

L'Abécédaire d'un cerveau en santé – Sensibilisation à la démence dans l'Ouest et le Nord

Research Component

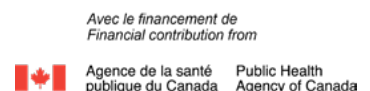
État des connaissances, ressources existantes et lacunes en matière de troubles cognitifs et de démence chez les francophones en Colombie-Britannique, en Saskatchewan, en Alberta et au Yukon

EXECUTIVE SUMMARY

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with the collaboration of Jean Nephetal Michel and Aline Moussard
(literature review)

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Study conducted by Solange van Kemenade and Bey Benhamadi, with the collaboration of Jean Nephetal Michel and Aline Moussard as part of the project “L’abécédaire d’un cerveau en santé - Sensibilisation à la démence dans l’Ouest et le Nord.”

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We also thank the coordinators in the three provinces and the territory involved in the project for their assistance in sharing relevant materials, recruiting interview participants, and organizing the survey.

As researchers, this process has helped us to better understand the issues of living with cognitive impairment, including dementia. The interviews allowed us to see what the literature strongly emphasizes, namely how much the disease can affect the life of the person with dementia and those close to them. We hope that the study will contribute to a renewed understanding of the issues and needs of Francophones in minority communities in Western and Northern Canada affected by this disease, as well as the needs of their family caregivers. We hope the knowledge gained will lead to the implementation of measures to meet these needs.

This report was written in the unceded traditional territory of the Algonquin people. We thank them for their hospitality. RésoSanté Colombie-Britannique recognizes that it is located on the unceded territories of the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Selilwitulh (Tsleil-Waututh) First Nations and thanks them for their hospitality.

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The linguistic revision of this French version was carried out by Ms. Johanne Chéné, retired lecturer at the Université du Québec en Outaouais and Ms Claire Mazuhelli, certified proof reader and translator.

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Part 1.

Introduction

The context

- In aging societies, the prevalence of dementia is increasing rapidly.
- Francophone minority communities are aging communities in all Canadian provinces, but not in the territories.
- In Canada, it is estimated that over 419,000 people aged 65 and over have been diagnosed with dementia (Government of Canada, 2019).
- “Dementia” is a “term used to describe symptoms affecting the brain that include a decline in cognitive abilities such as memory; awareness of person, place, and time; language; basic math skills; judgment; and planning. Mood and behaviour may also change as a result of this decline. Dementia is a progressive condition” (Government of Canada, 2019).
- In Canada, the prevalence rate of dementia, including Alzheimer’s disease, for people aged 65 and over was 6.54% in 2017 (Public Health Agency, Infobase 2022).
- The scientific community recognizes that it is possible to act on modifiable risk factors and to strengthen those that protect against the disease.



Project objectives

- The objectives of the “L’Abécédaire d’un cerveau en santé - Sensibilisation à la démence dans l’Ouest et le Nord” are aligned with those of Canada’s first National Dementia Strategy and are to: a) prevent dementia; b) reduce stigma; and c) encourage and support communities to become more inclusive of people living with dementia.
- The L’Abécédaire d’un cerveau en santé project focuses on the linguistic dimension and examines the issues facing Francophones in minority situations in three provinces and one territory in the West and North.
- The project is led by RésoSanté Colombie-Britannique. The other three partner networks are:
 - Réseau Santé en français de la Saskatchewan
 - Réseau Santé Alberta
 - Partenariat communauté en santé au Yukon
- The project has two components: a) awareness and b) research. The first component aims to inform Francophone communities, empower organizations and stakeholders, and support minority Francophone organizations and individuals.
- The research component of the project aims to produce knowledge to better understand the problem of dementia and its impact on Francophone communities in the targeted provinces and territory.
- The specific objectives were: a) to produce a summary of the scientific literature; b) to develop a sociodemographic and health profile of Francophone minorities in the three target provinces and territory; c) to document the needs and lack of services for Francophones with cognitive impairment and their family caregivers; d) and to mobilize knowledge.
- This report summarizes the results of the research component and presents the needs and shortcomings of Francophone minority communities in Western and Northern Canada.

Method

- The researchers used qualitative (semi-structured interviews) and quantitative methods (data from the 2016 Census, the Canadian Community Health Survey, and an online survey) to address the stated objectives.
- A brief review of the literature was carried out at the beginning of the project to inform the whole process.
- Socio-demographic and health profiles of Francophone populations in British Columbia, Alberta, Saskatchewan and Yukon were developed in order to gain a better understanding of the social determinants of health and lifestyle.
- Twenty-nine semi-structured interviews (N=29) were conducted with four groups of participants to learn more about existing services and resources for cognitive impairment, including dementia, in the three target provinces and in Yukon. These four groups were made up of : a) officials of local and/or provincial community organizations that offer programs and services to Francophones in the three targeted provinces and territory (N=12); b) coordinators for French-language services in each of the Health and Social Services ministries (N=4); c) the executive directors for the four health partner-networks in French involved in the project (N=4); d) family caregivers of relatives needing support for cognitive disorders, including dementia (N=9).
- A socio-demographic profile was prepared for each of the provinces and territory mentioned.
- The online survey (N=282) provided a portrait of knowledge about cognitive disorders/ dementia in the target communities; identified the needs and resources used by family caregivers, Francophone organizations, care providers and members of the Francophone community in general; and provided a better understanding of the gaps and priorities in terms of information, prevention, care, assistance and support.
- The triangulation of the results obtained will enable decision makers and stakeholders to better identify the needs of Francophone communities and to choose relevant and adapted intervention strategies.

Part 2. Review of the literature

- The purpose of the literature review was to produce a summary of knowledge on the specific issues affecting official language minority populations.
- More than 75 scientific and grey literature publications were selected. A neuropsychologist from the team enriched the section on actions to prevent and mitigate the disease.
- A total of six themes were identified:
 1. The social impact of cognitive disorders, including dementia.
 2. Risk and protection factors.
 3. The social construction of the disease and the stigmatization of those affected.
 4. Language barriers and cognitive impairment in a minority language context.
 5. The needs of people with cognitive loss, and of their family and professional caregivers.
 6. Interventions to prevent and mitigate cognitive impairment.
- The points that emerge from the literature relating to theme 4 are as follows:
 - Language is vulnerable to the aging process and is frequently affected in neurodegenerative diseases.
 - Bilingualism is associated with a delay in the onset of dementia symptoms,

according to studies conducted in the last decade. It contributes to the person's "cognitive reserve" (Bialystok et al., 2012).

- However, it is well documented that the progression of the disease can lead to a loss of the second language.
- Early diagnosis of dementia is essential; however, many consultations are done late and diagnoses can take, in some cases, up to 7 years from the first signs (Garcia et al., 2014; Pakzad et al., 2013).
- Late diagnoses are more common among Francophones in minority settings.
- The geographical context and language barriers that discourage consultation explain the non-use or delay in the use of services.
- Lack of awareness of dementia and the assumption that symptoms are related to normal aging may also delay help-seeking, not only in minority language settings (Leung et al., 2011).
- Language barriers can hinder access to health services and be a source of inequality.
- When a person with dementia is institutionalized, these barriers can lead to inappropriate care, inability to get help with self-care, as well as social isolation (Martin et al., 2019).
- Research on official language minority communities highlights the importance of the role of the family physician in the early diagnosis of dementia, the maintenance of a long-standing relationship with a health care professional, and the sharing of similar characteristics such as language and culture with these professionals.
- This sharing allows patients to receive emotional support, navigate the health system and understand the information being conveyed (de Moissac, 2016; de Moissac and Bowen, 2019).

- Other measures that promote the provision of services in both official languages, such as the designation of health care facilities, can play a beneficial role for residents, but more research is needed.



Part 3. The Francophone Community in British Columbia



Sociodemographic and health profile

- British Columbia's Francophone population was estimated at 64,323 in 2016. It has increased by 58% since 1971, with a lower growth rate than the total population. Its demographic weight, stable between 1981 and 2006, has since begun to decline to 1.4%.
- Francophones in the province have a high level of education that allows them to work more in skilled occupations, earning higher incomes than Anglophones in the province.
- The vast majority report satisfaction with life and good or excellent health. However, the frequencies of hypertension and diabetes are higher than among their English-speaking peers.
- In 2017, the prevalence rate of dementia was 5.93% for the province's total population aged 65 years and older, representing approximately 60,000 British Columbians with dementia (Public Health Agency, Infobase 2022).
- The aging of the Francophone population may have an impact on the rising incidence of dementia but, at the same time, life expectancy at age 65 for the total population in the province is the highest in Canada (20.7 years).
- This context could be conducive to prevention and awareness-raising interventions, even at a late age.

Services and gaps

- In 2012, British Columbia adopted a Dementia Action Plan and a Guide in 2016. The latter set four goals including increasing public awareness, better recognition of cognitive changes, keeping people with dementia in the community and improving the quality of care in health care facilities.
- The Plan also aimed to increase system support and the implementation of best practices in dementia care for people with dementia.
- The interviews revealed fairly long delays in diagnosis and care, a lack of bilingual professionals in hospitals and other health centres, and professionals with little knowledge of cognitive disorders, including dementia.
- These gaps are greater in rural and remote areas, where home care is difficult to obtain.
- Community organizations serving Francophones are active in disease prevention, providing activities and opportunities for socializing and lifelong learning to stimulate cognitive function in seniors.

Survey

- Francophones in British Columbia participated in the survey in significant numbers (39% of the total sample).
- Participants generally have a good knowledge of the problems related to cognitive disorders, including dementia.
- The most important challenges experienced by people with cognitive impairment/dementia and their relatives are, according to the participants: the loss of autonomy and the loss of abilities of the person with cognitive impairment.

- The top three resources they look for to learn about cognitive impairment and dementia are: information in general, information on prevention and information on diagnosis.
- The preferred sources of information are those available on the Internet and advice offered by health professionals.
- Participants usually look for resources or services in both official languages; however, they generally find them in English. Nevertheless, and particularly in the case of care offered, they place a high value on receiving them in French.
- To improve their knowledge, the first three protective factors they would like to know more about are, in order of importance: maintaining cognitive activity, engaging in cognitively stimulating activities, and thirdly, in equal measure, maintaining a social network and adopting a balanced diet. To reduce the risk of developing dementia, they would like to learn more about sleep disorders, chronic depression, sensory and hearing loss as well as head injuries and strokes.
- If funding were available, Francophones in British Columbia would give priority to information, prevention and counselling services.

Taking action in British Columbia

- The following courses of action are based on the interviews and the survey; they could contribute to fill some of the gaps identified:

Prevention and awareness

- Develop measures to address protective factors, including those identified by survey participants such as maintaining cognitive activity, maintaining social networks and adopting a balanced diet and other healthy lifestyle habits.
- Focus on addressing modifiable risk factors for dementia, concentrating on those identified as priorities by survey participants: sleep disorders, sensory and hearing loss, and chronic depression.
- Promote, through prevention and awareness-raising activities, the importance of early detection and the services available in general and in French in particular.
- Provide recurring and longer-term funding for Francophone community organizations that offer activities for seniors.



- Making rent and access to adequate premises more accessible for these same organizations
- Improve prevention and awareness information in French (Alzheimer Society and other major organizations with a dementia mandate).
- Reduce waiting times for cognitive screening.
- Explore the feasibility of information, prevention and counselling services in French, as suggested by the participants in the survey.

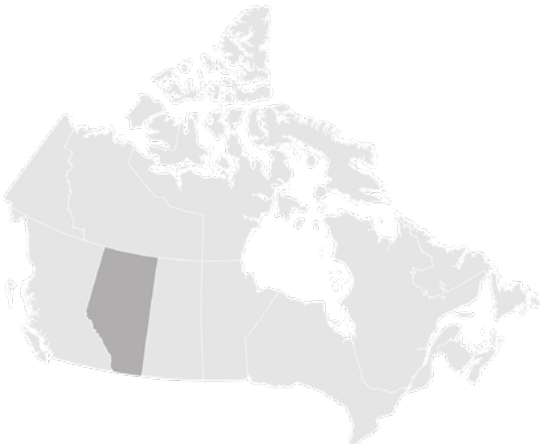
Health care

- Offer French-language places in long-term care facilities.
- Increase French-language services by recruiting bilingual staff to facilitate access to French-language services for Francophone seniors.
- Facilitate access to specialists in aging and cognitive disorders.
- Improve access to home care in rural and remote areas and ensure that French-speaking seniors have access to services in French (e.g., hiring bilingual personal support workers).
- Facilitate the provision of certain home care services (e.g., blood tests).
- Bridge the gaps for professionals who are not familiar with the Canadian health care system.

Support for family caregivers

- Facilitate the provision of certain home care services to reduce travel and ease the burden on family caregivers.
- Establish support groups or provide more information on existing provincial initiatives (e.g., "Helping without getting burned out").
- Adapt training and support for male family caregivers.

Part 4.
The Francophone
Community in Alberta



Sociodemographic and health
profile

- Alberta has the highest number of Francophones in a minority situation after New Brunswick and Ontario. In 2016, this population was estimated at 79,835. In 1971, the number was 48,485. It has increased by 58% since 1971, with a growth rate lower than that of the total population (1.1%). Its demographic weight stagnated at around 2% between 1996 and 2016.
- Francophones are mainly found in the 15 to 64 age group (74%); the proportion of seniors remains below the Canadian average (15%) (65 years and over).
- Calgary and Edmonton together account for 64% of the total population, which comes primarily from interprovincial migration. International Francophone migration was 21% in 2016.
- The level of education of Francophones is higher than that of Anglophones.
- Nine out of 10 Francophones are satisfied with life and 68% perceive their health as very good to excellent. Perceived life stress is quite high for one in five Francophones and some chronic diseases such as hypertension, arthritis and diabetes are at slightly higher levels.
- Certain lifestyle habits and health-related behaviours such as smoking, alcohol consumption, and fruit and vegetable consumption could be improved.
- In 2017, the prevalence of dementia was 6.71% for the total Alberta population aged 65 and over (Public Health Agency, Infobase 2022)—a rate higher than that of Canada as a whole and among the highest after Ontario and Quebec.

Services and gaps

- In 2017, Alberta adopted a Dementia Strategy and Action Plan.
- Measures for the early management of dementia, a specialist nurse program and community innovation projects have been put in place.
- However, in 2019, resources allocated to the health system were significantly reduced and long-term care facilities saw the abolition of programs.
- Severe budgetary restrictions prevent the development of recreational activities and psychosocial support in these institutions.
- Some residences for independent and non-independent people offer bilingual services.
- The Centre de Santé Saint-Thomas and the Société des Manoirs Saint-Joachim et Saint-Thomas have units for independent and non-independent Francophone residents.
- However, these residences have also been affected by budgetary constraints, and the beds are not reserved only for French-speaking seniors. A waiting list determines priority.
- Unilingual Francophone seniors with dementia and those living in rural and remote areas are more vulnerable, as access to services is more difficult.
- The re-emergence of the mother tongue as the primary language among these seniors, as well as the lack of services, can sometimes lead to a placement of the person outside the region.
- A French-language service coordinator provides a link between health care professionals and

- Francophones with dementia in the Northern Alberta region.
- The lack of appropriate training on dementia was also raised as a shortcoming in the interviews. Agencies are not sufficiently equipped.
 - The community organizations we met with in Alberta work on awareness and prevention. They offer programs and activities that directly or indirectly promote the cognitive health of Francophone seniors.
 - As in British Columbia, these activities create opportunities to break the isolation of seniors and to stimulate their cognitive functions.
 - The community sector also offers training based on innovative approaches for friends/family acting as caregivers (e.g., the Montessori method).

Survey

- Sixty-nine Francophones from Alberta participated in the survey (25% of total).
- These people have, in general, a good knowledge of the problems related to cognitive disorders, including dementia.
- The most important challenges experienced by people with cognitive impairment/dementia and their relatives would be, according to the participants: the loss of autonomy, the loss of the affected person's abilities, the feeling of being excluded from social activities and the lack of information about cognitive impairment.
- The top three resources they look for to learn about cognitive impairment and dementia are: general information on the issue, information on prevention and information on non-pharmacological approaches.
- The preferred sources of information for Francophones are those available on the Internet and presentations and advice offered by health professionals.
- The majority usually look for resources or services in both official languages; however, they find them mostly in English.

- Nonetheless, participants attach great importance to receiving assistance and support services for the person being cared for, care, information on non-pharmacological approaches, etc., in French.
- To improve their knowledge, the first three protective factors they would like to know more about are: maintaining cognitive activity, secondly, in equal measure, practising cognitively stimulating activities and learning memorization strategies, and thirdly, maintaining a social network.
- To reduce the risk of developing dementia, they would like to learn more about: sleep disorders, cardiovascular health, and sensory and hearing loss.
- If funding were available, Francophones in Alberta would prioritize assessment, diagnosis, referral and consultation services.

Taking action in Alberta

The following courses of action are based on the interviews and the survey; they could contribute to fill some of the gaps identified:

Prevention and awareness

- Focus on protective factors, concentrating on improving healthy lifestyles and those identified by survey participants, such as maintaining cognitive activity and engaging in cognitively stimulating activities, as well as anything that can help maintain a social network.
- Focus on modifiable risk factors for dementia, concentrating on those identified as priorities by survey participants, namely sleep disorders, cardiovascular health and sensory and hearing loss.
- Promote, through prevention and awareness-raising activities, the importance of early detection and the services available in general and in French in particular.
- Provide dementia screening tests administered by bilingual professionals in both official languages.

- Provide more information on resources to prevent dementia and on non-pharmacological resources to overcome the disease.
- Provide recurring and longer-term funding to community organizations that provide activities for seniors.
- Increase awareness among care staff of the needs of people with dementia and the communication barriers of Francophone patients.
- Organize information campaigns for newcomers to raise awareness of opportunities to work in French in the health field with seniors (e.g. in residences).
- Explore the feasibility of setting up an assessment, diagnosis, referral and consultation service, in French, as suggested by the survey participants.

Training

- Provide training focused on cognitive disorders, including dementia, to caregiving staff in seniors' residences.
- Offer French-language training in residences and long-term care facilities.
- Train more professionals in geriatrics, gerontology, neuropsychology and other disciplines related to aging and its pathologies.

Health care

- Increase funding to hire psychosocial resources in long-term care facilities.
- Recruit more bilingual staff (personal support workers, administrative staff, nurses, etc.) to facilitate access to French-language services for Francophone seniors.
- Support funding for the hiring of resources for social activities in residences housing independent seniors.
- Be more flexible when providing cognitive assessments and testing in French.

Support for family caregivers

- Provide more resources for emotional support.
- Develop practical guidebook for Alberta family caregivers or better disseminate existing resources.
- Provide more personalized approaches from organizations such as Alzheimer Alberta to meet the needs of family caregivers.
- Organize diversified approaches to offering respite to those caregivers (recreation centres do not cater for all people with dementia).



Part 5. The Francophone Community in Saskatchewan



Sociodemographic and health profile

- In 2016, Saskatchewan's Francophone population was estimated at 14,440, a decrease of 56% from 32,550 in 1971.
- The demographic weight of this community falls seriously to 1.3% from 3.5% in 1971.
- The aging of the population is very pronounced in Saskatchewan and, in particular, among Francophones, whose median age is 55.2 years. Seniors aged 65 and over are estimated at 29%, the highest level in French Canada.
- Saskatoon and Regina are home to almost half of the province's Francophone population.
- 10% of the Francophone population reported a First Nations identity, and 24% of the Francophone population are international Francophone immigrants.
- Francophones in Saskatchewan have a lower level of education than the average for Francophones outside Quebec, but their employment income is slightly higher than the average for Francophones in the rest of Canada outside Quebec. Despite the latter fact, the amount of government transfers is among the highest.
- 93% of Francophones are satisfied with life, but only 59% perceive their health as good or excellent; 17% report fairly high life stress and 86% have good or full functional health.
- Some health indicators for Francophones, such as physical activity and certain chronic health conditions such as diabetes and hypertension, could be improved; they

register higher values than for the general population.

- In 2017, the prevalence of dementia in Saskatchewan, including Alzheimer's disease, was 5.46% for the total population aged 65 and over. This is the lowest rate in Canada after Newfoundland and Labrador (Public Health Agency, Infobase 2022).

Services and gaps

- The province does not have a provincial dementia strategy or action plan. However, provincial stakeholders such as the Alzheimer Society are calling for tools to increase awareness and prevention of the disease in the province.
- Some support services for people with dementia and their caregivers such as the Saskatchewan Aids to Independent Living (SAIL) program exist, and some additional measures were announced during the conduct of this study.
- Until 2020, Saskatchewan did not have a legal framework for the provision of French-language services. Since 2022, guidelines have been formulated and the position of Official Languages Champion has been created in the province.
- Since then, efforts have been made more systematically to translate documents, of which those concerning the elderly are a priority.
- Further efforts are being made regarding training in active offer and the development of a language-identification registry for professionals. An interpreter-accompaniment

service supports French-speaking users who have to navigate the health system.

- Gaps were identified in home care, particularly for rural and remote areas, where the aging Francophone population is concentrated.
- Other gaps include the lack of bilingual residences or beds for French-speaking patients and the absence of bilingual staff in these facilities, which results in the isolation of French-speaking residents.
- The community sector responds to the needs of the Francophone senior community by offering programs and activities for seniors and their family caregivers. On the one hand, these organizations promote the prevention of cognitive disorders among seniors through physical, social and recreational activities. On the other hand, they contribute to the well-being of family caregivers and raise awareness among authorities and the general public about the importance of their role.

Survey

- Sixty-three Francophones in Saskatchewan participated in the survey (22% of the total).
- These participants have a good knowledge of the problems related to cognitive disorders, including dementia.
- They consider that the three most important challenges experienced by people with cognitive impairment/dementia and their relatives are: not recognizing the early signs of the disease; the loss of autonomy; and thirdly, in equal measure, the loss of the affected person's abilities and the feeling of being excluded from social activities.
- The top three resources they look for to learn about cognitive impairment and dementia are: information in general, information on prevention and information on non-pharmacological approaches.
- The preferred sources of information are those available on the Internet and presentations and advice given by health professionals.

- The majority of Francophones in Saskatchewan usually look for resources or services in both official languages; however, they find them mostly in English.
- However, they attach great importance to receiving care services, support for the caregiver and the person being cared for, and information on prevention **in French**.
- To improve their knowledge, the first three protective factors they would like to know more about are, in order of importance: adopting a balanced diet, maintaining cognitive activity, and thirdly, in equal measure, maintaining a social network and practising artistic activities.
- To reduce the risk of developing dementia, they would like to learn more about sleep disorders, chronic depression, sensory and hearing loss and cardiovascular health. Cigarette smoking and alcohol consumption are only a priority for two out of three French speakers.
- If funding were available, Francophones in Saskatchewan would give priority to services that would offer support and assistance.

Taking action in Saskatchewan

- The following courses of action are based on interviews with resource persons and family caregivers. They also take into account the results of the survey and could help improve certain services:

Prevention and awareness

- Develop measures focused on protective factors aimed at improving healthy lifestyle habits, particularly those identified by survey participants (adopting a balanced diet, maintaining cognitive activity, maintaining a social network and engaging in artistic activities).
- Include information and prevention activities, non-pharmacological approaches, resources mentioned in the survey.
- Focus on modifiable risk factors for dementia, concentrating on those prioritized by survey participants (sleep problems, cardiovascular health and sensory and hearing loss).

- Promote, through prevention and awareness-raising activities, the importance of early detection and the services available in general and in French in particular.
- Review the feasibility of setting up an assessment, diagnosis, guidance and consultation service, in French, as suggested by the Francophone survey participants.
- Develop municipal and provincial awareness campaigns to foster inclusive environments.
- Develop tools to make communities inclusive of people with dementia (kits, age-friendly communities and others).
- Increase funding to Francophone community organizations so they can better serve Francophones in remote areas and strengthen funding to community organizations that support family caregivers.

Training

- Better equip doctors to diagnose both dementia and its precise type early.
- Raise awareness among nursing staff in long-term care facilities.
- Developing the language skills of nursing staff in long-term care facilities.
- Promote, for training and information dissemination, the sources most often consulted by the Francophone community.

Health care

- Strengthen health services in both official languages for people with dementia.
- Provide more home-based services, particularly in small Francophone communities.
- Promote the recruitment of male home-care attendants.

Support for family caregivers

- Offer adapted services to reduce the responsibility of family caregivers and make what already exists (support groups,

Alzheimer Society meetings, therapeutic support, others) more widely accessible.

- Encourage disclosure of dementia diagnosis as a strategy to counteract stigma.
- Value and recognize the role of family caregivers by appropriate means.

Part 6. The Francophone Community in Yukon



Sociodemographic and health profile

- The Francophone population in Yukon has grown significantly over the past twenty years. Compared to other provinces, it has the highest demographic weight in Canada. It is characterized by one of the smallest senior populations in the country.
- In Yukon, the majority of Francophones live in the Whitehorse area and 90% come from other regions of Canada. The contribution of international Francophone migration is very small.
- The remarkable presence of Francophones in Yukon contributes to the improvement of the level of bilingualism, which has become the highest in Canada after Quebec and New Brunswick.
- They have one of the highest levels of education in Canada and, notably, work in skilled occupations.
- Members of the Francophone community in Yukon are satisfied with life and perceive their health status as very good or excellent.
- One out of three Francophones smokes every day or occasionally, and one out of three Francophones feels limited in activities at home, at school or at work.
- In addition, more than half consume fruits and vegetables five or more times a day, the highest level after Saskatchewan.
- In 2017, the prevalence rate for dementia was 5.81% for the total Yukon population aged 65 and over. This is lower than the rate for Canada

as a whole and among the lowest compared to the provinces and territories.

- In recent years, the Yukon has seen an influx of retirees from other Canadian provinces, some of whom are Francophones.
- This trend should be monitored because of the potential increase in home-care needs, long-term care needs and the responsibility that informal caregivers will have to assume.

Services and gaps

- In 2020, the Yukon government adopted the "Aging in Place Action Plan," which addressed some of the recommendations of an expert panel review of health and social services ("Putting People First," 2018).
- A training program for staff caring for people with dementia was launched ("Shine a Light on Dementia"), including a French version entitled "Spark: lumière sur la démence". This was developed through a partnership with Partenariat communauté en santé.
- The Yukon government funds home care, which is highly rated by those consulted.
- As of April 2021, a new support program has been offered to people in rural areas with a life-limiting illness.
- Respite services are available for family caregivers, but these services are not yet available in French.
- The public sector also manages the territory's four long-term care facilities, which have the lowest fees in Canada. The Whistle Bend Continuing Care Facility is designed to

accommodate residents with dementia and support all levels of care.

- Finally, the development of age-friendly communities is a priority of the action plan. It aims to equip municipalities, local advisory boards and community organizations to create inclusive environments.
- As in the three Western provinces, the two Francophone community organizations we met with are very active in and among the Francophone community in Yukon. They provide services in the area of cognitive impairment prevention, identify gaps and establish partnerships with the public sector and institutions of higher education for the implementation of French-language training, services and programs.

Survey

- Thirty Francophones participated in the survey (11% of the total) in Yukon.
- Participants generally have a good knowledge of the issues related to cognitive disorders, including dementia.
- They consider all the challenges experienced by people with cognitive impairment/

dementia and their loved ones listed in the question to be important. However, loss of capacity, not having had or not having quick access to specialized physicians, not having an early diagnosis, and not recognizing early signs or neglecting them are prioritized by all participants.

- The top three resources they seek for information on cognitive impairment and dementia are: general information, information on prevention and information on non-pharmacological approaches.
- The preferred sources of information for Francophones in Yukon are those available on the Internet and presentations and advice offered by health professionals.
- The majority usually look for resources or services in both official languages; however, they find them mostly in English.
- They attach great importance to receiving care, assistance and support services for the person being helped, information on non-pharmacological approaches and information in general **in French**.
- They deplore the lack of availability and access to services and resources.

- To improve their knowledge, the first three protective factors they would like to know more about are, in order of importance: maintaining cognitive activity, engaging in cognitively stimulating activities, and thirdly, in equal measure, engaging in artistic activities and maintaining a social network.
- To reduce the risk of developing dementia, they would like to learn more about sleep disorders and sensory and hearing loss, in equal measure; secondly, chronic depression; and thirdly, in equal measure, head trauma and strokes.
- If funding were available, Francophones in Yukon would prioritize assessment, diagnosis, referral and consultation services.
- More Francophones in Yukon than participants from all three provinces report the need for an **integrated service centre for Francophones**.

Taking action in the Yukon

The two sectors, public and community, are working together to build a welcoming and inclusive community for Francophone seniors in Yukon. However, some gaps have been identified. The following courses of actions are based on the interviews and the survey; they could contribute to fill some of the gaps identified:

Prevention and awareness

- Develop interventions focusing on protective factors, particularly those identified by survey participants, such as engaging in cognitively stimulating activities, engaging in artistic activities and adopting a balanced diet.
- Develop interventions focusing on modifiable risk factors, concentrating on improving healthy lifestyle habits and those identified as priorities by survey participants (sleep problems, sensory and hearing loss, chronic depression, etc.)
- Promote, through prevention and awareness-raising activities, the importance of early detection and the services available in general and in French in particular.
- Ensure more awareness and dissemination of information on dementia and information **in French** about non-pharmacological approaches (exercise program, cognitive stimulation, food supplements, diets, etc.).

- Provide recurring and longer-term funding to community organizations that offer activities for seniors.

Training

- When recruiting, focus on skills needed to work with people with dementia in long-term care facilities.
- Follow-up on the “Shine a Light on Dementia” training in French (entitled “Spark: lumière sur la démence”) that was implemented in February 2022; the lack of appropriate training was raised in this study.
- Provide training on neurocognitive disorders, behavioural and psychological changes, and reactive behaviours to better equip volunteers who assist residents in long-term care facilities.
- Provide training on non-pharmacological approaches (exercise program, cognitive stimulation, dietary supplements, diets, etc.).

Health care

- Improve navigation of services for cognitive disorders, including dementia.
- Provide care in French in general, and increase awareness among caregiving staff, especially bilingual individuals, of the importance of speaking French when providing services to Francophone residents in long-term care facilities.
- In these centres, it would be better to assign bilingual human resources to areas where Francophone residents are concentrated.
- Review the feasibility of an integrated assessment, diagnosis, referral and consultation service as suggested by survey participants.

Support for family caregivers

- Improve and disseminate the psychological support services available to family caregivers.
- Make family caregivers aware of the importance of using respite services and make these services available in French.



Part 7. The online survey

- The highlights presented in this summary are **for all participants**. Some results are broken down by socio-demographic variables, participant category, and province/territory.
- A total of 282 participants answered the questions in this survey.
- Overall, participants have good knowledge of the issue, as measured by a series of statements.
- The majority of participants do not have preconceived notions about cognitive impairment and dementia. Among other things, they believe that the disease does not only affect people living in nursing homes; nearly 80% believe that if a family member has dementia, their close relatives will not necessarily contract it and, in the same proportion, they are of the opinion that living long enough does not necessarily imply having dementia at some point. Finally, nearly 70% of Francophones perceive that if a person is diagnosed with dementia, she becomes a burden to the family.
- The loss of autonomy (85%) and the loss of abilities (83%) in the person with the disease are the challenges most frequently mentioned by participants.
- Family caregivers are looking first for general information about cognitive impairment and dementia (93%), followed by prevention and, third, diagnosis.
- When asked what resources participants look for most often for information, caregivers and care providers say that they prioritize looking for support resources for caregivers (100%), then they look for professionals with expertise in the field, and thirdly, information on prevention.
- Staff working in Francophone organizations look first for general information on cognitive impairment and dementia, second for resources related to accompaniment and support for the informal caregiver, and third for information on prevention.

- Members of the Francophone community are looking, first, for general information on cognitive impairment and dementia; second, for information on prevention (risk factors and protective factors); and third, for information on non-pharmacological approaches (exercise programs, cognitive stimulation, food supplements, diets, etc.).
- Presentations facilitated by health care providers (79%-100%), online information on websites (73%-96%) and videos (81%-82%) are the most appropriate resources for learning more about cognitive decline and dementia, according to participants. Webinars, peer counselling and infographics are also mentioned.
- Participants usually look for resources in both official languages (44% to 65%).
- Among the categories of participants, Francophone community members (32%) and staff of Francophone community organizations (44%) are more likely to search for resources and services in French.
- Participants confirm that resources and services are not widely available in French (between 0% and 14%).
- To keep up to date on cognitive disorders, including dementia, they look for information online, on social networks, watch documentaries, read newsletters and scientific articles, among other things.
- Regarding the availability of and access to services and resources, a higher proportion of the response "(I) disagree" was concentrated around these three statements: the location of services/resources is known; the quantity of services/resources is sufficient; and diagnosis is provided on time.
- Participants noted the importance of receiving services in French. However, care, accompaniment of the person being cared for and accompaniment of the caregiver are the top three areas where participants expect to receive services in French (91%, 90% and 89% respectively).
- People aged 65 and over tend to stress the importance of receiving services in French more than other age groups.
- To improve their knowledge, the first three protective factors that participants in the survey would like to know more about are: maintaining cognitive activity (93%), secondly, in equal measure, adopting a healthy and balanced diet (90%), and engaging in cognitively stimulating activities (90%), and thirdly, maintaining a social network (90%).
- To reduce the risk of developing dementia, they would like to learn more about sleep disorders, which is at the top of the list, with 89%. This is followed by sensory and hearing loss (85%) and chronic depression (84%).
- If funding was available for a service, participants prioritized the following areas in order of importance: accompaniment, support and assistance (28%), assessment, diagnosis and consultation (25%) and information, prevention and advice (22%).



