Official Language Minority Communities and Dementia

Public Health Agency of Canada

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This report summarizes the findings from seven online focus groups with members of Official Language Minority Communities (OLMC) 18 years of age and older and seven in-depth interviews with unpaid caregivers and persons living with dementia who are also members of OLMCs. Data collection was held between March 28th and June 16th, 2022. Each focus group lasted approximately 90 minutes and each interview lasted approximately 40 minutes.

Cette publication est aussi disponible en français sous le titre : Communautés de langue officielle en situation minoritaire et la démence

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Signed:

July 11, 2022
Rick Nadeau, President
Quorus Consulting Group Inc.

Table of Contents

Executive summary

Background

Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire* was released in June 2019. It supports the vision of a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, understood, and effectively treated. The strategy identifies three national objectives: prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers.

Official Language Minority Communities (OLMCs) consist of Francophones who reside outside of Quebec and English-speaking residents of Quebec. These communities are highlighted in the national dementia strategy as a population likely to face barriers to equitable care due to challenges related to accessing services and information in their first language, including being able to communicate with health professionals to correctly describe symptoms, understand health-related guidance, and receive appropriate care.

This research will assist in supporting the implementation of Canada's national dementia strategy. Furthermore, this research supports government and department priorities on dementia by contributing to the Public Health Agency of Canada's (PHAC) core responsibilities of health promotion and chronic disease prevention. Ultimately, the research findings will be used to inform PHAC programs and initiatives to ensure they reflect the distinct experiences and needs of OLMCs. It is also expected to be available to other organizations providing dementia-related services for OLMCs. Finally, this information will support annual reporting on the national dementia strategy to Parliament, as required by the *National Strategy for Alzheimer's Disease and Other Dementias Act*.

Research objectives

This project focused exclusively on OLMCs to obtain a deeper understanding of their knowledge, experiences, and attitudes related to dementia prevention and dementia-inclusiveness. Specifically, research objectives included, but were not limited to:

1. **Capture dementia prevention knowledge and attitudes:**
    - General beliefs and knowledge related to dementia, including the signs and symptoms of dementia
    - Knowledge of dementia risk and protective factors, including individual actions and environmental factors

- Reported steps taken or anticipated to prevent dementia or delay onset, intentionally or not
- Barriers and enablers to reducing dementia risk
- Availability and suitability of dementia prevention information, resources, supports, and, guidance, including whether OLMC individuals feel they have adequate access in their language of choice

2. **Assess dementia-inclusiveness experiences:**

- Availability and suitability of dementia information/guidance/supports, including whether OLMC individuals feel they have adequate access to these resources in their language of choice
- Familiarity with and experience with aspects of built and social environments that are dementia-inclusive
- Potential for their community to be dementia-inclusive in a way that meets the needs of OLMC individuals, including:
    - Barriers and enablers of social engagement/connection
    - The overall level of community support

Methodology

The research methodology consisted of seven online focus groups with members of OLMCs 18 years of age and older, and seven in-depth interviews with unpaid caregivers and persons living with dementia who are also members of OLMCs. Data collection was held between March 28th and June 16th, 2022 and included individuals from across the country. Each focus group lasted approximately 90 minutes and each interview lasted approximately 40 minutes. Participants were informed upfront that the research was being conducted on behalf of Health Canada and PHAC and they each received an honorarium of $120 for their participation. In total, 50 individuals participated in the research.

Research findings among OLMC general population

This section summarizes the findings from seven online focus groups with members of OLMCs across Canada.

Familiarity with and attitudes regarding dementia

Familiarity with dementia was quite mixed across all participants, where familiarity and personal experience with the condition increased as the age of participants increased. How well participants were able to describe dementia was largely tied to what they had observed through their personal experiences. As such, the bulk of the information participants were able to convey pertained to symptomology such as gradual loss of memory, being disoriented, changes in mood, etc. Many participants referred to Alzheimer's disease in this context.

The general sense, especially among younger participants, was that dementia was something that much older people can experience and that it involved the gradual decline in certain cognitive abilities, especially memory.

Prevention

The extent to which participants were worried about their own risk of developing dementia was largely linked to whether one of their relatives had experienced it. A few felt that they might be at a higher risk given a previous head-related injury, such as a concussion. There was also a generally accepted perception among participants that the risk of developing dementia was related to age. As such, older participants tended to be more concerned compared to younger ones, irrespective of whether any of their relatives had developed the condition.

Although there was a broadly accepted view that dementia was related to age, participants also believed that it is possible to reduce the risk of developing dementia and that this condition is not an inevitable part of aging. Many seemed to be under the impression that by remaining active and by making sure that their mind or brain was well "exercised," dementia could be delayed if not entirely held at bay.

Very few participants had had any sort of conversation with anyone, including a healthcare provider, or had done any research on their own to better understand the risk of developing dementia or what steps they could take to reduce their risk. Information pertaining to risk factors or what steps could be taken to reduce their risk tended to be online and it tended to be in English, whether among Quebec OLMC participants or among Francophones living outside of Quebec.

Many participants suspected that genetics played an important role and many also assumed that poor health in general, including a lack of intellectual stimulation, would be a likely risk factor. Additionally, a few suspected that trauma to the head, such as a concussion, could be a contributing factor.

When the moderator presented the risk factors associated with dementia, many participants felt this was both informative and eye opening. The list prompted some to revisit their own level of risk, leading some to conclude that they may in fact be at a higher level of risk than initially suspected, especially regarding the various factors related to a "healthy lifestyle."

With a better knowledge of the risk factors, some participants indicated they had taken certain steps on their own to reduce their risk, although reducing their risk of developing dementia was purely coincidental. The steps that were most likely to be mentioned included: eating better, more exercise, cutting back on alcohol and smoking, and leading a healthier life in general. If anything, a lack of motivation and a lack of time were the most common barriers to pursuing these steps. Participation in online or in-person programs or activities in their community was fairly limited with many pointing to the pandemic as the main cause.

Given the choice to participate in community-based programs and activities in English or in French, Francophone OLMC participants were more likely to be indifferent given their level of bilingualism. Most Anglophone OLMC participants in Quebec, whether in Montreal or beyond, would prefer programs and activities in English since many do not speak French well enough or at all.

Dementia-inclusive communities

Awareness of dementia-inclusive communities was nearly non-existent. To contextualize the discussion regarding dementia-inclusive communities, the following explanation was provided to all participants:

> In a dementia-inclusive community, measures are in place that make it more possible for people living with dementia to protect and improve their health and wellbeing, live independently, safely navigate and access local activities, and maintain social networks.

Given this information, all participants agreed that their community is not dementia-inclusive. With the benefit of a few examples, participants suggested that their community would become more inclusive if the following were done:

- Better public education about what dementia is and how to communicate, live with and/or work with someone living with dementia;
- More community programs and services dedicated to people living with dementia;
- Community action groups consisting of volunteers who could accompany people living with dementia in their community to get groceries, socialize, etc.

Access to information, programs and care in the preferred language

Few participants had actively sought information about symptoms or treatments. Similarly, very few were aware of or had sought information on programs or activities in their community that support people living with dementia, whether offered in English or in French.

Many explained that the healthcare system in their community would not likely meet the needs of a person living with dementia irrespective of their preferred official language. There was also some recognition that it would be important for members of OLMCs to access healthcare in their preferred official language.

Research findings among unpaid caregivers and persons living with dementia

This section summarizes the findings from seven in-depth interviews with members of OLMC's, among whom five were persons living with dementia and two were unpaid caregivers of persons living with dementia. The following regions are represented: Quebec, Ontario and British Columbia.

General quality of life

Most of the persons living with dementia had been diagnosed with dementia within the past few years, including a few who were persons with young-onset dementia. All these participants explained that they are fairly independent and for the most part, do not require constant support or supervision at this time. Nearly all persons living with dementia were living in their own homes, either with a spouse or a relative, including younger participants who lived with or had moved back in with their parents and sibling(s).

Persons living with dementia would for the most part say that their quality of life these days is fairly good. They felt they were very well supported and, other than having a diagnosis of dementia, they described their overall health as quite good. They further explained that, with the benefit of time and with more insight into their condition, they felt they had gained some perspective on their life and saw things in a brighter light than before.

When specifically asked what was most important to their quality of life, participants mostly focused on the family and friends providing them the help and support needed. Some also referred to their favourite hobbies or passions in life such as playing an instrument, singing, etc.

When asked to identify their preferred official language, participants explained that they are fairly bilingual. Anglophones living in Quebec (in the areas of Montreal and Sherbrooke) felt they had many opportunities to speak English, whereas the opposite was the case for Francophones living in Ontario and British Columbia who explained that they do not get to speak French as often as they would like, and that it was always a pleasant surprise when they met someone in their area who spoke French. Despite their bilingualism, all participants expressed a clear preference for one language over another and this was almost always the minority official language in their province. They felt more confident speaking this language, they felt they can be more open in their conversations, and a few explained that speaking the minority official language in their province was a source of comfort.

Support systems

Most persons living with dementia explained that they needed very little in terms of support to live comfortably and safely, although for most of these participants, various measures or changes in their living situation had taken place to foster this general sense of comfort and safety. Some of these changes included taking a break from work and/or their studies, staying at home/not going out, moving in or living with family, and greater involvement in their hobbies. Another important contributing factor to participants' general sense of comfort and safety was access to and the availability of friends and especially family. In the end, participants felt that their needs were being met.

Nearly all persons living with dementia in this study relied exclusively on unpaid caregivers for their day-to-day support. For nearly all persons living with dementia, at least one unpaid caregiver lives with them and would be described as very involved, with contact occurring daily. Furthermore, persons living with dementia are able to speak with unpaid caregivers most central to their care in their preferred official language, which was seen as quite important for participants.

Only a few of the older participants relied on a paid care provider who tended to needs in their home. Otherwise, participants had access to a variety of healthcare professionals which included family doctors, psychologists, nurses, therapists, and specialists. Persons living with dementia in Quebec (in the areas of Montreal and Sherbrooke) did feel they could interact with their healthcare team in their preferred language (English), while Francophones living in Ontario and British Columbia could not speak their preferred language (French). That said though, some participants preferred using the language used by the majority in their province whereas others felt it was important to their care and wellbeing that they have access to a healthcare team who could speak the language spoken by the minority.

Dementia-inclusive communities

In terms of their daily and social activities, English was the common thread across all participants. Participants living in Quebec felt they were well supported in English while Francophones living outside Quebec felt they were only supported in English. Only a few in Quebec felt that their daily and social activities would suffer if they could not access them in their preferred official language. Although Francophones outside Quebec explained that access to English-only activities did not represent a barrier to participation, they suspected that they would probably be interested in exploring additional activities if they were in French.

Based on an explanation of the concept of dementia-inclusive communities (as defined earlier in this summary for focus group participants), only one participant, an unpaid caregiver, was aware of the concept. Many had difficulty imagining what such a community would look like or what measures would be in place to make it dementia-inclusive. What they did seem to recognize was that their neighbourhood, community or city was not as inclusive as it could be. A few suggestions of activities or measures that could be considered to make their community more inclusive included the following: have more activities and clubs for persons living with dementia; make information more widely available for the general public about dementia; organize information sessions to find out about programs available for persons living with dementia; have a dedicated meeting place online and/or in-person for persons living with dementia; have a committee/organization to oversee the changes in the community; and, have more visual cues and signs to orient people when they are walking around the community.

The concept did get some pushback, however. A few participants felt that dementia is something personal, that as long as their family was around them, then they have what they need and that there is no need to get the entire community involved in supporting them.

Awareness of programs, clubs and activities for the general population in their community was high. Participants were confident that they would be able to easily find out about these programs and that the language in which these programs were available would not pose any sort of barrier or motivation to participation. Challenges to participation were more likely to be a lack of work-life balance, activities being too far from home, hours of operation, and pandemic-related closures.

None of the persons living with dementia were aware of activities specifically available to persons living with dementia in the community. As well, none had looked for these types of programs since their diagnosis and even if they were to be available in their community, a few would not be interested in participating. Among those who might be interested in activities tailored for persons living with dementia, possible activities of interest included:

- Activities that calm the spirit and help focus on emotions (e.g., anything to do with music);
- Physical activities to improve overall health that help control and focus emotions (e.g., weightlifting, yoga, swimming);
- Group cooking classes/discovering new recipes;
- Reading rooms/access to audiobooks;
- Knitting classes;
- Activities in a park (e.g., art in the park, music in the park, pet zoos/pet therapy);
- Adapted outdoor cafés; and,
- ‘Hybrid’ programs and spaces for the persons living with dementia and the unpaid caregiver so that the caregiver can have somewhere to go or something to do while the person living with dementia is participating in an activity.

Access to dementia-related information

Nearly all participants had done some research to find information related to dementia. Common topics included:

- Learning about dementia in general;
- Information on treatments;
- Information about the different stages of dementia and progression;
- Case studies, testimonials, and personal stories;
- Long term effects on the brain and the body;
- Types of activities that can slow or delay the progression of dementia; and,
- Nutrition and information about getting a good meal plan in place.

The vast majority of this research by participants was being done online through general Google searches. Other sources included word of mouth, healthcare teams, and social media. Most of the Quebec-based participants did their research in English, which was their preferred language for this type of information. Participants in Ontario and British Columbia relied mostly on English websites with only select use of French websites. These participants were not inconvenienced by any lack of French resources since in most cases they did not even try to find French content.

Nearly all participants felt they found the information they were looking for. If challenges were encountered, they were not language-related.

Moving forward, participants were interested in a few additional dementia-related topics, including: success stories of people who were able to delay progression of the condition; whether dementia is hereditary; whether having dementia puts a pregnancy or the mother at risk; dementia-care residences; and up-to-date treatments/treatment plans. A few expressed an interest in accessing information in their preferred official language moving forward, preferably through a bilingual website.

Impact of the pandemic

None of the participants felt they had lost access to any type of dementia-related information sources during the pandemic. The most notable impact on persons living with dementia was the more limited access to hospitals and their health care team and access to their social network.

A few participants explained how a greater shift to online had improved or maintained access to information and programs, including eliminating some transportation-related logistical challenges.

Moving forward, as public health restrictions continue to ease, there was some interest in returning to in-person activities and programs, although online options should not be entirely cancelled. A phased-in or gradual shift back to in-person was recommended.

Qualitative research disclaimer

Qualitative research seeks to develop insight and direction rather than quantitatively projectable measures. The purpose is not to generate “statistics” but to hear the full range of opinions on a topic, understand the language participants use, gauge degrees of passion and engagement and to leverage the power of the group to inspire ideas. Participants are encouraged to voice their opinions, irrespective of whether or not that view is shared by others.

Due to the sample size, the special recruitment methods used, and the study objectives themselves, it is clearly understood that the work under discussion is exploratory in nature. The findings are not, nor were they intended to be, projectable to a larger population.

Specifically, it is inappropriate to suggest or to infer that few (or many) real world users would behave in one way simply because few (or many) participants behaved in this way during the sessions. This kind of projection is strictly the prerogative of quantitative research.

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Research purpose and objectives

Dementia is an umbrella term used to describe a set of symptoms affecting brain function that are caused by neurodegenerative and vascular diseases or injuries. It is characterized by a decline in cognitive abilities including memory; awareness of person, place, and time; language; basic math skills; judgement; and planning. Dementia can also affect mood and behaviour. As a chronic and progressive condition, dementia can significantly interfere with the ability to maintain activities of daily living, such as eating, bathing, toileting, and dressing. Alzheimer's disease, vascular disease, and other types of disease all contribute to dementia. Other common types of dementia include Lewy body dementia, frontotemporal dementia, and mixed dementias. In rare instances, dementia may be linked to infectious diseases, including Creutzfeldt-Jakob disease. There is no known cure for dementia.

Dementia has a significant and growing impact on Canadians. Soon to be published data indicates that as of 2017-18, almost 452,000 Canadians 65+ or older (6.7% of all Canadians 65+) were living with diagnosed dementia. As this number does not include those under 65 who may have a young onset diagnosis nor those who have not been diagnosed, the true picture of dementia in Canada may be larger. Of those aged 65 years and older living with diagnosed dementia in Canada, almost two-thirds are women.[1] While dementia is not an inevitable part of aging, age is the most important risk factor. Data from the Canadian Chronic Disease Surveillance System indicates that 2.4% of Canadians aged 65-79 years had been diagnosed with dementia, including Alzheimer's disease in 2016–2017. The risk of diagnosis, however, increases exponentially with age, as 19% of individuals who were 80 years age and older in 2016-2017 were diagnosed with dementia, including Alzheimer's disease. With a growing and aging population, the number of Canadians living with dementia is expected to increase in future decades.[2]

Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire* was released in June 2019. It supports the vision of a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, understood, and effectively treated. The strategy identifies three national objectives: prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers.

Official Language Minority Communities (OLMCs) consist of Francophones who reside outside of Quebec and English-speaking residents of Quebec. These communities are highlighted in the national dementia strategy as a population likely to face barriers to equitable care due to

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[1] Public Health Infobase. Canadian chronic disease surveillance system data on dementia, excluding Saskatchewan and Yukon. Government of Canada. 2018; https://health-infobase.canada.ca/ccdss/data-tool/

[2] Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian chronic disease surveillance system. Government of Canada. 2017; https://publications.gc.ca/site/archivee-archived.html?url=https://publications.gc.ca/collections/collection_2018/aspc-phac/%20HP35-84-2017-eng.pdf

challenges related to accessing services and information in their first language, including being able to communicate with health professionals to correctly describe symptoms, understand health-related guidance, and receive appropriate care.

It has been observed that bilingual people living with dementia often revert to their first language as symptoms progress, potentially exacerbating difficulties in being understood and in understanding the information provided to them by a care provider if support is not available in their first language. Reverting to a first language may also occur in the absence of memory loss during stressful situations or when experiencing pain. As a result, the lack of resources in a person's first language may compromise the ability to effectively navigate the health care system and receive the best advice and care available. Language barriers that reduce the accuracy of communication may result in additional or unnecessary medical tests, being offered inappropriate treatment, and situations where the patient must return for further consultation about the same health problem as a result of inappropriate treatments or misdiagnosis, which can extend wait times and lengthen the time needed to accurately diagnose and treat the health concerns. For OLMCs, a lack of easily accessible information on dementia and a lack of access to care in the official minority language can have a negative impact on the quality of care, including diagnosis and treatment, as well as patient safety.

This research will assist in supporting the implementation of Canada's national dementia strategy. Development and implementation of the strategy is a requirement under the *National Strategy for Alzheimer's Disease and Other Dementias Act* which came into force in June 2017. The legislation references a number of key activities to take place under the strategy including developing, assessing and disseminating guidelines and best practices related to prevention, diagnosis, treatment, and quality of life.

Furthermore, this research supports government and department priorities on dementia by contributing to the Public Health Agency of Canada (PHAC)'s core responsibilities of health promotion and chronic disease prevention. Through this core responsibility, the investments contribute to the expected achievement of three Department results:

1. Canadians have improved physical and mental health;
2. Canadians have improved health behaviours; and,
3. Chronic diseases are prevented.

Ultimately, the research findings will be used to inform PHAC programs and initiatives to ensure they reflect the distinct experiences and needs of OLMCs. It is also expected to be available to other organizations providing dementia-related services for OLMCs. Finally, this information will support annual reporting on the national dementia strategy to Parliament, as required by the *National Strategy for Alzheimer's Disease and Other Dementias Act*.

Research objectives

This project focused exclusively on OLMCs to obtain a deeper understanding of their knowledge, experiences, and attitudes related to dementia prevention and dementia-inclusiveness.

To the extent possible and for consistency, questions were aligned with those from similar topics in the various Public Opinion Research (POR) studies being undertaken by the Division of Aging, Seniors and Dementia (DASD), including the 2020 *Dementia Survey: Final Report.*

Specifically, research objectives include, but are not limited to:

1. **Capture dementia prevention knowledge and attitudes:**
    - General beliefs and knowledge related to dementia, including the signs and symptoms of dementia
    - Knowledge of dementia risk and protective factors, including individual actions and environmental factors
    - Reported steps taken or anticipated to prevent dementia or delay onset, intentionally or not
    - Barriers and enablers to reducing dementia risk
    - Availability and suitability of dementia prevention information, resources, supports, and, guidance, including whether OLMC individuals feel they have adequate access in their language of choice
2. **Assess dementia-inclusiveness experiences:**
    - Availability and suitability of dementia information/guidance/supports, including whether OLMC individuals feel they have adequate access to these resources in their language of choice
    - Familiarity with and experience with aspects of built and social environments that are dementia-inclusive
    - Potential for their community to be dementia-inclusive in a way that meets the needs of OLMC individuals, including:
        - Barriers and enablers of social engagement/connection
        - The overall level of community support

Research findings among OLMC general population

This section summarizes the findings from seven online focus groups with members of OLMCs living in the following regions:

Region	Language spoken
Ontario	French
Quebec (Montreal)	English
Atlantic Canada	French
Prairies (Manitoba/Saskatchewan/Alberta)	French
Quebec (outside Montreal)	English
British Columbia (two groups)	French

Familiarity with and attitudes regarding dementia

Familiarity with dementia was quite mixed across all participants, where generally, familiarity and personal experience with the condition increased as the age of participants increased. Older participants were more likely to know a relative living with dementia, including some whose parent had dementia. Younger participants were more likely to have encountered dementia through their grandparents. It was largely through these experiences that participants had become familiar with dementia.

By extension, how well participants were able to describe dementia was also largely tied to symptoms they had observed through their personal experiences. Participants recounted how their relative had gradually lost their memory, they sometimes got lost or could not remember why they had gone to the store, that their mood and behaviour had changed, and that they needed increasing amounts of supervision and help.

Many participants referred to Alzheimer’s disease, unsure of whether this was in fact the same as dementia, a form of dementia or something entirely different. Very few other specific types of dementia were commonly known to participants although the descriptions provided by some would suggest that their relatives had experienced vascular dementia and dementia caused by an injury.

The general sense, especially among younger participants, was that dementia was something that much older people can experience and that it involved the gradual decline in certain cognitive abilities, especially memory.

Prevention

The extent to which participants were worried about their own risk of developing dementia was largely linked to whether one of their relatives had experienced it. Many participants were under the impression that dementia could be genetic or hereditary and so if one of their parents or grandparents had experienced it, they were more likely to feel like they were at a high risk themselves. A few also felt that they might be at a higher risk given a previous head-related injury, such as a concussion. Similarly, those who felt they were at a low risk explained that they did not know anyone in their family who had experienced dementia.

There was also a generally accepted perception among participants that the risk of developing dementia was related to age. As such, older participants tended to be more concerned compared to younger ones, irrespective of whether any of their relatives had developed the condition.

It is worth noting that when describing their risk of developing dementia, very few of the various risk factors explored later in the discussion were mentioned.

There was a widely held view that it is possible to reduce the risk of developing dementia and that this condition is not an inevitable part of aging. Although participants were not entirely certain about causality or risk factors beyond perhaps genetics, many seemed to be under the impression that by remaining active, dementia could be delayed, if not entirely held at bay. Many placed particular emphasis on making sure that their mind or brain needed to be well "exercised."

Very few participants had had any sort of conversation with anyone, including a healthcare provider, or had done any research on their own to better understand the risk of developing dementia or what steps they could take to reduce their risk. Those most likely to have done this were those who knew someone close to them living with dementia or were an unpaid caregiver for someone living with dementia. Some of the older participants had also explored the topic peripherally, mostly because they associate dementia with getting old. A few even felt that they had been getting a bit more forgetful over time and that this was worrying them a bit.

If any information had been found on the risk of developing dementia or what steps they could take to reduce their risk, it tended to be online and it tended to be in English, whether among Quebec OLMC participants or among Francophones living outside of Quebec. General feedback on access to and availability of this type of information in the participant's preferred official language included the following:

- **Among Francophone OLMC participants:**
  - The ease with which English information was found was much higher than in French. Most of the time, the default search language tended to be English.

- Among the few who accessed information in French, information tended to come from France or from the Alzheimer Society of Canada (ASC). Many tended to resort to Google to find what they were looking for.

- A few mentioned that sometimes French information can be poorly translated and that it is better to go straight to the English source.

- Many of these participants were quite fluent in English and, as such, were open to accessing information in either official language. Some did indicate they would prefer to access information in French since that was their mother tongue.

- Some explained that because their physician is Anglophone and/or because their spouse is primarily or exclusively Anglophone, that it would make more sense for them to access information in English since it would make it easier for them to share the information and have conversations with those around them.

Among Anglophone OLMC participants:

- The information these participants looked for in English was deemed easy to find and plentiful. They noted that the main language on the Internet is English anyways.

- A few also spoke French, so would be comfortable in either language, but few seemed to remember needing to resort to or being limited to French information online. That said, many felt it would be important for them to have access to information in English either because it would be easier for them to understand, or because they do not understand French at all.

- Many sources of information were quoted including resources in the United States, from Canadian universities, and a few mentioned the ASC, among others.

A focus on risk factors

When it came to discussing risk factors of developing dementia, participants generally seemed to be making assumptions and guessing. As noted earlier, many suspected that genetics played an important role and many also assumed that poor health in general, including a lack of intellectual stimulation would be likely risk factors. A few also suspected that trauma to the head, such as a concussion, could be a contributing factor. Very few of the participants had a firm grasp on the full range of possible risk factors.

When the moderator presented the modifiable risk factors associated with dementia, many participants felt this was both informative and eye opening. With this new information, some could "connect the dots" regarding how some of their relatives might have developed dementia, such as an unhealthy lifestyle, excessive alcohol use, obesity, isolation, an accident, an infection, etc.

The list also prompted some to revisit their own level of risk. Some worked their way down the list of factors (similar to a checklist) and noticed that they may in fact be at a higher level of risk than initially suspected, especially regarding the various factors related to a “healthy lifestyle.” Similarly, those who suspected they were at a low risk because they lead a healthy lifestyle felt the list confirmed their suspicions that they might be low risk. A few did notice that genetics were not part of the list, which surprised them.

With a better understanding of the risk factors (the list of factors remained on the screen for all to see for this part of the discussion), participants were asked whether they had taken specific steps, either on their own or due to advice of a healthcare provider, to reduce their risk for developing dementia. Some participants had taken certain steps, although without the intent to reduce their risk of developing dementia. The steps that were most likely to be mentioned included: eating better, more exercise, cutting back on alcohol and smoking, and leading a healthier life in general. Most of these participants had taken these steps on their own, with a few older participants remembering also being advised by their healthcare provider (albeit, with no specific reference to dementia in their guidance).

Participants explained that their motivations were generally to be healthier, with a few specifically referring to wanting to rectify or reduce their risk of developing certain cardiovascular-related conditions such as high blood pressure, high cholesterol, etc. Those who had a parent or a close relative who had experienced dementia also specifically referred to taking some steps to remain intellectually active (e.g., reading, puzzles, etc.).

Participants did not think much impeded them from pursuing these steps or measures – for the most part, participants tended to refer to a lack of motivation and a lack of time. None of the participants alluded to any language-related challenges, such as a lack of activities in their community available in their preferred official language.

Participation in online or in-person programs or activities in their community was fairly limited. Many explained that the pandemic had been a significant deterrent to signing up for or attending anything in person. Some did participate in online activities but few seemed to feel that this compensated for the lack of in-person community-based programs or activities. There was general agreement that as public health restrictions ease, most would be excited to return to in-person programs and activities, although some appreciated that online options should still remain to cater to all needs and preferences. As above, none of the participants explained that their lack of participation in online or in-person activities was in any way related to the language in which those activities were offered.

Given the choice to participate in community-based programs and activities in English or in French, most would opt for something in their preferred official language. Francophone OLMC participants were more likely to be indifferent, feeling that participating in such activities in French would be unexpected and quite a novelty since so few are currently available to them in French. In the end, if an activity were only offered in English, it would not deter them from participating since they were all fairly bilingual. Anglophone OLMC participants in Quebec located in Montreal felt that they had access to many programs and activities in English, which suited them. Most, whether in Montreal or beyond, would prefer programs and activities in English and many would not consider participating if these were only available in French.

Dementia-inclusive communities

Awareness of dementia-inclusive communities was nearly non-existent. Upon hearing the term, some suspected that this referred to certain types of long-term care facilities dedicated to people living with dementia and a select few referred to gated communities, or “villages.” But otherwise, very few could describe a dementia-inclusive community.

To contextualize the discussion regarding dementia-inclusive communities, the following explanation was provided to all participants:

> In a dementia-inclusive community, measures are in place that make it more possible for people living with dementia to protect and improve their health and wellbeing, live independently, safely navigate and access local activities, and maintain social networks.

In addition to this information, participants were informed that the concept referred to an entire neighbourhood or part of a city or town (and not just a building or a gated area). Based on this explanation, all participants agreed that their community is not dementia-inclusive. Many struggled to describe how their community would need to change to become more inclusive, and in most groups, the moderator needed to provide some examples of what some communities have done. With this extra information, a few of the suggestions proposed by participants included the following:

- Better public education about what dementia is and how to communicate, live and/or work with someone living with dementia;
- More community programs and services dedicated to people living with dementia; and
- Community action groups consisting of volunteers who could accompany people living with dementia in their community to get groceries, socialize, etc.

Most participants felt comfortable interacting with a person living with dementia in a social or work situation but many also felt that they would probably benefit from some "training."

Access to information, programs and care in the preferred language

As noted earlier, few participants had sought specific information on dementia in English or in French, including information about symptoms or treatments. If such information had been researched, it was for someone else they knew who was living with dementia. Similarly, very few were aware of any programs or activities in their community that support people living with dementia, whether in English or in French. Of the few who had accessed such programs, organizations like the ASC were mentioned. Most noted however, that they had never done any research to seek out these types of programs or services.

As for the healthcare system in their community, many explained that what was available in their communities would not likely meet the needs of a person living with dementia irrespective of their preferred official language. That said, participants tended to agree that the local healthcare system is extremely ill-equipped from a language skills perspective to support Francophones living with dementia outside Quebec and Anglophones in Quebec.

There was also some recognition that it would be important for members of OLMCs to access healthcare in their preferred official language. They came to this conclusion a few different ways. Some put themselves in the situation of someone living with dementia and determined that they would not be well served in the official language they know the least or not at all. A few could speak of someone they knew who lived with dementia and could see how important and valuable it was that they could speak to their healthcare team in their preferred official language. As well, a few had parents or relatives whose mother tongue was not English or French (although they could speak one of these two languages), and they could recall how they had reverted to their mother tongue more and more as their dementia evolved.

Research findings among unpaid caregivers and persons living with dementia

This section summarizes the findings from seven in-depth interviews with members of OLMC's, among whom five were persons living with dementia and two were unpaid caregivers of persons living with dementia. The following regions are represented: Quebec, Ontario and British Columbia.

General quality of life

The early part of each in-depth interview focused on the overall quality of life of persons living with dementia, with a particular focus on living arrangements, perceived quality of life and the factors contributing to that quality of life, including being able to speak their preferred official language.

Most of the persons living with dementia had been diagnosed with dementia within the past few years, including a few who were persons with young-onset dementia. All these individuals explained that they are fairly independent and, while some of their activities have in some ways been limited, for the most part they do not require constant support or supervision.

Living arrangements reflect this level of quasi-autonomy. Nearly all persons living with dementia live in their own homes, either with a spouse or a relative, while only one lived on their own. Younger participants live or had moved back in with their parents and sibling(s).

When asked to describe their quality of life these days, persons living with dementia would for the most part say that their life was fairly good. They felt they were very well supported, and, other than having a diagnosis of dementia, they would describe their overall health as quite good. A few explained how they had really struggled post-diagnosis – they had stopped working, they had taken a break from post-secondary studies, they were worried about experiencing the worst aspects of dementia, and they became homebound. Anxiety or depression were triggered in a few cases.

As well, the COVID-19 pandemic compounded some of these major changes in their life and, in some ways, introduced different types of barriers. For instance, the pandemic limited access to certain support networks or valued activities such as socializing with friends and family outside the home, going to the gym, etc.

The pandemic had more detrimental impacts on older persons living with dementia:

> *"With COVID unfortunately, her verbal and memory have gotten worse. The fact of being more isolated, the stress of all the changes with the regulations and activities. Physically she is well, cognitively she is moderate-severe. She is well taken care of but her daily living skills have deteriorated over the past 2 years."* – Unpaid caregiver in Quebec

They further explained that, with the benefit of time and insight into their condition, most of the participants living with dementia have gained some perspective on their life and saw things in a brighter light than before. Some of the sentiments shared in relation to this included the following:

- Learning that a diagnosis of dementia does not mean imminent cognitive breakdown. Rather, some have discovered that preventative measures can be taken to delay the progression of the condition.
- They are physically healthy.

- They are reassured and comforted by the resilience, accessibility and dedication of their support network. Although they do not want to be a burden on anyone, they appreciated how a close-knit group of individuals surrounds them, are there when they are needed, and will continue to be there no matter what.
- They have developed strategies to help them manage some of the more challenging aspects of their situation, including:
  - Talking to friends and family when they see a need for it;
  - Taking medication;
  - Learning how others with a similar diagnosis are managing news of their diagnosis and how they are adjusting to life with dementia; and,
  - Diving further into or learning a new hobby such as playing an instrument, singing, cooking, etc.

"…music helps manage my emotions and my negative thoughts." - Person living with dementia in Ontario

When specifically asked what was most important to their quality of life these days, participants mostly focused on those who are providing them the help and support needed. For most, this tended to be their family or close relatives. Some also referred to their favourite hobbies or passions in life such as playing an instrument, singing, etc.

For a person living with dementia who was much older and more advanced in the progression of the dementia, their unpaid caregiver explained that being safe in their own home was the most important consideration to their quality of life. The notion of safety was multi-faceted – being safe in their own home meant not being in a long-term care facility which by extension meant being safe from the many COVID-related outbreaks in those types of institutions during the pandemic. It also meant they were living in a controlled environment since their spouse lives with them at home, a paid care provider comes daily and there are various safety measures in place throughout the home (such as cooking safety features) to maximize their wellbeing.

None of the participants directly pointed to being able to speak their preferred official language as a contributing factor to their quality of life. To gain a better understanding of how important a factor this might be, the moderator needed to specifically ask about this topic which led to a handful of language-related considerations.

First, all participants explained that they were fairly bilingual. Although they have a preferred official language, which was the minority official language in their province, they explained that they would be able to confidently read documents or have a conversation in the dominant official language of their province.

Second, opportunities to speak the minority official language were mixed across participants. Those living in Quebec (in the areas of Montreal and Sherbrooke) did feel they had many opportunities to speak English. The opposite was the case for Francophones living in Ontario and British Columbia who explained that they primarily spoke French in their household and with friends and relatives living outside the province. These Francophones also explained that they do not get to speak French as often as they would like and that it was always a pleasant surprise when they met someone in their area who spoke French.

Thirdly, although they would consider themselves bilingual, all participants expressed a clear preference for one language over another and this was almost always the minority official language in their province. Participants explained that they generally felt more confident speaking this language and they felt they can be more sincere and open in their conversations, whether those conversations are personal or with healthcare professionals. A few also explained that speaking the minority official language in their province was a source of comfort, and one Franco-Ontarian explained that they get an emotional high when they speak and sing in French.

« C'est très important. C'est ma langue maternelle. La langue que je me sens le plus confortable à parler. Quand je parle avec les docteurs, je préfère le français. […] Quand on me parle de mon état de santé ou de ma santé mentale, je préfère que ce soit en Français. J'ai l'impression que c'est plus personnalisé. » - Person living with dementia in Ontario ["*It's very important. It is my mother tongue. The language I feel most comfortable talking. When I talk to the doctors, I prefer French. […] When someone talks to me about my physical or mental health, I prefer they use French. I feel it's more personal."*]

That said, a few participants felt that they had become so accustomed to their linguistic environment that they would now prefer to speak the language spoken by the majority. One Francophone did however explain that, despite a preference for French, they resorted to English for two main reasons: it is what everyone around them speaks and any attempt they made to find or use French material had led to frustration given the poor quality of the translation from English.

Support systems

Support systems were explored from a variety of perspectives in this research with a focus on how much support is needed, who provides this support (distinguishing between unpaid caregivers and paid care providers) and ultimately, how important language is in the overall support provided.

In terms of how much support participants felt they needed each day to live comfortably and safely in their current situation, nearly all felt they do not require much. Needs ranged from “nothing at all”, which was the case with one participant who had received their diagnosis within the past few years and actively worked full-time outside the home and lives by themselves, to 24-hour supervision, which was the case for an elderly person living with dementia whose unpaid caregiver described as having deteriorated a great deal over the past few years. All other participants explained that they needed very little in terms of support to live comfortably and safely, although for most of these participants, various preventative measures or changes in their living situation had taken place to foster this general sense of comfort and safety. Some of these changes included the following:

- Stopped certain activities such as taking walks at night and driving;
- Never straying far from home unaccompanied;
- Daily conversations (or “check-ins”) with a family member to make sure they are okay or not feeling suicidal;
- Moved back in with their parents;
- Took a break from college;
- Stopped working;
- Has become more home-bound; and,
- Greater involvement in their hobbies.

Another important contributing factor to participants’ general sense of comfort and safety was access to and the availability of friends and especially family. Persons living with dementia either lived with family members who supported them and/or they lived nearby. Support was also available from friends and family members further afield through videoconferencing, social media, and telephone conversations. All participants explained how members of their family had taken on new roles and responsibilities regarding their care, and although it might not require large efforts, these efforts were nonetheless noticed and impactful. Some of the actions taken by family members included preparing some meals, financial support, being available for conversations, doing research on dementia, and driving or accompanying persons living with dementia to appointments, to pick up medication, and to do chores outside the home such as groceries.

A few participants also explained that their sense of comfort and safety was in part derived from the support and impact of their healthcare team and their medication.

« J'ai ma famille, mes pilules et ma musique – je suis chanceux. Je n'ai besoin de rien d'autre! » - Person living with dementia in Ontario [*"I have my family, my medication and my music. I am lucky. I don't need anything else."*]

In the end, participants felt that their needs were being met. That said, a few did not want to appear as "needy" in life in general and this was reflected in their responses. These participants emphasized that they did not want to bring undue attention to themselves or to their condition and stressed that in the grand scheme of things, their needs were well met and they did not want people to see them any differently than they did before.

Nearly all participants saw themselves as healthy and not requiring any support for any other condition or disease beyond dementia. A few younger participants indicated they experienced depression or anxiety, but that this was quite secondary to their diagnosis of dementia.

A focus on unpaid caregivers

Nearly all persons living with dementia in this study relied exclusively on unpaid caregivers for their day-to-day support. While they all had a healthcare team that included some combination of a family doctor, therapists, specialists and nurses, only a few of the older participants relied on a paid care provider who tended to needs in their home.

As noted earlier, a significant number of unpaid caregivers live with the participants. These included spouses, parents, and siblings. Additionally, support was provided by friends and by other members of the extended family who do not live with the participant. There was only one mention of volunteers or students contributing to the support. All participants would describe these unpaid caregivers as very involved, with contact occurring daily.

Persons living with dementia were able to speak with unpaid caregivers most central to their care in their preferred official language, which was seen as quite important for participants. Participants explained how speaking their preferred language with their unpaid caregivers instilled a sense of comfort in them.

"It is very important. Especially given the cognitive restrictions, for her to feel comfortable she needs to be able to communicate in a language in which she feels comfortable. […] If she could not speak to her caregivers, she would not feel motivated, she would not want to participate in activities or engage." – Unpaid caregiver in Quebec

Some, especially younger participants, also explained how speaking their first official language stimulated childhood memories, which in turn conjured sentiments of safety and wellbeing.

"I've spoken in English with [my parents] since I was a baby so it does provide a feeling of protection. Speaking English makes me feel better, more reassured." - Person living with dementia in Quebec

A few also explained how speaking in French with their immediate circle of friends and family stimulated brain activity and helped them manage their dementia. One participant's psychologist encouraged them to use both official languages as much as possible to activate different parts of the brain.

« La démence c'est comme des trous dans ton cerveau, il y a des liens qui disparaissent, et en parlant français ça vient faire des connections. » - Person living with dementia in British Columbia ["*Dementia is like holes in your brain. Some links disappear and by speaking French, the links are established"*]

A focus on paid care providers

As noted earlier, only a few of the older participants relied on a paid care provider who tended to needs in their home. Otherwise, participants had access to a variety of healthcare professionals which included family doctors, psychologists, nurses, therapists, and specialists. It is worth noting that obtaining a comprehensive inventory of healthcare professionals for each participant was not a research objective and so the resulting list is general in nature.

When it comes to the official language used with their healthcare team, results aligned with the language that participants' felt they can use in the community in general. As such, those living in Quebec (in the areas of Montreal and Sherbrooke) felt they could interact with their healthcare team in English. The opposite was the case for Francophones living in Ontario and British Columbia, where interactions with healthcare professionals were exclusively in English.

In terms of preferences, some participants preferred using the language used by the majority in their province, whereas others felt it was important to their care and wellbeing that they have access to a healthcare team who could speak the language spoken by the minority. Some of the logic used by participants on this topic included the following:

- A bilingual person living with dementia in Quebec often alternated between English and French when speaking with various healthcare professionals but felt that when it comes to spoken and written information from these individuals, their preference was French.
- On the other hand, another person living with dementia in Quebec valued being able to interact with their healthcare team in English.

*"The doctor would explain some of the things about the patterns in my brain having to do with dementia. I understand this better in English. [**MODERATOR**: What does this lead to?] I have a better understanding of what is going on with me – I am more in control."* - Person living with dementia in Quebec

- A few Francophone participants explained that although access to a Francophone physician would be nice, they do not feel inconvenienced, nor do they feel their level of care suffers because all their interactions are in English. That expectation has never been there nor would they expect it moving forward.
- Admittedly, it would be "touching" if a physician or specialist spoke French but they did not believe it would significantly improve their level of care. They further explained that it would be more important for their unpaid caregiver(s) (in other words, those with whom they spend more time) to speak French than someone like a physician whom they might only see from time to time.
- Furthermore, they felt that there is limited value and perhaps even a risk in having an Anglophone physician trying to speak French, since that might be more challenging or detrimental compared to having that same physician use clearer and more accurate terminology in English. Besides, they are accustomed to speaking with physicians in English.
- Finally, seeing how much they felt they understood in both official languages, it was suggested that Francophone physicians should be reserved for those who probably need one more than they do, such as newcomers who might not know both official languages.

Dementia-inclusive communities

The research sought to explore how well participants felt their communities supported their preference for their official language of choice, and whether they had access to activities in their community. Overall, the discussion sought to understand the extent to which participants felt their community was dementia-inclusive, and what changes they would suggest to improve their community in that respect.

In terms of their various daily and social activities, English was the common thread across all participants. Participants living in Quebec felt they were well supported in English, while Francophones living outside Quebec felt they were only supported in English. Only a few in Quebec felt that their daily and social activities would suffer if they could not access them in their preferred official language. Although Francophones outside Quebec explained that access to English-only activities did not represent a barrier to participation, they suspected that they would probably be interested in exploring additional activities if they were in French.

To contextualize the discussion regarding dementia-inclusive communities, the following explanation was provided to all participants:

> In a dementia-inclusive community, measures are in place that make it more possible for people living with dementia to protect and improve their health and wellbeing, live independently, safely navigate and access local activities, and maintain social networks.

Based on this information, only one participant, an unpaid caregiver, felt they were aware of the concept of dementia-inclusive communities. They had heard of “dementia villages” in the United States, which they described as an area in which someone with dementia can navigate around in a secure setting - they can safely get groceries, there are safe delimited paths, etc. They further explained that in these villages, they have access to services, both paid and unpaid. Otherwise, participants had no knowledge of dementia-inclusive communities, and for the most part had difficulty imagining what one would look like or what measures would be in place to make such a community dementia-inclusive. What they did seem to recognize was that their neighbourhood, community, or city was not as inclusive as it could be. An indicator for one participant was how little they knew of others in their area with dementia or how widespread dementia is. Another indication that their community was not as inclusive as it could be was how others outside their home don’t know about their condition.

How well participants felt their communities supported their preference for their official language of choice was not a top-of-mind consideration when participants assessed how dementia-inclusive their communities were.

Participants proposed some activities or measures that could be considered to make their community more inclusive. Suggestions included the following:

- Have more activities and clubs for persons living with dementia.
- Make information more widely available for the general public about dementia.
- Organize information sessions to find out about programs available for persons living with dementia.
- Have a dedicated meeting place online and/or in-person for persons living with dementia. This space could host activities and be a place where PWLDs can speak freely without being judged. A participant explained that this type of space would be important for those who do not have a strong support network.
- Have a committee/organization to oversee the changes in the community.
- An unpaid caregiver explained that there are currently groups and there is information available to their mother but the community is limited in terms of how someone can get

around – "there is always a worry of someone getting lost or hurt." In light of this, they recommended putting up more signs to orient people and adapting bathrooms by adding more signs to help persons living with dementia unlock the door.

Although participants had suggestions to improve the dementia-inclusive nature of their community, a few were not entirely convinced that dementia should be a community-wide concern. The sentiment behind this opinion was that these participants felt that dementia is something personal and they were not interested in making their condition known to more people than is absolutely necessary. As such, there was no urgent or strong interest in seeing communities or cities change just to accommodate them – as long as their family was around them, then they have what they need. One participant also raised a concern for their personal safety by suggesting that if their situation were more widely known in the community, they might be taken advantage of somehow.

There was also some doubt about whether people in the community would want to volunteer to make the community more dementia-inclusive. A few suspected that dementia is something that communities are trying to avoid or forget about, rather than embrace. They explained that sometimes even close relatives struggled to support someone with dementia and by extension, they cannot see a community doing it.

« La démence n'est pas quelque chose donc les gens aiment parler. C'est quelque chose qui fait peur. […] Il y a des gens que je connaissais au collège qui me connaissaient bien et ils ont appris ça de bouche à oreille, des choses se répandent quand on ne le veut pas et ils ne me regardent plus jamais de la même façon. » - Person living with dementia in Ontario ["*Dementia is not something people like to talk about. It can be scary. […] People I knew in college and who knew me well heard about it from word-of-mouth, news go around even when we don't want to, and they don't look at me the same now."*]

"People don't want to talk about it. They don't want to see it. […] It's unfair – it's depressing." - Person living with dementia in Quebec

"My "community" is my family right now. It's very personal. […] I don't want to be a poster boy." - Person living with dementia in Ontario

A focus on general social activities

Awareness of programs, clubs and activities for the general population was high among participants. Participants were confident that they would be able to find out about these programs fairly easily and that the language in which these programs were available did not pose any sort of barrier or motivation to participation. Some of the challenges to participation that did surface included: not having the right work-life balance to find the time to participate, activities being too far from home, the times of the day or days of the week that activities are available do not align with their schedule, and closures because of the pandemic. Many participants also explained how they cut back on social activities after their diagnosis, either because they did not want to take any unnecessary risks by being in public or they did not feel like being around other people: “I did not want to go out, and my parents respected that.”

Examples of the some of the social activities in which persons living with dementia participated included:

- Male/35 years old: tennis, swimming, “thinking games” such as checkers, cards, board games, and video games.
- Female/53 years old: an exercise program; would be interested in bingo and dancing.
- Female/33 years old: goes to the gym, sings and plays music in local bars.
- Female/20 years old: nothing – scaled back post-diagnosis and during the pandemic; moving forward she would be interested in individual or small group activities such as running or exercising; online activities would be more interesting than in person (for the time being) – possible activities could include learning a new language (Spanish, Portuguese); watching videos or presentations about personal success stories and inspiring personal stories. These would feature people who are talking about what they’ve accomplished in the world of business, music, etc.
- Male/70 years old: singing and playing music

For participants from Ontario and British Columbia, these activities were rarely or ever available in the participant’s preferred official language. As noted earlier, this did not represent any sort of barrier to participation. Reactions were somewhat mixed when asked whether interest in social activities would be higher if they were available in French. While one participant felt “it would be nice” if more activities were in French since it would be new and different, others did not feel it would be necessary and preferred doing some activities, such as singing, in English.

Reactions were also mixed in Quebec where one participant would prefer activities in French primarily because it would be easier for those organizing the activity, while another participant felt access to English activities would be quite important to them.

A focus on social activities for persons living with dementia

None of the persons living with dementia were aware of activities specifically available to persons living with dementia in the community.

> *"I am not sure how to get the information – it is not very clear – access to get this information is not easy – maybe there needs to be more information on websites, in publicities, on the TV."* - Person living with dementia in Quebec

Awareness was low but feedback also suggests that interest is also somewhat limited among some of the persons living with dementia. None of them had looked for these types of programs since their diagnosis and even if they were to be available in their community, a few would not be interested in participating.

> *"I did not want to rely on the outside world more than I have to. I did not look for communities that spoke about dementia."* - Person living with dementia in Quebec

One of the unpaid caregivers in Quebec was aware that their mother participated in activities at a local recreation centre twice a week which includes yoga, walking, and art activities. They were also aware of programming made available by the ASC and the Cummings Centre. Local universities, including Concordia, University of Montreal and McGill, also have labs specifically for language and communication support. They felt that they do not face many barriers participating in these programs but admits that their mother's deteriorating language skills is making it more difficult for them to participate. They also explained how access to certain types of labs and research groups is contingent on certain eligibility criteria, which is making it harder for their mother to access them given the deterioration in their condition when in fact it is these types of individuals who need access to these programs the most.

Among persons living with dementia who might be interested in programming specifically for persons living with dementia, a few felt that these activities would need to be close to where they live since they would not be able to stray too far from home on their own. Another stressed that these activities would need to be a judgement-free and open-minded environment. A few participants provided a range of suggestions in terms of activities that could be considered and of interest:

- Anything to do with music – music lessons, singing lessons – these types of activities calm the spirit and help focus emotions.
- Weightlifting, yoga, swimming – physical activities that help control and focus emotions.

- Group cooking classes/discovering new recipes.
- Reading rooms where people can read out loud/access to audiobooks.
- Knitting classes – something relaxing and soothing.
- Activities in a park: art in the park, music in the park, pet zoos/pet therapy.
- Adapted outdoor cafés, with low stimulation, large font menus, etc.
- More 'hybrid' programs and spaces for the person living with dementia and their unpaid caregiver so that they could both be in the same building at the same time. They do not have to be participating in the same activity, this would simply allow the unpaid caregiver to have somewhere to go or something to do while the person living with dementia is participating in an activity.

Access to dementia-related information

Although participants had not done much research to find dementia-specific programs in their community, nearly all had done some research to find information related to dementia. The types of information sought have included the following:

- Learning about dementia in general.
- Information on treatments: treatments in general; if there is a cure; new treatments; naturopathic treatments; information on medications that can help manage things like anxiety, irritability, and aggressiveness; what is available without resorting to a trial-and-error approach to treatment.
- Information about the different stages of dementia and its progression.
- Case studies; testimonials; personal stories; understand whether all diagnosed people end up the same way; peer-driven forums/resources like PatientsLikeMe.com.
- Long term effects on the brain and the body.
- Types of activities that can slow or delay the progression of dementia.
- Nutrition; information about getting a good meal plan in place.

One of the unpaid caregivers explained that their mother was not the one doing this research, but rather the personal care team. As well, a few persons living with dementia explained that they were not interested in doing research on dementia. They were either afraid to find out more about their condition, or would rather not dwell on their condition and left the research to close family members.

The vast majority of this research was happening online through general Google searches. Many did their research post-diagnosis and resorted to a variety of websites, none of which could be remembered. Other sources of information included word of mouth such as parents, resources from their healthcare team, and social media (notably Facebook and Instagram).

Most of the Quebec-based participants did their research in English, which was their preferred language for this type of information. As one participant specified, “this allowed me to stay in my comfort zone.” The Quebecer who did their research in French explained that they were indifferent regarding the language of the information they found given their comfort with both official languages. Participants in Ontario and British Columbia relied mostly on English websites with only select use of French websites. These participants were not inconvenienced by the lack of French resources since in most cases, they did not even try to find French content.

Nearly all participants felt they found the information they were looking for. If challenges were encountered, they were not language-related. Challenges included trying to find up-to-date information (or finding it hard to remain updated on new resources and treatments), not finding information about a cure, and finding too much information on topics such as brain stimulation activities that is not validated.

“There is a lot of anecdotal information but it is really hard to get it validated. You are left in the unknown.” – Unpaid caregiver in Quebec

Moving forward, participants were interested in a few additional dementia-related topics, including the following:

- Success stories of people who were able to delay progression of the condition: How did they do it?
- Is dementia hereditary?
- Is it dangerous for me to have children before I am “healed”?
- Dementia-care residences.
- Anything to do with up-to-date treatments/treatment plans.

A few expressed an interest in accessing information in their preferred official language moving forward, preferably through a bilingual website. A few mentioned wanting to use established or government websites, and one participant stressed the importance of well translated French content.

Impact of the pandemic

The research also explored whether participants felt the COVID-19 pandemic had changed how they can access information, programs and care related to dementia. None of the participants felt they had lost access to any type of information in which they were interested. The most notable impact on persons living with dementia was the more limited access to hospitals and their healthcare team. They also explained how the pandemic limited their access to their social network and cut off from seeing friends and family. As one participant explained, the pandemic left them home-bound and too often in front of a television or a computer watching depressing news about what was happening in the world.

A few participants explained how a greater shift to online had improved or maintained access to information and programs, including eliminating some transportation-related logistical challenges. That said, this shift did not go without its challenges. In particular, an unpaid caregiver explained that because of their mother’s cognitive loss and greater dependence on visual stimuli, “using Zoom has created some confusion – there is a lack of stimulation…although it’s been logistically easier in terms of transportation.”

Moving forward, as public health restrictions continue to ease, there was some interest in returning to in-person activities and programs, although online options should not be entirely cancelled. A phased-in or gradual shift back to in-person was recommended especially since it might not be easy for home-bound persons living with dementia to suddenly be asked to interact with groups of people in person. As well, transportation challenges cannot be solved overnight, including the financial impact of the price of gas these days.

Methodology

Overview: The research methodology consisted of seven online focus groups with members of Official Language Minority Communities (OLMC) 18 years of age and older and seven in-depth interviews with unpaid caregivers and persons living with dementia who are also members of OLMCs. Data collection was held between March 28th and June 16th, 2022 and included individuals from across the country. In total, 50 individuals participated in the research.

Quorus was responsible for coordinating all aspects of the research project including working with the client team in designing and translating the recruitment screener and the moderation guide, coordinating all aspects of data collection logistics, including participant recruitment, providing the online and telephone-based data collection platforms, moderating all focus groups and interviews, and delivering required reports at the end of data collection. The research approach is outlined in greater detail below.

Target audience and sample frame

The target population of the focus groups were OLMC adults 18 years of age or older. The target population for the individual interviews were people living with dementia and/or unpaid dementia caregivers who reside in OLMC's.

In the design of the recruitment screener, specific questions were inserted to clearly identify whether participants qualified for the research program and to ensure, where applicable, a good representation across core socio-demographic dimensions such as age, gender, socioeconomic status, region, rural/urban location and ethnicity/cultural background.

In addition to the general participant profiling criteria noted above, additional screening measures to ensure quality respondents included the following:

- No participant (nor anyone in their immediate family or household) was recruited who worked in related government departments/agencies, nor in advertising, marketing research, public relations, as a paid caregiver to people living with dementia, as healthcare professional or worker with expertise in neurological disorders including dementia, or the media (radio, television, newspaper, film/video production, etc.).
- No participant acquainted with another participant was knowingly recruited for the same study, unless they were recruited into separately scheduled sessions.
- No participant was recruited who had attended a qualitative research session within the past six months.
- No participant was recruited who had attended five or more qualitative research sessions in the past five years.

- No participant was recruited who had attended a qualitative research session on the same general topic as defined by the Researcher/Moderator in the past two years.

- Recruitment excluded paid caregivers to people living with dementia.

- Recruitment also excluded healthcare professionals or workers with expertise in neurological disorders including dementia.

Description of data collection procedures

Data collection consisted of online focus groups with members of OLMCs at least 18 years of age, each lasting approximately 90 minutes. It also consisted of in-depth telephone interviews with unpaid caregivers and persons living with dementia who are also members of OLMCs, each lasting approximately 40 minutes.

For each focus group, Quorus recruited eight participants with the goal of achieving six to eight participants per session. All focus group and interview participants were offered an honorarium of $120 after their session.

Participants invited to participate in the focus groups were recruited by telephone through random digit dialing of the general public, through the use of a proprietary opt-in database and via referrals. Health Canada/the Public Health Agency of Canada (PHAC) and the recruitment partner also contacted various OLMC organizations and organizations supporting persons living with dementia so that they in turn could reach out to the target audience in an effort to promote and encourage qualified participants to contact the recruitment team.

Despite these various efforts, the recruitment process encountered important challenges when attempting to recruit persons living with dementia who are also members of OLMCs. This resulted in a final research frame that differed from the intended research frame. The following challenges were encountered:

- Members of OLMCs are a very low incidence segment of the population in Western Canada, certain parts of Quebec and in most parts of Atlantic Canada, making it extremely difficult to find them to participate in a public opinion research study.

- Within that population segment, persons living with dementia is an even smaller segment.

- Outreach to organizations and groups representing either OLMCs or persons living with dementia did not result in any eligible research candidates. A few individuals contacted Quorus as a result of this outreach, however they were disqualified because they were healthcare professionals or workers with expertise in neurological disorders, including dementia.

- A number of individuals who know someone living with dementia were reached through recruitment efforts, however these individuals refused to refer the study to the person they know living with dementia for two main reasons:
    - Friends and family members take it upon themselves to create a shield or bubble around the people they know living with dementia and are reluctant to expose them to unnecessary interactions.
    - Some of the people they know living with dementia were seen as incapable of participating in this type of research study given the advanced state of their dementia.

The recruitment of participants followed the screening, recruiting and privacy considerations as set out in the *Standards for the Conduct of Government of Canada Public Opinion Research–Qualitative Research.* Furthermore, recruitment respected the following requirements:

- All recruitment was conducted in the participant's official language of choice, English and French, as appropriate.
- Upon request, participants were informed on how they can access the research findings.
- Upon request, participants were provided Quorus' privacy policy.
- Recruitment confirmed each participant had the ability to speak, understand, read and write in the language in which the session was to be conducted.
- Participants were informed of their rights under the *Privacy* and *Access to Information Acts* and ensured that those rights were protected throughout the research process. This included: informing participants of the purpose of the research, identifying both the sponsoring department or agency and research supplier, informing participants that the study will be made available to the public in 6 months after field completion through Library and Archives Canada, and informing participants that their participation in the study is voluntary and the information provided will be administered according to the requirements of the *Privacy Act*.

At the recruitment stage and at the beginning of each focus group, participants were informed that the research was being conducted for Health Canada/PHAC. Participants were informed of the audio/video recording of their session and of the potential presence of Health Canada/PHAC observers. Quorus ensured that prior consent was obtained at the recruitment stage and before participants began their session.

All online focus groups were conducted in the evening after regular business hours whereas in-depth telephone interviews were conducted at the times that were most convenient to participants. The research team used the Zoom platform to host and record focus group sessions (through microphones and webcams connected to the moderator and participants' electronic devices, such as their laptop, tablet or smartphone) enabling client remote viewing.

A total of seven online focus groups were conducted. The details of these groups are outlined in the table below.

Date	Region	Language	Participants
March 28, 2022	Ontario	French	6
March 29, 2022	Quebec (Montreal)	English	6
April 4, 2022	Atlantic Canada	French	7
April 4, 2022	Prairies (MB/SK/AB)	French	6
April 6, 2022	Quebec (outside Montreal)	English	6
April 6, 2022	British Columbia	French	4
June 16, 2022	British Columbia	French	8
-	-	-	**TOTAL: 43**

The locations, attendance, language and dates for the in-depth interviews are presented in the grid below:

Interview #	Date	Region	Segment	Language
1	**March 29, 2022**	Quebec	Unpaid caregiver	English
2	**March 29, 2022**	Quebec	Unpaid caregiver	English
3	**April 8, 2022**	Quebec	Person living with dementia (male / 35 years old / diagnosed 1-2 years ago)*	English
4	**April 11, 2022**	British Columbia	Person living with dementia (female / 53 years old / diagnosed 1-2 years ago)	French
5	**April 12, 2022**	Ontario	Person living with dementia (female / 33 years old / diagnosed 1-2 years ago)*	French
6	**April 13, 2022**	Quebec	Person living with dementia (female / 20 years old / diagnosed 1-2 years ago)*	English
7	**April 15, 2022**	Ontario	Person living with dementia (male / 70 years old / diagnosed < 1 year ago)	French

*The research involved persons living with dementia across a range of ages, including individuals living with young onset dementia. While rare, someone can be diagnosed with dementia in their 20s and 30s.

Appendices

Specifications

- 6 focus groups with OLMC individuals and 10 one-on-one telephone in-depth interviews with individuals living with dementia or dementia caregiver across 5 regions:
  - Atlantic Canada (NS, PEI, NFLD, NB)
  - Ontario
  - British Colombia/Yukon
  - Quebec (split between Montreal and outside of Montreal)
  - Prairies (Manitoba/Saskatchewan/Alberta)
- For focus groups - recruit 8 participants per group, for 6 to 8 to show.
- Interviews are exclusively with individuals living with dementia (diagnosed), recruiting caregivers as needed to assist during the interview. We can recruit current unpaid caregivers (normally a family member or friend) as back-ups for one-on-one interviews in case we cannot find enough people living with dementia.
- Focus group duration will be ~90 minutes while one-on-one interview duration will be ~40 minutes.
- Participants to be paid $120.

All times are stated in local area time unless specified otherwise.

Group 1
Ontario - FR
March 28
5:30 pm EST

Group 2
Quebec (Montreal) - EN
March 29
5:30 pm EST

Group 3
Atlantic Canada - FR
April 4
5:30 pm AST

Group 4
Prairies (MB/SK/AB) - FR
April 4
6:00 pm CST

Group 5
Quebec (Outside Montreal) - EN
April 6
5:30 pm EST

Group 6
BC/Yukon - FR
April 6
5:00 pm PST

Individual Interview Structure	Language	Approximate Number of Interviews per Region
Atlantic (Nova Scotia, PEI, NFLD, New Brunswick)	French	2
Ontario	French	2
B.C. /Yukon	French	2
Quebec	English	2
Prairies (AB, SK, MB)	French	2
Total		**10**

**Interviews will be scheduled from March 21 to April 10. At least 4 of the 10 interviews should be scheduled on or before March 31st.

Questionnaire

A. Introduction

Hello/Bonjour, my name is [**NAME**]. I am calling from Quorus Consulting Group, a national public opinion research company. We're conducting a research study on behalf of the Government of Canada with people in your area. Would you prefer to continue in English or French? / Préférez-vous continuer en anglais ou en français?

As I was saying – we are conducting research with people in your area on behalf of the Government of Canada, more specifically, Health Canada and the Public Health Agency of Canada.

[INSERT FOR REGIONS OUTSIDE QUEBEC] This is for the purposes of hearing from those whose mother tongue or preferred official language is French living outside Quebec on their level of awareness of various health conditions and to hear their views on access to information and support in their official language of choice in their region.

[INSERT FOR QUEBEC] This is for the purposes of hearing from those whose mother tongue or preferred official language is English living in Quebec on their level of awareness of various health conditions and to hear their views on access to information and support in their official language of choice in their region.

Participation is completely voluntary and your decision to participate or not will not affect any dealings you may have with the Government of Canada. We are interested in your opinions and your experiences. No attempt will be made to sell you anything and at no point will you be asked to share personal information. We are not asking you to participate right now – at this stage we are simply reaching out to invite Canadians to focus groups and interviews scheduled for late March and early April. People who take part will receive a cash gift to thank them for their time. No matter how you participate, all your opinions will remain anonymous and will be used for research purposes only in accordance with laws designed to protect your privacy.

1. Before we invite anyone to attend, we need to ask you a few questions to ensure that we get a good mix of people. This will take 5 minutes. May I continue?

Yes	1	**CONTINUE**
No	2	**THANK/DISCONTINUE**

B. Qualification

2. First of all, can you please confirm that you live in [**INSERT PROVINCE/TERRITORY**]?

Yes	1	
No	2	**ADJUST AS NEEDED OTHERWISE THANK/DISCONTINUE**

3. **[FOR RESPONDENTS LIVING OUTSIDE OF QUEBEC]** Do you consider yourself to be a member of a Francophone minority community? A member of a Francophone minority community refers to individuals whose first language is French or whose preferred official language is French and who live outside of Quebec.

Yes	1	
No	2	**THANK/DISCONTINUE**
Prefer not to say	3	**THANK/DISCONTINUE**

4. **[FOR RESPONDENTS LIVING IN QUEBEC]** Do you consider yourself to be a member of an Anglophone minority community? A member of an Anglophone minority community refers to individuals whose first language is English or whose preferred official language is English and who live in the province of Quebec.

Yes	1	
No	2	**THANK/DISCONTINUE**
Prefer not to say	3	**THANK/DISCONTINUE**

5. **[IF LOCATED IN QUEBEC]** Are you located in the Greater Montreal Area?

Yes	1	**SKIP TO Q7**
No	2	

6. In which community (town, city or village) do you currently live?

RECORD NAME OF COMMUNITY: ______________________

RECRUIT ANGLOPHONES IN MONTREAL FOR QUEBEC GROUP 1 AND ANGLOPHONES OUTSIDE OF MONTREAL FOR QUEBEC GROUP 2. ALSO AIM FOR A MIX FOR EACH INDIVIDUAL INTERVIEW.

7. How long have you lived in this community?

RECORD: ______________________

PARTICIPANT NEEDS TO HAVE LIVED IN THEIR CURRENT COMMUNITY FOR AT LEAST 2 YEARS.

8. Do you or does anyone in your immediate family or household work in any of the following areas? **[READ LIST]**

	Yes	No
A marketing research firm	1	2
A magazine or newspaper, online or print	1	2
A radio or television station	1	2
A public relations company	1	2
An advertising agency or graphic design firm	1	2
An online media company or as a blog writer	1	2
The government, whether federal, provincial or municipal	1	2
Paid caregiver to people living with dementia	1	2
Healthcare professional or worker with expertise in neurological disorders including dementia	1	2

IF YES TO ANY OF THE ABOVE, THANK AND DISCONTINUE.

9. We are looking to speak with a variety of people for this study, including people who have been diagnosed with dementia by a health care professional. Would there be someone in your household, including you, who has been diagnosed with this condition? [**AS NEEDED:** Dementia is characterized by a decline in cognitive abilities (ex. memory, language, awareness of person/place/time, etc.) and includes Alzheimer's disease, vascular dementia, Lewy body dementia, Frontotemporal dementia and mixed dementias.]

Yes, self	1
Yes, someone else from household	2
No	3

IF "YES, SELF", SCHEDULE FOR INDIVIDUAL INTERVIEWS WITH PEOPLE LIVING WITH DEMENTIA AND CONTINUE TO Q10;

IF "YES, SOMEONE ELSE FROM HOUSEHOLD", ASK TO SPEAK TO THAT PERSON IF POSSIBLE AND REPEAT INTRO;

IF "NO", CONTINUE TO Q13.

10. **[IF "YES, SELF" AT Q9, INDIVIDUAL WITH DEMENTIA]** When were you diagnosed with dementia?

Within the past year	
1-2 years ago	1
3-5 years ago	2
6 or more years ago	3

11. **[IF "YES, SELF" AT Q9, INDIVIDUAL WITH DEMENTIA]** For this study we are conducting individual interviews with people living with dementia to obtain feedback on their experiences including access to resources and support in their preferred official language in their region. Those who qualify and take part in the interview will receive a financial incentive. If you prefer that a caregiver or companion to attend the interview with you, this can be arranged however this individual will not receive an additional incentive. Is this interview something you might be interested in?

Yes	1	**CONTINUE TO Q12**
No	2	**THANK/DISCONTINUE**

12. **[IF YES AT Q11]** Thank you. To make sure we have a good mix of study participants, may I ask you a few more questions? **We can provide you with the questions to review before answering them if you prefer.**

Yes	1	**CONTINUE**
No	2	**THANK/DISCONTINUE**

IF INTERESTED IN REVIEWING QUESTIONS, RECORD EMAIL AND SEND SCREENER QUESTIONS. SCHEDULE A CALL-BACK TO COMPLETE PROFILING QUESTIONS.

C. Profiling questions

13. What is your gender identity? [If you do not feel comfortable disclosing, you do not need to do so] **[DO NOT READ LIST]**

Male	1
Female	2
Prefer to self-describe, please specify: _____	3
Prefer not to say	4

AIM FOR 50/50 SPLIT OF MALE AND FEMALE, WHILE RECRUITING OTHER GENDER IDENTITIES AS THEY FALL

14. We are looking to include people of various ages. May I have your age please?

RECORD AGE: ______________

RECRUIT A MIX OF AGES IN EACH FOCUS GROUP.

15. Do you identify as any of the following?

An Indigenous person (First Nations, Inuit or Métis)	1
A member of an ethnocultural or a visible minority group Other than an Indigenous person	2
None of the above	3

16. **[ASK ONLY IF Q15=2]** What is your ethnic background?

RECORD ETHNICITY: ______________

RECRUIT A MIX ACROSS ALL GROUPS AND INTERVIEWS AS MUCH AS POSSIBLE.

17. What is the highest level of education that you have completed?

Some high school only	1
Completed high school	2
Some college/university	3
Completed college/university	4
Post-graduate studies	5
Prefer not to say	6

RECRUIT A MIX ACROSS ALL GROUPS AND INTERVIEWS AS MUCH AS POSSIBLE.

18. Which of the following categories best describes your total household income. That is, the total income of all persons in your household combined, before taxes.

Under $20,000	1
$20,000 to just under $40,000	2
$40,000 to just under $60,000	3
$60,000 to just under $80,000	4
$80,000 to just under $100,000	5
$100,000 to just under $150,000	6
$150,000 and above	7
[DO NOT READ] Prefer not to say	8

RECRUIT A MIX ACROSS ALL GROUPS AND INTERVIEWS AS MUCH AS POSSIBLE.

19. **[DO NOT ASK IF "YES, SELF" IN Q9]** Do you, or someone in your household currently provide personal care or assistance to a person or more than one person who have been diagnosed with dementia?

Yes, self	1
Yes, someone else from household	2
No	3

IF "YES, SELF", RECRUIT FOR FOCUS GROUPS BUT FLAG AS POTENTIAL ONE-ON-ONE INTERVIEW.

IF NEEDED: A caregiver is defined as a person who provides care and support to a person with dementia, and who is not a paid care professional or personal care worker. A caregiver is likely to be a relative, close friend, neighbour or volunteer. Support provided by a caregiver may include assisting with the activities of daily living and helping with advance care planning.

20. **[DO NOT ASK IF "YES, SELF" IN Q9]** How often do you interact with people who have been diagnosed with dementia? Would you say…

Daily	1
A few times a month	2
Once a month	3
A few times every year	4
Once a year or less	5
Don't know	6

RECRUIT A MIX ACROSS ALL GROUPS AND INTERVIEWS AS MUCH AS POSSIBLE.

21. **[DO NOT ASK IF "YES, SELF" IN Q9]** Do you currently have one of the following conditions or illnesses?

Hypertension	1
Diabetes	2
High cholesterol	3
Obesity	4
None of the above	5
[DO NOT READ] Prefer not to say	6

RECRUIT A MIX ACROSS ALL GROUPS AND INTERVIEWS AS MUCH AS POSSIBLE.

22. Do you identify as a member of the LGBTQ2+ community?

Yes	1
No	2
[DO NOT READ] Prefer not to say	3

23. Do you currently live in… **[READ LIST]**

A city or metropolitan area with a population of at least 100,000	1
A city with a population of 30,000 to just under 100,000	2
A city or town with a population of 10,000 to just under 30,000	3
A town or rural area with a population of less than 10,000	4

FOR EACH GROUP, RECRUIT ~2 INDIVIDUALS WHO LIVE IN A CITY OR TOWN WITH A POPULATION OF NO MORE THAN 30,000 (Q20=3 or 4)

24. **[DO NOT ASK TO PARTICIPANTS IN THE GREATER MONTREAL AREA]** Does the community in which you live typically offer access to public services in [**OUTSIDE QUEBEC SAY:** French / **IN QUEBEC SAY:** English] including schools, recreational facilities, health care services, etc? Would you say…**READ LIST**

Yes, all, or almost all public services are available in this language	1
Some public services are available in this language	2
Very few or no public services are available in this language	3

FOR EACH GROUP, RECRUIT A MIX OF THOSE FROM OLMC CLUSTERS ("ALL OR ALMOST ALL SERVICES ARE AVAILABLE TO THEM IN LANGUAGE OF CHOICE") AND MORE ISOLATED AREAS.

25. Have you ever attended a discussion group or taken part in an interview on any topic that was arranged in advance and for which you received money for participating?

Yes	1	
No	2	**GO TO APPROPRIATE INVITATION**

26. When did you last attend one of these discussion groups or interviews?

Within the last 6 months	1	**THANK & TERMINATE**
Over 6 months ago	2	

27. Thinking about the groups or interviews that you have taken part in, what were the main topics discussed?

RECORD: _______________

THANK/TERMINATE IF RELATED TO DEMENTIA

28. How many discussion groups or interviews have you attended in the past 5 years?

Fewer than 5	1	
Five or more	2	**THANK & TERMINATE**

RECRUITER NOTE: WHEN TERMINATING AN INTERVIEW, SAY: “Thank you very much for your cooperation. We are unable to invite you to participate because we have enough participants who have a similar profile to yours.”

C. INVITATION TO PARTICIPATE – ONLINE FOCUS GROUPS

29. I would like to invite you to participate in an online focus group session where you will exchange your opinions in a moderated discussion with other individuals in your region. The discussion will be led by a researcher from the national public opinion research firm, Quorus Consulting. The session will be recorded but your participation will be confidential. The group will be hosted using Zoom, taking place on **[DAY OF WEEK], [DATE]**, at **[TIME]**. It will last 90 minutes (1 hour and 30 minutes). People who attend will receive $120 to thank them for their time.

    Would you still be interested and available to take part in this study?

Yes	1	
No	2	**THANK & TERMINATE**

30. The discussion group will be video-recorded. These recordings are used to help with analyzing the findings and writing the report. The results from the discussions will be grouped together in the research report, which means that individuals will not be identified in anyway. Is this acceptable?

Yes	1	
No	2	**THANK & TERMINATE**

31. Individuals from the Health Canada, the Public Health Agency of Canada (PHAC) and/or the Government of Canada involved in this research project may be observing the session. They will not take part in the discussion, and they will not know your full name. Is this acceptable?

Yes	1	
No	2	**THANK & TERMINATE**

32. Thank you. Just to make sure, the group will take place on **[DAY OF WEEK]**, **[DATE]**, at **[TIME]** and it will last 90 minutes (1 hour and 30 minutes). Following your participation, you will receive $120 to thank you for your time. Are you interested and available to attend?

Yes	1	
No	2	**THANK & TERMINATE**

To conduct the session, we will be using a screen-sharing application called **Zoom**. **We will need to send you by email the instructions to connect.** The use of an Internet-connected computer, tablet, or smartphone and a quiet room are necessary.

We recommend that you click on the link we will send you a few days prior to your session to make sure you can access the online meeting that has been setup and repeat these steps <u>at least 10 to 15 minutes prior to your session</u>.

As we are only inviting a small number of people to attend, your participation is very important to us. If for some reason you are unable to attend, **you cannot send someone to participate on your behalf** - please call us so that we can get someone to replace you. You can reach us at **[INSERT NUMBER]** at our office. Please ask for **[INSERT NAME]**.

So that we can contact you to remind you about the focus group or in case there are any changes, can you please confirm your name and contact information for me? **[READ INFO AND CHANGE AS NECESSARY.]**

First name____

Last Name____

Email____

Day time phone number_________________________________

Night time phone number_______________________________

Thank you!

If the respondent refuses to give his/her first or last name or phone number please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the interview. If they still refuse **THANK & TERMINATE**.

D. INVITATION TO PARTICIPATE – IN-DEPTH INTERVIEWS

33. How comfortable would you feel participating in a 40-minute one-on-one conversation with one of the research consultants? Participants would still receive $120 for their time and effort. Would you be able to participate if this were arranged?

Yes	1	
No	2	**THANK & TERMINATE**

34. **[IF NEEDED FOR INDIVIDUALS WITH DEMENTIA]:** Would you prefer to do the interview alone or would you prefer to participate in the interview with the support of a care partner or family member? Note that they <u>would not</u> receive the incentive of $120 as well.

Alone	1
With a caregiver or family member	2

35. Would you prefer doing this type of interview over the telephone or would you prefer using an online video conference platform like Zoom which would allow you to see the researcher and they could see you?

Telephone	1
Web-based	2

36. The session will be audio-recorded but your participation will be confidential. We have openings on the following dates and times [**PROVIDE OPTIONS AND SELECT ONE OPTION**]. It will last 40 minutes and you will receive $120 to thank you for your time.

    Would you still be interested and available to take part in this study?

Yes	1	
No	2	**THANK & TERMINATE**

37. The interview will be audio-recorded. These recordings are used to help with analyzing the findings and writing the report. The results from the discussions will be grouped together in the research report, which means that individuals will not be identified in anyway. Is this acceptable?

Yes	1	
No	2	**THANK & TERMINATE**

38. Individuals from Health Canada, the Public Health Agency of Canada (PHAC) and/or the Government of Canada involved in this research project may be observing the session. They will not take part in the discussion, and they will not know your full name. Is this acceptable?

Yes	1	
No	2	**THANK & TERMINATE**

39. **[ASK INDIVIDUALS WITH DEMENTIA ONLY]** Will you be accompanied by a caregiver or companion during the interview? Please note that this individual would not receive additional compensation.

Yes	1
No	2

40. Thank you. Just to make sure, your interview will take place on **[DAY OF WEEK]**, **[DATE]**, at **[TIME]** and it will last 40 minutes. Your interview will be with a research consultant from Quorus Consulting.

    Do you require any other accommodations or assistance in order to participate in your interview? Please note that sometimes participants are asked to read text or write out answers during the discussion.

Yes – please specify: ____________________________	1
No	2
Don't know/Prefer not to say	9

As we are only inviting a small number of people to attend, your participation is very important to us. If for some reason you are unable to attend, **<u>you cannot send someone to participate on your behalf</u>** - please call us so that we can get someone to replace you. You can reach us at **[INSERT NUMBER]** at our office. Please ask for **[INSERT NAME]**.

So that we can contact you to remind you about your interview or in case there are any changes, can you please confirm your name and contact information for me? **[READ INFO AND CHANGE AS NECESSARY.]**

First name____

Last Name____

Email (OPTIONAL)____

Day time phone number_________________________________

Night time phone number________________________________

Thank you!

If the respondent refuses to give his/her first or last name or phone number please assure them that this information will be kept strictly confidential in accordance with the privacy law and that it is used strictly to contact them to confirm their attendance and to inform them of any changes to the interview. If they still refuse **THANK & TERMINATE**.

Focus group moderation guide

Focus Group Moderation Guide
Health Canada and the Public Health Agency of Canada
OLMC Dementia Study 2022

Introduction (10 minutes)

Thank you all for joining this online focus group!

- Introduce moderator/firm and welcome participants to the focus group.
    - Thanks for attending.
    - My name is [INSERT MODERATOR NAME] and I work with Quorus Consulting, and we are conducting research on behalf of the Government of Canada.
    - Today I will be eager to obtain your views and general understanding of a condition called dementia as well as your thoughts on access to resources and information in your preferred official language, which you've indicated as being English/French.
    - The discussion will last approximately 90 minutes.
    - If you have a cell phone or other electronic device, please turn it off.
- Describe focus group.
    - A discussion group is a "round table" discussion, meaning we will discuss something and everyone has an equal chance to express an opinion.
    - My job is to facilitate the discussion, keeping us on topic and on time.
    - Your job is to offer your opinions on the topics I'll bring up and to share your experiences. You are not required to answer every question so if there is a question you don't want to answer, just let me know. Your honest opinion is valued.
    - There are no right or wrong answers. This is not a knowledge test.
    - Everyone's opinion is important and should be respected.
    - We want you to speak up even if you feel your opinion might be different from others. Your opinion may reflect that of other Canadians.
    - To participate in this session, please make sure your webcam and your microphone are on and that you can hear me clearly. If you are not speaking, I would encourage you to mute your line to keep background noise to a minimum…just remember to remove yourself from mute when you want to speak!
    - **[AS NEEDED]** I will be sharing my screen to show you some material.
    - **[AS NEEDED]** We might make use of the chat function. [MODERATOR EXPLAINS HOW TO ACCESS THE ZOOM CHAT FEATURE DEPENDING ON THE DEVICE THE PARTICIPANT

IS USING]. Let’s do a quick test right now - please open the chat window and send me a short message (e.g., Hello everyone).

- Explain research process.
  - Please note that your participation is voluntary and that anything you say during this group will be held in the strictest confidence. We do not attribute comments to specific people. Our report summarizes the findings from all the group discussions and interviews I do but does not mention anyone by name.
  - The report can be accessed through the Library of Parliament or Library and Archives Canada website.
  - Your responses will in no way affect your dealings with the Government of Canada.
  - The session is being audio-video recorded for report writing purposes and to verify feedback. The recordings remain in our possession and will not be released to anyone, even to the Government of Canada, without your written consent.
  - Some of my colleagues from Health Canada and the Public Health Agency of Canada involved in this project are observing this session and this is only so they can hear the comments first-hand.
- Please note that I am not an employee of the Government of Canada and may not be able to answer questions about what we will be discussing. If questions do come up over the course of the group, we will try to get answers for you before we wrap up the session.

  Any questions?

INTRODUCTIONS: Let’s go around – please tell us your name and a little bit about yourself, such as where you live, who lives with you, what you do for a living, etc.

Familiarity With and Attitudes Regarding Dementia (15 minutes)

1. Generally, how knowledgeable would you say you are about dementia?
    - **AS NEEDED:** What have you seen, read or heard about dementia? If you were to explain dementia to your neighbour, what would you say?
    - Up until now, where have you been getting your information about dementia?

[MODERATOR TO SHARE DEFINITION ON SCREEN]

> Dementia is a term used to describe symptoms affecting brain function. It may be characterized by a decline in cognitive abilities such as: memory; planning; judgement; basic math skills; and awareness of person, place and time. Dementia can also affect language, mood and behaviour, and the ability to maintain activities of daily living.
>
> Dementia may be caused by neurodegenerative diseases (affecting nerve cells in the brain), vascular diseases (affecting blood vessels like arteries and veins) and injuries.
>
> Types of dementia include vascular, Lewy body, frontotemporal, Alzheimer's disease and mixed. In rare instances, dementia may be linked to infectious diseases, including Creutzfeldt-Jakob disease, or caused by injuries.

2. Do you have any current or past personal experience with dementia, such as a family member or friend, or through work?
    - Can you please describe your personal experience with dementia a bit for the group?

Prevention (40 minutes)

3. How worried are you about your own risk of developing dementia? Help me understand where you are coming from on that.
    - **IF NEEDED:** As far as you know, are you at a high risk, moderate risk, or low risk of developing dementia? What leaves you with that impression?

4. How many of you believe that it is possible to reduce the risk of developing dementia and how many of you see dementia as an inevitable part of aging? Please explain this a bit.

5. Have any of you ever had a conversation with anyone, such as a healthcare provider, or done any research on your own to better understand what affects the risk of developing dementia or what steps you can take to reduce your risk?

- Were you able to access this information in English/French[3]?

  IF YES:

  - Please describe the resources you accessed – what were they?
  - Where did you find them?
  - Were they easy to find?
  - Were you satisfied with those resources? Why/why not?

- **[IF DID NOT ACCESS RESOURCES IN THE MINORITY LANGUAGE]** Did you try to find information that was in English/French?
  - If yes, where did you look?
  - If not, why not?
- How important is it for you to be able to find these types of resources in English/French? What difference does it make?

6. Let's get back to discussing risk factors. What can you tell me about what you know about the risk factors related to dementia? What risk factors come to mind? Let's draw up a list.

[MODERATOR TO SHARE RISK FACTORS ON SCREEN]

Just so we are all on the same page – here are the risk factors associated with dementia.

- High blood pressure
- Harmful alcohol use
- Lack of physical activity
- Unhealthy diet
- Sleep disruption (e.g., sleep apnea)
- Obesity
- Smoking
- Diabetes
- High cholesterol
- Loneliness/social isolation
- Fewer years of formal education
- Air pollution
- Hearing loss

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[3] This refers to the participant's preferred official language – reference will be made to English for participants in Quebec and French for participants outside Quebec.

- Depression
- Traumatic brain injury

7. In the last 12 months, have you taken any specific steps on your own to reduce your own risk for developing dementia? …by "on your own" I mean these were not steps recommended by a healthcare provider.

   IF YES:

   - What steps have you taken exactly?
   - What inspired or motivated you to take those steps?
   - Are you encountering any challenges that might prevent you from continuing to take those steps?

8. In the last 12 months, have you taken any specific steps on the advice of a health care provider to reduce your risk for developing dementia?

   IF YES:

   - What steps have you taken exactly?
   - Are you encountering any challenges that might prevent you from continuing to take those steps?

9. What online or in person programs or activities in your community do you access that could help to prevent dementia? These could include social groups, exercise or nutrition programs, etc.

      - **AS NEEDED:** Are they offered in English/French?

   - How important is it to you to be able to access programs like these in English/French? Why is that – what difference does it make?
   - Is there anything preventing you from participating in community programs that could help to prevent dementia? Help me understand this.
      - What do you feel could be done to make these types of programs more accessible for you?

10. Are there any programs or activities that you would like to see offered in English/French in your community that are not available now?

- Where or how would you want to find information about programs and activities offered in English/French?

11. Would you like to do more to reduce your risk of developing dementia?

- What would help you to do more?
- Are there information or resources about reducing the risk of dementia that you are interested in or could imagine you might be interested in in the future? Please describe.
- Where would you want to find this kind of information in English/French?

12. When you think about the past two years, has the pandemic changed access to dementia-related information, programs, guidance and other resources in English/French? In other words, has the pandemic made it easier or more difficult for you to access any of these things in English/French? Help me understand this a bit.

- Many programs, services and interactions have shifted to online over the past few years. To what extent has this helped to compensate for any lack of in person community-based programs or guidance?
- What would you like to see change in the future about these programs as public health restrictions ease?

Dementia-Inclusive Communities (10 minutes)

13. Have you ever heard the term "dementia-inclusive community?"

[MODERATOR TO SHARE ON SCREEN]

> In a dementia-inclusive community, measures are in place that make it more possible for people living with dementia to protect and improve their health and wellbeing, live independently, safely navigate and access local activities, and maintain social networks.

14. Would you describe your community as dementia-inclusive?

- In what ways is your community dementia-inclusive – what works well? …what is available exactly?
- In what ways does your community need to change to be more inclusive and supportive of people living with dementia?

15. Have any of you had any experience interacting with a person who you know or suspect may be living with dementia in your community?

- Would you feel comfortable interacting with a person living with dementia in a social or work situation? Why is that?

16. When you take a step back and you assess how dementia-inclusive your community is, how important do you believe having information, resources and support available in English/French is? …or does the language not really matter in your assessment?

Access to Information, Programs and Care in the Preferred Language (15 minutes)

Let’s turn our attention to information and programs available to individuals living with dementia and those who care for them.

17. If you have looked or would be looking for information about symptoms or treatment, would it be important for the information to be in English/French? If so, why is that?

- Where would you want to find this kind of information in English/French? **PROBE AS NEEDED:** Would you want to access it from government sources, an advocacy organization, a health care provider, etc.?

18. Are you aware of any programs or activities in your community that support Anglophones/Francophones living with dementia? These might be day programs, respite, etc.

- What are they? What can you tell me about these programs or activities?
    - Are they easy to access?
    - Are they meeting the needs of Anglophones/Francophones in your community living with dementia?

19. As far as you know, how well can the health care system in your community meet the needs of Anglophones/Francophones living with dementia?

- Can any of you speak to any experience you might have in this area?
- Was care provided in English/French?
- As far as you know, what impact did the ability / inability to provide care in the person with dementia’s language of choice have on their level of care or quality of life?

Wrap-up (1 minute)

Before I let you go, is there anything else you believe I need to understand regarding your access to information, resources or support related to dementia in English/French?

Thanks again! The team that invited you to participate in this session will contact you regarding the manner in which you can receive the incentive we promised you.

Thank you – have a nice evening!

In-depth interview guide

In-Depth Interview Guide (for people living with dementia)
Health Canada and the Public Health Agency of Canada
OLMC Dementia Study 2022

Introduction (5 minutes)

Thank you for agreeing to participate in this interview.

- Introduce moderator/firm and welcome participant.
    - Thanks for attending.
    - My name is [INSERT MODERATOR NAME] and I work with Quorus Consulting, and we are conducting research on behalf of the Government of Canada.
    - Today I will be eager to obtain your views on how easy or difficult it is for you to access information and support related to dementia in your preferred official language, which you've indicated as being English/French.
    - The discussion will last approximately 40 minutes and we can take a short break half way through if you like.
    - If you have a cell phone or other electronic device, please turn it off.
- Describe interview process.
    - My job is to facilitate the discussion, keeping us on topic and on time.
    - Your job is to offer your opinions on the topics I'll bring up and to share your experiences. You are not required to answer every question so if there is a question you do not want to answer, just let me know. Your honest opinion is valued.
    - There are no right or wrong answers. This is not a knowledge test.
    - **[FOR WEBCONFERENCE INTERVIEWS]** To participate in this session, please make sure your webcam and your microphone are on and that you can hear me clearly.
    - **[AS NEEDED]** I will be sharing my screen to show you some things.
    - **[AS NEEDED]** We might make use of the chat function. [MODERATOR EXPLAINS HOW TO ACCESS THE ZOOM CHAT FEATURE DEPENDING ON THE DEVICE THE PARTICIPANT IS USING]. Let's do a quick test right now - please open the chat window and send me a short message (e.g., Hello).

- Explain research process.

  - Please note that your participation is voluntary and anything you say during this interview will be held in the strictest confidence. We do not attribute comments to specific people. Our report summarizes the findings from all the group discussions and interviews I do but does not mention anyone by name.
  - The report can be accessed through the Library of Parliament or Library and Archives Canada website.
  - Your responses will in no way affect your dealings with the Government of Canada.
  - The session is being audio/audio-video recorded for report writing purposes and to verify feedback. The recordings remain in our possession and will not be released to anyone, even to the Government of Canada, without your written consent.
  - **[AS NEEDED]** Some of my colleagues from Health Canada and the Public Health Agency of Canada involved in this project are observing this session and this is only so they can hear the comments first-hand.

- Please note that I am not an employee of the Government of Canada and may not be able to answer questions about what we will be discussing. If questions do come up over the course of the group, we will try to get answers for you before we wrap up the session.

  Any questions?

Warm-up (5 minutes)

I'd like to start off with a few questions to help me get to know you a bit better.

1. In what city or town do you live?
    - …and how long have you been living in that area?
    - And what do you like the most about living there?

2. Where are you living now – in your home on your own, in your home with someone else, in long term care, etc.?

3. Generally, how would you describe your quality of life now? Why is that?
    - What is most important to you for quality of life?

4. When we invited you to participate in this interview, you told us that your preferred official language is English/French.
    - In the community of [INSERT CITY/TOWN], how often are you able to speak English/French?
    - How important to your quality of life is being able to speak English/French? What difference does it make? Help me understand this a bit.
    - **[REGARDING <u>MAJORITY</u> OFFICIAL LANGUAGE]** How comfortable are you speaking French/English?
    - Are there situations where you feel **more** comfortable or confident communicating in English/French? Please give me a few examples.
    - Are there situations where you feel **less** comfortable or confident communicating in English/French? Please give me a few examples.

Support Systems (8 minutes)

One of my main goals today is to get your feedback on how easy it is for you to access support, resources and information related to dementia. As a person living with dementia, you are in a great position to help me understand if there are important things missing in your community.

5. For starters, how much support do you feel you need each day to live comfortably and safely in your current situation?
    - How well do you feel those needs are being met?
    - Which needs, if any, **are being well met** and why?
    - Which needs are **NOT being well met** and why?

6. Besides dementia, do you require support for any other health condition?
    - **[AS NEEDED]** Do you feel that the support you need is primarily related to dementia or to your other health condition(s)?

7. How would you describe your support network? **IF NEEDED:** …are they very close and involved? Please describe how they support you.

8. People living with dementia may have family or friend caregivers that provide unpaid support. They might also pay out-of-pocket for care. Please describe the paid and unpaid support you receive, if any.

    IF NEEDED: A caregiver is defined as a person who provides care and support to a person with dementia, and who is not a paid care professional or personal care worker. A caregiver is likely to be a relative, close friend, neighbour or volunteer. Support provided by a caregiver may include assisting with the activities of daily living and helping with advance care planning.

EXPLORE AS NEEDED:

- Who is/are your unpaid caregivers?
- How would you describe your relationship with your unpaid caregiver(s)?
- What type of care do your unpaid caregivers provide?
- How often do you see your unpaid caregiver(s)?
- Do any of your unpaid caregivers speak with you in English/French?

IF YES:

- ○ How important is having your unpaid caregiver speak English/French with you?
- ○ In what ways does your unpaid caregiver's ability to speak English/French with you make a difference in your quality of care or your quality of life?

IF NO:

- ○ How important would it be to you that your unpaid caregiver(s) speak with you in English/French?
- ○ What if your unpaid caregiver could speak English/French with you – what difference would this make in your quality of care or your quality of life?

9. What paid care providers do you see specifically for dementia, if any? (e.g., doctor, nurse, specialist, therapist, personal support worker)
   - Do any of these paid care providers speak English/French with you? How often?

IF YES:

- ○ How important is speaking English/French with these paid care providers for you?
- ○ In what ways does a paid care provider's ability to speak English/French with you make a difference in your quality of care or your quality of life?

IF NO:

- ○ How important would it be to you that paid care providers speak English/French with you?
- ○ What if these paid care providers could speak English/French – what difference would this make in your quality of care or your quality of life?

PARTICIPANT CHECK-IN

How are you doing so far? Would you like to take a short break or keep going with a few more questions?

Dementia-Inclusive Communities (12 minutes)

Let's talk a bit more broadly about the community of [INSERT CITY/TOWN].

10. How well does your community support your preference to use English/French when it comes to…
    - …daily activities, such as grocery shopping, banking, and restaurants?
    - …social activities such as clubs, exercise programs, places of worship, so on and so forth?

    - How important is it to you to have daily and social activities available in English/French?

IF NO ACTIVITIES ARE AVAILABLE IN ENGLISH/FRENCH:

- You mentioned that activities are only available in French/English. To what extent does this prevent you from participating in them?

11. Have you heard of the term "dementia-inclusive community?"

In a dementia-inclusive community, measures are in place that make it more possible for people living with dementia to protect and improve their health and wellbeing, live independently, safely navigate and access local activities, and maintain social networks.

12. Would you describe your community as dementia-inclusive?

- In what ways is your community dementia-inclusive – what works well? …what is available?
- In what ways does your community need to change to be more inclusive and supportive of people living with dementia?

13. If you were to assess how dementia-inclusive your community is, is access to information, resources and support in English/French an important consideration? …or does the language not really matter in your assessment?

14. Do you participate in any community programs, such as day programs, social activities, etc.

IF YES:

- Which ones?
- How easy or difficult is it for you to take advantage of those programs?
    - **IF DIFFICULT OR IMPOSSIBLE:** How could we make it easier for you to access these types of programs?
- Are they offered in person, or online, or both?
- Are they offered in English/French?
    - How important is it to you for programs to be available in English/French?

    - In what ways does having programming available in English/French make a difference in your quality of life?

15. To the best of your knowledge, does your community offer any programs that specifically support people living with dementia?

IF YES:

- What is available?
- How easy or difficult is it for you to participate in community programs that support people living with dementia?

    IF DIFFICULT OR IMPOSSIBLE:

    - What might be preventing you from using dementia programs offered in your community?
    - What would make it easier for you to access dementia programs?
- Are programs that specifically support people living with dementia offered in person, or online, or both?
- Are any of these programs available in English/French?
    - How important is it to you to have community programs that support people living with dementia available in English/French?
    - In what ways does/would having these community programs available in English/French make a difference in your quality of life?
    - Are there any programs or activities for people living with dementia that you would like to see offered in English/French in your community that are not available now?

- **[IF NO PROGRAMS AVAILABLE OR DOES NOT PARTICIPATE IN ANY]** Would you like to be able to participate in community programs for people living with dementia?
    - In what types of programs or activities would you be the most interested?
    - How important would it be to you to have these types of programs available in English/French?
    - In what ways would having programs available in English/French make a difference in your quality of life?

    - Are there any programs or activities for people living with dementia and/or dementia caregivers that you would like to see offered in English/French in your community that are not available now?

PARTICIPANT CHECK-IN

How are you doing so far? Would you like to take a short break or keep going with a few more questions?

Access to Dementia-Related Information (7 minutes)

Let’s turn our attention to how easy or difficult it is for you to find or access information about dementia.

16. Describe for me the types of information about dementia you look for.

- Where do you typically look or who do you talk to for information about dementia?
- How would you prefer to access the dementia-related information you need? …and how is this different from what you do now?
- When you do look for information, do you look for information that is in English or in French? How often? Why is that?
- When you do look for information about dementia, how important is it to you to access information that is in English/French?
    - In what ways does having information available in English/French make a difference in your quality of care or your quality of life?

17. Thinking specifically about information on dementia you have sought in English/French…

    - Have you been able to find what you were looking for?
    - Did it meet your needs and expectations? Why or why not?
    - Is there anything that makes it difficult for you to access information about dementia in English/French?
    - What could be done to help you find information about dementia in English/French?

18. What type of information about dementia do you wish you could more easily find in English/French? …does a particular topic come to mind?

Impact of Pandemic (3 minutes)

We’ve talked about accessing various resources and information in English/French. We’ve talked about access to **care and support**, access to **community programs and services** for people living with dementia and we’ve talked about accessing **information** related to dementia.

19. When you think about the past two years, has the pandemic changed how you access information, programs and care to support you in English/French? In other words, has the pandemic made it easier or more difficult for you to access any of these things in English/French? Help me understand this a bit.

    - Many programs, services and interactions have shifted to online over the past few years. To what extent has the switch to online programming helped to compensate for any lack of in person community-based information, programming or care?
    - What would you like to see change in the future as public health restrictions ease?

Wrap-up (1 minute)

Before I let you go, is there anything else you believe I need to understand regarding your access to information, resources or support related to dementia in English/French?

Thanks again! The team that invited you to participate in this session will contact you regarding the manner in which you can receive the incentive we promised you.

Thank you – have a nice evening!