCACs are generally able to provide case management/care coordination in French through a French-speaking staff member, though some also rely on interpretation services. The standardized assessment tools are available in French. A certain number of the third party service agencies under contract to the CCAC are contractually required to provide service in French. However, actual service availability is spotty. Integration with the LHINs, whose French language service obligations were strengthened in the *Patients First Act*, should provide a platform for enhancement of CCAC and contractual providers' French language services capacity.

Alzheimer Society

As the champion of people with dementia, their families and caregivers and the health professionals serving them, the Alzheimer Society plays multiple roles. It offers support, information and education to people with dementia, their families and their caregivers, works to increase public awareness of dementia, promote research, and advocate for services that respect the dignity of the individual. At the national and provincial level, the Alzheimer Society has produced research studies, policy recommendations and a wide variety of support materials, many of them in both English and French.

Although the services provided by individual Alzheimer Society chapters vary somewhat, all of them provide counselling, support programs like Active Living, Minds in Motion and the Music project and support groups for people with dementia and their caregivers. They also provide training for PSWs and other health care workers (U-First, dementia certificate program). One major initiative is First Link, a program that enables health care practitioners to connect their patients and their caregivers with the Alzheimer's Society and the services it can provide as soon as possible after diagnosis. By making this connection early, it is possible to put people in touch with Alzheimer Society and other community supports with a view to reducing ER visits and helping them to stay at home as long as possible. The Alzheimer Society of Toronto maintains the Toronto Dementia Network, an inventory of dementia services.

Although many written materials are available in French through the national and Ottawa sites, most local chapters have little or no capacity in French. The Alzheimer Society of Durham does have capacity and already provides some services in French. It is most interested in obtaining CE LHIN support in order to build its service capacity in French so as to provide better promotion, education, prevention and support services to Durham's Francophone population. Other local societies also have an interest in developing partnerships to enhance their French language services capacity and in reaching out to the Francophone community.

Adult Day Programs

There are a wide variety of adult day programs across the GTA that provide services for older adults, including frail seniors and people with dementia, ranging from mild cognitive impairment to moderate or severe dementia. In some cases the agencies also house an elderly persons' centre, which allows for smooth transition along the care journey as the individual experiences physical, mental and cognitive decline. As a general rule, adult day programs provide activities that promote physical, mental and cognitive wellness, reduce isolation and encourage socialization, provide recreation and also respite for caregivers. Some include additional services like bathing, foot care, transportation or case management, and most, if not all, include a hot meal and snacks in their programming. Some long-term care facilities, affordable housing buildings and retirement homes also host adult day programs that are open to both residents and the broader community. Most programs are small with limited capacity and they often have wait lists.

There are a number of programs, like those delivered by India Rainbow Health, Villa Colombo and Yee Hong Centre for Geriatric Care, designed for specific ethno-cultural and linguistic groups.

The only programming in French is provided by Centres d'Accueil Héritage at its downtown Toronto and Oshawa sites.

Bendale Acres, which provides long-term care in French, also has an adult day program, but this program is not currently available in French. Bendale would be very interested in obtaining CE LHIN support for such a French language program.

Carers Program/Enriches Program

Designed and delivered by the Reitman Centre of Mount Sinai hospital, the CARERS program is a 10-week group intervention designed to address the needs and support the efforts of family caregivers caring for individuals with dementia at home. It combines therapeutic principles for managing caregiver stress and burden with education and skills training, and formal problem solving techniques derived from cognitive behavioural theory. One special focus is the high-risk caregiver whose well-being is in jeopardy or who may be unable to continue to provide the same level of care. The program incorporates a concurrently run arts-based program for care recipients in small group sessions. The techniques developed adapt well to different languages and cultures; the program is delivered Chinese by the Yee Hong Centre for Geriatric Care and is also available in Portuguese.

The Reitman Centre has recently launched a partnership with the Alzheimer Society of Toronto, North York Community House, WoodGreen Community Services, and Canadian Mental Health Association (ENRICHES Collective) to identify, engage and support isolated senior caregivers, connect with them through community-based educational activities, and build public awareness.

The CARERS program is available in French. The Reitman Centre has signed a Memorandum of Understanding with Centres d'Accueil Héritage to provide training to CAH staff so that CAH can start delivering this program in French to caregivers and care recipients.

Supportive Housing

There are many supportive housing providers serving vulnerable populations across the GTA; some of them specialize in specific groups like frail seniors, people with mental health and addictions issues, people with developmental delays and physical disabilities, victims of domestic violence and their children, the LGBTQ community, the homeless and the precariously housed. Most supportive housing providers deliver services like personal care, light housekeeping and laundry, medication reminders, security checks and light meal preparation to clients in a variety of living situations including private homes and rental accommodation, community and non-profit affordable housing and seniors' residences, with the goal of helping clients maintain their independence. A number of these providers, like WoodGreen, Social Housing in Peel (SHIP), LOFT, Yee Hong and others, also maintain their own affordable housing buildings serving specific populations. SHIP is identified to provide French language services but does not yet have the capacity to provide services other than some administrative supports. The need for more innovative and affordable supportive housing options for seniors, including people with dementia, has been pointed out in several studies and reports[44].

One interesting model is Ewart Angus SPRINT Homes. The model provides housing in a home-like atmosphere for 20 people with dementia whose families can no longer look after them at home but who are medically stable and do not need nursing care or long-term care.

Centres d'Accueil Héritage is the only provider of affordable housing, supportive housing and assisted living serving the Francophone population of the GTA. It has been working on enhancing its supports for its frail residents and community-dwelling clients with some emphasis on those with cognitive impairments as their share of CAH's client base is growing. CAH has submitted a report to TC LHIN regarding extension of the SPRINT or a similar model to CAH[45].

Other Community Support Services

Community support services that help people with the activities of daily living and allow them to live at home or in a community setting can have a significant impact on the health and quality of life of people with dementia and their care partners. Examples include Meals on Wheels, homemaking, transportation and escort services, friendly visiting and security calls.

Health Promotion and Illness Prevention

A key component of any dementia strategy is the use of prevention programs designed to delay or prevent the onset of dementia, keep people in the community for as long as possible and support care partners. In addition to the programs and services described elsewhere in this chapter (Alzheimer Society, Baycrest, Glendon), a number of other agencies provide such programs including community

[44] For example, one of the recommendations in *Living Longer, Living Well* is that the province ensure there is a "variety of accessible housing options that are safe, affordable, and conveniently located while promoting independence as the functional needs of older Ontarians change". (Dr. Samir K. Sinha. *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. Toronto, December 20, 2012*)

[45] Santis Health. *Op. cit.*

health centres, elderly persons centres and community groups. The programs often focus on physical activity, continuous learning opportunities, and health promotion activities like nutrition. French language health service providers like Centres d'Accueil Héritage and Centre francophone offer such programs (e.g. Dr. Actif,).

An interesting innovation is the increasing number of bilingual system navigator/health promoter positions in community health centres, especially in underserved areas of the GTA (Wellfort, Black Creek CHC, Toronto North Support Services, TAIBU). In addition to helping Francophone clients connect with French language health services, they provide health promotion activities like chronic disease management and mental health first aid.

Long-Term Care

Although the overall goal is to keep people with dementia living independently in the community for as long as it is safe to do so, the time comes when the individual needs to move to an institutional setting, either because they need a more intensive level of care or because their caregivers are no longer able to look after them. About 65% of the residents of long-term care facilities suffer from dementia along with a variety of other complex chronic conditions. Those with severe dementia must be housed in secure units. There is a shortage of long-term care beds and wait lists are long (the wait is often two years or more). The majority of patients occupying alternate level of care (ALC) beds in hospitals have dementia. The need to develop long-term care beds over the next twenty years is one of the priorities highlighted by the Alzheimer Society of Canada in its *Rising Tide* report.

The programming provided by long-term care facilities to their dementia patients may include Montessori techniques, music therapy (iPod program), doll therapy, validation therapy and exercise programs. Staff may include a behavioural supports team and there is usually access to additional resources like GEM and GAIN teams and regional geriatric program staff.

The only long-term care in French in the GTA is provided by the Pavillon Omer-Deslauriers at Bendale Acres in Scarborough. There are 37 beds set aside for Francophones and, since June 2013, there has been a policy in place giving priority for those beds to Francophones applying to Bendale Acres. Currently 16 beds are occupied by Francophones and there are another four or five on the waiting list. There is a staffing model in place to support care in the client's language of choice. Bendale Acres also has an informal arrangement with Centres d'Accueil Héritage for placement of its residents once they can no longer live independently. However, when residents decline to a point at which it is unsafe for them to remain in the general population, they are transferred to one of the secure dementia units. These units are not identified for French language services, although the staff includes one French-speaking behavioural supports person along with another French-speaking staff member. Bendale is aware that this situation is not ideal and would like to expand its French-language capacity.

Specialized Geriatric Services

Baycrest

Baycrest is the only institution in the GTA focused entirely on care and services for older adults along with education and research. Services include a retirement home, assisted living, long-term care and a panoply of services and programs dealing with physical and mental health and memory and cognitive impairment on both an inpatient and an outpatient basis. The focus of much of its work is helping older adults to live well in the community as they age. It is the TC LHIN lead for Behavioural Supports Ontario (BSO) and the provincial and national lead for the Canadian Centre for Aging and Brain Health Innovation (CC-ABHI). Its Behavioural Supports for Seniors Program includes a number of outreach teams and a 23-bed behavioural supports unit.

Of particular interest to this project is Baycrest's work at its Centre for Memory and Neurotherapeutics. Programs include the Memory and Aging Program for healthy older adults, the Learning the Ropes Program for people with mild cognitive impairment and their families/caregivers, and the Memory Link program for adults who have developed memory problems as the result of a traumatic event. It also has a number of community support programs for families and caregivers and has developed several clinical tools including the Kaplan-Baycrest Neurocognitive Assessment (KBNA). The French version of this tool has been validated and will soon be published while the French version of the Memory and Aging Program materials are being developed in French by the Glendon Centre for Cognitive Health.

Baycrest does not formally provide French language services although it does have French-speaking staff who on occasion deal with Francophone clients.

Specialized Memory Clinics

There are eight or so hospital-based specialized memory clinics across the GTA. Locations include Baycrest, Sunnybrook, UHN, North York General, Ontario Shores, St. Michael's, CAMH and Toronto East General. They focus on early assessment and diagnosis and conduct comprehensive assessments that include recommendations to patients, care partners and primary care providers and may make the links to support services in the community. The goal is generally to provide people with the tools and supports they need to remain in the community or, depending on the person's overall health, in a long-term care setting.

In addition to the hospital-based clinics there are several private-practice memory clinics across the GTA.

No specialized memory clinic services are currently available in French on a formal basis.

Regional Geriatric Program (RGP) of Toronto:

The RGP supports health care professionals in Toronto and surrounding areas in the provision of interdisciplinary, senior-friendly, and evidence-based care that helps seniors stay independent and continue to live at home. It supports a network of 26 organizations in the GTA and surrounding areas. Each network member provides a set of specialized geriatric services that might include outreach teams, ambulatory care clinics, day hospitals, acute geriatric assessment units, internal consultation teams,

geriatric rehabilitation programs, geriatric emergency management, and psychogeriatric services. It has also developed toolkits on senior-friendly hospitals, geriatric emergency management, psychogeriatric consultation program and geriatrics inter-professional collaboration in primary and community-based care. Members include all large GTA hospitals, among them Baycrest, Sunnybrook, North York General, Sinai Health System, Ontario Shores, UHN, Trillium, CAMH and Lakeridge.

No services in French are provided through any of these programs on any formal basis though some of these institutions do have French-speaking staff who on occasion deal with Francophone clients.

Seniors Care Network in the Central East LHIN

The Seniors Care Network supports many of the same programs as the RGP of Toronto. Its programs and services include:

- Geriatric Emergency Management (GEM) Nurses: specialized geriatric nurses in emergency departments provide support with assessment, diagnosis, identification and referrals for "at risk" seniors.
- Nurse Practitioners Supporting Teams Averting Transfers (NPSTAT): They provide direct clinical care to the residents of the long-term care homes by responding to acute and episodic changes in the residents' condition to reduce unscheduled transfers to a hospital.
- Behavioural Supports Ontario (BSO): The program provides support to patients and caregivers who live and cope with responsive behaviours associated with dementia, mental illness, substance use, and other neurological conditions both in long-term care and in the community.
- Geriatric Assessment and Intervention Network (GAIN): GAIN teams provide specialized geriatric care to support frail seniors living at home or in retirement residences, who have multiple complex medical and social problems including cognitive impairment, responsive behaviours, decreased function, and falls or risk of falls.
- Senior friendly hospitals

The Seniors Care Network was also a partner in the development of Central East LHIN's Action Plan for Dementia and is a key player in its implementation along with the Alzheimer's Society of Durham.

No services in French are provided through any of these programs on any formal basis. The Seniors Care Network has identified its bilingual staff and is open to discussions on how best to use these resources.

Dementia Work Force

Training

A variety of training is available for health professionals working with people with dementia and their caregivers, at the undergraduate and graduate levels as well as through professional development opportunities. This report will deal only with those available to French-speaking health professionals in the GTA through institutions such as Collège Boréal, the Glendon Campus of York University, the French language health networks and the Alzheimer Society.

Collège Boréal

At the undergraduate level, the Toronto Campus of Collège Boréal offers Practical Nursing and Personal Support Worker programs as well as Social Services Techniques. The Personal Support Worker Program includes a module that focuses on working with people with dementia, including those exhibiting responsive behaviours, and other mental health issues. The programs, which are delivered primarily in French, include practicums that may be served with French language health service providers like CAH, Bendale Acres and CFT. Additional health sciences programs like Nursing and post-graduate programs in gerontology are available at the Sudbury campus in partnership with local universities.

Cité collégiale

As of September 2017, the Toronto Campus of Cité collégiale will also be offering a Personal Support Worker program in French with practicums served with local French language health service providers. Segments of the program deal with working with clients with health issues, including dementia and mental illness. The main campus in Ottawa offers a wide variety of programs in health and social sciences, including Social Work Techniques and Social Work Techniques-Gerontology.

Glendon Campus of York University

Glendon is the Centre of Excellence for French-language and Bilingual Postsecondary Education for Southern Ontario. Among the health-related bilingual programs offered at Glendon is the undergraduate psychology program, which can include a concentration in cognitive neuropsychology, with its emphasis on the relationship between the brain and behaviour and cognitive abilities like memory, language and attention.

Attached to the Glendon Campus is the Glendon Centre for Cognitive Health, which supports research in neuropsychology with a focus on cognitive aging. The Centre, which works closely with Baycrest Centre for Geriatric Care and Sunnybrook Health Sciences Centre as part of the Neuroscience Network, provides advanced training to senior undergraduate and graduate students, conducts research into aging and cognition, and has done a great deal of work on the development of clinical assessment and intervention tools, with a special emphasis on the Francophone community. The Centre has a keen interest in the establishment of memory clinic services in French in the GTA.

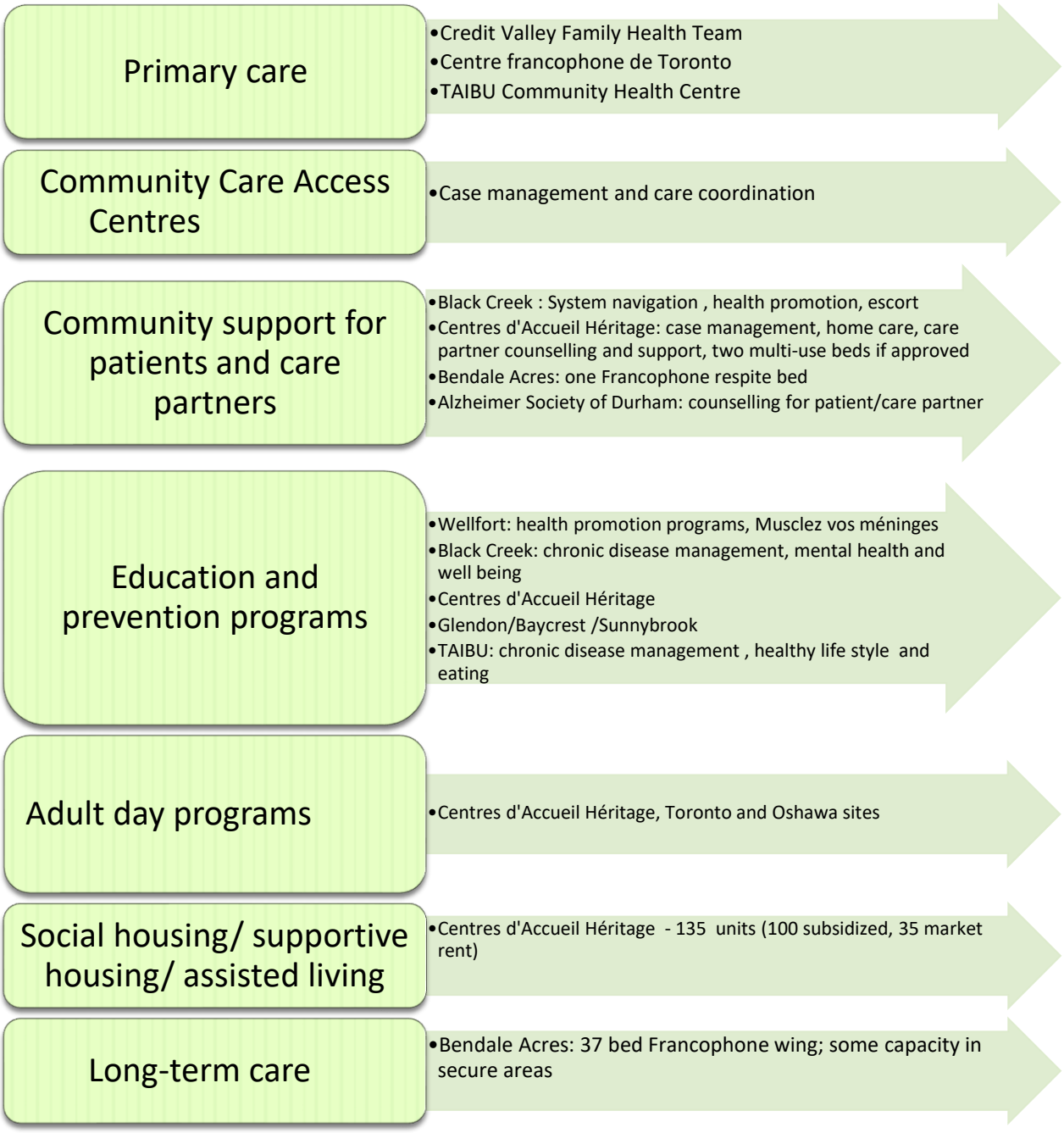
Development of Assessment Tools and Support Programs in French

As just indicated, the Glendon Centre for Cognitive Health has been focusing on making culturally sensitive clinical assessment and intervention tools available in French. Under the direction of Dr. Guy Proulx, the Centre has completed validation in French of the Kaplan-Baycrest Neurocognitive Assessment tool (KBNA) and is working on the French version of Baycrest's Memory and Aging Program. Once this work is completed, the Centre will turn its attention to Baycrest's Learning the Ropes Program for people with mild cognitive impairment and the validation of other French clinical tools such as the "Test d'attention Glendon" (TAG). Clinical internships will also be extended to the Francophone community.

A number of other assessment tools are also available in French including cognitive assessment tools like the MMSE and MOCA and the whole series of inter-RAI assessment tools.

Summary: Cognitive Health Services Available in French

These services do not on the whole focus solely on people with cognitive impairments and their care partners. Most do however provide the kinds of support needed for healthy aging and for helping people with cognitive impairments to lead active lives in the community for as long as possible and provide service to people who need higher levels of care. Though they are far from sufficient to meet the need and are even more fragmented than what is available in English, they do constitute a basis from which to develop a more comprehensive care pathway for those with cognitive impairments and their care partners and families.



Cognitive Health Needs Identified by the Francophone Community

To identify the needs and priorities of the Francophone community, consultations in the form of focus groups and on-line surveys were conducted across the GTA. Five consultations were held in total, consisting of two surveys covering the Central and Toronto Central LHINs, and three focus groups in Durham, Scarborough and Peel. Appendix D contains the discussion guide and survey questionnaire.

The single most important finding that came out of all the community consultations was the need for culturally competent services in French for both the person with dementia and his/her family and caregivers at every stage of the dementia journey, from initial testing and diagnosis, including the memory clinic, as the disease progresses and at the end of life. And in a fragmented system with few health services available in French, how few people had access to such services.

Participants' survey responses underscored the key role played by primary care providers (family physician, family health team, community health centre) as a source of information and in the assessment, diagnosis, treatment and management of dementia, a response that was echoed in the focus groups. In every case, the primary care provider was the first resource that both people with dementia and their caregivers/families turned to for help and information. However, a number of respondents/participants expressed reservations about their practitioners' knowledge and the quality of the information or care provided. One person pointed out some of the difficulties primary care providers face in serving the elderly as the work is labour-intensive, time-consuming and not adequately recognized in the compensation system. Although most respondents/participants highlighted the need for services in French, particularly as the person with dementia's decline progresses, only a small minority had access to health services in French (33-10%), figures that are congruent with other study results. Another need mentioned was for primary care providers to make house calls.

If primary care providers were the first source of information and advice on dementia, the second was the Internet. People researched the disease and potential treatments, and could more easily do so in their own language. This may be an indication of how to improve public education and knowledge on dementias, their symptoms and treatment.

A lack of resources, both in general and in French, came up fairly often, around a shortage of specialized geriatric services, of supportive housing, assisted living and long-term care, of adult day programs and the resulting unacceptably long wait times and difficulty in navigating an overly complex system. Some people raised concerns about the difficulty the system had in tailoring services to the particular needs of the person with dementia and his/her family/caregivers (for example, doctors' making house calls), about obtaining reliable, consistent, informed and culturally and linguistically appropriate home care, and about the financial burden resulting from paying out of pocket for services from the private sector. It was also pointed out that services, especially services in French, tend to be clustered in Toronto, especially in the downtown area, so that they are not very accessible; transportation was raised as a real issue, as outside the downtown core there are essentially no services in French.

It was clear that for many people the health system is confusing. In response to a question about why a person might delay seeking help for memory issues, the most common response was that he/she did

not know where to go for help. Many were familiar with the Alzheimer's Society though most indicated that no services were available in French. They were also familiar with CCACs, CAMH and the Canadian Mental Health Association, though again there was doubt about the availability of services in French.

Familiarity with memory clinics and what they do varied quite a bit; some people were quite aware of them while others had not really heard of them and were not sure what they were or what they did. Participants familiar with memory clinics were strongly in favour of the establishment of a memory clinic able to provide testing, diagnostic and management services in French.

There was also some discussion of referrals; it was suggested that it would be helpful if the primary care provider did not simply give people a list of available services but explained what these services were, how to access them and helped make the connection. Help with navigation was also brought up, and especially navigation to services in French.

One person asked whether CCACs had an obligation to conduct assessments of French speakers in French and whether assessment tools were available in French. Another person pointed out the importance of assessing a person in his/her first language as when her mother was assessed in both English and French, there was a ten-point difference in the scores. Another person's mother was diagnosed with dementia following a stroke when she was tested in English; when, at the daughter's insistence, the mother was re-tested in French, the results came back negative – no dementia.

One theme that came back constantly and consistently in both the focus groups and the surveys was the necessity of providing services in French, in general across all areas of health, but even more so in relation to mental illness, memory issues and cognitive impairment, and for seniors. And these services need to be not only in French, but adapted to the culture and background of the patient and his/her family and caregivers.

Connected with this was the notion that health care providers needed to be more knowledgeable – about the backgrounds and cultures of their patients, about dementia, including memory loss and mild cognitive impairment, as well as about services available in French in the community. Participants further pointed out that it was important to consider how to handle situations in which the patient reverted to his/her first language but the partner/caregiver did not speak that language – a situation that is not uncommon since the majority of Francophones marry outside their linguistic group.

The need for public awareness and education about dementia was brought up consistently. For instance, in addition to not seeking help because they did not know where to go, people mentioned not seeking help because they did not understand the illness, were afraid to learn the results if they did investigate, and were concerned about stigma and marginalization, about being labelled. In some cultures, dementia is perceived as a curse, the result of witchcraft or ill-wishing or simply as madness.

Some participants talked about their lack of confidence in the health care system, especially larger institutions like hospitals and long-term care facilities, because of the way they sometimes treated both the patient and the family or caregiver, separating husband and wife, tying patients down or chemically

restraining them. The system was seen as lacking a humane approach that considered the whole person and his/her entourage.

Respondents/participants consistently spoke of the role of the family and other informal caregivers – how important it was, how family caregivers helped the patient remain more independent, stay true to him/herself longer but also talked about the stresses and burdens involved. It was strongly felt that family caregivers needed help, advice, counselling and training, supports and respite. Better informed and trained, less stressed caregivers would lead to a reduction in hospitalizations and ED visits.

In one group, there was a lot of stress on the support role that could be played by community partners, not just those in the health care system like community health centres and supportive housing providers, but other community organizations whether they serve a particular community or the broader Francophone community (Kay Créole, Retraite active, faith groups)

A few people also mentioned positive aspects, things like the “Musclez vos meninges” training offered by Wellfort, care received by a loved one in a specialized setting, care provided by a family member, help from a trusted health professional or by the CCAC. In one group, in an area where the Alzheimer Society does have French-speaking staff able to provide services in French, a person with dementia talked about her positive experiences with a support group/training program and the follow-up activities that she could pursue on her own to help maintain her independence – regular physical and brain exercises, volunteer work to maintain social contacts and helping others with their dementia.

Below is a summary of the most important needs and wants that emerged from the consultations. They were quite consistent across all of the communities consulted and essentially aim for a less fragmented, more coordinated system of care that considers both patients and their caregivers/families and provides them with services in French that take account of people’s culture, background and experience.

Most important needs/wants in order of priority

1. **Service in French at every stage of the journey (testing, diagnosis, memory clinic, management, treatment, support, home care, long-term care, palliative care), for both the person with dementia and the caregiver and family**
2. **A French language services hub with a single phone number that can provide emergency assistance in French, refer the person with dementia and the caregiver to FLS providers, refer HSPs and other support agencies to FLS providers and resources and act as a resource centre**
3. **Consistent and reliable care (same person, same routine) that is linguistically appropriate and culturally competent, for example, from the CCAC and home care agencies**
4. **Knowledgeable, trained primary care providers able to test and diagnose, refer to appropriate resources, create a care pathway or continuum of services in French, tailor services to needs, make house calls.**
5. **Access to a memory clinic able to conduct tests, do follow-up interventions and help manage the illness in French and in a culturally appropriate manner.**
6. **Linguistically and culturally appropriate training, support and respite for caregivers, including for dealing with responsive behaviours and after the person with dementia has been transferred to long-term care (support with transition and continued family involvement in the care of the person with dementia).**
7. **Linguistically and culturally appropriate training and support for the person with dementia (coping strategies, counselling) and easily accessible adult day programs in French (including help with transportation)**
8. **Help with navigating the system with a view to accessing as many services in French as possible in as coordinated and consistent a way as possible**
9. **Linguistically and culturally appropriate affordable housing designed for people with dementia who are not yet ready for long-term care but who are unable to continue living at home.**

And an overarching concern – a desire for a humane and comprehensive approach that sees beyond medical and physical needs to the whole person and their entourage.

Toward a Care Pathway for Francophone Older Adults

Regional Approach

As part of the ongoing system transformation, and in the context of a population health approach, LHINs have divided their service areas into sub-regions with a view to better defining the specific health-related characteristics and needs of the population of a given area and targeting services to meet those needs. However, on the whole, the French-speaking population of the GTA is scattered fairly evenly across the area served by the five GTA LHINs, Francophones make up only a very small percentage of the population of each sub-region and the resources available to serve them in French are very limited.

It is therefore strongly recommended that the five GTA LHINs adopt a regional approach to planning and implementing dementia services for Francophones in order to provide the most equitable possible access to the few services available without creating additional geographic barriers.

A regional approach will also make it possible to make optimum use of those limited resources and create a care pathway in French that encourages the development of innovative models like mobile teams and technology-based solutions, resource sharing and creation of partnerships.

A regional approach within the GTA should go beyond the confines of each individual LHIN to consider service models that would serve broader swathes of the GTA. This is all the more important as many GTA municipalities are divided among several LHINs (all five in the case of the City of Toronto) and the most suitable services available in French may easily be located in a neighbouring LHIN. It would also make sense for highly specialized services like a hospital-based memory clinic providing service in French to serve the largest possible client group by opening them up to French speakers from across the GTA and beyond.

This recommendation echoes that[46] of the *Regroupement des entités de planification des services de santé en français de l'Ontario* in its response to the *Developing Ontario's Dementia Strategy* discussion paper and the approach to French language health services already being adopted by several LHINs.

A Step-by-Step Approach

The availability of health services in French varies widely across the GTA. As previously discussed, at present, the best access to services in French is found in downtown Toronto (TC LHIN) with some additional services provided in Scarborough and Oshawa (CE LHIN) and Mississauga (MH LHIN). The only French-language dementia services are currently found in TC LHIN and CE LHIN. In addition, Markham has been recently added to the list of designated areas with a FLS implementation deadline of July 2018. It would be logical to consider a step-by-step approach that would start in TC LHIN and CE LHIN, building on existing resources, and then move on to the other LHINs.

[46] Recommendation 8: In regions where there is a low concentration of Francophones, LHINs should adopt a regional approach for French language services, particularly concerning dementia services, in order to align available resources with needs of Francophone clients.

It is therefore recommended that the basket of services be implemented in phases, starting with TC LHIN and CE LHIN, then moving on to MH LHIN and CW LHIN with C LHIN in a final phase, aligned with FLS implementation planning for Markham. Planning for French language health services in Markham should incorporate dementia services from the beginning.

Proposed Phases

2017-18	2018-19	2019-20	2020-21	2021-22	2022-23
TC LHIN	TC LHIN	TC LHIN	TC LHIN	TC LHIN	TC LHIN
CE LHIN	CE LHIN	CE LHIN	CE LHIN	CE LHIN	CE LHIN
	MH LHIN	MH LHIN	MH LHIN	MH LHIN	MH LHIN
	CW LHIN	CW LHIN	CW LHIN	CW LHIN	CW LHIN
		C LHIN	C LHIN	C LHIN	C LHIN

Some Basics

Health Equity/Reduction in Health Disparities

One of the key elements of current planning at the provincial and local levels is health equity and reduction of health disparities. Yet, as previously mentioned and as indicated in the *Patients First* discussion paper, equitable access to health services in French continues to be a challenge for Ontario's Francophones, including those in the GTA. One way to address the equity issue as it affects GTA Francophones would be to develop a core basket of services in French for Francophones facing cognitive health challenges, services to which they and their care partners would have equitable access along the entire dementia journey.[47] And a further key element would be the active offer of services in French by all health service providers working with Francophones facing cognitive health issues and their care partners.

Language: Identification of Francophone Clients

A foundational step for the creation of a dementia care pathway in French is identification of the patient's language and that of their care partner. The information should be obtained at the point at which the patient accesses the health system, most often the primary care provider, and should follow the patient as she navigates the health care system. The question should be asked regardless of the health service provider's language of service as this make it easier for the health service provider to refer the patient to the most linguistically and culturally appropriate services.

The questions proposed by the Regroupement des entités in 2013 are a good starting point:

1. What is your mother tongue? French, English, Other

[47] For more on an equitable access approach to cognitive health services for Francophones, see the response to the Dementia Strategy discussion paper of the *Regroupement des entitiés de planification des services de santé en français*.

2. If your mother tongue is neither French nor English, in which of Canada's official languages are you most comfortable? French, English

For care planning purposes, it is very important both to identify as Francophones people whose first language is not French but for whom it is their preferred language of communication in Canada, and to identify patients' mother tongue. People with dementia often revert to their mother tongue and this will make it easier to accommodate their needs, for example, by assigning a Creole-speaking PSW to a Francophone who has reverted to Creole as her primary language of communication.

Given the high rate of marriage between Francophones and non-Francophones, it is important to identify the care partner's language in order to provide supports in the language in which the care partner is most comfortable. This is consistent with Recommendation 3 of the Regroupement's response to the dementia strategy discussion paper: *Recommendation 3: Patient linguistic identity should be systematically included in the case file and taken into consideration in referrals and care coordination.*

It is therefore very strongly recommended that the preferred official language and mother tongue of both patient and care partner be identified and used as an essential element in referrals, care planning and treatment.

Language: Services in French and Active Offer ⇨Greater Equity and Better Outcomes

In a field like dementia care, where language is a critical factor in diagnosis, intervention and illness management, it is essential that patients be assessed in their own language.

This produces a more accurate diagnosis, providing a better idea of where the patient is at and her true degree of functionality, and will result in a care plan better adapted to the patient's needs. It has also been shown that providing care in the patient's language leads to better understanding of the patient's illness, better compliance with treatment plans, greater patient satisfaction and a better patient experience – and this in turn may help the patient maintain a good quality of life and remain in the community for longer.

For Francophones, especially the most vulnerable, like seniors and people with cognitive issues, when they are faced with navigating a complex system where French language services are few and far between and not well known, it is very important that they receive an "active offer" of services in French. As the Regroupement des entités has indicated, an "active offer" of services in French respects the principle of equity; aims for service quality comparable to that provided in English; is linguistically and culturally appropriate to the needs and priorities of Francophones; and is inherent in the quality of the services provided to people (patients, residents, clients) and an important contributing factor to their safety[48].

Focus on Healthy Aging, Early Diagnosis and Intervention, and Community Care

Currently the bulk of resources spent on dementia care are allocated to the later stages of the illness – long-term care, behavioural supports, alternate level of care, etc. Yet the scenarios developed by the

[48] Regroupement des entités de planification des services de santé en français. Response to the Discussion Paper Developing Ontario's Dementia Strategy Discussion Paper – November 2016.

Alzheimer Society of Canada in *Rising Tide* and also by the World Health Organization show that there are enormous savings to be made by concentrating on preventing or delaying the onset of dementia and subsequently preventing or delaying institutionalization.

As many writers have indicated, this requires public education and awareness; programs to promote physical activity, healthy lifestyles and healthy aging; education of primary care providers to improve their capacity to recognize and respond appropriately to early signs of cognitive impairment; early diagnosis and intervention capacity at both the community and more specialized levels; community-based supports for patients and caregivers and help with navigating a complex and fragmented system; and a knowledge base to which primary care providers and system navigators/care coordinators can turn to help their patients and their care partners meet cognitive health challenges.

And above all, for Francophones, this requires the building of a care pathway that provides access to linguistically and culturally appropriate services and supports that will help them live active lives in the community for as long as possible, thus both improving their experience and reducing the burden on the health care system.

Building on Existing Resources

Although there are not many services available in French to serve Francophones with cognitive health issues, there exists a core of services and providers that can act as the foundation for building additional capacity. Any effort to improve cognitive health services should leverage the resources of community support services agencies like Centres d'Accueil Héritage, with its focus on services for older adults, and primary care providers like Centre francophone de Toronto, Credit Valley Family Health Team and TAIBU Community Health Centre, which not only provide primary care but also do a lot of community development work. Several other community health centres (Black Creek, Wellfort, TAIBU) have bilingual navigators/health promoters whose expertise, contacts and community role could contribute to the development of a care pathway and support system for Francophones living with dementia and their care partners.

Partnerships among agencies providing services in French and with agencies in the field that do not provide services in French but have expertise and capacity to contribute would be essential for development of a care pathway in French for Francophones faced with cognitive health issues and their care partners (Alzheimer Society, GEM and GAIN teams, Seniors Care Network, regional psychogeriatric programs). Recommendations along this line have previously been made by Entité 4 and the *Regroupement des entités de planification des services de santé en français*[49].

With regard to the more specialized services provided by memory clinics, there is the work and expertise of the Glendon Centre for Cognitive Health and its close association with GTA speciality medical institutions and organizations including Baycrest and Sunnybrook. And finally there is the network of Francophone community groups (L'Amicale, Centre de l'Amitié, AFRY, and their associated seniors and other clubs) whose community knowledge and interest in improving services could be

[49] Entité 4. Recommendation from Entité 4 to the Central East LHIN as part of the Behavioural Supports Ontario (BSO) Project. *Regroupement des entités de planification des services de santé en français.* Op. cit.

integrated into efforts to improve services for Francophones (community engagement, easily accessible sites, etc.).

Finally, it would be necessary to ensure that if these agencies take on greater roles in the delivery of dementia care along the full journey from healthy aging to long-term and end-of-life care, they would need to be adequately resourced to provide quality care to an underserved and vulnerable French-speaking population – sufficient, appropriately trained human resources, adequate financial support, a network of partnerships and facilities adapted to client needs.

Potential Basket of Services

Education and Prevention Programs

Public Awareness and Education

As *the Regroupement des entités* pointed out in its response to the dementia strategy discussion paper, better use will be made of dementia care services in French (including the public awareness and education components) if they are advertised and offered throughout the health care system. There are some best practices already in place around the province, many of them available in French, which could be publicized more widely. This can be done at little or no cost.

Options

1. Add a link to the Ottawa Dementia Network's Re-Think Dementia site (http://demencesonyrepense.ca/) to health service provider and health policy organization sites across the five GTA LHINs. Organizations to be included: Centres d'Accueil Héritage, Centre francophone de Toronto, RIFSSSO, TAIBU, Credit Valley Family Health Team, Alzheimer Societies of Peel, Toronto, York and Durham, the five LHIN Healthlines.
2. Add a link to Dementia Friends Canada site (http://www.dementiafriends.ca/fr/) to health service provider and health policy organization sites across the five GTA LHINs. Organizations to be included: Centres d'Accueil Héritage, Centre francophone de Toronto, RIFSSSO, TAIBU, Credit Valley Family Health Team, Alzheimer Societies of Peel, Toronto, York and Durham, the five LHIN Healthlines.
3. Publicize the programs; for example, during January Alzheimer Awareness Month, put a special announcement on provider sites with links to the two French public education sites.
4. There is a lot of information on dementia available in French on the national and Quebec Alzheimer Society sites. Much of it is identical on all sites. Either duplicate this material directly on the Peel, York, Toronto and Durham Alzheimer Society sites, as well as the provincial site, or make the link to the materials available in French on the national and Quebec sites easier and more user-friendly. The current popup when you click on *français* seems designed to discourage people from accessing information in French.
5. The Toronto Alzheimer Society has no "français" option. Add on that goes to either a mirror site in French or a user-friendly link to the national and Quebec sites

6. Add information, in English and French, on any services or programs available locally in French to all GTA Alzheimer Society sites.

Programs to Promote Healthy Aging and Healthy Memories

According to the Alzheimer Society of Canada, delaying the onset of dementia through prevention programs is an effective way to reduce the economic and societal burden of dementia. Some of these programs, for instance, those focused on staying physically and mentally active, will help improve the quality of life of people with mild cognitive impairment or dementia and delay institutionalization.

Options

Elderly Persons Centres

Funded by the Ministry of Seniors Affairs and local municipalities, Elderly Persons Centres offer a range of programs and services for seniors that promote active and healthy living, social engagement and learning[50]. Their legislation is currently being updated under the *Seniors Active Living Centres Act.*

1. Centres d'Accueil Héritage:
    - Only French-language Elderly Persons Centre in the GTA;
    - Some funding from province and city ($90,000);
    - Partially self-funded through membership and activity fees;
    - Fitness, nutrition, learning and social activities designed to encourage healthy eating and lifestyle, provide intellectual stimulation and reduce isolation;
    - Members have been involved with Glendon Centre for Cognitive Health's work on developing cognitive health assessment tools and memory programs and with CMHA on piloting "The Living Life to the Full Course" in French;
    - Could be a setting for offering programs like "Musclez vos meninges", "Memory and Aging", "Living Life to the Full" on a periodic basis in partnership with other providers with only incremental increases in costs.
2. Centre pour personnes âgées de Peel-Halton
    - With funding from Reflet Salvéo and in cooperation with Francophone seniors organizations in Peel and Halton, feasibility study has been done on possible service model that could be implemented without ongoing government funding (no funding is currently available);
    - The study recommended a mobile model that would hold activities in different community organization premises around the region and be partially self-funding with the possibility of applying for start-up and operating money under various grant programs (Trillium Foundation, New Horizons, Seniors Community Grant Program).
    - If implemented, the model would lend itself to delivery of healthy aging programs and healthy memory programs in locations fairly close to where potential participants live,

[50] Ministry of Seniors Affairs web site: http://www.seniors.gov.on.ca/en/homecommunity/elderly_persons_centres.php. Consulted on January 30, 2017.

and in partnership with agencies with a mandate to deliver particular programs. Funding would need to be worked out on program-by-program basis.

Healthy Aging Memory Programs

Such programs are designed to provide seniors with normally aging memories with education on memory, support for adopting a memory-healthy lifestyle and memory training.

1. "Musclez vos meninges"
    - Workshop series developed by Centre Cavendish in Quebec and used in Ontario; has been offered by Wellfort in the past as part of its health promotion for Francophone seniors program (10 sessions).
    - Cavendish Centre offers train-the-trainer workshops as well as a program kit ($65) for health and social service professionals. There are no user fees for participants.
    - Could be delivered periodically through a variety of organizations serving French speaking seniors or as part of the health promotion activities of community health centres working with the Francophone community. Potential sites/partners: Centres d'Accueil Héritage, Centre francophone de Toronto, TAIBU, Credit Valley Family Health Team, Black Creek CHC, Cercle de l'amitié, Retraite active, Cercle des aînés noirs francophones de l'Ontario (CANFO), Jeunesse d'Hier, other seniors' clubs, Bendale Acres.
    - The French language planning entities could help to make the connections.
2. "Memory and Aging" Program:
    - Developed by the Baycrest Neuropsychology and Cognitive Health Team and delivered by Baycrest in English; Baycrest provides train-the-trainer workshops and program kits (combined cost of $750) for health professionals to deliver the program locally. There are user fees for program participants ($140) and for participant workbooks ($20); 10 hours over 5 weekly sessions.
    - Glendon Centre for Cognitive Health is currently completing validation of the French version of the program with community input. Delivery of the program could be integrated into the broader memory clinic initiative in partnership with Francophone community organizations. Train-the-trainer workshops could also be developed. Workshop and kit costs are unknown at this point as are user fees. Program is broader in scope than "Musclez vos meninges".
    - Potential delivery partners would be the same as for "Musclez vos meninges". French language planning entities would need to play a role in making the connections with Glendon taking on responsibility for coordinating the program.

General Healthy Aging and Health Promotion Programs for Seniors

1. Dr. Actif (Centres d'Accueil Héritage):
    - Developed in collaboration with Glendon's Psychology Department, this activation program provides PSWs and case managers with a tool box to use with clients, to help them remain physically and mentally active and stay engaged with the community. The

tool box includes an assessment tool, a guide for PSWs and case managers, suggested relaxation, physical and cognitive exercises and a monitoring dashboard. There is also a video. CAH staff use the program with clients both at Place Saint-Laurent and in the community and adapts the program to individual needs and goals. It has been well received by people in the community.

- Program development was funded under the Canada-Ontario Agreement on Official Languages and there is no charge to participants.
- The full tool kit is available on the CAH website (http://caheritage.org/dractif/).
- This is a best practice that should be publicized and adopted elsewhere. Perhaps CAH could work with the French language planning entities and its existing partners to explore how to scale up and distribute the program.

2. Alzheimer Society Brain Booster program (Cyboulot^{MD})
    - Web-based program that includes suggestions and exercises for lifelong fitness, brain health and healthy eating available in English and French on the Society's national site that individuals can put into practice on their own: http://www.alzheimer.ca/fr/Living-with-dementia/BrainBooster. Could be publicized on FLS provider websites and shared with primary care providers serving the Francophone community (TAIBU nurse practitioner, CFT, etc.).
3. CMHA program for older adults:
    - "The Living Life to the Full" Course (eight weekly sessions) was piloted in French ("Vivre sa vie pleinement") at Centres d'Accueil Héritage as part of the Ontario Older Adult Project.
    - Improves quality of life and general wellbeing, so a useful adjunct for seniors. It would be particularly useful for care partners. There are no fees for participants.
    - The program will be offered in partnership with Francophone community organizations, starting in the spring of 2017 (Action positive, Association marocaine). A community engagement session is planned for March 29, 2017.
    - Two staff from Centres d'Accueil Héritage and the Centre francophone are being trained to deliver the program.
    - Information on the program should be disseminated widely.
4. Chronic disease management and education programs
    - Such programs are offered from time to time in French by several community health centres with a mandate to provide health promotion services in French (often along with system navigation support). As people with dementia often have concurrent conditions like heart disease and diabetes, and also often live alone, illness self-management tools are important for maintaining the best possible quality of life, avoiding emergency room visits and hospitalization.
    - Some examples: "Vivre en santé avec une maladie chronique", a train-the-trainer program, piloted in French in the GTA by Central East LHIN and offered from time to time; chronic disease self-management programs are also offered by community health centres providing service in French (e.g. "Parlons de vivre mieux avec une maladie

chronique" offered by the Centre francophone de Toronto); "Santé mentale et bien-être" and "Premiers soins en santé mentale", mental health first aid programs offered from time to time by community health centres (e.g. TAIBU, Black Creek); diabetes education programs offered by community health centres.

Information on such programs needs to be more widely disseminated, to the community as a whole, to primary care providers, whether or not they offer service in French, and to patients and their care partners and families.

Early Detection, Diagnosis and Intervention

The Alzheimer Society has stressed the importance of early detection and diagnosis, both to reduce the risks to the person with dementia and his care partner and to give the individual an opportunity to adjust to the diagnosis and participate actively in planning for the future. The importance of assessing the individual in his own language for accurate diagnosis and appropriate care planning has already been mentioned. Most Francophones do not have a French-speaking primary care provider. Even when they do, **there is currently nowhere that the provider can refer the patient for assessment in French beyond initial screening**. There are two service models that could help address this challenge.

Mobile Primary Care Memory Services

This model has been successfully implemented in Central East LHIN with a number of Family Health Organizations and Teams, though none offer service in French. The LHIN and initiative sponsors are very interested in extending the model to the Francophone community and the initial proposal included a Francophone primary care provider. There are over 75 such clinics across Ontario, including some providing service in French in the Ottawa area; the Ontario government recently announced the creation of 17 additional clinics in remote, rural and underservices areas under the Adopting Research to Improve Care (ARTIC) program[51].

With the support of a primary care memory clinic, family physicians are generally able to manage care for their patients with cognitive impairments effectively. Usually they can handle about 80% of cases, which reduces the burden on hospital memory clinics and so reduces wait times and costs.

Given the geographic scattering of Francophones across the GTA and the scarcity of resources to serve them, a mobile team approach seems the most practical. Such a team should work with family physicians serving French-speaking patients, other health and social service professionals serving French-speaking patients, Francophone community and faith groups and the broader French-speaking public with a view to bringing awareness and support around dementia as close as possible to those

[51] ARTIC. Memory Clinics expanded to underserviced areas in Ontario. New ARTIC project helps patients living with dementia receive care, closer to home. Media release dated January 23, 2017. Retrieved from http://www.hqontario.ca/portals/0/Documents/qi/artic/artic-pcmc-media-release-2016-en.pdf?utm_medium=email&utm_campaign=Health%20Quality%20Ontario%20e-Newsletter%20January%202017&utm_content=Health%20Quality%20Ontario%20e-Newsletter%20January%202017+CID_5274b33390e6df9efa16d86104455a5c&utm_source=email%20CM&utm_term=17%20Primary%20Care%20Memory%20Clinics%20Opening%20in%20Underserved%20Communities. Accessed on January 30, 2017.

most concerned with it. An important element of the project would be delivering training on dealing with cognitive impairments, on dementia care and on the primary care memory services model to family physicians involved with the team as well as staff of the team, the host agency and partner agencies; such training is available in French and English through the Centre for Family Medicine. The model would be greatly enhanced by an approach like the York South Simcoe youth mental health bus project (MOBYSS) in Central LHIN, which would be well aligned with the specific characteristics of the GTA's Francophone community and bring care to them. The team could assume the following functions in support of the provision of a continuum of services to patients and their caregivers while providing support to health care professionals:

- Outreach to the Francophone community and primary care providers serving Francophone patients and their care partners
- Public education and awareness building
- Support for healthy aging memories/healthy brain activities
- Early detection of cognitive impairments and intervention
- Help with system navigation and referrals to specialist and community resources
- Support for case management
- Data collection, management and analysis
- Support to family physicians, patients and families/care partners

Rough potential budget (based on Central East LHIN experience) based on one full-time team that does not include a physician (4 FTEs) to serve the catchment areas of the five GTA LHINs:

- One-time costs (training, some equipment): $ 20,200
- Ongoing costs (human resources, supplies, equipment): $367,500
- Bus purchase or lease, adaptation, insurance and maintenance:

There would be additional costs for contributions from partner agencies.

It is recommended that creation of mobile primary care memory services to cover the five GTA LHINs be the top-priority item in the recommended basket of services and be implemented by the LHINs.

Mobile Specialist Memory Clinic

Although family physicians can successfully manage about 80% of cases of dementia with support from a primary care memory services team, 20% or so require more specialized intervention from speciality memory clinics, usually hospital based. Intervention by such specialty memory clinics is most effective at the earliest stages of the disease. Wait times can be long, sometimes as much as 18 months, which reduces the effectiveness of the intervention. **At present such specialized services are not available in French. And, as previously indicated, assessments in a person's second language can produce misleading results, leading to misdiagnosis and inappropriate care plans. It would thus be preferable by far for Francophones needing more specialized intervention to have access to such assessments, interventions and care recommendations/planning in French**.

Glendon Centre for Cognitive Health has long had an interest in providing this service in French in partnership with an existing health service provider and has produced a validated French version of one of the tools often used for such neurodiagnostic assessments, the Kaplan Baycrest Neurocognitive Assessment (KBNA). KBNA provides important information for a general overview, in-depth diagnosis, or treatment planning and monitoring. It combines behavioural neurology and traditional neuropsychological approaches to assessment and evaluates the major areas of cognition: Attention/ Concentration, Immediate Memory—Recall, Delayed Memory—Recall, Delayed Memory—Recognition, Verbal Fluency, Spatial Processing, and Reasoning/ Conceptual Shifting.

Other complex diagnostic tools such as the TAG (Test d'attention Glendon) have also been developed. The TAG is particularly sensitive for early detection and has the advantage of being a digitized instrument permitting testing at a distance through telemedicine technology. The broader Francophone community has shown great interest in these instruments. The Francophone norms, collected by the Glendon Centre thanks to the Francophone community of the GTA, are being submitted to international clinical journals and will benefit other Canadian Francophones.

A partnership could be developed with existing health service providers (agencies providing French language health services and institutions providing specialized memory services), which would give Francophones access to a clinic that served the five GTA LHINs and provided service on a mobile basis, potentially in conjunction with the mobile primary care memory services team recommended above, or else via a telemedicine platform.

The annualized costs of a full-time memory clinic in French would be around $470,000. However, a pilot could be envisaged that would provide an opportunity to evaluate potential demand, the effectiveness of the model and the potential for appropriate intervention and management of more complex cases. Based on the information provided by the Glendon Centre, a pilot providing service one day a week would cost around $86,000; expansion of the program could be envisaged if the pilot is successful and there is sufficient demand. The reach and effectiveness of this model would be enhanced through inclusion of a telemedicine platform, the cost of which is estimated at about $10,000 in addition to the costs shown below.

Item	Funding source	Cost for one year
Junior neuropsychologist	Tbd	$24,000
Psychometrician	Tbd	$17,400
Project coordination	Tbd	$13,200
Senior consultant	Tbd	$ 8,000
Clinical consultants (2)	Tbd	$ 10,000
Equipment and supplies	Tbd	$10,000
Travel	Tbd	$ 4,000
Total cost		$86,600

It is recommended that the potential of a pilot project mobile memory clinic be explored including possible partnerships with existing health service providers and with the proposed mobile primary care memory services team.

Training for Health Professionals

As the dementia strategy discussion paper pointed out, a well-informed and well-trained work force will be crucial for effective management of dementia care for patients and care partners. To quote the paper, "Dementia-specific education and training can help [health professionals] to provide excellent services to people with dementia and their care partners and to support the strengths of people with dementia. This might include training in identifying or diagnosing dementia, understanding responsive behaviours, communicating with people with dementia or working in interdisciplinary teams". For services to Francophones, it is essential that such training include information on the importance of language in dealing with cognitive issues as well as cultural sensitivity and active offer. Glendon College, for example, will be offering a certificate in neurosciences in French as of 2017 with a focus on dementia and neuropsychology.

Support for Navigation

Approach Based on Hubs/Single Entry Points

The desire for a single portal for equitable access to information and services was expressed by both community members and health professionals. The hub and spoke model is also increasingly seen by the LHINs as an effective and efficient way of providing clients with information and directing them to the most appropriate services. Such hubs can be both virtual (single telephone number, consolidated website) and real (single physical location where a variety of services for a specific population can be accessed e.g. Community Door in Peel). For a scattered and diverse population like the Francophones of the GTA, a single entry point with links to information and services across the GTA would be recommendable.

Seniors' Line (Unique Number)

Integrated access is important for helping seniors connect in a timely and client-centered way with the services they need from any point of entry into the system. In the community consultations on dementia care, participants clearly expressed a need for a single number which they could call for information and referral in French to community and other resources to support people living with dementia and their care partners. In the summer of 2016, Toronto Central LHIN launched the Seniors' Line, a central telephone access point that takes callers in hand, performs a preliminary triage by getting a clear picture of the client's needs and then ensures secure and complete transitions across the continuum of home care to the appropriate services. It serves all older adults and their care partners, including those with cognitive issues. At the moment, this access point provides no active offer of French language services for French-speaking callers.

Centres d'Accueil Héritage has proposed a pilot project that would ensure equitable access for Francophone older adults looking for services by providing direct service in French through a dedicated

French-speaking intake responder. This pilot project could act as a stepping stone in the learning process on how best to integrate French services into central access and begin building French-language capacity and flexibility as health system transformation moves forward. If successful, the model could also be replicated in or extended to other parts of the GTA.

If the French language Seniors' Line provides the same level of access as the English language line (71 hours/week), annualized costs for human resources (salary and benefits) would be about $117,000. There would also be one-time technical adaptation and staff training costs along with a need to develop/maintain an inventory of French language services to which clients could be referred.

It is recommended that this pilot be funded and if successful, expanded to/replicated in other LHINs of the GTA.

Bilingual Navigators

The Alzheimer Society of Canada has estimated that system navigation support for people newly diagnosed with dementia and their care partners would result in a national thirty-year savings in health costs of $114 billion. Furthermore, navigation of a complex, fragmented health care system has been consistently identified by patients and caregivers as well as health professionals as one of the biggest challenges in providing support to people with cognitive health challenges and their care partners. For Francophones, it is important that this navigation support be actively offered in French, in a culturally sensitive manner by a health professional with a good knowledge of the disease and of the resources available within the individual's community.

A growing number of health service providers have French-speaking navigators/health promoters tasked with helping Francophones navigate their local health system and find the services they need in French. They often also provide health promotion/illness prevention programs in French to their French-speaking clientele. These navigators/health promoters represent a resource that, with appropriate training and at minimal additional cost, would be able to guide their clients with cognitive issues to appropriate resources. In addition, the transfer of the CCACs to the LHINs and the proposed embedding of care coordinators in community settings present an opportunity to increase and diversify navigation supports and referral to appropriate levels of care.

It is recommended that the possibility of leveraging existing navigator and care coordinator positions (and new ones as they come on line) be explored with a view to providing navigation support in French to people with cognitive issues and their care partners.

First Link (Premier Lien)

Provided by local Alzheimer Societies, First Link is a referral program under which primary care providers can refer patients newly diagnosed with dementia and their caregivers to a First Link Outreach Counsellor who will help connect the family with available services and supports of all kinds, including support groups and counselling, and provide long-term support. The program also aims to improve linkages between primary care providers and diagnostic and treatment services, community service

providers, and the Alzheimer Society. At present this support is not available in French. It could be implemented gradually starting with Durham and Toronto.

1. Alzheimer Society of Durham (ASD)/Ontario Shores:
    - Link Centres d'Accueil Héritage with the Alzheimer Society of Durham to encourage referrals to the Adult Day Program provided by CAH in Oshawa.
    - ASD already has French language capacity and connections with Jeunesse d'Hier and L'Amicale. Build on this connection/capacity to develop First Link in French in Durham. Counsellor functions: in addition to the normal responsibilities of a First Link counsellor, outreach to health practitioners and Francophone community organizations, including schools and churches, to publicize program; build a data base of resources available in French (in conjunction with Central East Healthline); explore what other resources can be developed (Brain Wave Café at Jeunesse d'Hier?); create links with those resources. If successful, such an initiative could serve as a model for other local Alzheimer Societies. Catholic Family Services of Durham is an example of a recent successful similar initiative. As the older Francophone population is concentrated in Oshawa, this would be a good place to start.
    - Costs: primarily for staffing and travel with some operational – perhaps only an incremental increase from the costs for moving the current part-time person to full-time.
2. Alzheimer Society of Toronto (AST):
    - AST currently has no capacity in French and is not an identified agency; it is interested in developing partnerships with local Francophone organizations to develop programs.
    - Explore with AST the possibility of creating a First Link counsellor position with the same functions as listed for ASD. The primary costs would be for staffing and travel. An initial partnership could be established with Centres d'Accueil Héritage and Centre francophone. Outreach would be a crucial aspect of the job along with gradual expansion of AST programs into French.
    - It might be possible for one position to cover two local societies, for example, Toronto and Peel.

It is recommended that the option of offering the First Link program in French, with a strong outreach and capacity-building component, be explored with the local Alzheimer Societies, starting with Durham and Toronto, and the LHINs concerned. It may be possible to provide this service via the mobile primary care memory services team in partnership with the Alzheimer Societies.

Information Sources

Thehealthline.ca/lignesanté.ca

Within each LHIN, the CCAC maintains an on-line directory of health and related services available within the LHIN to help members of the public locate the services they need. Organized by disease,

client group and service category, the directory is available in both English and French and includes a section on French language services. The information on French language services is limited and often not up-to-date. It is up to providers to keep the information current. The directory is also not very well known by the public and is not very well publicized. It could be strengthened by incorporating more accurate and current information and by raising public awareness of this interesting resource.

211

211 is the equivalent of thehealthline.ca for social and community services. Organized by municipality, like the healthline it is an on-line directory of social, community and related services available within a given municipality to help members of the public locate the services they need. Help is also available by phone 24/7 by dialling 211; the service provides information and referrals. The sites include information in French and information on French language services. 211 may be better known than the healthline.ca and contains much of the same information.

Supports for Individuals with Dementia

The great majority of people with dementia live in the community and wish to remain in their familiar settings as active participants in family and community life for as long as possible. By providing them with the supports they need to continue to live safely in the community, we can improve their quality of life and satisfaction with the patient experience throughout their dementia journey while reducing costs to the health care system.

The communication skills of people with dementia decline as they move along the disease trajectory and most will eventually lose their second language and revert to their mother tongue. Yet communication is essential to effective management of this illness. Providing Francophones with supports in their own language thus remains crucial as does the active offer of such supports in French.

Adult Day Programs

Adult day programs provide physical, mental and social activities for physically frail and/or cognitively impaired adults living in the community. They also provide respite for care partners. Although there are a fairly large number of adult day programs around the GTA, including some designed specifically for people with dementia, only two are currently available in French, both provided by Centres d'Accueil Héritage.

1. Centres d'Accueil Héritage (CAH):
    - Toronto site: Though not designed specifically for people with dementia, clients include people with mild-moderate cognitive impairments. Staff providing the program have received training in dementia care through the Alzheimer Society of Toronto. The program is delivered four days a week in a secure room at Place Saint-Laurent. As CAH also has an Elderly Persons Centre, it is possible for people to transition smoothly from one program to the next as their health and their care needs evolve. This program also includes case management and some transportation is provided. It is funded by the Toronto Central LHIN.

- Oshawa site: Offered two days a week, this program also includes clients with mild-moderate cognitive impairments. Some transportation is provided. Although the room is not secure, CAH is considering a move to larger, better equipped quarters. The program is funded by Central East LHIN.
- Current budgets:
    - Toronto site: $176,000
    - Oshawa site: $77,000 (2017-18)

2. Bendale Acres :
    - Bendale currently has an adult day program for physically frail and cognitively impaired individuals living in the community that runs five days a week. The program is not currently offered in French but Bendale is very interested in making the program available in French and has previously applied to Central East LHIN for funding.
    - Bendale has close ties with the Francophone community of Scarborough, which is aging; it provides long-term care in French (Pavillon Omer-Deslauriers) and has a large, well-qualified French-speaking staff. It would be a logical place to establish an adult day program in French to meet a growing need. The program would need to make some provision for transportation of attendees as transportation is often a major challenge for individuals attending an adult day program.
    - Based on the costs for the CAH adult day program, a five-day program would run around $200,000 per year.

It is therefore recommended that a French language adult day program be established at Bendale Acres.

3. Other adult day programs:
    - There are no other adult day programs offering service in French in the GTA. There is a growing need in the northern and western areas of Toronto as well as in Brampton and Mississauga. The option of developing partnerships with Francophone community organizations and health care providers offering service in French (Credit Valley FHT, Black Creek CHC, Toronto North Support Services, Centre francophone – Fairview) should be explored over the next few years. Although the populations of these areas are still fairly young overall, in Peel there is an aging population interested in further developing the services available to Francophone seniors in Peel. As there are at present no French-language community resources to which primary care providers can refer patients diagnosed with dementia, development of adult day programs in these areas would help to meet a growing need.

Support Groups

1. Alzheimer Society of Durham:
    - At present there are no support groups for Francophones with dementia or their care partners in the GTA. The Alzheimer Society of Durham is interested in working with Francophone seniors to provide support to people with dementia and their care

partners and has established links with Jeunesse d'hier, the Oshawa Francophone seniors club. The Francophone population of Oshawa is aging. This would be a good place to start. Collaboration on dementia issues for Francophones should also be explored with TAIBU CHC, which provides primary care, health promotion and community development services to Francophones of African origin in northern Scarborough.

It is recommended that the creation of a support group for Francophone seniors in Oshawa be explored with the Alzheimer Society of Durham and the Central East LHIN.

2. "Learning the Ropes":
    - This program, offered by Baycrest in English, focuses on optimizing cognitive health through lifestyle choices, memory training, and psychosocial support. It is aimed at older adults and their close family members/friends, who are living in the community, and are experiencing mild cognitive impairment (MCI). The overarching long term goals are to prevent or delay the onset of clinical dementia in persons with MCI and to prevent or minimize health declines in their care partners.
    - Program facilitation kits and participant workbooks are available to registered health professionals ($600); there are user fees for participants ($150); family members are free.
    - This is the next program on the to-do list of the Glendon Centre for Cognitive Health once development of the "Memory and Aging" program is completed. Timing and costs remain to be determined. Like the "Memory and Aging" program, delivery of the program could be integrated into the broader memory clinic initiative in partnership with Francophone community organizations.

Support for Care Partners

As noted in the *Developing Ontario's Dementia Strategy* discussion paper, a large proportion of the care provided to people with dementia is given by informal caregivers, often the patient's spouse or children. Almost half of care partners are distressed. Providing them with supports will enable them to look after their care recipient for longer and allow the patient to remain in the community for longer, thus both improving the patient's quality of life and reducing costs to the health care system.

This support needs to be multi-faceted, easily accessible and available in the preferred language of both the care recipient and the care partner.

Respite Care

1. Bendale Acres:
    - Bendale Acres has two short-stay beds that can be booked for stays of up to 30 days to provide relief for care partners. One of them is in the Francophone wing, Pavillon Omer-Deslauriers, where services are provided in French.
2. Centres d'Accueil Héritage:

- CAH is planning to convert one apartment into a respite, recovery and transitional care unit with two multi-use beds, a fully accessible shower and toilet and a work station. In addition to providing respite for care partners, the beds would be used to serve clients discharged from hospital until they are able to cope on their own and also those waiting for long-term care. In this way, in addition to helping to keep people with dementia in the community, the initiative could help reduce hospital ALC days.
- Funding: CAH has applied to Toronto Central LHIN for project funding (as a pilot project). It would also absorb some of the costs itself.
- Budget:

Item	Funding source	One-time costs	Annualized costs
Apartment conversion	Centres d'Accueil Héritage	$35,000	
Accommodation (rental)	Centres d'Accueil Héritage		$6,720
Equipment	Centres d'Accueil Héritage	$10,000	
Equipment	TC LHIN	$11,000	
Maintenance	TC LHIN		$600
Training	TC LHIN	$1,500	
Accommodation (rental)	TC LHIN		$6,720
Human resources	TC LHIN		$64,995

3. Other respite beds:
    - There are other public and private respite beds in the GTA at long-term care homes, retirement homes and in specialty settings. The Alzheimer Society of Peel, for example, has a five-bed residence dedicated to respite care for individuals with dementia. None of them offers service in French.

Carers Program

As previously mentioned, the CARERS Program, developed by the Reitman Centre of Sinai Health System, is a 10-week group intervention and support program to help informal care partners better care for their care recipient and themselves. It includes a concurrent program for care recipients. The program is available in French and there is a memorandum of understanding between the Reitman Centre and Centres d'Accueil Héritage to pilot the program in French in the GTA. Centres d'Accueil Héritage is planning to pilot the program once its staff is fully trained. Estimated costs for one session with concurrent programs for care partners and care recipients are as follows:

Item	Funding Source	Costs per 10-week session (2.5 hours/session)
Training	In kind (Reitman Centre)	One-time cost
Supplies and Equipment:		
Care partner program	Centres d'Accueil Héritage	$ 66
Care recipient program	Centres d'Accueil Héritage	$150
Human Resources:		
Care partner program	Tbd	$2,750
Care recipient program	Tbd	$ 760

Total costs/session		$3,726

Adapted Housing/Transitional Services

Between the time when it is no longer safe for people with dementia to live at home with support from their informal caregivers and home care providers and the time they need to go to long-term care, there is a transitional period when it is possible for those without other complex medical needs to live in a secure home-like group setting in which they are semi-autonomous but receive services from a dedicated team trained to support people with mild-to-moderate dementia. Some retirement homes provide such settings. And as previously mentioned there are existing models like Sprint Ewart House in Toronto and Elizabeth Bruyère Village in Ottawa.

Congregate Living

Centres d'Accueil Héritage has submitted a report to Toronto Central LHIN on creation of an adapted housing model within Centres d'Accueil Héritage to meet the needs of its clients both at Place Saint-Laurent and in the community as their cognitive issues become more complex. This would be one way of meeting the growing needs of Francophones with dementia while delaying institutionalization and reducing the burden on long-term care and ALC beds in hospitals and potentially also reducing emergency room use for preventable causes by people with dementia.

As pointed out in the report, prepared by Santis Health,

> *CAH's new model will serve as a system resource in multiple ways. Certain programs (e.g., activation) will be available to the broader community living in the sub-LHIN geography. This model is an opportunity to test an approach that could be replicated and adapted for other populations with dementia and geographic areas. It is anticipated to be a particularly relevant example for how to create a culturally responsive environment that improves the experience, quality of life and health outcomes of non-English and ethno-culturally diverse populations. The best practices created by the early dementia care model will be shared and leveraged by other providers to enhance the overall system of care for people with dementia.*

Such a model should be part of a common basket of services and integrated into coordinated access systems for seniors and people with dementia at the LHIN sub-region, LHIN and GTA levels. It would need to be adequately resourced with appropriately trained staff and an adapted physical setting that would ensure the safety, security, comfort and social interaction of residents, staff and care partners.

Referrals for More Advanced Stages

Long-Term Care

Bendale Acres (Pavillon Omer-Deslauriers)

The Bendale Acres (Pavillon Omer-Deslauriers) model works well and should be maintained and expanded. In addition to providing long-term care in French, Bendale has developed close links with the Francophone community and with educational institutions providing training to French-speaking health

professionals (e.g. Collège Boréal, Glendon College, University of Toronto) and has become an integral part of the Francophone community. No additional funding would be required to maintain existing services or expand the French language unit to the entire 56-bed wing. People with behavioural and other issues who enter the secure dementia units are often stabilized and returned to their home unit. Consideration should be given to expanding the French language capacity of the secure units as part of Bendale Acres broader plan to increase its French-speaking staff.

If as part of its dementia action plan the Central East LHIN creates dementia care hubs in long-term care homes for people living in the community, Bendale Acres would be an ideal location for a French language service hub, especially working in partnership with other French language service providers (like Centres d'Accueil Héritage). It should certainly be part of a dementia care pathway for Francophones in Central East LHIN.

Bendale Model as Basis for Additional Services

A study jointly sponsored by Reflet Salvéo and Entité 4 is currently underway of the success factors and transferability of the Bendale Acres model of French language long-term care services. Once the study is completed, the French language planning entities and LHIN FLS coordinators could work together to identify opportunities for expansion of the model to other areas of the GTA within municipal, not-for-profit and for-profit long-term care facilities.

Recommendations

Implementation of the entire basket of programs and services would provide Francophone older adults with reasonable access to services that would meet a broad range of needs related to cognitive health and cognitive impairment. Some work has been done toward the realization of several of them, including multi-use beds, care partner support, a central seniors' line, congregate housing and further development of the Bendale Acres long-term care model, and work on them should continue. The introduction of models like bilingual navigators helps lay the foundations for increased support for older adults facing cognitive issues and their care partners.

Top Priority Recommendation

Early detection, assessment and intervention/Case management/Support for patients and care partners: Mobile integrated community and primary care memory services, as a regional service for the entire GTA based out of Centres d'Accueil Héritage and working in partnership with primary care providers, hospitals, health links and other organizations serving the Francophone community, especially those with a focus on older adults.

The importance of early diagnosis and intervention as a tool for enabling people with dementia to live useful lives in the community for as long as possible and allow them and their care partners to plan for the future and manage the disease has been consistently stressed. The need for assessing and serving people with dementia in a culturally and linguistically appropriate way, and preferably in their mother tongue, in an effort to avoid over-diagnosis and develop a suitable coordinated care plan that meets their needs at every stage of their dementia journey has also informed the selection of regional mobile

primary care memory services as the most important service essential for laying the foundation for an incremental improvement of services for this vulnerable population.

Click here: Mobile Integrated Community and Primary Care Memory Services for a fuller description of the recommended service model, including approximate costs.

Two Other Priority Recommendations

Two other areas have been identified as additional points of focus for more equitable delivery of services to Francophone older adults in the GTA and as key steps toward the creation of a continuum of services for older Francophones with cognitive impairments. Factors identified as essential for maintaining people with dementia in the community, reducing care partner burden and distress, reducing emergency room and ALC bed use and delaying institutionalization include community supports for both patients and care partners and support for navigation.

Support for navigation: Development of First Link in French, as a partnership among local Alzheimer Societies, the mobile integrated community and primary memory care services team (see project description) and community support providers like Centres d'Accueil Héritage;

Support for patients and care partners: Expansion of linguistically and culturally appropriate adult day programs, located in areas with larger numbers of Francophone older adults and developed/delivered through partnerships among existing FLS providers, Francophone community groups and centres. A quick win would be the development of a French-language adult day program at Bendale Acres.

Other Recommendations

The other recommendations scattered through the basket of services, though more local in nature, would make a significant contribution to the development of a care pathway for Francophone older adults facing cognitive health issues and their care partners. They can be phased in over time and adapted to changing circumstances as part of a global approach to meeting needs and leveraging existing resources. The following are some of the options.

Early diagnosis and intervention: Explore the potential of a pilot project specialized mobile memory clinic (Glendon Centre for Cognitive Health, Baycrest, Sunnybrook), including possible partnerships with existing health service providers and with the proposed mobile integrated community and primary care memory services team. An approximate costing for such a pilot (one day a week) is included in the mobile integrated community and primary care memory services project description (a regional project).

Support for navigation: Carry out the Centres d'Accueil Héritage Seniors Line pilot project and if it is successful, expand it to other GTA LHINs (TC LHIN).

Support for navigation: Explore the possibility of leveraging existing navigator and care coordinator positions (and new ones as they come on line) with a view to providing navigation support in French to people with cognitive issues and their care partners (CE LHIN, C LHIN, CW LHIN).

Support for care partners: Pilot the CARERS program at Centres d'Accueil Héritage to support care partners (TC LHIN).

Support for care partners: Support the multi-use beds project at Centres d'Accueil Héritage (TC LHIN).

Long-term care: Explore the potential for expanding the Bendale Acres model to other areas the GTA.

Alignment with LHIN Priorities

All of the LHINs have identified two priority populations, Francophones and Indigenous people and are "committed to improve access to equitable and accessible programs and services to both Aboriginal and Francophone residents … and reducing the impact of linguistic and cultural barriers on health system performance"[52].

They have also identified as a priority, providing better care to seniors, including those with dementia and other complex conditions, and better supports for their care partners. In their IHSPs, many of the GTA LHINs highlighted improvement of services and supports for people living with dementia and their care partners so as to enable them to remain in the community as contributing members of society as long as possible; timely and easily navigated access to such services and supports; and appropriate long-term care when the time comes.

Throughout the IHSPs, there was a consistent focus on coordinated and integrated quality care in the community, building system capacity to meet the increasingly complex needs of an aging and diverse population, introducing innovative models of care, promoting a greater role for patients and caregivers in care management and encouraging partnerships both within the health system and with municipal and other external partners.

These recommendations are well aligned with the priorities and strategic directions the LHINs identified in their plans. Creation of mobile integrated community and primary care memory services as a GTA-wide initiative closely connected with the community support sector would see the introduction of an innovative model of care adapted to the needs and circumstances of the Francophone community of the GTA in a way that leverages limited resources while building system capacity. The mobile integrated community and primary care memory services model promotes integration of the primary care provider, the patient and the care partner into management and planning of every stage of the disease while

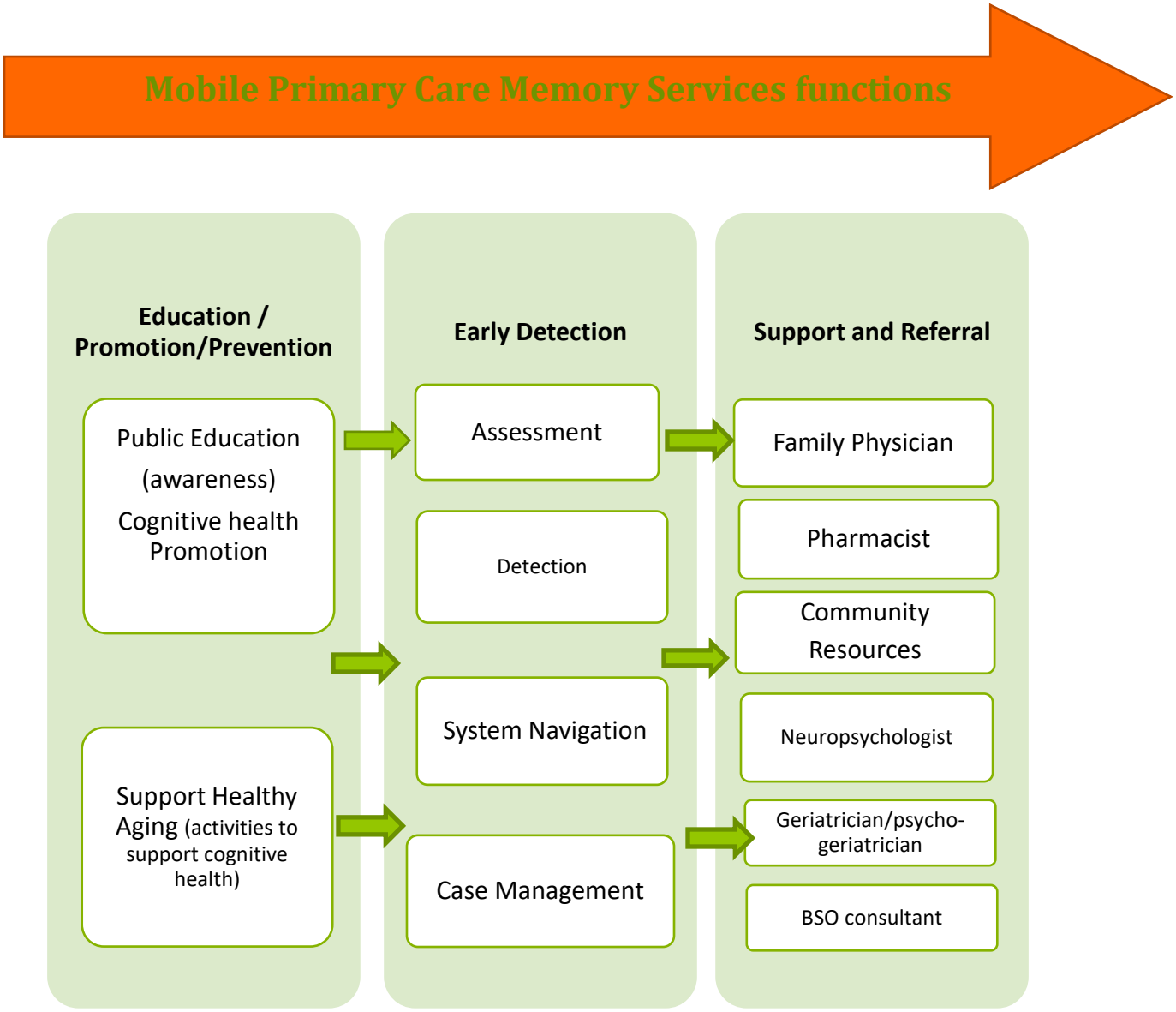
[52] Central Local Health Integration Network. *Caring Communities, Healthier People Integrated Health Service Plan (IHSP4) for the Central Local Health Integration Network 2016-2019*. Aurora, April 2016.

encouraging partnerships with a variety of organizations both inside the health system and in the broader community. All of the top three recommendations support easier navigation of the system.

Mobile Integrated Community and Primary Care Memory Services: A Regional Program

Functions

- Outreach to the Francophone community and primary care providers serving Francophone patients and their care partners
- Public education and awareness building
- Support for healthy aging memories, including cognitive/brain health programs like “Musclez vos meninges” or “Memory and Aging Program” or some Alzheimer Society activities
- Early detection of cognitive impairments, assessments and intervention
- Help with system navigation and referrals to specialist and community resources
- Support for case management
- Data collection, management and analysis
- Support to family physicians, patients and families/care partners



Proposed Composition of the Interdisciplinary Team

- Patient's Family Physician:
  - Phase 1: Family physicians from CFT and TAIBU (including TAIBU's bilingual nurse practitioner)
  - Phase 2: Credit Valley FHT
  - Phase 3: Collaboration with other family physicians serving Francophone patients

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- Nurse practitioner
- Social worker
- Occupational therapist

- Coordinator and administrative support

- On as-needed basis:
    - Pharmacist
- Linkages with Specialist Services (may have to be LHIN specific and may vary from LHIN to LHIN; could include French-speaking specialists at Baycrest)
    - Neuropsychologist
    - Geriatrician/psycho-geriatrician
    - BSO consultant
    - Etc.

Partnerships:

Bring in partners as model is phased in, starting with Toronto Central and Central East LHINs in Phase 1, Mississauga Halton and Central West LHINs in Phase 2 and Central LHIN in Phase 3:

- LHINs (starting with Toronto Central and Central East)
- Health Service Provider Partners
    - Centre francophone de Toronto
    - TAIBU
    - Credit Valley Family Health Team
    - Centres d'Accueil Héritage
    - Community health centres with bilingual navigators (Black Creek, Wellfort)
    - Alzheimer Societies (Durham, Toronto, Peel, York)
    - Community Care Access Centres
    - Health Links
    - Hospitals including St. Michael's
    - Glendon Centre for Cognitive Health, Baycrest and Sunnybrook (for more complex patients needing more specialized assessments, interventions and care planning)
    - Seniors Care Network
- Community Partners
    - Centres d'Accueil Héritage
    - Retraite active
    - Cercle des aînés noirs francophones de l'Ontario
    - Cercle de l'Amitié/Club du Bel Âge
    - Kay Créole
    - Club Jeunesse d'hier
    - L'Amicale
    - Others….
- Training Partners
    - Glendon College, Collège Boréal (for instance, team could present its work to PSW students as well as psychology students at Glendon)

- Glendon College and Baycrest could also be training partners for training for team on tools and programs like KBNA and Memory and Aging Program and additional support programs such as data base management as they become available in French

Training

Training in the primary care memory services model for physicians involved as well as interdisciplinary team staff and possibly specialists with whom team will establish linkages for more complex cases. The training is a five-day program available in French. This model is based on the Centre for Family Medicine Family Health Team (CFFM) Memory Clinic Model. The comprehensive inter-professional training program developed by the CFFM consists of a 2 day workshop, 1 day observership, and 2 days of mentorship at the physician's site. Costs are about $1600/participant. Although the initial time investment for family physicians is quite heavy, once the model is in place, the physician time commitment is estimated at 0.6-0.7 hour per patient[53].

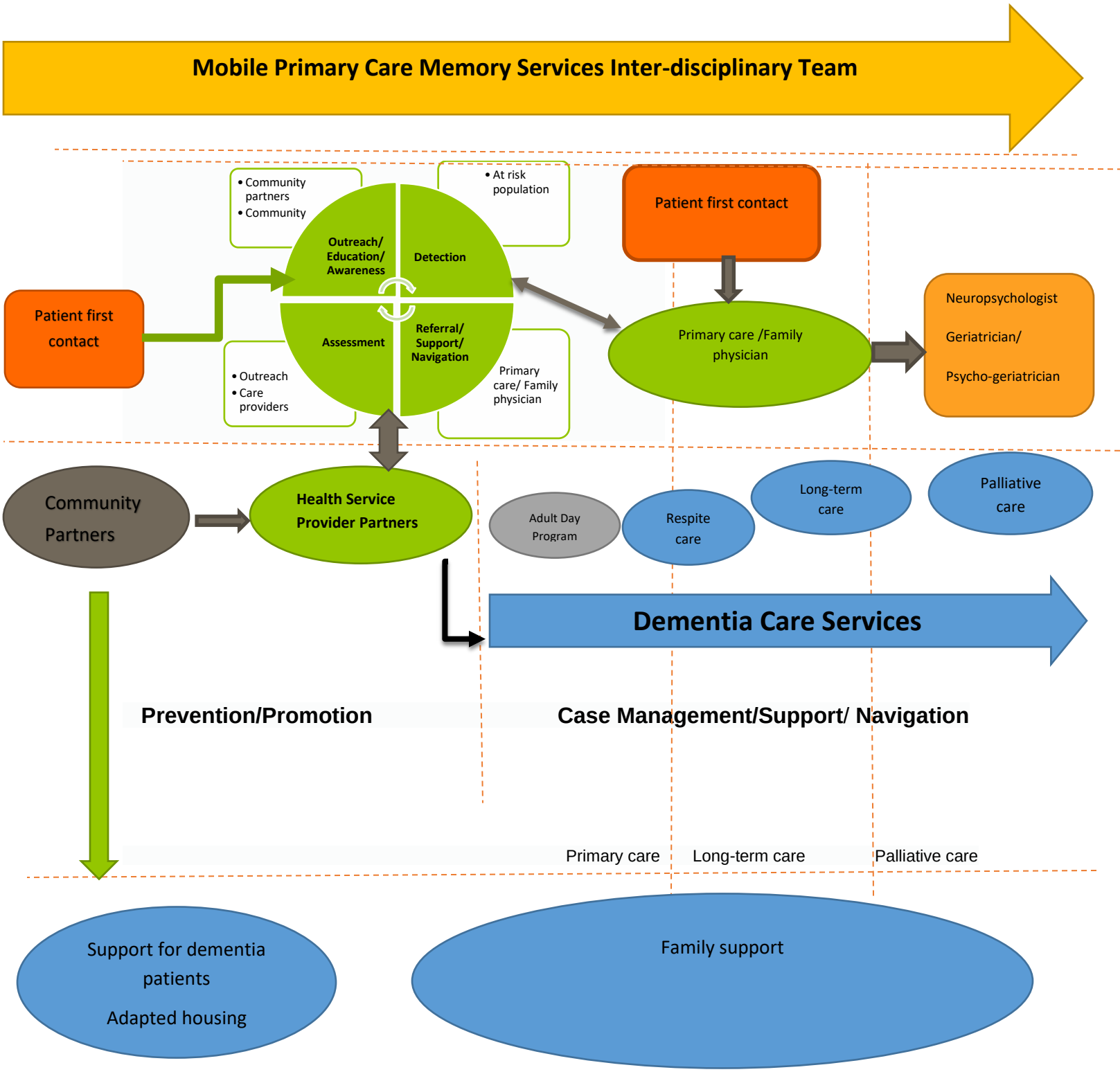
Team members may also need training in the use of the assessment instruments including MMSE, MOCA as well as the cognitive health programs they will deliver. Training is also available for KBNA, but this instrument can be interpreted only by registered psychologists or equivalent.

Outreach

Experience has shown that outreach is a key component of any French language health initiative, especially in the early stages, and that it takes longer for programs delivered in French to reach full capacity. Allowance will have to be made for this in program planning and implementation.

- To broader Francophone community to publicize program and get buy-in, to show how it is accessible, meets needs and takes account of the specificity of the Francophone community and to demonstrate that it is of equal or higher quality to English language programs
- To Francophone community organizations to build partnerships around education and awareness programs
- To family physicians to publicize program and get buy-in – demonstrate how the team is a useful resource that will help them better manage their patients with cognitive issues and make the best use of their limited time
- To health care provider organizations like hospitals
- To community support and home care sector (both French and English)

[53] Centre for Family Medicine Family Health Team (CFFM) Memory Clinic Model. Information for FHT physicians. Accessed at http://www.rgpeo.com/media/68301/memory%20clinic%20-%20information%20for%20fht%20physicians.pdf Retrieved on November 11, 2016.


Mobile Primary Care Memory Services Inter-disciplinary Team
• Community partners
• Community
• At risk population
Outreach/ Education/ Awareness
Detection
Assessment
Referral/ Support/ Navigation
• Outreach
• Care providers
Primary care/ Family physician
Patient first contact
Patient first contact
Primary care /Family physician
Neuropsychologist
Geriatrician/
Psycho-geriatrician
Community Partners
Health Service Provider Partners
Adult Day Program
Respite care
Long-term care
Palliative care
Dementia Care Services
Prevention/Promotion
Case Management/Support/ Navigation
Primary care
Long-term care
Palliative care
Support for dementia patients
Adapted housing
Family support

Flow Chart[54]

Education and Public Awareness/Support for Healthy Aging Memories

- In partnership with CHCs/FHT/EPCs, Alzheimer Societies and community groups with a focus on older adults, offer workshops for older adults and care partners:
    - What is dementia
    - Self-assessment opportunities
    - Support for healthy aging memories/cognitive health
    - Prevention strategies – healthy life style, chronic disease management
    - Advice on next steps where appropriate (when to follow up with family doctor, for instance)
- Website with links to many information sites/tools available in French
- Social media presence

Early detection of cognitive impairments, assessments and intervention/ Help with system navigation and referrals to specialist and community resources/Support for case management

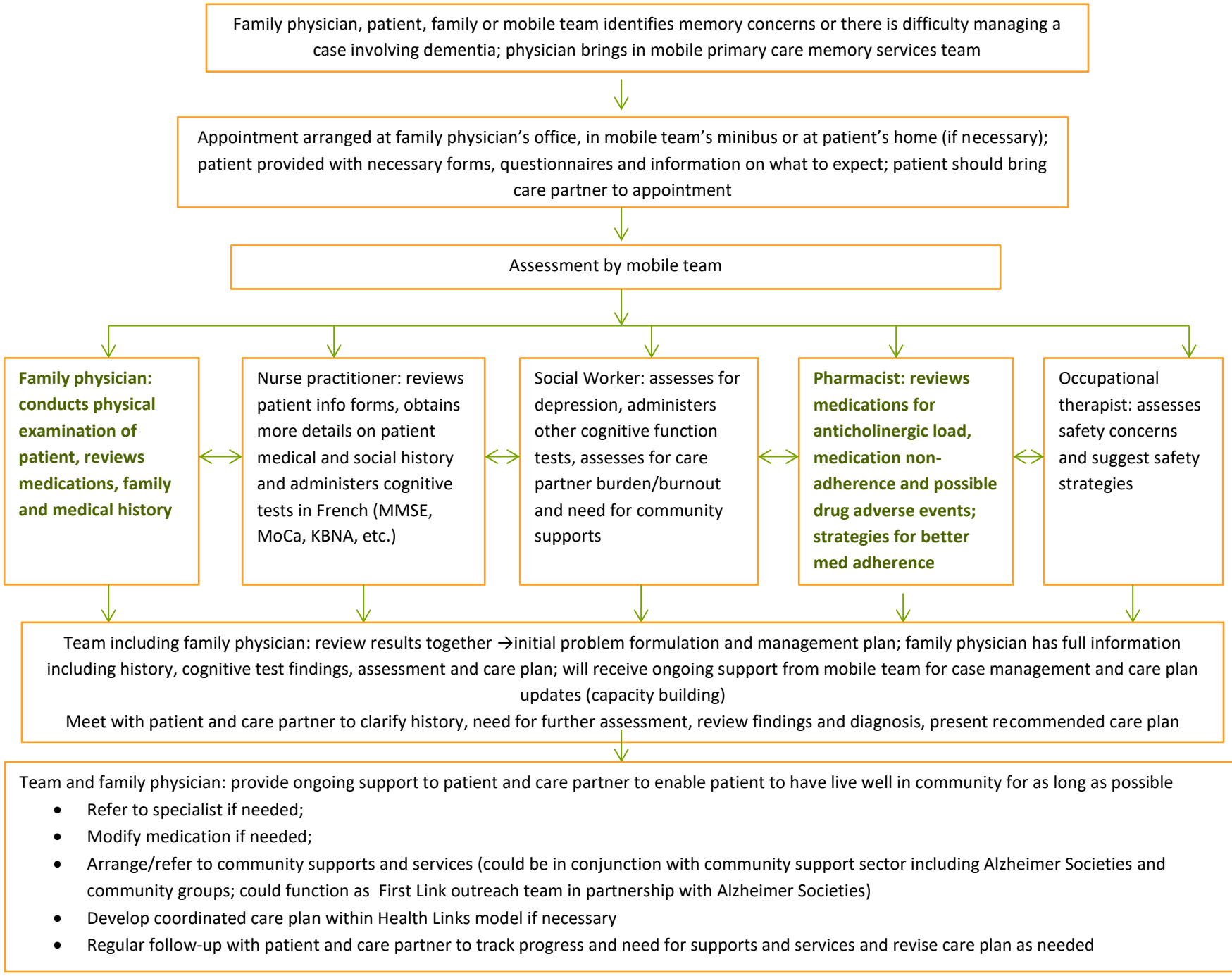
- In partnership with CHCs/FHT with patient's physician as integral team member
- Perform comprehensive dementia assessment, screening for alternate diagnoses, functional and medication assessments, and strategic support and treatment for patient and family, leveraging the available community resources.

The family physician would be the lead and would play the role of principal care coordinator for the patient and care partner/family. With their knowledge of the family background, medical history and culture, the family physician plays a crucial role. The family physician is the health professional with whom the patient has usually developed a long-standing relationship of trust and the one to whom the patient turns first for advice.

It is proposed that the model be phased in, starting with French-speaking physicians at the CFT, Credit Valley and TAIBU (nurse practitioner). A second phase would be outreach to and inclusion of non-French speaking family physicians in a variety of settings with French-speaking patients with cognitive issues.

Another key component is the inclusion of the patient in all planning and decision making for as long as possible. The care partner is also important with a view to managing care partner burden and avoiding burnout. The linguistic and cultural needs of both patient and care partner will be taken into account at every stage of the journey.

[54] The flow chart is based on two documents: Linda Lee et al. "Enhancing Dementia Care: A Primary Care-Based Memory Clinic", Canadian Journal on Aging / La Revue canadienne du vieillissement, 33, pp 307-319 doi:10.1017/S0714980814000233; and "Central East LHIN Primary Care-Based Memory Services Project Proposal", Submitted to Central East Local Health Integration Network, Initial Submission August 14, 2015, Updated September 18, 2015.


Family physician, patient, family or mobile team identifies memory concerns or there is difficulty managing a case involving dementia; physician brings in mobile primary care memory services team
Appointment arranged at family physician's office, in mobile team's minibus or at patient's home (if necessary); patient provided with necessary forms, questionnaires and information on what to expect; patient should bring care partner to appointment
Assessment by mobile team
Family physician: conducts physical examination of patient, reviews medications, family and medical history
Nurse practitioner: reviews patient info forms, obtains more details on patient medical and social history and administers cognitive tests in French (MMSE, MoCa, KBNA, etc.)
Social Worker: assesses for depression, administers other cognitive function tests, assesses for care partner burden/burnout and need for community supports
Pharmacist: reviews medications for anticholinergic load, medication non-adherence and possible drug adverse events; strategies for better med adherence
Occupational therapist: assesses safety concerns and suggest safety strategies
Team including family physician: review results together →initial problem formulation and management plan; family physician has full information including history, cognitive test findings, assessment and care plan; will receive ongoing support from mobile team for case management and care plan updates (capacity building)
Meet with patient and care partner to clarify history, need for further assessment, review findings and diagnosis, present recommended care plan
Team and family physician: provide ongoing support to patient and care partner to enable patient to have live well in community for as long as possible
• Refer to specialist if needed;
• Modify medication if needed;
• Arrange/refer to community supports and services (could be in conjunction with community support sector including Alzheimer Societies and community groups; could function as First Link outreach team in partnership with Alzheimer Societies)
• Develop coordinated care plan within Health Links model if necessary
• Regular follow-up with patient and care partner to track progress and need for supports and services and revise care plan as needed

Beyond the clinical elements in the flow chart, team members would play an important role in outreach, public education and awareness and cognitive health/prevention aspects of the program. All team members would play a crucial role in getting the program going, including outreach to the community and health service providers. The social worker, for instance, could provide a link to the community as well as the Alzheimer Society's First Link program and deliver education and cognitive health activities.

Approximate Costs

Host Agency			
Item		**One-time costs**	**Annualized costs**
Start-up Costs			
Memory services training (10 x $1600)		$16,000	
Laptops (4)		$4,200	
Ongoing Costs			
Human resources			
Family physicians (as part of regular patient care)			In kind
Nurse practitioner (1 FTE)			$100,000
Social worker (1 FTE)			$85,000
Occupational therapist (1 FTE)			$90,000
Coordinator & admin support (1 FTE)			$76,000
Operations			
Mobile telephones (4)			$4,000
Travel			$5,000
Rent/utilities			In kind
Program expenses			$7,500
Total costs – host agency		**$20,200**	**$367,500**
Partner Agencies			
Ongoing Costs			
Human resources			
SGS Pharmacist (consult as needed, estimated at equivalent of .13 FTE)			$16,225
BSO clinician (consult as needed, estimated at equivalent of .5 FTE)			$42,500
Specialized memory clinic services (consult as needed, estimated at equivalent of one day per week):			$86,600
Human resources			
Junior psychologist:	$24,000		
Psychometrician	$17,400		
Project coordination	$13,200		
Senior consultant	$8,000		
Clinical consultants	$10,000		
Operations			
Travel	$4,000		
Program costs	$10,000		
Total costs – partner agencies			**$145,325**
Total costs – project		**$20,200**	**$512,825**

Potential Enhancements

Telemedicine

By tapping into the OTN network and including a telemedicine platform in the model, its reach and effectiveness could be enhanced, especially for physicians, patients and care partners in more remote or rural areas where the Francophone population is more widely scattered and access to services in French is extremely limited or non-existent (Georgetown, Caledon, Peterborough, for example). A rough estimate of the additional costs involved is $10,000.

Travelling Mobile Clinic

A model particularly well suited to a Francophone population scattered across the GTA, including in non-designated, suburban, rural and underserved urban areas where transportation is often an issue is the bus-based travelling mobile clinic model (MOBYSS) instituted in York Region by the CMHA to serve youth. By travelling to places where Francophone older adults and families gather (churches, community centres, cultural associations, golden age clubs, retirement homes, community cultural events, FLS information fairs), staff would be able to reach out to seniors and their families to provide information, conduct public education and awareness activities and brain health activities and even, if a suitable space were built into the vehicle, conduct assessments and provide counselling. A link to the OTN could be included for referrals to/delivery of more specialized services.

In the case of the MOBYSS, a partnership among a range of health and social service providers, funding is provided by a hospital charitable foundation combined with funds raised directly by the CMHA and other partners. Capital costs were covered through the Trillium Foundation.

Appendices

Appendix A – Steering Committee Members

Gilles Marchildon, Executive Director, Reflet Salvéo, French Language Health Planning Entity

Josée Roy, Health Planner, Reflet Salvéo, French Language Health Planning Entity

Estelle Duchon, Executive Director, Entité 4, French Language Health Planning Entity

Nancy Steben, Planning Officer, Entité 4, French Language Health Planning Entity

Ameth Lo, Director of Planning, Entité 4, French Language Health Planning Entity (as of January 2017)

Ameth Lo, Lead, Health System Development & Community Engagement, French Language Services, Mississauga Halton LHIN (until January 2017)

Elizabeth Molinaro, Lead, Health System Development & Community Engagement, French Language Services, Mississauga Halton LHIN (as of March 2017)

Patrick Boily, French Language Health Services Coordinator and Aboriginal Health Consultant, Central West LHIN (until September 2016)

Dieufert Bellot, French Language Health Services Coordinator and Aboriginal Health Consultant, Central West LHIN (as of January 2017)

Tharcisse Ntakibirora, French Language Services Coordinator, Toronto Central LHIN

Christelle Bony, Bilingual Health Planner (FLS), Central LHIN (until August 2016)

Lisa Gotell, Bilingual Health Planner (FLS), Central LHIN (as of October 2016)

Dieufert Bellot, Planner, French Language Health Services, Central East LHIN (until January 2017)

Khedidja Hmamad, Coordinator of the Cognitive Health Center of Glendon, York University

Barbara Ceccarelli, Assistant Executive Director, Centres d'Accueil Héritage

Appendix B – Overview of GTA LHIN IHSP Strategic Directions, Priorities and Initiatives

Strategic Directions/Priorities	Strategic Initiatives
Central West LHIN[55]	
Build integrated networks of care	- Health links and primary care - Home and community care renewal - Mental health and addictions services - Palliative and end-of-life care - Long-term care renewal
Drive quality and value	- Improve the patient experience - Quality and innovation - Health system funding reform - Enabling technology integration
Connect and inform	- Community engagement - French language services - Aboriginal health
Demonstrate system leadership	- System capacity planning - Population health - Dementia strategy - Build on the momentum
Mississauga Halton LHIN[56]	
Access	- Integrate and partner for improved access and services through coordinated efforts - Bring care closer to home - Make it simpler to navigate the system and reduce barriers
Capacity	- Quantify capacity needs and expand supports to care providers - Enhance program capacity to support right care at right place - Recognize and address the role of the social determinants of health in sustainable person-centred health care management
Quality	- Ensure the needs and the voice of patients and families shape how care is delivered - Coordinate and integrate care with the person at the heart of the health care system - Foster a culture of health and community wellness
Toronto Central LHIN[57]	
Designing health care for the future	- Align funding mechanisms and service design with specific targets for improved patient outcomes - Engage diverse populations in service redesign

[55] Central West Local Health Integration Network. Healthy Change, Integrated Health Service Plan 2016-2019.
[56] Mississauga Halton Local Health Integration Network. Partnering for a Healthy Community, Integrated Health Service Plan 2016-2019.
[57] Toronto Central Local Health Integration Network. Strategic Plan 2015-2018.

Strategic Directions/Priorities	Strategic Initiatives	
	- Work with health service providers to re-organize the system to enable strategies based on the best available evidence - Integrate the patient experience by allocating funding to the patient journey rather than individual tests, visits and procedures - Leverage funding tools to encourage health service providers to align their services with broader health care objectives - Encourage strategic integration of services - Use TC LHIN's local data sets to plan for implementation of the Ministry's long-term plan for capacity of the health care system.	
Taking a population health approach	- Establish accountability for ensuring that all residents within our catchment area have access to services - Foster the evolution of the Health Links model which brings together teams of local health service providers to ensure consistent and effective care for complex patients through coordinated care planning - Harness a robust data collection system that captures the unique needs of the communities we serve. This data will support our ability to stratify populations into meaningful groups for planning, allow us to identify health inequities and other unmet needs and develop appropriate and targeted solutions - Work with patients and health service providers within subpopulations to implement targeted solutions that bridge gaps in access and appropriateness of care - Build strategic relationships with other partners (for example, Toronto Community Housing, United Way, Toronto Police Service and Toronto Paramedic Services) to strengthen community and social supports and improve health. - Engage marginalized populations	
Transforming primary health and community care	- Increase capacity for services and service integration - Develop technology that allows for sharing patient data across sectors and providers - Develop common tools and IT infrastructure to support the community - Draw on a range of supports outside of the health portfolio - Create new models to integrate providers around the needs of patients and neighbourhoods - Co-locate services in a way that is meaningful to the local community - Target funding to drive strategic integrations	
Achieving excellence in operations	- Facilitate integration and partnerships via shared tools and projects - Build the core competencies of the Toronto Central LHIN - Initiate public reporting of performance metrics to drive provider excellence in care delivery - Build leadership capacity to support change management in the system - Develop policy frameworks to guide health equity and community engagement activities	
Central LHIN[58]		
Better seniors care	Develop specialized strategies and support systems to help older adults stay healthy and independent at home for as long as possible. Reduce reliance on	- Seniors will have better and more timely access to care in the community to help them live safely and independently at home

[58] Central Local Health Integration Network. Caring Communities, Healthy People, Integrated Health Service Plan 2016-2019.

Strategic Directions/Priorities	Strategic Initiatives	
	acute care by exploring and implementing other options that are senior-friendly and cost-effective	- Seniors will have better outcomes and will be less likely to decompensate in hospital - Seniors with dementia or behavioural issues will receive timely access to appropriate care - The number and types of long-term care beds will align to what the community needs
Better palliative care	Provide holistic, proactive and continuous care and support for patients with progressive, life-limiting illness and for their families. Support families through the entire spectrum of care before and after death by helping patients to live as they choose, and to die in their preferred location of choice – with quality of life, comfort, dignity and security.	- Patients have the choice to live their end-of-life period in their preferred location - Improved community access to essential supports and services, including advanced care planning - Easier navigation system for patients and caregivers - Palliative residents in long-term care homes will benefit from care providers with enhanced knowledge and skills to support them - Specialists will provide support and education to primary care providers to support their patients through their end of life journey
Better care for kids and youth	Develop new partnerships and innovative models to bring specialized care closer to home, for children and youth	- Prevention of unnecessary hospital admissions and more efficient discharge from hospital when hospitalization is required - Children and their families will benefit from paediatric care, in the Emergency Department and in the hospital that's closest to their home - More equitable access to hospital paediatric care, as close to home as possible - More community supports for children from birth to 18 who have complex medical needs, and for their families
Better community care	Create stronger links to integrated community services and to primary care, to help patients recover and receive more of their health care at home, with safety and independence	- Patient and family caregivers will understand what services to expect and be better able to participate in the development of their care plan - Patient experience across transitions will improve, with standardized assessments and care plans that are shared across providers - Patients will have more timely access to home and community care, with better outcomes - Services will be more consistent, efficient, aligned and evidence-based across all providers

Strategic Directions/Priorities	Strategic Initiatives	
		- Transparency and ease of navigation will improve for patients and families Services will be delivered more efficiently
Better care for underserved communities	Create organized, integrated systems of care to improve early intervention and treatment of disease in neighbourhoods where there are recurring patterns of chronic and acute or episodic health conditions. Develop partnerships that will improve long-term health by addressing the key factors that determine healthy outcomes	- More equitable access to appropriate health services, including home and community services, leading to better outcomes Patients and their families will be able to manage their chronic conditions - Chronic conditions for these populations will be addressed in the most appropriate settings - Patients will have an improved experience and more satisfaction with their care Increased access to culturally and linguistically competent services leading to improved outcomes - Marginalized populations are better informed regarding existing resources - Focus on Francophone and Aboriginal communities
Better mental health	Integrate a supportive system of programs and services to enhance the wellness of people with mental health and addictions, and to promote and sustain recovery	- More efficient discharge from hospital after an admission for mental health and addictions - Increased awareness of health care options, coordination and ease of navigation - Increased access to housing supports for sustaining housing tenancy for those living with mental health and addictions challenges - Increased ability for people with mental health and addictions to access needed services in a timely way
Central East LHIN[59]		
Strategic directions/outcomes	Strategic directions	- Transformational leadership - Quality and safety - Service and system integration - Fiscal responsibility
	Population health	- Focus on population health - Equitable
	Patient experience	Integrated Accessible Person-centred Effective Safe
	Cost control	Efficient Appropriately resourced
Strategic aims: reduce need for hospital care for target groups	Seniors	- Continue to support frail older adults to live healthier at home

[59] Central East Local Health Integration Network. Living Healthier at Home, Integrated Health Service Plan 2016-2019.

Strategic Directions/Priorities	Strategic Initiatives	
		- Better health care for seniors and caregivers
	Vascular health	- Continue to improve vascular health
	Mental health and addictions	- Continue to support people for optimal level of mental health - Provide proper supports for faster more sustainable recovery
	Palliative care	- Continue to support palliative patients to die at home - Ensure timely access to palliative care
Direct care priorities	Health links	
	Primary health care	
	Patient and family caregivers	
	Home and community care	
	Supported living environments	
	Health equity – diversity	
	Child and family	
Health system enablers	Pursuing quality and safety through effective access and transitions	
	System design and integration	
	Enabling technologies and integration (EHIM)	
	Health system funding reform	

Appendix C – Definitions of Some Types of Dementia

Excerpted from *Developing Ontario's Dementia Strategy: A Discussion Paper*

Alzheimer's Disease:	A type of dementia that causes problems with memory, thinking, behaviour, mood and emotions, physical abilities and the ability to perform familiar activities. Alzheimer's disease is the most common type of dementia, accounting for approximately 65 per cent of cases. While most people who develop Alzheimer's Disease are over the age of 65, some people in their 40s or 50s also develop it.
Frontotemporal Dementia:	A type of dementia that affects parts of the brain that involve personality, behaviour and language. Changes associated with frontotemporal dementia may include becoming more withdrawn, inappropriate social behaviour and speaking less or difficulty finding the right words. Frontotemporal dementia is a rarer type of dementia and tends to occur between the ages of 40 and 75.
Lewy Body Dementia:	A type of dementia that affects parts of the brain that involve thinking, memory and movement. Changes associated with Lewy body dementia may include visual hallucinations, changes in sleep patterns, memory loss, stiffness of muscles, shaking, and slow movement. Lewy body dementia is a rarer type of dementia and tends to occur in people over the age of 60.
Mild Cognitive Impairment:	A person with mild cognitive impairment may experience problems with memory, language, thinking or judgment that are greater than those experienced in normal aging. In general, these changes are usually not serious enough to interfere with a person's ability to carry out daily activities or to live independently. A person with mild cognitive impairment is at increased risk of developing dementia.
Parkinson's Disease with Dementia:	Parkinson's disease affects parts of the brain that involve movement, resulting in stiffness of muscles, shaking and slow movement. As this disease progresses, some people may also develop dementia. This may result in changes such as visual hallucinations, memory loss and difficulty concentrating or thinking.
Responsive Behaviours:	A term used to describe how a person's actions, words or gestures may be a response to circumstances within their personal (e.g., an infection), physical (e.g., noise, lighting) or social (e.g., boredom) environment that may be important, frustrating or confusing to a person. Examples of responsive behaviours include actions interpreted as agitation, aggression and wandering, among others. Placing negative labels on a person living with dementia (e.g., challenging, aggressive) can strongly influence how a person with dementia is perceived or treated. The term responsive behaviours is intended to assist care partners and care providers in providing high quality care by using language that encourages these individuals to understand the actions of a person with dementia and respond in appropriate, compassionate ways.
Vascular Dementia:	A type of dementia caused by restricted blood flow to the brain, such as from a stroke. Changes associated with vascular dementia may include confusion, memory problems and difficulty concentrating or organizing thoughts. It is a common form of dementia, accounting for approximately 20% of all cases.

Appendix D – Community Consultations and Surveys

Mississauga Halton and Central West LHINs

Focus group, Cercle de l'Amitié, Brampton on April 22, 2016 (10 participants)

Toronto Central LHIN

Survey, August 16-September 7, 2016 (25 respondents)

Central LHIN

Survey, July 20-29, 2016 (32 respondents)

Central East LHIN

Focus group, L'Amicale, Oshawa on March 15, 2016 (15 participants)

Focus group, TAIBU Community Health Centre, Scarborough on May 28, 2016 (8 participants)

Discussion Guide/Survey Questionnaire

Guide de discussion pour les organismes communautaires francophones

But du projet

Pour répondre aux besoins grandissants des personnes aînées francophones de la Région du Grand Toronto, Reflet Salvéo et l'Entité 4 collaborent sur une étude de faisabilité sur la santé cognitive. Le but de l'étude est d'élaborer des options pour des modèles de services de mémoire, incluant un centre de mémoire, axé sur la détection et l'intervention très précoce en matière de troubles cognitives légères ainsi qu'un volet référencement pour les troubles plus sévères. Ces modèles comprendront la création d'outils de prévention et de traitement. Ils s'aligneront sur les priorités énoncées par les RLISS dans leurs plans de services de santé intégrés 2016-2019 ainsi que les stratégies provinciales en matière de démence et priorité aux patients, ils reposeront sur le travail accompli jusqu'à présent et les ressources déjà en place, exploreront les possibilités de partenariat et répondront aux critères de financement.

Dans ce contexte, nous cherchons l'input, entre autres, des organismes communautaires francophones. Notre objectif est d'apprendre de vos expériences quand vous avez eu à vous occuper d'un(e) proche qui avait des petits problèmes de mémoire ainsi que de recueillir vos idées sur ce qui marche bien en ce qui concerne les services pour les gens atteints de troubles cognitives, ce qui pourrait être amélioré et comment.

Questions à explorer

Connaissances en matière de santé cognitive/démence

1. Si quelqu'un de votre famille avait des problèmes de mémoire ou manifestait des signes de troubles cognitives légères, où iriez-vous chercher de l'information sur les services disponibles dans votre communauté? En français?

2. Où iriez-vous chercher de l'aide? (pour votre proche ou pour vous-même comme aidant)

3. Connaissez-vous les services des centres de mémoire (« memory clinics »)?

Expérience des services de santé cognitive/démence

4. Pouvez-vous nous parler des expériences que vous ou quelqu'un que vous connaissez avez vécues avec des services en matière de problèmes de mémoire ou de démence? Avez-vous des exemples d'expériences positives? Avez-vous des exemples d'expériences négatives?

5. À votre avis, qu'est ce qui pourrait empêcher les gens de chercher de l'aide quand ils soupçonnent que quelque chose ne va pas?

Besoins/priorités

6. Basé sur votre expérience ou celle d'une connaissance, quels sont les plus grandes lacunes et les plus grands défis auxquels on fait face en matière de soutien pour les personnes atteintes de troubles cognitives et leurs aidants?

7. D’après vous, quels sont les besoins de la population francophone de votre région (ou de votre communauté) en termes de services de santé cognitive/démence?

Stratégies d’amélioration

8. Pouvez-vous nous donner vos idées sur ce qu’il faudrait faire pour combler les besoins des gens de votre communauté? Et pour mieux répondre aux besoins ou difficultés particuliers de certains groupes?

9. D’après vous quel rôle pourrait jouer votre groupe ou organisation dans ce projet?

10. Y a-t-il autre chose que vous aimeriez ajouter?

Sondage

Reflet Salvéo, responsable de la PLANIFICATION DES SERVICES DE SANTÉ EN FRANÇAIS dans la région du Grand Toronto, en collaboration avec une autre entité de planification de la région, fait une étude de faisabilité afin de développer des options pour des services en français pour les personnes qui ont des problèmes de mémoire ou des troubles cognitifs légers.

Le mot « cognitif » englobe toutes les fonctions gérées par le cerveau : langage, mémoire, raisonnement, coordination, perception, planification, jugement et organisation.

Avec ce sondage, nous cherchons l'input des membres de la communauté et des organismes francophones. Nous voulons apprendre de vos expériences lorsque vous avez eu à vous occuper d'un(e) proche qui avait des problèmes de mémoire.

Le sondage nous aidera aussi à recueillir vos idées sur ce qui fonctionne bien dans le système actuel en services de santé pour les gens atteints de troubles cognitifs, ce qui pourrait être amélioré et comment.

Le sondage est confidentiel.

Connaissances en santé cognitive/démence

11. Si quelqu'un de votre famille avait des problèmes de mémoire ou manifestait des signes de troubles cognitives légères, où iriez-vous chercher de l'information sur les services disponibles dans votre communauté? Cochez toutes les réponses pertinentes.

    ☐ Médecin de famille ☐ Centre de santé communautaire/Équipe de santé familiale

    ☐ Centre d'accès aux soins communautaires (CCAC) ☐ Société Alzheimer

    ☐ Lignesanté.ca ☐ Internet ☐ Centre de mémoire (memory clinic) ☐ Hôpital

    ☐ Autre : _____

12. Où iriez-vous chercher de l'aide? (pour votre proche ou pour vous-même comme aidant), Cochez toutes les réponses pertinentes.

    ☐ Médecin de famille ☐ Centre de santé communautaire/Équipe de santé familiale

    ☐ Centre d'accès aux soins communautaires (CCAC) ☐ Société Alzheimer

    ☐ Centre de mémoire (memory clinic) ☐ Hôpital

    ☐ Autre : _____

13. Avez-vous accès aux services d'information ou d'aide en français en matière de santé cognitive?

    ☐ Oui ☐ Non Si oui, où? _____

Expérience des services de santé cognitive/démence

14. Si vous ou quelqu'un que vous connaissez avez de l'expérience avec des services de mémoire ou de démence, pouvez-vous décrire brièvement une expérience positive?

_____
_____
_____

15. Une expérience négative?

_____
_____
_____

16. À votre avis, qu'est ce qui pourrait empêcher les gens de chercher de l'aide quand ils soupçonnent que quelque chose ne va pas? Cochez toutes les réponses pertinentes.

☐ Manque d'information sur la maladie ☐ Ne pas savoir où aller ☐ Pas de services en français

☐ Il n'y a rien à faire ☐ Crainte des résultats ☐ Stigma/tabou

☐ Autres : _____

Besoins/priorités

17. D'après vous, quels sont les besoins de la population francophone de votre région (ou de votre communauté) en termes de services de santé cognitive/démence? Cochez toutes les réponses pertinentes.

☐ Formation pour les patients et aidants ☐ Services/ressources en français ☐ Soins à domicile

☐ Aide à la navigation dans le système ☐ Services de soutien pour les patients

☐ Services de soutien pour les aidants ☐ Professionnels de la santé mieux informés

☐ Autres : _____

Stratégies d'amélioration

18. Comment peut-on combler les besoins des gens de votre communauté? Et mieux répondre aux besoins ou difficultés particuliers de certains groupes?

_____
_____
_____

19. Y a-t-il autre chose que vous aimeriez ajouter?

_____
_____
_____

Merci beaucoup de votre collaboration !

Appendix E – Interviews with Key Informants

Local Health Integration Networks

Liane Fernandes, Senior Director, Health System Performance, Mississauga Halton LHIN
Sandra Gagnon, Senior Lead, Health, System Development and Community Engagement, Mississauga Halton LHIN

Mark Edmonds, Director, Health System Integration, Central West LHIN

Patrick Boily, French Language Health Services Coordinator and Aboriginal Health Consultant, Central West LHIN

Shehnaz Fakim, Senior Consultant, Health System Integration, Design and Development, Toronto Central LHIN
Tharcisse Ntakibirora, French Language Services Coordinator, Toronto Central LHIN

Ashley Hogue, Senior Planner, Central LHIN
Christelle Bony, Bilingual Health Planner (French Language Services), Central LHIN

Antoinette Larizza, Director, System Design and Integration, Seniors Portfolio, Central East LHIN
Dieufert Bellot, Planner, French Language Health Services, Central East LHIN

Academic Partners

Dr. Guy Proulx, Glendon Campus, York University

Khedidja Hmamed, Coordinator, Centre for Cognitive Health, Glendon, York University

Dr. Geneviève Quintin, Researcher, Centre for Cognitive Health, Glendon, York University

Dr. Andrée-Anne Cyr, Researcher, Centre for Cognitive Health, Glendon, York University

Dr. Josée Rivest, Researcher, Centre for Cognitive Health, Glendon, York University, affiliated with Baycrest Centre for Geriatric Care

Community Care Access Centres

Lara De Sousa, Director, Patient Care Services, Mississauga Halton Community Care Access Centre
Faith Madden, Manager, Placement Programs, Mississauga Halton Community Care Access Centre

Josée Coutu, Patient Care Services, Central West Community Care Access Centre

Gayle Seddon, Director, Community Programs, Toronto Central Community Care Access Centre

Deanna Argue, Senior Manager, Patient Services, Central East Community Care Access Centre
Wanda Parrott, Program Director, Chronic Disease Management, Central East Community Care Access Centre
Sandra Armstrong, Senior Manager, Patient Services, Central East Community Care Access Centre

Health and Social Service Providers

Mississauga Halton LHIN

Christopher Rawn-Kane, Executive Director, Alzheimer's Society of Peel
Cindy Deakin, Administrative Assistant, Alzheimer's Society of Peel

Rosslyn Bentley, Executive Director, Credit Valley Health Team
Dr. Kerrie Shaw, Family Physician, Credit Valley Health Team

Central West LHIN

Patrick Padja, Francophone Health Promoter, Four Corners Health Centre (Wellfort)

Christina Halladay, Director of Operations, Spectra Help Line
Raji Aujli, Telecheck and Language Lines Manger, Spectra Help Line

Irena Zmyslowski, Community Mental Health Counsellor, Supportive Housing in Peel (SHIP)
Jasmine Mullings, Community Counsellor, Integrated Seniors Team, Supportive Housing in Peel (SHIP)

Toronto Central LHIN

Alison Stewart, Executive Director, Action positive

George Torys, Manager, First Link Partnership, Alzheimer Society of Toronto

Dr. Angela Troyer, Program Director, Neuropsychology and Cognitive Health, Baycrest Health Sciences

France Dorion, Program Director, Centre francophone de Toronto

Linda Legault, Program Director, Centres d'Accueil Héritage
Isabelle Girard, Executive Director, Centres d'Accueil Héritage

Keith Hambly, Executive Director, Fife House

Edward McAnanama, Program Manager, Outpatient Geriatric Psychiatry Program and Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital

Dada Gazirabo, Executive Director, Oasis Centre des femmes

Central LHIN

Stanislas Etiegne, Bilingual Health Promoter and Navigator, Black Creek Community Health Centre

Central East LHIN

Denyse Newton, Executive Director, Alzheimer Society of Durham

Margaret Areola, Administrator, Bendale Acres, Long-Term Care Homes and Services, City of Toronto

Kelly Kay, Executive Director, Seniors Care Network

Liben Gebremikael, Executive Director, TAIBU Community Health Centre

Discussion Guides

Discussion Guide for Meetings with LHIN Leads

Purpose of project

To meet the growing needs of the aging Francophone population of the Greater Toronto Area, Reflet Salvéo and Entité 4 are partnering on a feasibility study on cognitive health. The purpose of the study is to develop options for service models for a (virtual) memory clinic focussing on very early detection and intervention for mild cognitive impairment but will also address the need for referrals for those with more severe dementia. These models will include the creation of prevention and treatment tools. They will align with LHIN priorities set out in the 2016-19 integrated health service plans and the province's dementia strategy and patients first initiatives, build on existing resources and previous work, explore possible partnerships and fit in with funding criteria.

One of the early steps is to meet with LHIN leads for seniors and mental health and addictions to explore current and potential opportunities, learn more about existing capacity within the system, including the capacity to provide dementia services in French, identify current providers of early detection and intervention programs with a view to meeting with them to learn more about the programs and services they provide, how they can benefit the Francophone community and explore synergies.

Guiding questions

1. Has the LHIN conducted capacity studies in the area of services to seniors and if so, can you share the findings and recommendations? (I have the studies for Central West and Mississauga Halton)
2. How do they address early detection and intervention for mild cognitive impairment?
3. How does the LHIN envisage the continuum of care/services for patients with cognitive impairment and for their families/caregivers?
4. What agencies within your LHIN currently provide dementia services, including early detection and intervention?
5. What supports are currently available for patients and their families/caregivers?
6. What supports are in place or planned for primary care providers to help them identify and diagnose mild cognitive impairment, initiate treatment and refer patients and their families/caregivers for appropriate help? And as the disease progresses?
7. Are you aware of any agencies, models, programs are services that are particularly successful in serving adults suffering from cognitive impairment and their families and caregivers?
8. And that are culturally and linguistically appropriate to the client community and could be adapted to the Francophone community?
9. What opportunities do you see for improving services for Francophones with (mild) cognitive impairment and their families/caregivers?
10. Can you provide me with contact info and guidance for following up with current providers with a view to learning more, building on resources and creating partnerships for dementia services for Francophones

Discussion Guides for Health and Social Service Providers
Discussion Guide for Interviews in English

Purpose of project

To meet the growing needs of the aging Francophone population of the Greater Toronto Area, the two French language health planning entities, Reflet Salvéo and Entité 4, are partnering on a feasibility study on cognitive health. The purpose of the study is to develop options for service models for memory services, including a memory clinic focussing on very early detection and intervention for mild cognitive impairment but that will also address the need for referrals for those with more severe dementia. These models will include the creation of prevention and treatment tools. They will align with LHIN priorities set out in the 2016-19 integrated health service plans and the province's dementia strategy and patients first initiatives, build on existing resources and previous work, explore possible partnerships and fit in with funding criteria.

One of the steps is to meet with existing service providers to learn more about their approach and vision and their programs and services for both patients and their caregivers/families along the continuum from healthy aging memories to mild cognitive impairment/memory loss to more advanced stages of dementia, to explore how they can help the Francophone community, including their capacity to provide dementia services in French and explore potential synergies.

Areas to explore

11. Your approach to dementia and your vision of your role in dementia services along the full continuum from healthy aging memories to more advanced stages, for both patients and their families/caregivers (also training and research if applicable).
12. Your services and programs
13. Your clientele – for example, healthy seniors, patients, families, caregivers, health service providers, both in primary care and for specialized services
14. How you work with primary care providers
15. How you fit into Health Links
16. Your links with other service providers
17. Adaptations for cultural and linguistic minorities (if applicable)
18. How you work with the Francophone community and your capacity to provide services in French (if applicable)
19. Opportunities for potential partnerships to build capacity to provide services in French

Discussion Guide for Interviews in French

But du projet

Pour répondre aux besoins grandissants des personnes aînées francophones de la Région du Grand Toronto, Reflet Salvéo et l'Entité 4 collaborent sur une étude de faisabilité sur la santé cognitive. Le but de l'étude est d'élaborer des options pour des modèles de services de mémoire, y compris un centre de mémoire, axé sur la détection et l'intervention très précoce en matière de troubles cognitives légères ainsi qu'un volet référencement pour les troubles plus sévères. Ces modèles comprendront la création d'outils de prévention et de traitement. Ils s'aligneront sur les priorités énoncées par les RLISS dans leurs plans de services de santé intégrés 2016-2019 ainsi que les stratégies provinciales en matière de démence et priorité aux patients, ils reposeront sur le travail accompli jusqu'à présent et les ressources déjà en place, exploreront les possibilités de partenariat et répondront aux critères de financement.

Dans ce contexte, nous cherchons l'input, entre autres, des fournisseurs francophones de services sociaux et de santé et plus particulièrement de ceux dont la clientèle inclut les aînés. Notre objectif est de mieux comprendre votre capacité de servir des gens qui manifestent des signes de troubles cognitives légères – quels services vous êtes en mesure d'offrir à ces patients et leurs aidants, à qui vous les référez le cas échéant, les lacunes et défis que vous constatez et les opportunités de partenariat/ synergies que vous voyez.

Questions à explorer

1. Avez-vous des patients/clients qui souffrent de problèmes de mémoire ou de troubles cognitives légères?
2. Si oui, quels sont les services/programmes/appuis que vous mettez à la disposition de ces patients/clients et leurs aidants? En français?
3. Comment procédez-vous pour diagnostiquer les problèmes de ces patients? En français?
4. Avec quels autres organismes travaillez-vous pour répondre aux besoins de ces patients/clients et leurs aidants? Expliquez la relation/les services…
5. Avez-vous accès à des soutiens (formation, outils, conseils, ressources) pour vous aider à diagnostiquer et traiter ces patients/clients? Lesquels? En français?
6. À votre avis, en général quels sont les obstacles systémiques et les défis principaux auxquels vous faites face dans vos efforts pour aider ces patients/clients?
7. À votre avis, quels sont les plus grands défis et les lacunes les plus importantes en ce qui concerne la prestation de services de santé cognitive en français?
8. Voyez-vous des opportunités au niveau systémique?
9. Connaissez-vous des modèles de service particulièrement intéressants qu'on pourrait adapter à la communauté francophone de la RGT? Lesquels? Pourquoi?
10. Si vous aviez à définir un panier de services/soutiens à offrir à vos patients/clients à risque (par exemple, les aînés), atteints de problèmes de mémoire ou de troubles cognitives légères, ou à une étape plus avancée, qu'est-ce que vous suggériez comme éléments essentiels à mettre en place de

façon uniforme à travers le système de santé? À offrir aux aidants? À offrir aux professionnels de la santé et des services sociaux?

11. Quelles sont selon vous les opportunités de partenariat et de collaboration à saisir et les stratégies gagnantes pour améliorer l'accès et la disponibilité des services pour les patients/clients atteints de troubles cognitives légères et leurs aidants?
12. Auriez-vous autre chose à ajouter?

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