Health Canada Santé Canada

Priorities for an Information Portal on Dementia (HCPOR-20-16)

Final Report

Prepared for Health Canada and the Public Health Agency of Canada

Prepared by Narrative Research
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For more information, please contact: hc.cpab.por-rop.dgcap.sc@canada.ca

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Canada

Priorities for an Information Portal on Dementia (HCPOR-20-16)

Final Report

Prepared for Health Canada

Supplier Name: Narrative Research
March 2021

This public opinion research report presents the results of focus groups conducted by Narrative Research on behalf of Health Canada and the Public Health Agency of Canada to inform the development of an online portal providing information on dementia. The research included a total of 25 online focus groups conducted from February 1-11, 2021, divided into the following categories: members from the general public, individuals whose health and living conditions put them at higher risk of developing dementia, unpaid care providers to people living with dementia, and people who have been diagnosed with dementia who confirmed their ability to participate. Additionally, three focus groups were conducted with each of the following paid care provider audiences, who care for and interact with people living with dementia at work: first responders, healthcare professionals, and care and support personnel. Good geographic coverage was achieved across Canada and various community sizes were represented, including large urban, small/medium size urban, and rural areas.

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Executive Summary

Narrative Research Inc.
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Background and Research Methodology

In June 2019, Canada's first dementia strategy, *A Dementia Strategy for Canada: Together We Aspire* was released. The strategy sets out the vision of a Canada in which all people living with dementia and care providers are valued and supported, quality of life is optimized, and dementia is prevented, well understood and effectively treated.

The main objective of this research is to inform the development of an online portal providing useful and comprehensive information on dementia. More specifically, the research is intended to provide insight on the types of features and resources target audiences are looking for when using an information portal, including source and type of content, and to examine measures that make information more accessible.

Specific research objectives related to the study included:

- To capture awareness and perceptions of existing dementia information online resources;
- To understand current dementia information needs and gaps;
- To evaluate perceptions and preferences related to features, tools and information resources that users expect to see as part of a dementia information portal; and
- To determine whether additional tools are needed to effectively educate the general public, people living with dementia, care providers and health care providers beyond an online portal (e.g., resources that can be printed out, links to local support groups, etc.)

To achieve these objectives, a qualitative research approach was undertaken. Four focus groups were conducted with each of the following audiences: members from the general public, individuals whose health and living conditions put them at higher risk of developing dementia, unpaid care providers to people living with dementia, and people who have been diagnosed with dementia who confirmed their ability to participate. It is noteworthy that members from the general public and those in higher risk groups included a few who reported a family member with dementia, despite not actively caring for that person. These participants are referred to as family members in this report where relevant. Additionally, three focus groups were conducted with each of the following paid care provider audiences, who care for and interact with people living with dementia at work: first responders, healthcare professionals, and care and support personnel. Good geographic coverage was achieved across Canada and various community sizes were represented, including large urban, small/medium size urban, and rural areas. This entailed a total of 25 online focus groups conducted from February 1-11, 2021.

Group discussions were held in English with the exception of those in Quebec, which were conducted in French. Sessions with individuals living with dementia each lasted one hour, while sessions with other audiences lasted one and a half hours. Participation incentives ranged from $100 to $200 based on the target audience. Across all groups, a total of 181 individuals were recruited and 151 participated. Four additional participants had technical issues and could not take part in the sessions but still received remuneration.

All participants were recruited in accordance with Government of Canada specifications. Recruitment was conducted through qualitative panels stored on Canadian servers, with follow up calls to confirm the details provided, and to ensure quotas were met. This report presents the findings from the study. Caution must be exercised when interpreting the results from this study, as qualitative techniques are used in marketing research as a means of developing insight and direction, rather than collecting quantitatively precise data or absolute measures. Results cannot be attributed to the overall population under study, with any degree of statistical confidence.

Political Neutrality Certification

I hereby certify as a Representative of Narrative Research that the deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Directive on the Management of Communications. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate or ratings of the performance of a political party or its leaders.

Signed

Margaret Brigley, CEO & Partner | Narrative Research
Date: March 4, 2021

Key Findings and Conclusions

The following summarizes the key findings and conclusions from the focus groups on the ***Priorities for an Information Portal on Dementia*** (POR-078-20) research study.

Findings suggest that there is a strong desire and a clear need for an online portal on dementia that would provide a cohesive, comprehensive and trustworthy source of information and help to locate services and support. Information on dementia appears currently to be scattered on different websites, incomplete, not sufficiently detailed and not always relevant to people living with dementia, as well as paid and unpaid care providers.

Understanding dementia was considered paramount to enable people living with dementia and unpaid care providers to create the best and most positive living environment, as well as plan for the future. Family members who do not provide active care are also interested in better understanding dementia, to ensure their interactions with the person living with dementia remain positive. The need for information is varied and topics of interest ranged from better understanding dementia, caring for someone living with dementia, identifying the risk factors, and understanding how to prevent or manage dementia over time. Apart from information, participants expressed a desire to more easily locate services and resources available to both people living with dementia and unpaid care providers. As such, to meet their needs, an online portal on dementia was expected to be a comprehensive library of detailed information and services, including local resources.

Given that the target audiences under study have different roles and levels of engagement with people living with dementia, it is not surprising that their information needs vary. People living with dementia, family members and unpaid care providers indicated being focused on managing their daily lives in the best way possible, while trying to plan for the future. This entails understanding how to create a favourable environment for people living with dementia, how to establish positive interactions and communication, how to minimize or address crisis situations, and planning for future care. Unpaid care providers were also acutely aware of their own need for support and respite. As such, these audiences were looking for a portal that offers practical information and local, accessible resources.

Unpaid care providers also voiced a desire for more information on how to positively interact with people living with dementia, especially during a crisis situation. This was also of greatest interest to first responders who mentioned that they are mostly involved in managing and de-escalating crisis situations rather than providing ongoing care. The information needs of healthcare providers and personal care attendants are more limited given their current knowledge and access to workplace resources. That being said, healthcare professionals expressed interest in having dementia-related information in a format that can be relayed to their patients (e.g., a brochure or pdf document with information in simple language).

Nonetheless, all audiences saw value in an online portal on dementia that is primarily designed for unpaid care providers, other people close to those living with dementia who do not provide active care (relatives, friends, colleagues, neighbours), and to a lesser extent for higher risk groups within the general population. While people living with dementia were recognized by others as needing information, it was believed by many paid and unpaid care providers that an online tool may not be the right vehicle for them depending on the stage of dementia. However, people living with dementia expressed interest in a site that is easy to use and provides actionable information and resources to assist with their day-to-day lives. In addition, this audience felt it would also be important to receive assistance by phone to navigate information online or locate the resources and services they need. In terms of how information is presented on the portal, all audiences felt that in addition to on-screen, text-based information, the portal's content should be provided in a variety of formats (for example videos; checklists; podcasts) for different usage and to appeal to different audiences.

During the focus group, participants, with the exception of those living with dementia, were briefly shown an existing online portal on dementia (Dementia Australia: www.dementia.org.au) and asked for their general reactions on its structure, format and content. Given the shorter session length, the discussion with people living with dementia focused on the information gaps and needs for the Canadian portal, rather than a review of the Australian site.

The Dementia Australia website was considered an excellent template for the development of a Canadian online portal. The site's clean and calming design, its positive imagery, as well as its perceived comprehensive content and ease of navigation contributed to its appeal. Most notably, the manner in which the information is organized was praised. A single, simplified menu on the home page with a quick-view access to section contents helped quickly locate information of interest on the Dementia Australia site. At the same time, organizing the information by topic and by audience was appreciated. In fact, it was believed that a Canadian portal should give more prominence on grouping information by audience in its structure than what is on the Australia site, including groups such as people living with dementia; family, friends, colleagues and neighbours; unpaid care providers; healthcare professionals; and first responders. Accessibility features, such as the email support helpline web chat, the 'listen' and 'share' functions and having materials available in multiple languages, were noticed, appreciated and considered essential.

Trust was viewed as an important consideration with online resources, and decisions about the development of the online portal must consider how to establish its credibility. There were various ways suggested to establish trust in the online portal, most notably hosting the portal on the Canada.ca website and using a URL that ends in '.ca' or '.gc.ca'. That said, if the site was hosted through a non-governmental partner organization, but funded by the Public Health Agency of Canada, most felt strongly that such a site should be visibly supported and endorsed by the government to instill confidence. This could be done by displaying the Canadian flag; visibly stating the Government of Canada's endorsement; providing a link to the online portal from the Canada.ca website; providing contact information for validating the site; identifying the sources of information posted on the site; and getting endorsement from well-known and respected associations in the healthcare field or those related to dementia. Participants also expect that links to online resources found on the dementia portal would be endorsed by the Government of Canada, and thus that information on those sites can be trusted.

Given that multiple online resources on dementia currently exist, there is a need to clearly position a new government-sponsored online dementia portal and create general awareness, perhaps by working with healthcare professionals, first responders and specialized associations to promote this tool, and by advertising the portal on social media, among other things. Online search engine optimization is also important given that a general internet search was often identified as the first step in locating online information on dementia.

Finally, despite the appeal of an online portal as a source of information on dementia, suggestions were made to also consider the development of a variety of other complementary resources, or to raise awareness of those that currently exist. The resources that were mentioned included such items as: printed information; a social media awareness campaign; podcasts; listings of local support groups and resources for people living with dementia; self-diagnosis tools; an ombudsman for people living with dementia; as well as various tools to assist people living with dementia, family members and unpaid care providers during emergency situations (e.g., listing of personal information; GPS tracking; registering a person).

Introduction

Context

Dementia has an increasingly significant impact on Canadians, with more than 432,000 Canadians aged 65 year and older living with diagnosed dementia in 2016-17.[1] Additionally, two-thirds of those diagnosed are women.[1] With a growing and aging population, the number of Canadians living with dementia is expected to increase in future decades.

In June 2019, Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire* was released. The strategy sets out the vision of a Canada in which all people living with dementia and care providers are valued and supported, quality of life is optimized, and dementia is prevented, well understood and effectively treated.

The main objective of this research is to inform development of an online portal providing useful and comprehensive information on dementia. More specifically, the research is intended to provide insight on what features and resources the target audiences are looking for in using a portal, including the source and type of content, and to examine measures to make information more accessible.

Objectives

Specific research objectives included:

- To capture awareness and perceptions of existing dementia information online resources:
    - Sources of dementia information
    - Credibility and quality of content
    - Essential and popular dementia topics

- To understand current dementia information needs and gaps:
    - Identify which dementia topics were seen as lacking accessible and credible online resources/information (such as signs and symptoms of dementia; prevention and risk reduction; screening and diagnostic tools/tests; treatment and management; stigma; and dementia inclusive communities)
    - Assess dementia information/resource gaps and/or barriers for a variety of key target populations: paid care providers; people living with dementia; family / friend care providers; populations at higher risk of developing dementia and those facing barriers to equitable care; and the general public

- To evaluate perceptions and preferences related to features, tools and information resources that users expect to see as part of a dementia information portal:

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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/

  - Determine elements of a portal that support credibility, accessibility and visibility
  - Assess perceptions of sample approaches to dementia information portal related to: navigation; visual appeal; resources; overall content; credibility; accessibility, inclusivity; and community creation or development

- To determine whether additional tools are needed to effectively educate the general public, people living with dementia, care providers and health care providers beyond an online portal (e.g., resources that can be printed out, links to local support groups, etc.)

This report presents the research findings. It includes a high-level executive summary, a description of the methodology used, and findings of the online focus group discussions, including recommendations made. Working documents appended to the report include the recruitment screener (Appendix A), moderator's guides (Appendix B), and materials tested (Appendix C).

Research Methodology

Target Audience

For the purpose of the study, there were seven target audiences, namely:

- Members of the general public (including a mix of age, gender, household types and cultural background). Of note, a few of these participants reported having, or having had, members of their family living with dementia, and thus they at times commented on this situation.
- Those who have been identified as likely to be at higher risk of developing dementia or facing barriers to equitable care (i.e., individuals with hypertension/diabetes/high cholesterol/obesity, older adults, Indigenous people, those with an intellectual or physical disability, racialized groups, those who identify as LGBTQ2+, those living in rural and remote communities). Recruitment included a mix of gender and household types. This audience also included a few individuals who reported having, or having had, relatives with dementia.
- Unpaid care providers, which were often family members, friends, or neighbours providing care without financial compensation. Support provided by an unpaid care provider may include assisting with the activities of daily living and helping with advance care planning. This group included a mix of gender and cultural backgrounds.
- Paid care providers (PCP), including:
    - First responders (PCP First responders; e.g., police officers, firefighters, paramedics, search and rescue personnel).
    - Healthcare providers (PCP Healthcare; e.g., family physicians, nurse practitioners, geriatric specialists, registered nurses, and pharmacists). In their professional role, these individuals are directly involved in providing healthcare to people living with dementia.
    - Social assistance/general care providers (PCP Care; e.g., social workers, occupational therapists, developmental service workers, personal care workers; nutritionists). In their professional role, these individuals are providing support services to people living with dementia and their family, by offering personal care and addressing situational changes related to housing, nutrition, and support services, among other things.
- People diagnosed with dementia who confirmed their ability to participate in the research. Where possible, a mix of gender and cultural backgrounds was selected for each session.

Paid care providers acting in healthcare and care positions included only those who are currently interacting with people living with dementia, while first responders included a mix of those who had already had such interactions, and those whose position offered the potential for this interaction.

Research Approach

The study included a total of 25 online focus groups conducted from February 1-11, 2021. The following tables provide a breakdown of sessions based on audience region and language and specifies the number of focus groups, the number of recruits per group and the length of the session. Although group segmentation was initially planned to include a geographic component (e.g., west and east), difficulties in securing participation in rural communities led to expanding recruitment for the rural groups to include communities across Canada. At the same time, the population size criteria for each of the small/medium and large urban areas, as well as rural areas, was modified to ensure that these groups were well represented.

Number of Online Focus Groups							
Audience	Large Urban	Rural	Small/Medium Urban	Mixed Urban	Session Length	Total Groups	Total Recruits
General Public	1 English Full Group West (MB/SK/AB/BC)	1 English Full Group Canada-wide	1 English Full Group East (ON/NB/NS/PE/NL)	1 French Full Group Quebec	1.5 to 2 hours	4 Full	40
Higher Risk Population	1 English Full Group East (ON/NB/NS/PE/NL)	1 English Full Group Canada-wide	1 English Full Group West (MB/SK/AB/BC)	1 French Full Group Quebec	1.5 to 2 hours	4 Full	40
Unpaid Care Provider	1 English Mini Group East (ON/NB/NS/PE/NL)	1 English Mini Group Canada-wide	1 English Mini Group West (MB/SK/AB/BC)	1 French Mini Group Quebec	1.5 to 2 hours	4 Mini	24
PCP (First Responders)	N/A	1 English Mini Group Canada-wide	1 English Mini Group West (MB/SK/AB/BC)	1 French Mini Group Quebec	1.5 to 2 hours	3 Mini	18
PCP (Healthcare)	1 English Mini Group East (ON/NB/NS/PE/NL)	1 English Mini Group Canada-wide	N/A	1 French Mini Group Quebec	1.5 to 2 hours	3 Mini	18
PCP (Care)	1 English Mini Group West (MB/SK/AB/BC)	N/A	1 English Mini Group East (ON/NB/NS/PE/NL)	1 French Mini Group Quebec	1.5 to 2 hours	3 Mini	18
People living with Dementia	1 English Mini Group West (MB/SK/AB/BC)	1 English Mini Group Canada-wide	1 English Mini Group East (ON/NB/NS/PE/NL)	1 French Mini Group Quebec	1 hour	4 Mini	24
TOTAL	6	6	6	7		25	182

Community sizes are defined as follow:

- Large Urban (pop. 150,000+; and within 50 km of it)
- Small/Medium Urban (pop. 10,000-150,000)
- Rural (population of up to 9,999 and min. 50 km from urban centre)
- Mixed Urban (pop. 30,000+)

Sessions with people living with dementia each lasted one hour while all other sessions lasted between one and a half and two hours. Each participant of the general population and higher risk population groups received an incentive of $100, while unpaid care providers were each provided with a $125 incentive. Individuals living with dementia were each provided with an incentive of $150, as were paid care providers working as first responders and social assistance/general care providers. Paid care providers in the area of healthcare each received an incentive of $200. In total, 181 individuals were recruited to take part, while 151 attended a focus group. More specifically, participation totalled 21 people living with dementia, 32 members of the general population, 33 individuals with higher risk, 19 unpaid care providers, and 46 paid care providers (16 paid care providers who offer social assistance and general care and support, 15 first responders, and 15 within healthcare). In addition, four recruits were paid although they did not participate in the focus groups due to experiencing technical difficulties.

A number of measures were put in place to enhance accessibility, especially for people living with dementia. The discussion length for those focus groups was kept at one hour, each session included a small number of participants, and the sessions were scheduled earlier in the day. In addition, an assistant was on hand prior to, and during the session, to help participants with the technology, if required. People living with dementia were also offered to receive the research instruments (i.e., recruitment questionnaire and discussion guide) in advance, giving them an opportunity to prepare for their session.

During the focus groups, the moderators adjusted their facilitation approach when needed. This included restricting unnecessary probing, using simple or familiar language, using shorter, more pointed questions that offer simple choices in response, providing participants sufficient time to respond, speaking slowly, minimizing distractions during the session, and offering reassurance. In addition, if responses appeared out of context, moderators would encourage more details or rephrasing and assist in structuring thought processes when required. A number of participants received assistance from a care provider during the focus group.

All participants were recruited according to the Government of Canada's recruitment specifications. Recruitment was conducted through qualitative panels stored on Canadian servers, with follow up calls to confirm the details provided and to ensure quotas were met. Those with current or past employment in sensitive occupations were excluded from the research, in addition to those who have others in the household in this situation. These sectors included marketing, marketing research, advertising, media, web development, and health-related communications positions for the federal or provincial government.

Context of Qualitative Research

Qualitative discussions are intended as moderator-directed, informal, non-threatening discussions with participants whose characteristics, habits and attitudes are considered relevant to the topic of discussion. The primary benefits of individual or group qualitative discussions are that they allow for in-depth probing with qualifying participants on behavioural habits, usage patterns, perceptions and attitudes related to the subject matter. This type of discussion allows for flexibility in exploring other areas that may be pertinent to the investigation. Qualitative research allows for more complete understanding of the segment in that the thoughts or feelings are expressed in the participants' own language and at their own levels of passion. Qualitative techniques are used in marketing research as a means of developing insight and direction, rather than collecting quantitatively precise data or absolute measures. As such, results are directional only and cannot be extrapolated to all Canadians falling within the key groups participating in this project.

Research Findings

This section provides a detailed account of the focus group discussions and the topics are presented in the order in which they were discussed. Each session began with participants describing their previous searches for information on dementia, as well as identifying what information was of greatest interest to them regardless of the sources and what information was unavailable or difficult to find. Following that, participants were asked to express their opinion regarding the possibility of a new Canadian online portal on dementia, in addition to identifying topics and related content they would like to find on this website. Finally, participants were briefly shown an existing online resource on dementia, the Dementia Australia website, and asked to comment on the relevance of its content, as well as its navigation and functionality, in order to better understand preferences and priorities for a Canadian portal on dementia. Keeping the session format in mind, findings presented below may appear repetitive at time, although they present different points of views on information needs and interests.

Information Needs and Sources

There were wide-ranging needs pertaining to dementia information, although interest in specific topics varied based on the role of the person in interacting with someone living with dementia.

Prior to introducing the idea of a Canadian portal on dementia, the first part of the discussion entailed better understanding what information related to dementia is of interest and where this information has been found. In addition to information needs and sources of information, the discussion aimed to assess information gaps.

Information Needs

Regardless of the type of participants in the focus groups, a variety of basic information needs were consistently identified. Specially, participants were interested in having a clear definition of what dementia is, what are the signs and symptoms, how it is diagnosed, information on the various types of dementia that exist, what the stages of dementia include, what progression looks like depending on the type of dementia, treatment options, and what can be done to prevent or mitigate risks of developing dementia (i.e., what proactive steps can people take to diminish the likelihood of having dementia in the future). Some would also like to understand if dementia is a direct result of other pre-existing medical conditions.

With the exception of those working in health-related fields, there was often confusion between dementia and Alzheimer's disease, with participants often viewing Alzheimer's disease as being separate from dementia, rather than being a type of dementia. Some felt the two terms were synonymous. Even those who have done past research on the topic of dementia often noted a lack of clarity between terms in the information they found online.

> *"In my experience, the information is not clear, and it doesn't often distinguish between Alzheimer's and dementia." General Population*

Those who have been impacted by dementia (such as those living with dementia or providing unpaid care) identified additional information needs including what can be done to delay or slow down the progression of dementia (i.e., physical activities, diet, medication, brain stimulation activities), whether or not dementia is hereditary, how quickly progression will occur, and when lifestyle choices or changes (i.e., home care, assisted living, institutionalization) will need to be considered for someone living with dementia. In addition, they believed that information is needed to clearly outline what supports (physical, emotional and financial) are available for those who have been diagnosed with dementia, and where someone would go to access such supports.

The following provides further details on how some information needs varied by audience.

Paid Care Provider - Healthcare

Healthcare providers were most interested in information on health and community resources to provide assistance to people living with dementia and their family upon diagnosis. Some also felt that it is important to inform the patient and their relatives about the legal aspects of caring for someone during the later stages of dementia.

> *"C'est quoi le processus pour ce qui est de curatelle, le curateur; ça peut être compliqué à prendre des décisions. Souvent quand les patients ne sont plus aptes à prendre ces décisions il n'y a pas d'autres personne dans leur entourage qui savent cela." (What is the process for curatorship, the curator; it can be complicated to make decisions. Often times when patients are no longer able to make these decisions there are no others around them who know it.) Paid Care Provider - Healthcare*

Most healthcare providers who frequently interact with people living with dementia believed that they have sufficient understanding of dementia to conduct their work, or felt that if they did have questions, they would simply rely on their professional connections (e.g., they would have easy access to specialists in the field of dementia to get information). That said, those who did not have frequent contact with people living with dementia expressed an interest to learn more about the best ways to interact and communicate with this audience.

> *"L'autre info qui est utile de savoir comme intervenant c'est au niveau comportemental comme l'anxiété. C'est utile pour obtenir la collaboration avec les patients. Il faut savoir comment interagir avec le patient." (The other information that is useful to know as a person interacting with them is at the behavioural level, such as anxiety. It is useful to gain patient collaboration. You need to know how to interact with the patient.) Paid Care Provider - Healthcare*

> *"There are different approaches – gentle persuasive approaches, non-violent crisis intervention, how to redirect their frustration, etc. We all have the benefit of it being taught to us, but having resources for others who aren't in those pathways would be good." Paid Care Provider – Healthcare*

In addition, it was identified that it would be useful to access information on the specific situation of a person living with dementia, to provide immediate and tailored care, although privacy concerns were identified.

Paid Care Providers – First Responders

The role of first responders was somewhat more limited in terms of assisting people living with dementia and their family. Indeed, their interactions were often happening in a time of crisis where medical assistance is needed. As such, they were mostly interested in properly assessing the situation and finding immediate resources to care for people living with dementia and their family, as well as being able to guide family members to assistance they may require in the future.

> *"Quand ils (les personnes atteintes de démence) sont en crise, c'est rare que j'ai une conversation avec eux. C'est au niveau de la famille (avec qui j'ai des contacts) parce qu'ils ne savent pas comment gérer la situation et quelles sont les ressources." (When people living with dementia are in crisis, I rarely have a conversation with them. My contacts are with the family because they don't know how to handle the situation and what the resources are.) Paid Care Provider - First Responder (Police Officer)*

For many first responders, having the ability to accurately assess the situation is largely dependent on having information about the individuals involved, specifically knowing prior to intervening that the situation involves someone living with dementia. Understanding how much the person living with dementia and the people with them during the crisis knows about dementia, if there is erratic behaviour anticipated, and what is the best way to respond based on the family's experience, were expressed as important information to determine the best way to handle the situation.

> *"What I need is information. They are usually in a state where they are confused. They believe we can solve their problems. We need more information on how to deal with specific situations. Often times a person is missing. Sometimes they may remember a house they lived in 30 years ago in the area. Any past history would be good." Paid Care Provider – First Responder (Firefighter)*

> *"Families don't always offer the info we need up [front] prior to arrival. How do they function? What year are they functioning in? What part of their life are they in? That lets us adapt our response." Paid Care Provider – First Responder (Paramedic)*

As such, first responders did not consider that they need information on dementia beyond the basics they learned at work through formal training, informal discussions with colleagues, access to specialized resources (e.g., police officers trained in mental health issues) or their knowledge learned from experience.

> *"On a une section qui s'occupe des personnes vulnérables et on fait le dossier et eux font les démarches. On fait un peu de recherche et avec toutes les interventions qu'on a eu,*

> *on a une façon de faire." (We have a section that deals with vulnerable people and we fill out the paperwork and they do the legwork. We do a little research and with all the interventions we have had, we have developed a way of doing things.) Paid Care Provider - First Responder (Police Officer)*

Across first responders, police officers, security guards and firefighters were least likely to believe they required additional information or knowledge about dementia as part of their work. As they most often get involved with people living with dementia in a crisis situation, it is likely that paramedics or other healthcare professionals would also be involved to address the situation from a medical perspective.

> *"On n'a pas beaucoup de temps de fureter sur Internet. Quand on a des gens qui ont la santé mentale ou la démence souvent on est accompagné par des ambulanciers et les gens sont déjà référés à même le service hospitalier." (We don't have a lot of time to browse the Internet. When we have people with mental health issues or dementia, we are often accompanied by paramedics and people are already referred to the hospital.) Paid Care Provider - First Responder (Police Officer)*

First responders recognized the need for themselves to have basic knowledge about dementia, but they also mentioned that the work they do is influenced by how much family members know about the person living with dementia and the condition itself. For instance, one first responder mentioned that family members need to understand the implications of dementia decline, and how family members' own actions could impact a first responders' ability to offer assistance in a time of need.

People Living with Dementia

People living with dementia who indicated having recently been diagnosed expressed during the focus groups great interest in understanding the various forms of dementia, and how their condition might evolve over time. They were also looking for tools and resources to assist with their daily tasks (e.g., checklists; information with pictograms for ease of understanding).

For people living with dementia, there seemed to be a sense of urgency to better understand what actions can be taken to live a quality and positive life to the fullest while they are still able to. They were looking for practical guidance for daily living as dementia progresses, and how to manage symptoms. Further, there was a need for information that is positive and uplifting, offering direction as someone learns how to navigate their life with dementia.

> *"[It's important to have information on] living well with dementia – it's not all doom and gloom…what can you do to have a good day." Person living with dementia*
>
> *"Fear of the unknown is scary. I don't know what to expect. It's scarier than it has to be." Person living with dementia*

Some of the general questions people living with dementia expressed having include:

- Can a diagnosis of dementia evolve over time to become one for Alzheimer's?
- What can I do to slow down the development of dementia?
- Does everyone go through all the same stages?
- What stage am I at currently (where on the scale do I fit)?
- What is a realistic timeline (i.e., what will I be like in 2 yrs. and 5 yrs.)?
- What local resources are available through government and other organizations to provide assistance to those living with dementia?
- What treatments are being researched?
- What treatment options are there?
- What are the side effects or risks associated with treatments?
- How can I tackle daily tasks as the symptoms of dementia evolve?
- What supports will I need in the future?
- What tools might help me as dementia progresses?
- What resources are available for me if I don't have access to care providers and live alone?
- What activities or social groups are available for people living with dementia?
- How do I prepare for the future? How do I make decisions now about my long-term care?
- What healthcare professionals specializing in dementia can I access?

> *"What state am I going to be in, what are the consequences, how do I live in the future – this scares me. I need to know how it's going to affect me. My family needs to know if they'll have to look after me." Person living with dementia*
>
> *"I don't need a lot of information. I want basic things. I need to know how to deal [with dementia] in the simplest of ways." Person living with dementia*

Paid and unpaid care providers were asked what information they believed people living with dementia should have regarding the condition, based on their interactions with them. Understanding dementia and how it evolves over time, as well as what can be done to manage or delay the development of symptoms were topics often cited. A good number considered it important for people living with dementia and their families to know what resources are available to them, as well as being informed of anything that could improve their daily lives and assist with long-term planning. This could include guiding them to organized activities or support groups for those living with dementia, available supports for unpaid care providers (e.g., respite care services), and financial supports.

> *"Pour nous en médecine souvent (les gens atteints de démence) demandent quelles sont les options thérapeutiques, des informations sur les médicaments, des ressources dans la communauté, des groupes de soutien, d'autres organismes dans la communauté, et des façons de préserver l'autonomie de la personne le plus longtemps possible." (For us in healthcare, people living with dementia often ask what treatment options there are, information on medication, community resources, support groups, other organizations*

> *in the community and ways to stay autonomous as long as possible.) Paid Care Provider - Healthcare*

Information that provides direction and a sense of preparedness was deemed by paid and unpaid care providers as essential to people living with dementia and their family members.

> *"Early on, give them (people living with dementia and family members) ideas of what to expect, what they can do to help themselves, and what actions can be done to assist. Help them prepare for the transition and for the hard conversations." Paid Care Provider – First Responder (Police Officer)*

Unpaid Care Providers

Unpaid care providers wanted to understand and get advice on how to better care for their loved one as their condition evolves. This was also expressed by family members of people living with dementia who were included as part of the general public and were not the primary care providers. Both of these audiences expressed an interest to better understand how their interactions or responses can be improved, as well as what actions or reactions should be avoided. Appreciating and recognizing how to best address specific behaviours was considered paramount as the situation evolves, as well as finding out the best ways to interact or communicate to minimize anxiety. Further, understanding how to deal with changes in behaviour, sleeping adjustments, and repeating stories were all deemed important.

> *"What I really need is a practical guide on what I should do, and how I should react and interact as things change. What coping mechanisms are there?" Unpaid Care Provider*

> *"How do I validate the experience of the person? I know I should agree with them and go along with what they say to diffuse the situation. Learning to agree with them - not challenge or correct - is modifying my behavior." Unpaid Care Provider*

It was also believed by paid care providers that unpaid care providers, relatives and close family members of people living with dementia also need to be informed of how to best interact with people living with dementia, how to interpret the signs and symptoms, how to adapt their communication approach when interacting with a loved one with dementia, and how to diffuse or address feelings of anxiety or agitation.

General Public

Members from the general public were less interested in learning about dementia at this time. Apart from those who currently care for someone living with dementia, or those with a relative with dementia, few saw a need for increased knowledge, as it is not something which is relevant to them at this time.

Higher Risk Populations

Similar to members from the general public, participants in the higher risk focus groups expressed more limited interest in dementia-related information. That said, a number of them would like to learn more about correlations between dementia and other health conditions, as well as location and socio-economic status. Their desire for information was driven primarily by a personal concern for potential links with their own medical conditions.

> *"Are there correlations between dementia and existing health conditions? As a three-time cancer survivor, we joke that I have 'chemo brain'. Does that predispose me to dementia? I tried to find out, but information is very generic." General Population – Higher Risk*

> *"I've had a brain injury from an accident. My mind is not as sharp as it was before the accident. What does that mean in relation to dementia? Should I be concerned?" General Population – Higher Risk*

Sources of Information on Dementia

Health professionals were identified as the most trusted source of information on dementia. While there was a general perception that considerable information is available on the subject online, those directly impacted by dementia often struggled to find information that is clear, concise, complete and personally relevant.

Current Sources of Information

Participants who had searched for information on dementia in the past were asked to describe their experience, including what sources of information they used. For those directly impacted by dementia (people living with dementia and unpaid care providers), the primary source of information was health professionals, most often a family doctor, but also sometimes a nurse, pharmacist or social worker. That said, participants noted not always being able to readily access their family doctor as questions arise, even though their doctor would be their preferred information source.

> *"My family doctor would be the one I'd trust the most [for information on dementia], but the problem is that they don't have the time to discuss what's going on, and a lot of the doctors are not that well informed themselves [on dementia specifically]." Person living with dementia*

Unpaid care providers also turned to seniors' homes, community groups and long-term care facilities for information and guidance about dementia and relied on advice and insights from friends and family who have been personally impacted by dementia in the past. In addition, the Alzheimer Society was consistently named as a resource explored, with the Society being often recommended to them by a health practitioner, particularly following diagnosis.

Across audiences, those who looked for information on dementia were most likely to turn to the internet initially, with a general online search. Search results were consistently described as daunting and overwhelming, given the wide range of listings and links for information to any specific question. There was often no clear starting point, and many were unsure as to which listings or links would provide the most relevant, up-to-date, trustworthy and accurate information. As such, many reported randomly exploring a wide variety of sites to cross-reference information. Indeed, as a matter of course, most indicated that multiple sites were visited and numerous links explored, in an effort to validate any information they found. In essence, if information was consistent across multiple resources or sites then the information was deemed credible and trustworthy.

> *"A person can easily get lost on the internet – one article leads to another, to another…" General Population*

> *"It's difficult to see what's fact-based information versus someone's opinion." Person living with dementia*

> *"…if it follows the rest of the information I'm seeing, and it's repetitive – then it's credible." General Population*

Other key sources for information included public health agencies or government departments (both provincially and federally), with Health Canada often mentioned by name. Governments were consistently deemed both reliable and credible in the information they provide, primarily because their information was considered fact-based and supported by health professionals and scientific evidence. Further, it was felt that governments generally have a vested interest to provide accurate information, given their responsibility for the public's health and wellbeing in Canada. That said, government sites in general were often considered difficult to navigate to get to desired information.

> *"For me personally, I try to stay with government websites like Health Canada. If I find information somewhere else, I try to fact check on Health Canada's website…" Person living with dementia*

Due to association, any site linked to a government website was also often deemed credible, as individuals felt government would only provide links to external resources that have been thoroughly vetted in terms of quality and accuracy of information.

Online discussion forums, Facebook groups, and books on dementia were also considered a resource for people living with dementia and unpaid care providers, often providing a much-needed opportunity to share comments with others going through similar experiences. That being said, there was an expectation that any forum on a government-sponsored portal would be professionally moderated. Moreover, given that those living with dementia can have very different experiences, these resources were seen as a way to reach out to others for support and advice.

> *"I saturated myself with reading about other people's experiences." General Population (who is also an unpaid care provider)*

> *"I want to share information with others who are dealing with the same situation. Those who give us the best information, they are the first line of defence." Unpaid Care Provider*

> *"If a site is not trying to sell a product or push a service, then I consider it legitimate." Unpaid Care Provider*

Paid care providers expressed that they typically rely on their work training or employer for education and information on topics such as dementia, and most do not actively search out dementia information elsewhere. Healthcare providers tended to place greater reliance on medical peer reviewed journals or formal research papers. Although information on dementia was generally known and accessible to healthcare providers, they lacked easy access to information on local resources to support or assist people living with dementia and their families. In hospital settings, this information is often sourced from social workers, with printed materials also being readily available in some pharmacies.

> *"Pour les services dans la communauté, c'est plus les travailleurs sociaux à l'hôpital. Sinon on peut chercher via Internet mais on a quand même des listes pré-faites à l'hôpital qu'on peut remettre aux familles et patients." (Social workers provide information on community services. Otherwise, we can search on the Internet but we still have lists available at the hospital that we can give to families and patients.) Paid Care Provider - Healthcare*

Specific Websites Used

As mentioned, across audiences and locations, online searches for information about dementia were typically generic in nature and not site-specific. When asked which websites come to mind when considering information on dementia, very few were named, with the Alzheimer Society and Mayo Clinic most often mentioned. These sites were usually found as a result of a general internet search. A few family members also cited Dementia Alliance International (DAI) as a site that they or their family member living with dementia had either visited for information or to take part in discussion forums. Other broader mentions included Health Canada, Wikipedia, web.md, health authorities from other countries, the World Health Organization, and university sites.

When looking for more general health related information online, participants generally relied on information provided by public health agencies or government departments, as well as information recommended or supported by health professionals. To be considered reliable, medical information needs to be perceived to be endorsed by well-known and trusted organizations or grounded by sound, medical research. In addition, the inclusion of contact information and credible resources helped to make a site legitimate to many.

> *"I evaluate whether a site is credible or trustworthy by what it includes. Is it updated regularly? Are sources named? If it's legitimate, they put contact information, and their location is listed so you can find them. And their web address is important. Websites with '.edu' or '.gov' usually mean it's coming from a credible source." Paid Care Provider - Care*

> *"Government of Canada sites are trusted. You trust the science behind the source – anything government related. Web.md makes my eyes roll." Paid Care Provider - First Responder*

Information Gaps

Being able to obtain specific and detailed information on dementia from a single, credible location was felt to be lacking, including information about local resources and support groups.

Based on past personal experiences, information on dementia was generally viewed as limited both in terms of scope and availability. While there may appear to be much information on the topic available online, it was considered incomplete, disorganized, scattered, and sometimes untrustworthy, making researching information difficult. Those closely impacted by dementia (people living with dementia and unpaid care providers) also expressed frustration with finding ***information relevant to their specific needs*** (e.g., information on a specific type of dementia), and presented in a manner that is easily understandable (e.g., short bullet points, presenting information in visuals rather than only in text). Further, those living in rural and remote areas considered it hard to find easy access to ***advocacy support services***.

> *"…there's definitely resources available to patients and families, but getting the families on the right track to find the information that they need [can be difficult]." Paid Care Provider – Healthcare*
>
> *"It's difficult to navigate for advocacy services. You have to be living in a larger city to find any organizations that offer support services." Unpaid Care Provider*

In addition, a few healthcare workers in a number of locations mentioned difficulty in sourcing ***culturally-appropriate resources***. At the same time, Quebec healthcare providers cited the lack of sufficient ***resources and information available in French***.

> *"Il n'y a pas assez d'endroit où on peut référer les gens de différentes ethnies pour recevoir cette aide. Il y a une barrière de langue et de croyances." (There are not enough places where we can refer people from different ethnic backgrounds for help. There is a language and belief barrier.) Paid Care Provider – Healthcare*

Across most audiences, participants consistently voiced frustration with the apparent lack of a ***comprehensive online resource on the topic of dementia***, and frustration with trying to find a ***credible online starting point*** in their search for information. People living with dementia and unpaid care providers were especially hindered by an inability to locate thorough and reliable resources to satisfy all of their information needs, particularly if trying to find ***specific information on rarer types of dementia***. Having to sift through many different links to ascertain which sites are relevant, and then checking other sites to confirm the information's legitimacy was deemed problematic and at times stressful.

> *"I found there was a wide variety of information available from many different websites. Going from website to website there is a lack of uniformity." Unpaid Care Provider*
>
> *"The information is scattered and because there are so many forms of dementia the information is so broad." Unpaid Care Provider*

This situation was felt more acutely by people living with dementia and some of the unpaid care providers who have to deal with the shock and grief resulting from a diagnosis of dementia, in addition to difficulties finding information and specialized care or support.

> *"On est dans un flou et on ne sait pas trop où s'informer et à qui le dire, le partager." (We are in the fog and we don't really know where to get information and who to tell, with whom to share.) Person living with dementia*

Due to these information gaps, even those personally impacted by dementia had limited knowledge of some dementia topics. Participants consistently felt that ***a 'one-stop' credible resource was needed to provide accurate and directional information for multiple audiences***. This was believed to be necessary especially as they ***learn to deal with the emotional impact*** of a diagnosis of dementia over time.

> *"Part of the struggle for me – they sit you down and tell you this is what you have and send you out the door. A social worker gives you a contact at the Alzheimer society, but that hasn't been helpful at all for me…all the information that I need is simply not out there." Person living with dementia*
>
> *"I know very little about dementia…I want basic information about what it is, are there treatments I can get involved in? Is it curable? Is there a place I can go for information…?" Person living with dementia*

While there appeared to be sufficient information available on dementia in general, including the signs and symptoms, some felt that ***information specific to different types of dementia and the stages of dementia*** is not easy to locate, especially in understanding how dementia and Alzheimer's disease relate to each other.

> *"Démence versus Alzheimer; la ligne est mince et c'est très mélangeant de savoir comment on catégorise les deux." (Dementia versus Alzheimer's; the line is thin and it is very confusing to know how to categorize the two.) Unpaid Care Provider*
>
> *"The stages of dementia. I would like to learn that. How do you determine what stage? Understanding how the situation evolves." Unpaid Care Provider*

Another type of information deemed important but difficult to find is the ***housing options*** available to people living with dementia, and ***what steps need to be taken to prepare for future housing needs***. Indeed, a number of participants felt that family members were focused on taking care of the immediate needs of their loved one, but were not sufficiently informed of planning for the future.

Similarly, ***information on legal matters***, including setting up power of attorney and personal care directives, was felt to be lacking despite its perceived importance. While some information is currently available, it was mentioned that it is not always presented in a manner that is easy to understand to effectively assist people living with dementia and family members with navigating long-term planning.

> *"Ce qui m'a chicoté c'est le volet juridique : quels sont mes droits versus les siens? Quoi faire dans le cas X pour l'aidant naturel. J'aimerais savoir : voici les étapes. Quelque chose de plus pratico-pratique." (What bothered me was the legal aspect: what are my rights versus his? What should the unpaid care provider do in situation X? I would like to know: here are the steps. Something more practical.) Unpaid Care Provider*

A number of unpaid care providers also mentioned a lack of ***easy-to-understand information on current treatment and medication*** for dementia, as well as ***current research*** being done in the field, both in Canada and abroad.

> *"Ce qui manque c'est de l'information vulgarisée sur les différents traitements. On aide la personne au jour le jour mais j'aimerais savoir qu'est-ce que les médicaments que je lui donne font." (What is missing is information in simple language on the different treatments. We help the person day-to-day but what I want to know does the medication I provide do?) Unpaid Care Provider*

Unpaid care providers also expressed an interest for ***resources and information to help manage their own stress***. Although few have looked for this information, there was a sense that it is somewhat lacking.

> *"I am losing my patience at times and I am trying my best not to. But my husband can read my body language good. He can see my annoyance and he says, 'don't get mad at me'. I am trying to learn some answers or methods and ways to [be more patient]." – Unpaid Care Provider*

> *"L'information sur la démence elle est là. Il y a beaucoup d'information. Mais pour aider aidants c'est ça qui manque." (Information on dementia exists. There is a lot of information. But to help care providers that is what is lacking.) Unpaid Care Provider*

A few unpaid care providers felt that they lack sufficient ***information to prepare them to deal with crisis situations***, including how to recognize signs and behaviours that can lead to such a situation, how to interact and communicate with someone living with dementia when in a crisis, how to protect themselves and their loved one, and how to de-escalate the situation.

> *"We had an incident a couple of weeks ago…… my husband got weepy and he said, 'I don't know what is wrong with me and I want to say so many things and the words just*

> *don't come out'. He is having more and more trouble understanding... instructions and conversations are not happening any more. He does not know or understand what I am saying. I can't explain to him what is going on; I don't know how to tell him what is going to happen." Unpaid Care Provider*

There were a few mentions regarding the lack of ***information specific to family members that may not provide care to a person living with dementia*** and who may have varying degrees of interaction with that person. Knowing what to expect and how to communicate so as to ensure a successful interaction with their family member was of interest.

> *"You might not be the primary care provider [but you need to know] how to interact with them; how the interaction might change; how to not cause additional stress for the person." Unpaid Care Provider*

In general, paid care providers were most interested in additional information to assist people living with dementia and their family, rather than inform their professional activities. The most acute need is for a ***centralized list of local resources and support*** available to people living with dementia and their family.

Members from the general public and those in higher risk groups were less likely to know what information is missing, because they were less likely to have searched for it in the past.

As mentioned, first responders and paid healthcare providers generally relied on courses offered by their licensing body to provide them with information on dementia and other related topics. However, first responders recognized that in these training sessions information is lacking on topics related to dealing with people living with dementia.

Online File Format

There was widespread appreciation for information being provided in a broad range of online formats primarily based on the type of audience.

Participants were told there are many ways information could be accessed online on any website, including: reading text on a website; downloading files; seeing listings or libraries of information or resources; using assessment tools / questionnaires; reviewing videos or audio files; or taking part in an online forum.

File Format

Across groups, participants generally made use of multiple formats when accessing information online. Which format is used at any given time was largely dependent on when the information is sought, what the information is used for, what level of detail is required and who the information is intended for. There was general agreement that having information available in multiple formats is necessary for any effective website.

> *"I hate to say this, but I would like to have them all. I like watching videos, downloading information, taking part in forums. When I'm hungry for information, I like to have them all so I can figure out what's going on." General Population*

For many, **reading text on a screen** was the preferred format, particularly if looking for a quick reference or answer to a question. This was especially the case for those searching for information on a mobile device.

By contrast, others indicated that they preferred to **download a document on their computer** so they can print it off to share with others, save it as an easy reference in the future, and mark up any comments or questions on the document itself. Multiple participants living with dementia voiced preference for downloading and printing documents, primarily so they don't have to navigate how to find the information in the future. Having a hard copy on hand or saved on their desktop was appreciated for ease of reference, allowing individuals the ability to consume information at their own pace.

That being said, it was believed by a few people across audiences that to make text-based or printed information useful to people living with dementia and their relatives, it is important that it remains concise, visually attractive and uses simple language.

> *"Si je veux aller chercher de l'information à transmettre c'est bien quand il n'y a pas trop d'information et que c'est bien vulgarisé. Par sous points, par exemple." (If I am looking for information to give away, it is good when there isn't too much information and it is well popularized. In bullet point format, for example.) Paid Care Provider - Care*

Having access to **videos or podcasts** was especially appealing to some. Many participants were self-professed visual or active learners, and found it easier to absorb and comprehend information in an audio or video format, rather than exclusively through text. Others appreciated having the ability to listen to a podcast while multitasking. It was also noted that an audio-visual format could be useful for individuals with lower literacy levels. However, healthcare providers noted that access to video or audio file formats are blocked in some workplaces.

> *"I like something that keeps me connected. Watching videos and listening to podcasts. The use of social media and watching stories on Instagram." Unpaid Care Provider*

> *"Dans le cadre de mon travail à l'hôpital tous les fichiers audio et vidéo sont bloqués au travail. Les trucs qui se lisent c'est plus accessible pour moi." (In the course of my work at the hospital, all audio and video files are blocked at work. Things that can be read are more accessible to me.) Paid Care Provider - Healthcare*

> *"Les balados ou les 'audiobook' c'est quelque chose que j'ai découvert récemment. Des fois, il faut que je relise la même page deux, trois fois. Donc je peux faire autre chose en même temps que j'écoute les balados." (Podcasts or audiobooks are things I recently*

> *discovered. Sometimes I have to reread the same page two or three times. So, I can do other things while listening to podcasts.) Person living with dementia*

It was mentioned that audio and video files should be short, visually attractive, present information in an easy-to-understand format, and be professionally produced to be of interest.

> *"Dans un site gouvernemental je m'attends à ce que les capsules soient bien faites, courtes et efficaces. Les vidéos, ça vient alléger la prise d'information." (On a government site I expect the capsules to be well made, short and effective. Videos make it easier to take in information.) General Population*
>
> *"Videos are particularly helpful, especially when sharing with others. You might catch their [people living with dementia] attention. But it needs to be visually attractive and short – like 2-3 minutes." Unpaid Care Provider*
>
> *"J'aime les capsules vidéo d'information et de témoignages quand c'est orchestré par des professionnels avec des exemples concrets." (I love video information and testimonial videos when orchestrated by professionals with real life examples.) General Population - Higher Risk*

It was also expressed that video files are appropriate to relay information that was originally shared during an event, like a conference. During the discussion, a number of rural participants conveyed a desire to have easier access to this kind of information/event, and having a link to a recording of presentations or conferences would be appealing to them.

> *" S'il se donne une conférence à Montréal, j'aimerais y assister en ligne [ou] de voir l'enregistrement." (If there is a conference in Montreal, I would like to attend online or to watch the recording.) Unpaid Care Provider*

Having access to **listings of resources and supports** (either with or without links), was well received and considered extremely useful on any site. Such information was especially valuable if local resources and supports are included.

Questionnaires or surveys were considered helpful tools to guide action and decision-making, although with some reservation. Unpaid care providers and people living with dementia felt that such tools could be useful and directional to help identify when help should be sought, or what resources would be most appropriate based on the stage of dementia they have reached.

> *"Cet outil pourrait être utile si la personne n'est pas certaine de la situation et pour diriger à des ressources – pour la gestion des risques et des symptômes." (This tool could be useful if the person is unsure of the situation and to refer to resources - for risk and symptom management.) Unpaid Care Provider*

That said, some health professionals and first responders expressed concern with the potential of individuals self diagnosing or inaccurately interpreting results, and felt caution was needed in designing such tools.

> *"I caution against memory tests. They're difficult to interpret and I'd be worried about people misconstruing results." Paid Care provider - Care*

Finally, the use of **online discussion forums** where individuals can share conversations with others was well received, particularly among unpaid care providers, people living with dementia, and members of the general public (especially those in higher risk groups). These audiences welcomed the opportunity to learn from others' experiences, and were generally receptive to both reading comments from others and actively engaging in the exchange of information. That said, participants expressed the importance of having such a resource be well-structured and carefully facilitated and monitored to ensure accurate and reliable information is being shared and that privacy is being respected.

> *"Having a group discussion can help you feel like you're not alone." General Population*

> *"I know several people who have or had dementia and their experiences are totally different, but out in the web world, someone is going to be going through what you are going through with the same symptoms." Person living with dementia*

Other audiences (notably paid care providers) had less interest in an online discussion forum, and typically indicated that they would not likely interact with others on a forum on dementia.

> *"I stay away from chat rooms. You don't know who is on the other end." Paid Care Provider - First Responder (Police Officer)*

Online Portal Content and Functionality

There was recognized value in having an online dementia portal that is all-inclusive in terms of content.

At this point in the focus group discussion, participants were informed that the Public Health Agency of Canada is working on a website that would provide information on dementia.

Overall Reactions

Not surprisingly given the perceived lack of a central credible source of information on dementia, participants across all audiences were receptive to the idea of a government-sponsored online portal on dementia. Across groups, it was felt that this tool would be most useful to unpaid care providers and family members, as a source of information and to identify local resources. Paid and unpaid care providers believed that apart from those who have mild symptoms of dementia, people living with dementia would be unlikely to use an online portal given its complexity. That being said, the idea of a centralized online resource for information on dementia held appeal among people living with dementia as long as the navigation remains simple (e.g., not too many clicks needed; not too much information on each page) and provides access to information that can guide immediate actions (e.g., where to find resources locally). In addition, people living with dementia felt it would be important to make information accessible on the website by also including a phone number where questions could be answered or where someone could provide direction on how to easily access information and resources.

Paid care providers, including healthcare providers and to a lesser extent those providing more general care and first responders, expressed that they would be most likely to recommend the website to people living with dementia and their families rather than use it as a source of information for themselves. However, some felt that such a resource would provide an effective training tool for first responders.

> *"Honnêtement je ne l'utiliserais pas sauf pour le référer à des familles. C'est utile pour les familles parce qu'ils se sentent démunies et laissées à eux-mêmes." (I honestly wouldn't use it except to refer it to families. It is useful for families because they feel helpless and left to fend for themselves.) Paid Care Provider – First Responder*
>
> *"Including brief courses or quizzes on dealing with people with dementia would be helpful. We have … training in our hall where every morning we have a quick briefing on something we learned today. Having something on how to approach a person living with dementia [ranging from them being cooperative, scared to aggressive] would be good to have." Paid Care Provider – First Responder*
>
> *"I think if they are going to make a website, it should be the only one that family members should have to go to [for information] …it [would be] so comprehensive you don't have to go elsewhere." Paid Care Provider - Healthcare*

Regardless of expected use, it was largely believed that an online portal on dementia is an important tool and one that is currently lacking.

Topics of Importance

This section explores the expectations for an online portal on dementia, including what information and functionalities it should include. Participants were shown a list of topics that could be included on the portal, in addition to being asked what else would be of interest to them for the online portal. The topics shown included (with bolded italicized topics being most commonly selected as important to include on the portal):

- ***Signs and symptoms of dementia***
- ***Dementia care such as management of symptoms***
- ***Information needed by care providers***
- ***Dementia service organizations (listings / links to organizations / support groups available for those living with dementia)***
- ***Care provider resources (services / self-care / groups)***

- Prevention / how to reduce risks of developing dementia symptoms
- Tools that help with diagnosis
- How to reduce stigma (negative stereotypes) and make communities more inclusive and supportive for people living with dementia?
- Government policies and strategies about dementia
- Current dementia research projects and results
- Dementia information adapted to specific populations
- Online forum (ability to ask questions / have discussion online with other people using the website)

Nearly all topics listed were considered important despite those listed in bold and italics being most commonly selected as important for the portal. Participants also mentioned a variety of other information type they would like to find on the portal, as listed below. Unsurprisingly, many of the topics deemed important were consistent with the information needs and gaps expressed in the beginning of the session. Across audiences, participants concurred that an online portal on dementia should be all-inclusive and provide a wide range of information as informational needs would vary notably across audiences. It should also be noted that for most of the topics of interest, there was a desire for detailed information to be available to assist with unique, unusual or infrequent situations.

> *"Everyone would be looking for different things, at different stages. All that information will be important to someone." General Population*

In general, priority topics consistently included:

Understanding and Defining Dementia

There was a desire for the portal to define dementia, notably in terms of the signs and symptoms, the different types of dementia, how it compares to Alzheimer's disease, the genetics of dementia, information on the various stages of dementia, understanding the progression of dementia, how to reduce risks of developing dementia and tools that help with diagnosis. Gaining a better understanding of dementia was particularly important to unpaid care providers and people living with dementia.

> *"Je veux savoir la définition exacte de la démence en comparaison avec les autres formes de maladies mentales. Une anxiété profonde est-ce que ça fait partie de la démence?" (I want to know the exact definition of dementia compared to other forms of mental illness. Deep anxiety is that part of dementia?) General Population - Higher Risk*

> *"Understanding the different types of dementia and how it affects your loved ones – that is important to know early on. Focusing on distinguishing the types of dementia and how it can look." Unpaid Care Provider*

“Mieux comprendre dans quel état je suis et quelle maladie je pourrais avoir selon les symptômes.” (Better understand in what state I am and what type of illness I could have based on the symptoms.) Person living with dementia

When providing information on the signs and symptoms of dementia, it was felt that the manner in which the information is provided and the tone should be carefully chosen to avoid being alarmist. Paid care providers largely believed that a self-diagnosis tool should not be provided on its own, without guidance on how to interpret the results. As such, there is perhaps a need to position such tool carefully if it is used on the portal, so as not to give the idea that it can be used on its own without professional assistance.

“I worry about people diagnosing themselves or their family members without health advice. Signs and symptoms are one thing, diagnosis is another.” Paid Care Provider – Care

It was also mentioned that dementia should be explained to children in a manner that is age-appropriate.

“[There should be] a section for small kids because when they see grandpa and grandma go through this it is confusing and it is so hard to explain to them. Short animated videos, games and activities.” Unpaid Care Provider

Living with Dementia

There was an interest on the part of both people living with dementia and unpaid care providers to understand how dementia affects someone’s daily life. Specific information of interest for the portal included a practical guide of how to live well with dementia, as well as a list of dementia service organizations that provide information, assistance, and activities for people living with dementia and care providers/relatives.

A few healthcare professionals also noted the importance of including information regarding key decisions that need to be made by people living with dementia and family members as the symptoms of dementia evolve, such as assessing driving capabilities and the use of a vehicle, or how to react when a person living with dementia removes their clothes for comfort. It was also believed that information should be provided to assist care providers and family members in how to bring up difficult topics in discussions with people living with dementia.

“J’ai une cliente qui ne peut plus conduire mais elle a le droit de conduire. Elle prête son auto à n’importe qui qui va faire des courses pour elle mais elle ne connait pas les conséquences. Elle ne comprend pas ses responsabilités légales.” (I have a client who can no longer drive but is allowed to drive. She lends her car to anyone who goes shopping for her, but she doesn't know the consequences. She does not understand her legal responsibilities.) Paid Care Provider – Healthcare

"Addressing the feeling and caring for people who have dementia is about the lived experience. Allowing them to share what they live and the behaviour patterns would be useful; they don't know how to handle what comes up. Nudity for example. The person who has dementia starts taking their clothes off for comfort. Things like that. How do people live that experience? They need day-to-day practical advice. And see that someone else has gone through the same thing." – Paid Care Provider - Care

A suggestion was made to clearly identify what services are available from resources, thus guiding unpaid care providers and people living with dementia in contacting the right resource to meet their needs. Indeed, there was a great level of frustration among unpaid care providers in searching for resources available to them as the need for various supports arise.

Treating Dementia

Although many realized that dementia is currently incurable, a few participants were under the impression that a cure might be found eventually. Nonetheless, there was a desire from unpaid care providers and people living with dementia for information to be included on the portal on what type of treatments might be available, including various types of medication and their respective roles, understanding what dietary choices are best, and what activities or exercises are recommended, including brain stimulation.

Care Information

Not surprisingly, unpaid and paid care providers (those in a caring or support role only) were highly interested in information related to dementia care, including practical advice for dealing with dementia and managing symptoms. Providing tips and tricks on how to respond, how to help others, and how to best interact and communicate with people living with dementia were topics of interest for the portal.

"Somewhere to see what steps to take when someone has dementia. What to do next. You also need to know where to access local resources and financial support." General Population – Higher Risk

Across locations, care providers, most notably unpaid care providers, felt that information on how to deal with stress and anxiety, how to protect themselves in crisis situations, and what resources, support and assistance are available for unpaid care providers was paramount. Paid and unpaid care providers also mentioned that a discussion forum would be most useful for people living with dementia and their families to share experiences with others in the same situation.

"A forum is a good idea to apply a sense of family or community for families and care providers, as long as it is moderated." Paid Care Provider – Care

Planning for the Future

Unpaid care providers and, to some extent, people with mild dementia symptoms conveyed they would be looking to the portal for information and assistance to help them plan for the future. The most acute need was for legal information (e.g., when and how to set up power of attorney) and housing options (e.g., what specialized housing options exist and when and how to access continuing care facilities). It was also mentioned that family members, regardless of their care provider role, sometimes have difficulty with obtaining consent from people living with dementia to be formally assessed and thus they may benefit from information and guidance on how to obtain a treatment order.

"Tout l'aspect financier et l'assurance. Qui s'occupe de quoi. Par rapport à une personne qui n'est plus indépendante." (All the financial and insurance aspects. Who does what? Compared to a person who is no longer independent.) General Population

"Have a good focus on care planning; these are the behaviours; this is what we will do with them. And also, advanced care planning: attorneys and directives. People want to plan." Paid Care Provider – Care

"Avant d'avoir un diagnostic la personne [qui est atteinte de démence] ne veut pas aller voir le médecin donc la famille doit avoir une ordonnance de traitement ou d'évaluation psychiatrique. Les personnes [la famille] ne sont pas au courant que c'est eux qui doivent le faire. Nous on peut le faire pour un traitement de 48 ou 72 heures mais pas pour plus longtemps." (Before being diagnosed, the person who has dementia does not want to see the doctor, so the family must have a prescription for treatment or psychiatric assessment. Family members are not aware that they have request it. We can do it for a 48- or 72-hour treatment but not for longer.) Paid Care Provider – First Responder

Multiple first responders felt that it would be helpful if family members or people living with dementia were directed to provide key information on a secure platform that is readily accessible in case of emergency. Providing a description of the person living with dementia's current situation, how symptoms will progress, what to do if they are prone to wander, and medications were key items that could be especially helpful in a time of crisis.

It was also mentioned to include information to help people living with dementia, parents and unpaid care providers to speak about dementia to children, especially if dementia is affecting a close relationship. It was believed that information would be helpful regardless of the age of the children, whether young or in adulthood. Similarly, information on how to make the home safe for someone living with dementia was deemed useful and relevant for an online portal on dementia.

"It would be how much information or how to relate to my growing children who are concerned about their dad and what is happening to him. As a mother I want to protect them from having to worry about their dad. A lot of time I don't relate how their dad is doing, I don't give them the information they are asking from me. I don't want to add more stress to their lives. [It would be nice to have information about] accepting the

diagnosis of a parent and how to relay that information to your children, even to growing children. How they can accept what their parents are going through." Unpaid Care Provider

Some topics presented for consideration received less enthusiasm. Although these topics were still considered important by a majority of participants, they were deemed more secondary topics for the portal:

- **How to reduce stigma (negative stereotypes) and make communities more inclusive and supportive for people living with dementia.** Many, in fact questioned if there was actually a negative stigma toward dementia; however, those who did see it as a concern (particularly those with a personal connection to dementia) felt stigma was very real and may prevent individuals from reaching out and seeking assistance. Across audiences, healthcare professionals and unpaid care providers were more likely to have selected it as a 'must have' topic for the portal. While there is recognition for the need to address stigmatisation for people living with dementia, some questioned if the online portal was the most appropriate channel to do so.

  "Comment réduire la stigmatisation, c'est trop théorique. Les débats de société n'ont pas leur place ici." (How to reduce stigma is too theoretical. Social debates have no place here.) Unpaid Care Provider

- **Government policies and strategies about dementia.** Unless directly related to service provision for those living with dementia, there was a general perception that information on policies and strategies lacked actionable relevance in people living with dementia's day to day lives, and thus the portal might not be the best place to provide this information.

  "Less about government policies and more about the practical day-to-day stuff. If you are a care provider or may have dementia, policies don't matter." Paid Care Provider – First Responder

- **Current dementia research projects and results.** This topic was considered less actionable, though of interest to those who were keen to better understand dementia and what can be done to address it. This topic was also more commonly chosen as important among healthcare providers, first responders and to a more limited extent among people living with dementia (notably those with early symptoms of dementia). A few people expressed a desire for simplified information on research initiatives to assist with comprehension. Others were interested because of the sense of hope research projects might offer.

  "Les études doivent bien être vulgarisées et non seulement donner un lien qui mène à Pub Med." (Research findings should be popularized and not only provided through a link that goes to Pub Med.) Paid Care Provider – Care

- **Dementia information adapted to specific populations.** Many participants felt dementia is not a condition that is more prevalent in specific groups within the general population (e.g., based on ethnicity), but is relevant to the community at large. Accordingly, they questioned why information should be adapted to specific populations.

- **Online discussion forum.** Across audiences, this tool had mixed appeal, with some finding it a good idea to share experiences and gain knowledge on dementia. Consistent with previous parts of the session, respondents expressed an expectation that a discussion forum on the portal would be professionally moderated to ensure respectful discussions and prevent unsound medical advice from being shared. That said, a good number of unpaid care providers felt it could be a useful tool for them to communicate with other care providers for advice and support. They especially appreciated the opportunity to converse directly with those who are experiencing the same challenges in their life.

  It was also mentioned by some, including unpaid care providers and members from the general public, that this kind of tool would be useful if it would allow individuals to ask questions to healthcare providers who are knowledgeable about dementia.

- **Preventing Dementia.** Some questioned if 'prevention' was appropriate and considered it a misleading topic, given that many did not believe dementia could be prevented. It should be noted that information related to prevention and how to reduce the risk of dementia was considered less important by paid and unpaid care providers and people living with dementia. While it may be perceived as an important consideration for the general public and higher risk populations, participants in these target groups did not express a particularly strong interest in this topic. Nonetheless, it was believed it would still be an interesting component of the online portal.

  "Pour une personne atteinte, la prévention n'a rien à voir là. Les projets, la recherche, c'est trop tard. Ce qui nous intéresse comme professionnel c'est d'avoir une liste de choses d'urgence. Qu'est ce qui arrive quand on ne peut pas avoir accès à des logements sociaux? Si les gens se retrouve sans droits parce qu'ils n'ont pas rempli leurs obligations de citoyens?" (For someone who is affected, prevention is no longer possible. Projects, research, that's too late. What is of interest to us as professionals is to have access to a list of urgent things to take care of. What happens when you cannot access social housing? What if people find themselves without rights because they have not fulfilled their obligations as a citizen?) Paid Care Provider - Healthcare

In addition to the topics presented above, it was felt that the tone of information on the website was paramount and needs to convey a sense of optimism and hope, rather than being presented in a way reflective of doom and gloom or suggestive of a death sentence. Further, across audiences, participants generally concurred that priority should be given to both people living with dementia (i.e., people with early symptoms of dementia who still have the cognitive capabilities to use this kind of online tool) and their family members / unpaid care providers in the way the portal is designed, with the information needs of those audiences given priority.

Functionalities and Tools

A variety of tools and functionalities were suggested to enhance an online portal on dementia. These included:

- Inclusion of **Frequently Asked Questions** (FAQs)
- **Live chat with a health professional** (ability to ask specific questions to a nurse or other health professional in real time that may not be adequately covered on the site).
- **Search bar**, to assist site navigation, if necessary.
- **Inclusion of a prominent national hotline**
- Ability to download an **emergency information guide sheet** (recommended by first responders so information is readily at hand if first responders arrive at the home).
- Offer the **option to sign in and create an account** to enable users to create a personal library where they can save or flag site contents, as well as access a personal virtual notepad.
- A **translation feature**; to provide the ability to have the site content translated.
- **Social media** presence, including live Facebook chats with a feed.

Reactions to an Existing Online Portal on Dementia

The Dementia Australia site was considered a good template for a Canadian portal. It was held in high regard for its visual appeal, ease of navigation and the breadth, depth and trustworthiness of information.

For the last part of the discussions, participants were briefly shown an Australian website (Dementia Australia) that provides information on dementia (dementia.org.au). Following a brief live tour of the site, participants were asked for their reactions to the site, particularly in terms of its look and feel, general layout, organization and presentation. The Dementia Australia website was not shown nor discussed with people living with dementia given the shorter session length. The following section provides comments for all other audiences (paid and unpaid care providers, general population and those with higher risk).

Overall Reactions and Graphic Elements

Across audiences and locations, participants overwhelmingly endorsed the Dementia Australia site. The website was considered visually appealing, well designed, very professional and easy to navigate. The site's colours and use of graphics were generally well liked and considered calming, positive and attractive, although a few felt that it was too bland.

> *"It looks easy to navigate. Well presented. People don't want to dig for information. Often you don't know what you want until you see it. It seems easy to narrow down information." Paid Care Provider - Healthcare*

> *"Les couleurs sont calmes. Les personnes avec la démence on doit les garder calme. Pas trop de stimulant." ("The colors are calm. People with dementia should be kept calm. Not too much stimulus.) Paid Care Provider – Healthcare*

The design was believed to include a good level of contrast, though some felt it was text-heavy. The website's overall optimistic design created a sense of hope for some. The presence of visuals and photographs of happy people/situations also helped set the tone, although it was believed at times that the images should show a wider age range to recognize that dementia also affects younger people.

Site Content and Navigation

The Dementia Australia site was praised for its extensive and thorough information, presented in an easy to navigate format. While there appeared to be a lot of information on the site, simple banner points and extensive drop-down menus provided easy direction for visitors. As such, participants appreciated the fact that the site could be easily navigated both by those looking for basic information, as well as by those looking to do a deep dive for more detailed information on dementia.

> *"You don't have to search around for what you are looking for, it is right there (in the menu and sub-menus). For me that is easy to navigate that way." Unpaid Care Provider*

> *"This is very informative and covers a lot of material. It's very user-friendly and looks like it's being kept up-to-date. Knowing what we have with the Alzheimer Society [website]- this is really, really good. It gives people options." – General Population – Higher Risk*

> *"Je trouve ça intéressant – Le menu du haut est bien fait et tu sais aisément où te diriger pour aller chercher l'information que tu recherches. C'est facile à utiliser. Le fait qu'on voit le menu sans avoir à cliquer c'est bien pour visualiser rapidement ce que tu recherches." (I find it interesting - The top menu is well done and you easily know where to go to get the information you are looking for. It's easy to use. The fact that you can see the menu without having to click is good for quickly seeing what you are looking for.) Paid Care Provider – Healthcare*

Quite a few participants noted that the information is presented in small chunks, which makes it manageable. Yet, the site appeared to provide detailed information for those who are interested in digging further. The topics are presented from general and gradually become more specific as you move through the site.

> *"Ça va du plus général [sujet] au plus détaillé. Les textes ne sont pas trop chargés mais on peut aller chercher plus loin si on veut plus d'information." (It goes from the most general topic to the most detailed. The texts are not too busy but we can look further if we want more information.) General Population*

> *"I personally find the colours and layout of the site to be bright and cheerful. It is a bright turquoise and immediately there are pictures. If you go and click on something, you see that you go from general [information] to more specific to even more specific as you click. It's certainly not overwhelming." Unpaid Care Provider*

Further, having the ability to see each section's content by hovering the mouse over each of the main menu items was generally considered useful. Only a few felt that the listings were too long and suggested visual clutter.

> *"Tout est accessible rapidement et le téléphone est mis en avant plan. Les sous-titres dans le menu c'est quand même bien détaillé." (Everything is accessible quickly and the phone is in visible. The subtitles in the menu are still very detailed.) Paid Care Provider – First Responder*

Headers on the Dementia Australia home page was suggestive of the sections' content. Including the option of a more icon-based menu (when clicking on a topic), which was appreciated for its brevity, limited text and visual appeal.

Some felt the site would be further enhanced if it provided a more upfront division of audience on the home page, rather than having to go to the information tab to get there. This approach would ensure that visitors do not get overwhelmed with the amount of information on the site and are only presented with content that is more relevant to their situation and information needs. In fact, the desire to have information organized by user type was mentioned in some of the focus groups while discussing the topics to be included in an online portal on dementia (before showing the Australian website), suggesting that this is an intuitive way of organizing the information. Suggested breakdown by audience included: people living with dementia; family/friends/colleagues; unpaid care providers; and various sections for paid care providers based on the type of work or workplace (e.g., first responders; healthcare professionals; personal care providers).

In addition to breaking down the information by user-type, it was believed that resource listings should be provided by region, or at the very least, by province/territory. Further, it was considered important that any Canadian site include both urban and rural resources.

> *"Il faudrait que ce soit divisé par personne-cible. À qui l'information serait le plus utile. De réfléchir à comment diviser tous les thèmes. Il faut aussi diviser les services par région ce qui permettrait de voir si dans certaines régions on manque de service et (déterminer) comment ajuster le système de santé pour soutenir ces résidents." (It should be divided by target audience. Who the information would be most useful to. Thinking about how to divide all of the themes. Services should also be grouped by region which would allow to see if services are missing in some region, and determine how the healthcare system could support those residents.) Paid Care Provider - Care*

Site Functionalities and Accessibility Features

The prominence of the National Helpline and other accessibility features (free tool kit, email support, helpline web chat, and multiple language options) were well liked and appreciated, especially given the fact that many individuals with dementia tend to be older. However, a few participants were under the impression that the helpline would provide assistance to locate the desired information on the website or from other resources, thus suggesting the need to clarify its purpose.

> *"Je ne sais pas combien de fois j'ai été obligé d'expliquer ma situation pour avoir des ressources. Là tu appelles des gens qui savent ce qu'est la démence." (I don't know how many times I had to explain my situation in order to have the resources. There you call people who know what dementia is.) Unpaid Care Provider*

Inclusion of a 'listen' feature that reads site content was also enthusiastically received, as was the prominent search bar. Some suggested that inclusion of a font size adjuster tool (the ability to enlarge font size) and a zooming function would further enhance the site's accessibility.

The ability to share the site contents with others via email was well liked, especially by paid care providers who would use this tool to provide information to people living with dementia and their family members, as well as share interesting information with colleagues.

> *"I really like the 'share' option. Instead of printing everything or telling a family to go to the website I could email them specific resources, or to other colleagues." Paid Care Provider – Care*

Many also looked favourably on having resources available in diverse languages and would want to see this incorporated into a Canadian portal. It was suggested to incorporate a translate function into the website, thus allowing users to have all of the website contents translated, rather than only selected areas.

> *"Is there a way to have a translate function instead of having separate documents translated? Language is definitely an issue. The most important thing is to empower people who have dementia as much as we can." Paid Care Provider - Care*

Trustworthiness

Information on the Dementia Australia site was perceived to be trustworthy and reliable, primarily because of the site's professional design, the depth of information provided, the inclusion of multiple contact sources, the presence of the acronym 'org' in the URL, and its hosting of the National Dementia Helpline. Having the site display a registered charity symbol further added to its credibility. That said, the presence of a "donate" section made some question the objectiveness of the information provided on the website.

Perceived Target Audiences

It should be noted that across paid and unpaid care providers, as well as some members of the general public and higher risk groups, questions were raised as to the usefulness of an online portal like the Dementia Australia site for people living with dementia given the amount of information included and the text-heavy layout. It was generally felt that this type of site would be most useful to unpaid care providers and family / relatives. Paid care providers believed they would primarily recommend it to those audiences, or as a means for them to source out local resources to assist people living with dementia. Since the review of the Dementia Australia portal was excluded from the sessions for people living with dementia, their views on who would benefit from an online portal were not captured.

Trust/Confidence

Given the inherent level of trust in governments, there would be merit in clearly identifying a Canadian online portal on dementia as being endorsed by the Government of Canada.

There would be great confidence in the information included on a website sponsored by the Government of Canada. That said, if the site was hosted through a non-governmental partner organization, but funded by the Public Health Agency of Canada, most felt strongly that such a site should be visibly supported and endorsed by the government to instill confidence.

Across groups, consistent suggestions included making it easy to determine the source of information, prominently indicating that the site is supported and endorsed by the Public Health Agency of Canada, and potentially ensuring a '.ca', 'gc.ca', or '.edu' URL or the lock symbol in the address bar. Other suggestions included displaying a Canadian flag on the site, and providing clear contact information (phone, address, contact listings) to add legitimacy, and providing a means for someone who may not be computer-savvy to still access information. These approaches were considered particularly important if the portal is to be hosted outside of the Canada.ca website.

> *"At school a few years ago, they told us that when doing a website review, you are checking the name [.org] and copyright logo; and one thing that is important is contact numbers on how to reach them." Paid Care Provider - Care*
>
> *"Definitely there needs to be the Canada logo and branding. If it is a joint partnership or project funded by PHAC, you need to have that level of branding in the 'About Us' category. Who helped to create the content; where the information come from; the resources and sources." Paid Care Provider - Care*
>
> *"After the domain name. I see 'dot com', 'dot ca', 'dot edu' to know what kind of website it is. "Dot org' and 'doc edu' are generally more reliable than the regular 'dot com' site." Unpaid Care Provider*

On the Australian site, information suggesting that resources are available nationally elicited a sense of confidence to a few participants, who felt that national resources would normally be endorsed or supported by government. At the same time, the overall breadth and depth of information, the variety of tools, the community presence through activities and the organisation's presence on social media all contributed to participants having trust in the information provided on the Dementia Australia website.

> *"Je rechercherais un logo gouvernemental. J'irai vérifier les références sous les articles si elles sont crédibles. Le nom 'Dementia Australia' suggère que c'est national, c'est à la grandeur du pays. Le 'National Dementia Helpline', c'est national aussi et ça donne l'impression que c'est fait par le gouvernement." (I would look for a government logo. I will check the references under the articles if they are credible. The name 'Dementia Australia' suggests that it's national, it's nationwide. The 'National Dementia Helpline' is national too and it looks like it's done by the government.) Paid Care Provider – Care*
>
> *"Any site that has gone to the effort to include so much information, be so easy to access and have a 1-800 resource, suggests to me that it is trustworthy. You recognize the level of effort. It has a familiar feel – and you trust what is familiar." Paid Care Provider – First Responder*
>
> *"Oui j'ai confiance [dans le site Dementia Australia]. C'est comme une encyclopédie [le site Dementia Australia]; c'est complet. Il semble en partenariat avec d'autres organismes; il y a un calendrier, des activités, la possibilité de chatter et d'aller sur les réseaux sociaux. Ils ont une version mobile. Donc c'est très élaboré." (Yes I trust the Dementia Australia site. It's like an encyclopedia [the Dementia Australia site]; it is complete. It seems in partnership with other organizations; there is a calendar, activities, the ability to chat and go on social media. They have a mobile version. So, it's very elaborate.) General Population - Higher Risk*
>
> *"It is so complete. Headings for all the things people want to know. They have the 'about us' link, so you can see who it includes. The fact that they have the option for health care professionals means a lot. If health care professionals would go there you would trust the site." Paid Care Provider - Healthcare*
>
> *"Le contenu [du site Dementia Australia] est quand même fourni, il est bien rédigé. Il y a un éventail d'articles différents qui va des symptômes à la prise en charge. Les dernières recherches en la matière. Il met aussi en relation les gens à travers des rencontres." (The content of the Dementia Australia site is comprehensive; it is well written. There is a variety of different articles ranging from symptoms to management. The latest research in the field. It also connects people through meetings.) General Population*

In addition to having the site endorsed by government, a few felt that it would be beneficial to have the Canadian dementia portal endorsed by key health organizations and associations (e.g., Canadian Medical Association, Alzheimer Society of Canada, etc.) or perhaps respected and well-known scientific bodies or educational institutions. This would add further credibility to the quality of information provided on the site. Adding a link to the portal from the Canada.ca website was also suggested to further legitimize the portal, if it is hosted outside of government.

Finally, knowing the sources of information provided and ensuring that they are credible would contribute to enhancing a sense of trust in the Canadian portal. This includes ensuring that the published information is endorsed by qualified experts.

> *"Du point de vue scientifique, sans alourdir la présentation du site, donner des citations et des références pour prouver la source d'informations et pour savoir qu'elles viennent de sources crédibles." (From a scientific point of view, without overloading the presentation of the site, include quotes and references to prove the source of the information and to know that it comes from credible sources.) Paid Care Provider - Care*

Additional Resources

While development of a portal on dementia held high appeal, additional resources were deemed necessary to meet the diverse needs of those looking for dementia information.

When asked what other tools or support about dementia should be made available, beyond a website or online resource, participants provided a number of suggestions:

- **Printed information** (e.g., brochures) in public places such as retail stores, pharmacies, doctors' offices and senior centres/complexes. One person mentioned the Berkshire Blue Book on dementia as a good example of a printed reference tool. Having information available in multiple languages (beyond English and French) was deemed important.
- **Develop a national helpline** (1-800 #) with health professionals (e.g., nurse) available to quickly answer questions about dementia.
- **Develop a podcast** with key information on dementia.
- **Establish a presence on social media**, including a Facebook page, where users could obtain information and exchange with other users. This could be part of an awareness campaign on dementia or a means to promote the portal. Social media could also be used to post notices for the latest information posted on the portal.
- **Listing of local support groups for people living with dementia, as well as unpaid care providers.** A few paid care providers suggested to show this information in a listing format but also in a visual format (e.g., a "care map"). At the same time, many stressed the importance of developing accessible healthcare resources to support unpaid care providers and family members.

"Il faut des groupes de soutien pour l'entourage et la famille qui eux aussi vivent de la détresse. Ils ne savent pas comment communiquer [avec une personne atteinte de démence] et comment aborder les sujets importants avec eux." (Support groups are needed for those around people living with dementia, and their families, who are also in distress. They don't know how to communicate with a person with dementia and how to discuss important matters with them.) Paid Care Provider – Care

- **Offer self-diagnostic tools** that provide tailored advice on support and resources based on the results (i.e., based on the stage of dementia). There was an interest to use this tool multiple times as the situation of a person living with dementia evolves over time.
- **An ombudsman or advocate** to ensure the rights of patients and family members are respected when they receive treatment.

In addition, first responders suggested a number of other supports for people living with dementia, including:

- **A card that lists the dementia website and 1-800 number** that first responders can give to those in need.
- An **emergency help sheet template/form** that can be provided to those diagnosed with dementia, whereby information is completed and ready to access if a first responder is called to their home. Alternatively, development of an app that would provide quick and easy access to important information was suggested.
- **Increase availability of GPS bracelet or tag** that can be worn by those with dementia, similar to a medic alert bracelet, to aid first responders should the person living with dementia wander away from home. Such a tool would allow police to tag or track an individual and ensure a more efficient recovery.
- Information on the **Vulnerable Persons Registry**, whereby family members can register a person living with dementia so first responders have access to information when needed.

Participant Suggestions

At the end of the sessions, participants were asked if they had any final suggestions for the Public Health Agency of Canada as it looks to develop a portal on dementia. A number of consistent suggestions were given, including:

- Use the Dementia Australia site as a template; don't re-create the wheel
- Ensure the site provides information on all types of dementia
- Information directed to the general public should be void of medical jargon, ensuring content is easily understood at various reading levels
- Once developed, educate the public about the site (via traditional media, social media, inserts in CPP payments, printed materials at doctors' offices / clinics / pharmacies, etc.)
- Establish a national toll-free helpline, with a live person on the line (using a simple number) that can provide immediate assistance, but also provide information and access to resources
- Include province/territory-specific (and if possible, region-specific) resources / supports, as available resources may vary considerably across provinces / territory / regions; ideally include a searchable resource tool
- Ensure any chat / online forum is regulated or monitored
- Ensure an online resource is supplemented by printed materials
- Do not include advertising on the website
- Include multiple information formats on the site (video, podcasts, downloadable docs, etc.)
- Make sure the portal is well formatted for mobile usage
- Provide the ability to adjust the font size on the site
- Ensure the portal is regularly updated to showcase latest developments in the field of dementia research and treatments
- Consider inclusion of multiple languages (in addition to English / French), or ideally a language translator
- Consider inclusion of a glossary of terms
- Display a Canadian flag on the site for added credibility

As mentioned, once the site is developed, the importance of proper positioning and communication was underscored across groups. Most notably, it was deemed that the site would be an important resource, either directly or indirectly, for a wide range of audiences, though with greatest perceived use for those personally impacted by dementia (people living with early onset dementia and their unpaid care providers).

The site's ease of use was considered fundamental to its success. Aside from ensuring the site is formatted with mobile usage in mind, it was felt that any site should be tested among older Canadians to ensure that it is truly easy to navigate.

Further, recognizing the breadth of information on dementia available online, participants expressed the importance of a broad public education awareness campaign to inform the population and professionals of the portal and related resources. Moreover, since many participants often began their online search for information through a general internet search, several participants noted the importance of search engine optimization and ensuring Canada's dementia information portal is at the top of search results.

> *"Il faut rendre l'information plus visuelle et faire de la publicité pour qu'on sache que c'est disponible." (We need to make the information more visual and advertise it so that we know it's available.) Person living with dementia*

Conclusions

The following provides broad conclusions from the summary of research findings.

- ***There were wide-ranging needs pertaining to dementia information, although interests in specific topics varied based on the role of the person interacting with someone living with dementia.***

  To varying degrees, there was interest in understanding what is dementia, the different forms of dementias, the expected signs and symptoms, the stages of dementia, treatment options and what can be done to prevent, reduce or delay the development of symptoms, the influence of genetics, and how other conditions or illnesses affect the development of dementia symptoms. In addition, with the exception of those working in the health sector, there was confusion as to what differentiates dementia from Alzheimer's disease. Knowing what services and assistance are available, especially local resources, was also considered important, notably for people living with dementia, family and unpaid care providers.

  While these topics were broadly considered as important to inform people living with dementia, family and care providers, the need for information was somewhat different across audiences. Specifically, paid care providers who are healthcare professionals generally felt they have the knowledge needed to understand dementia, though they were seeking information and resources to provide to people living with dementia and their families. Better understanding the stages of dementia would also enable them to adapt their interactions and the care they provide. By contrast, first responders (other than paramedics) were primarily concerned with how to deal with people living with dementia and their relatives during crisis situations and the relevant supporting resources available.

  For people living with dementia and their close relatives, there was a sense of urgency in understanding how to navigate their daily lives with dementia in a positive manner, as well as how to plan for the future. Relatives and unpaid care providers are also looking to better understand how to care for and communicate with a person living with dementia, as well as accessing respite and support resources for themselves. Interest in dementia-related information was less prevalent among members from the general public, though higher risk groups were somewhat more inclined to be interested in understanding the correlations between dementia and other health conditions, as well as location and socio-economic status.

- ***Health professionals were identified as the most trusted source of information on dementia. While there was a general perception that considerable information is available on the subject online, those directly impacted by dementia often struggled to find information that is clear, concise, complete and personally relevant.***

  People living with dementia and their family members mostly relied on health professionals to learn about dementia, as well as specialized organizations (e.g., Alzheimer Society) and general online searches. Paid care providers primarily relied on their existing knowledge, their employer and colleagues, and to a much lesser extent the internet, to find dementia-related information to inform their work. Across audiences, however, there was a sense that there is no single online source of information on dementia that is reliable and comprehensive.

Likely due to accessibility, the internet was an important source of information on dementia, with most investigating the topic first through a general internet search. This led to a random exploration of websites listed in search results to try to identify reliable online sources. Cross-referencing the same information across sources was another way to establish credibility. Known organizations (e.g., Mayo Clinic; Alzheimer Society) and government sites were most trusted overall. Other websites used included Dementia Alliance International, Wikipedia, WebMD, health authorities from other countries, the World Health Organization and university websites. Online forums and Facebook groups were also often relied upon.

- ***Being able to obtain specific and detailed information on dementia from a single, credible location was felt to be lacking, including information on local resources and support groups.***

Information on dementia was generally viewed as limited both in terms of scope and availability. While there appeared to be a lot of information available on dementia, it was perceived to be generic, incomplete, disorganized and scattered, making researching information difficult. Difficulties in sourcing culturally-appropriate resources and French-language material were also mentioned.

Most notably, there was a strong interest for more detailed information on the different types and stages of dementia, and a simple explanation of the various medication and treatments available, to provide people living with dementia, their family members and care providers a positive experience in their daily lives. Better explaining dementia would also help differentiate it from the more well-known Alzheimer's disease. Information and resources for long-term planning, whether related to legal matters or housing, was also deemed insufficient. Resources specific to unpaid care providers, such as information about support group and respite services, were viewed as lacking, especially outside of large urban centres. It was also felt that information generally targets people living with dementia and unpaid care providers, but less so other family members and children in particular.

- ***There was widespread appreciation for information being provided in a broad range of online formats, primarily based on the type of audience.***

When using the internet in general, the type of online format used was generally dependent on when the information is required, what it will be used for and who will access it. As such, there was widespread belief that the same information should be provided in different formats. On-screen information was considered most accessible to the general public and care providers, although participants underscored the importance of ensuring that such information is presented in a mobile friendly format. Downloadable files were considered useful across audiences as reference material, particularly when shared with others. Audio-visual files provided an opportunity for multitasking, while being accessible for people with lower literacy levels. This format was also considered appropriate to relay event presentations or conferences.

Of the other formats discussed, the listings of resources and supports were particularly valued to identify what help is available. Likewise, questionnaires and surveys can help to direct personal action and decision-making, though care providers cautioned their use without proper medical supervision/interpretation of survey results. Finally, the value of an online discussion forum was seen in the opportunity it could provide to exchange with other people who are in similar situations, not only for information, but also for support, as long as the forum discussions are moderated. In addition, paid and unpaid care providers mentioned that formats considered most useful for people living with dementia included concise printable information using lots of illustrations, and audio-visual materials (videos and podcasts).

- ***There was a recognized value in having an online dementia portal that is all-inclusive in terms of content.***

There was a high degree of appeal for a central credible source of online information on dementia, especially one that is government-sponsored. While this type of tool held great appeal across audiences, its content was perceived as most useful for people recently diagnosed with dementia, their family members and unpaid care providers. Paid care providers would mostly recommend it to people living with dementia and their families rather than using it themselves.

There was an expectation that an online portal would provide a comprehensive tool on dementia, and include diverse and detailed information. Topics of greatest interest related to understanding and demystifying dementia and how it manifests itself, and how to adapt to or live well with dementia now and as the symptoms of dementia evolve. Additional topics of interest included existing medication and treatment options to address dementia, how to reduce the risk of dementia, care information including how to establish positive interactions with people living with dementia, and what to consider when planning for the future. A listing of resources for supports and services available to people living with dementia, their families and unpaid care providers was considered important as well. The manner in which information is provided on the portal, including the tone, needs to stay positive and avoid being alarmist.

Some topics were deemed less important in comparison, though still of value for the online portal. These included addressing the stigma associated with dementia, making communities more inclusive, government policies and strategies about dementia, dementia research projects and results, dementia information adapted to specific populations, and an online discussion forum. Referring to 'preventing' dementia was also questioned as it was seen as not fully preventable.

A variety of tools and online functionalities were suggested for the portal, including: a frequently asked question section; a live chat with health professionals; a search bar; a national hotline; and a downloadable emergency information guide/sheet. An option to create an account enabling users to create a library of contents and take notes was also suggested by a few.

- *The Dementia Australia site was considered an excellent template for a Canadian portal. It was held in high regard for its visual appeal, ease of navigation and the breadth, depth and trustworthiness of information.*

  A brief review of the Dementia Australia website (dementia.org.au) revealed the site's high appeal primarily because of its simple layout, pleasing design, perceived ease of navigation, and comprehensiveness of information. For the most part, the blue and green tones and use of white spacing were deemed calming and the presence of visuals/images of people helped convey warmth and positivity. While the site was considered text-heavy and there appears to be a lot of information, it is streamlined through a simple main menu with meaningful labels. Further, navigation was facilitated by detailed sub-menus available directly from the home page on the main menu, as well as by organizing the information by topic and target audience. In fact, it was felt that the primary categorization should be done by audience (including people living with dementia; relatives, friends and coworkers; unpaid care providers; and paid care providers segmented by type of work or workplace). The site's structure that entails 'drilling down' into topics was appreciated for its provision of extensive information in an organized and manageable way, presenting each topic from general to more specific.

  Accessibility features were highly visible and appreciated, especially the National Helpline, email support, helpline web chat, 'listen' and 'share' functions, and having materials available in multiple languages. It was suggested to add a zooming function, a font size adjuster and a translation tool.

- *Given the inherent level of trust in governments, there would be merit in clearly identifying a Canadian online portal on dementia as being endorsed by the Government of Canada.*

  Regardless of where the Canadian online portal on dementia is hosted, findings clearly suggest that demonstrating clear endorsement by the Government of Canada will be important in establishing its credibility. Suggestions included to use a recognized URL suffix (whether it be '.ca' or '.gc.ca'), displaying the Canadian flag on the website, visibly stating the federal government endorsement on the home page, and providing a link to the dementia portal from the Canada.ca website.

  The provision of contact information (e.g., physical address, telephone number), a public presence on social media, and identifying sources of information were also mentioned as additional means of instilling confidence in the website. Consideration should also be given to having the portal endorsed by well-known organizations such as the Canadian Medical Association and the Alzheimer Society of Canada.

- *While development of a portal on dementia held high appeal, additional resources were deemed necessary to meet the diverse needs of those looking for dementia information.*

  Apart from the website, participants suggested a number of additional tools that would be useful for information on dementia. These included: printed information; a national helpline; a series of podcasts; establishing a presence on social media; listing of local support groups for people living with dementia and unpaid care providers; self-diagnosis tools; and access to an ombudsman or advocate to represent the rights of people living with dementia.

First responders also suggested providing people living with dementia with a card that lists the dementia website and a toll-free number for support; an emergency help sheet to record personal information that can easily be accessed by first responders, increase accessibility to a GPS bracelet or tag, and information on the existing Vulnerable Persons Registry.

Direction

As the Public Health Agency of Canada works on the development of an online portal on dementia, findings suggest the following actions should be considered:

1. **An online portal on dementia should be developed and structured primarily to respond to the needs of people diagnosed with dementia, their family members and unpaid care providers.**

   Although the online portal was considered by participants to be an important tool for a variety of audiences, many felt it would be most helpful in assisting people living with dementia and those who frequently interact with a person living with dementia with a focus on understanding the condition and adjusting to it. The site must therefore place priority on these audiences when designing its structure and content.

   Organizing the information based on the audiences and their needs will help provide easy access to valuable information. In addition to structuring the website by topic, consideration should be given to including a different section for each of: people living with dementia; unpaid care providers; relatives, friends, colleagues and neighbours who interact with but do not care for someone living with dementia; healthcare professionals; personal care attendants; and first responders. While the general public may be interested in accessing more general information about dementia by topic, those who have closer interactions with dementia are likely to look for information that can help guide their choices.

2. **Accessibility should be considered in terms of the tools and functionalities included on the portal, as well as in the provision of information in various formats.**

   Making the portal accessible was deemed imperative given the breadth, depth and complexity of information. This could be done by incorporating a range of tools and functionalities such as web chats (for emergencies and for questions), 'listen' and 'share' tools, and the ability to resize the font or zoom in on contents. Enhancing accessibility also included making the content accessible through an information phone line or by providing the same information in various formats, levels of detail or language, for example. In addition, participants underscored the importance of any portal being mobile friendly in its functionality.

3. **Including national, provincial/territorial and local services, resources and guidelines are paramount in making the site a complete reference on dementia.**

   To respond to the acute need for local resources and access to information that is highly actionable, consideration should be given to include information of national relevance, but also information and resources specific to each province and territory. Where possible, there would be value in including regional information as well. This could be done by providing links to provincial or local organizations of relevance, rather than including the information itself on the portal.

4. **The credibility and trustworthiness of the online portal must be clearly established.**

   Given that the credibility of online information is often questioned, especially for medical information, it is important to establish trust in an online portal on dementia. This should be done by either hosting the portal on the Canada.ca website, or by clearly identifying that the portal is endorsed by the Government of Canada if it is to be hosted by a partner organization. Ways to do that could include prominently explaining the Government of Canada's involvement in the portal on the home page; illustrating the Canadian flag; providing contact information for validation; and identifying the sources of information included on the portal.

Appendix A:

Recruitment Screener

Health Canada: Portal on Dementia Study Recruitment Screener – FINAL

Name:____

Home phone: ________________ Work phone:___________________ Cell: ____________________

Email: ____

Community: __________________________________ Province: ______________________________

SECTION 1: Schedule & Specifications

NETFOCUS GROUP SCHEDULE

Date	Group	AST	EST	Participant Time	Length (min)	Audience	Language	Moderator
Mon, Feb 1	1	6:30pm	5:30pm	7:00pm NL 6:30pm AT 5:30pm ET	90	Gen Pop – Rural - East (ON/NB/NS/PE/NL)	EN	MB
	2	8:30pm	7:30pm	6:30pm CT/SK 5:30pm MT 4:30pm PT	90	Gen Pop – Large Urban – West (MB/SK/AB/BC)	EN	MB
Tue, Feb 2	3	6:30pm	5:30pm	7:00pm NL 6:30pm AT 5:30pm ET	90	High Risk – Large Urban – East (ON/NB/NS/PE/NL)	EN	MB
	4	6:30pm	5:30pm	5:30pm ET	90	PCP Healthcare – Mixed Urban - Quebec	FR	CP
	5	8:30pm	7:30pm	7:30pm ET	90	PCP First Responders – Mixed Urban - Quebec	FR	CP
	6	9:00pm	8:00pm	7:00pm CT/SK 6:00pm MT 5:00pm PT	90	Unpaid Care Providers – Small/Med Urban – West (MB/SK/AB/BC)	EN	MB
Wed, Feb 3	7	2:00pm	1:00pm	2:30pm NL 2:00pm AT 1:00pm ET	60	PLWD – Small/Med Urban – East (ON/NB/NS/PE/NL)	EN	MB
	8	6:30pm	5:30pm	5:30pm ET	90	High Risk - Mixed Urban - Quebec	FR	CP
	9	7:00pm	6:00pm	7:30pm NL 7:00pm AT 6:00pm ET	90	Gen Pop – Small/Med Urban - East (ON/NB/NS/PE/NL)	EN	MB
	10	8:30pm	7:30pm	7:30pm ET	90	Gen Pop - Mixed Urban - Quebec	FR	CP
	11	9:00pm	8:00pm	7:00pm CT/SK 6:00pm MT 5:00pm PT	90	High Risk – Small/Med Urban – West (MB/SK/AB/BC)	EN	MB

Date	Group	AST	EST	Participant Time	Length (min)	Audience	Language	Moderator
Thu, Feb 4	12	2:00pm	1:00pm	12:00pm CT/SK 11:00am MT 10:00am PT	60	PLWD – Large Urban - West (MB/SK/AB/BC)	EN	MB
	13	2:00pm	1:00pm	1:00pm ET	60	PLWD - Quebec – Mixed Urban	FR	CP
	14	6:00pm	5:00pm	6:30pm NL 6:00pm AT 5:00pm ET	90	PCP First Responders – Rural - East (ON/NB/NS/PE/NL)	EN	MB
	15	6:30pm	5:30pm	5:30pm ET	90	Unpaid Care Providers - Quebec – Mixed Urban	FR	CP
	16	8:30pm	7:30pm	7:30pm ET	90	PCP Care - Quebec – Mixed Urban	FR	CP
	17	9:00pm	8:00pm	7:00pm CT/SK 6:00pm MT 5:00pm PT	90	Unpaid Care Providers – Rural - West (MB/SK/AB/BC)	EN	MB
Mon, Feb 8	18	2:00pm	1:00pm	2:30pm NL 2:00pm AT 1:00pm ET	60	PLWD – Rural - East (ON/NB/NS/PE/NL)	EN	MB
	19	6:00pm	5:00pm	6:30pm NL 6:00pm AT 5:00pm ET	90	PCP Healthcare – Large Urban - East (ON/NB/NS/PE/NL)	EN	MB
	20	8:00pm	7:00pm	6:00pm CT/SK 5:00pm MT 4:00pm PT	90	PCP Healthcare – Rural - West (MB/SK/AB/BC)	EN	MB
Tue, Feb 9	21	6:00pm	5:00pm	6:30pm NL 6:00pm AT 5:00pm ET	90	PCP Care – Small/Med Urban - East (ON/NB/NS/PE/NL)	EN	MB
	22	8:00pm	7:00pm	6:00pm CT/SK 5:00pm MT 4:00pm PT	90	PCP First Responders – Small/Med Urban - West (MB/SK/AB/BC)	EN	MB
Thu, Feb 11	23	4:00pm	3:00pm	2:00pm CT/SK 1:00pm MT 12:00pm PT	90	PCP Care – Large Urban - West (MB/SK/AB/BC)	EN	MB
	24	7:00pm	6:00pm	7:30pm NL 7:00pm AT 6:00pm ET	90	Unpaid Care Providers – Large Urban - East (ON/NB/NS/PE/NL)	EN	MB
	25	9:00pm	8:00pm	7:00pm CT/SK 6:00pm MT 5:00pm PT	90	High Risk – Rural - West (MB/SK/AB/BC)	EN	MB

Specification Summary

- **Number of groups:** Twenty-five (25) focus groups in total; specifically, 8 full groups and 17 mini groups. A total of 18 groups in English and 7 groups in French. The distribution of focus groups by length, size, audience, geographic location and language is specified in the tables below.
- **Community sizes:** these are defined as:
    - Large Urban (pop. 100,000+)
    - Rural (min. 75km from urban centre)
    - Small/Medium Urban (pop. 1,000-99,000)
    - Mixed Urban (pop. 30,000+)
- **Geography:** In each group, include a good mix of provinces within each region and a good mix of locations within Quebec
- **Recruits:** Total of 182 recruits across all groups.
- **Seven (7) Audiences:**
    - **General Population (4 full groups; 40 recruits):** Mix of age, gender, household type and cultural background.
    - **Higher Risk Population (4 full groups; 40 recruits)**: Higher risk of developing dementia and / or facing barriers to equitable care (Recruit per group: 2 Indigenous people, 3 individuals with a disability,5 with either hypertension, diabetes, high cholesterol or obesity, older adults (skewing 40+), skewing women, 5 non-Caucasians, 4 individuals who identify as LGBTQ2+, skewing rural and remote communities). Mix of gender and household type.
    - **Unpaid Care Providers (4 mini groups; 24 recruits)**: Family member, friend, or neighbour providing care. Support provided by a caregiver may include assisting with the activities of daily living and helping with advance care planning. Mix of gender and cultural background.
- **Audiences (continued):**
    - **Paid Care Providers – First Responders (3 mini groups; 18 recruits)**: Includes police officers, firefighters, paramedics and search and rescue personnel.
    - **Paid Care Providers – Healthcare (3 mini groups; 18 recruits)**: Includes healthcare providers (e.g., family physicians, nurse practitioners, geriatric care specialists, registered nurses, and pharmacists) primarily involved in providing healthcare services to people living with dementia
    - **Paid Care Providers – Care (3 mini groups; 18 recruits)**: Paid resources offering social assistance and general care. Could include social workers, occupational therapists, developmental service workers, and personal care workers.
    - **People Living with Dementia (4 mini groups; 24 recruits)**: Individuals who have been diagnosed with dementia. Only includes individuals who have the capacity to take part in an online group discussion without assistance. Mix of gender and cultural background.
- **Incentive**:
    - $100 (General Population/Higher Risk Population)
    - $125 (Unpaid Care Provider)
    - $150 (Paid Care Provider – First Responders)
    - $150 (Paid Care Provider – Care)
    - $150 (People Living with Dementia)
    - $200 (Paid Care Provider – Healthcare)
- **# of participants recruited per group**
    - Full groups: 10 recruits (8 to show)
    - Mini group: 6 recruits (4 to show)
- **Length of discussion:**
    - People living with dementia: 1 hour
    - All other audiences: 2 hours

Number of Online Focus Groups
Length of discussion: 2 hours

Audience	Large Urban	Rural	Small/ Medium Urban	Mixed Urban	Total Groups	Total Recruits
General Public	1 English Full Group West (MB/SK/AB/BC)	1 English Full Group East (ON/NB/NS/PE/NL)	1 English Full Group East (ON/NB/NS/PE/NL)	1 French Full Group Quebec	4 Full	40
Higher Risk Population	1 English Full Group East (ON/NB/NS/PE/NL)	1 English Full Group West (MB/SK/AB/BC)	1 English Full Group West (MB/SK/AB/BC)	1 French Full Group Quebec	4 Full	40
Unpaid Care Provider	1 English Mini Group East (ON/NB/NS/PE/NL)	1 English Mini Group West (MB/SK/AB/BC)	1 English Mini Group West (MB/SK/AB/BC)	1 French Mini Group Quebec	4 Mini	24
Paid Care Provider (First Responders)	N/A	1 English Mini Group East (ON/NB/NS/PE/NL)	1 English Mini Group West (MB/SK/AB/BC)	1 French Mini Group Quebec	3 Mini	18
Paid Care Provider (Healthcare)	1 English Mini Group East (ON/NB/NS/PE/NL)	1 English Mini Group West (MB/SK/AB/BC)	N/A	1 French Mini Group Quebec	3 Mini	18
Paid Care Provider (Care)	1 English Mini Group West (MB/SK/AB/BC)	N/A	1 English Mini Group East (ON/NB/NS/PE/NL)	1 French Mini Group Quebec	3 Mini	18
TOTAL	5	5	5	6	21	158

Number of Online Focus Groups
Length of discussion: 1 hour

Audience	Large Urban	Rural	Small/ Medium Urban	Mixed Urban	Total Groups	Total Recruits
People living with Dementia	1 English Mini Group West (MB/SK/AB/BC)	1 English Mini Group East (ON/NB/NS/PE/NL)	1 English Mini Group East (ON/NB/NS/PE/NL)	1 French Mini Group Quebec	4 Mini	24

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."

RECRUITER NOTE: If a respondent wishes to verify the validity of the study, please contact: Narrative Research: 888-414-1336; focusgroups@narrativeresearch.ca

SECTION G: General Introduction

Hello, my name is _______________ and I am calling on behalf of Narrative Research, a national market research company. Would you prefer that I continue in English or French? / Préférez-vous continuer en français ou anglais?

> *RECRUITER NOTE - FOR ENGLISH GROUPS, IF PARTICIPANT WOULD PREFER TO CONTINUE IN FRENCH, PLEASE RESPOND WITH:* "Malheureusement, nous recherchons des gens qui parlent anglais pour participer à ces groupes de discussion. Nous vous remercions de votre intérêt."

Let me assure you that we are not trying to sell you anything. We are conducting market research on behalf of the Government of Canada and are looking for a variety of people to take part in a small online group discussion called focus groups.

A1. We are looking to speak with a variety of people for this study, including people who have been diagnosed with early stages of dementia. Would there be someone in your household, including you, who has this condition?

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

> INSTRUCTIONS: If yes, self, consider for PEOPLE LIVING WITH DEMENTIA GROUPS and skip to QA3; if yes, someone else, ask to speak to that person if possible and repeat intro; if no, continue to QA2 and consider for all other groups

A2. We are also looking to speak with someone who is currently caring for, or interacting with, a person or more than one person living with dementia, either in a personal or professional capacity. Would that describe your situation or that of someone else in your household?

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

> INSTRUCTIONS: If yes, self (Code 1), consider for PAID AND UNPAID CARE PROVIDERS GROUPS; if yes, someone else (Code 2), ask to speak to that person if possible and repeat intro; if no (Code 3), continue and consider for GEN POP GROUPS AND HIGHER RISK GROUPS
>
> If necessary, specify that the type of person we are looking for include unpaid caregivers (friend, relative, neighbour) or paid caregiver (including first responders, healthcare providers, social workers, occupational therapists, developmental service workers and personal care workers among other types of work).

The research also includes members from the general public even if they are not in contact with people living with dementia.

A3. The focus groups we are recruiting for will be held from <INSERT DATES>. The purpose is to gather feedback and suggestions to assist the Government of Canada in developing an online portal that provides information on dementia. **[IF NO AT QA1 OR QA2: At this time, we are looking for the input of the general public, regardless of their experience with dementia or interactions with people living with dementia.**] Those who qualify and take part in the group discussion will receive a financial incentive. Is this something you might be interested in?

Yes..1
No...2

INSTRUCTIONS: If yes, continue; if no thank & terminate

A4. Participation in this research is voluntary and completely anonymous and confidential. No attempt will be made to sell you anything or change your point of view. The format of the focus group is an informal small group discussion led by a professional moderator. The session is held online and will require the use of a computer and access to a phone. May I ask you a few quick questions to see if you are the type of participant we are looking for? This should take about 7 to 10 minutes. **[IF "YES, SELF" AT QA1 – PEOPLE LIVING WITH DEMENTIA:** We can provide you with the questions to review before answering them if you prefer.]

Yes..1
No...2

INSTRUCTIONS: If yes continue; if no, thank & terminate

A5. **[IF "YES, SELF" AT QA1 – PEOPLE LIVING WITH DEMENTIA]** Would you like to take the time to review the list of screening questions before answering them, or would you like to go through the screening questionnaire right now? Note that this is not a test and there are no right or wrong answers to those questions.

Prefers to review questions......................................1
Prefers to go through screening questions now ...2

INSTRUCTIONS: If prefers to review questions (code 1), record email and send them the screener questions. Schedule call-back to go through the screener with them. If prefers to go through screening questions now, continue.

SECTION P: Profiling Questions – ASK ALL

P1. To begin, do you or anyone in your household currently work or have ever worked in any of the following areas?

	Current Work	Past Work

Marketing/Market Research	1	5
Advertising or Media (TV, Radio, Newspaper)	2	6
Web developer	3	7
Health-related communications position for the federal or provincial government	4	8

INSTRUCTIONS: If yes to any of the above, thank & terminate

P2. In which community (town, city or village) and province/territory do you currently live?

Record name of community: ________________________
Record name of province/territory: __________________

INSTRUCTIONS: Note geographic breakdown by provinces/territories for English groups and Quebec regions for French groups. Recruit a good mix of locations in each group. Note the community size to align with the focus group breakdown; Skew rural and remote locations in HIGHER RISK GROUPS

P3. How long have you lived in <INSERT PROVINCE/TERRITORY >?

RECORD # of Years: __________

INSTRUCTIONS: Thank & Terminate if less than 2 years

SECTION P: Profiling Questions – ASK IF YES, SELF AT QA2 – CARE PROVIDER

P4. Do you currently provide personal or professional care or assistance to a person or more than one person who have been diagnosed with dementia?

Yes	1
No	2

INSTRUCTIONS: If yes, continue; if no, skip to QP15

P5. Which of the following best describes your role in providing care or assistance?

I interact with people who have been diagnosed with dementia as part of my work or my professional activities	1
I am an unpaid caregiver to a person who has been diagnosed with dementia, providing support in a personal capacity	2

INSTRUCTIONS: If code 1 (professional), consider for PAID CAREGIVER GROUPS; if code 2 (personal, unpaid), consider for UNPAID CAREGIVER GROUPS

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

INSTRUCTIONS: Recruit at least 3 per group who answered daily or a few times a month for PAID CAREGIVER GROUPS and all in UNPAID CAREGIVER GROUPS must be at least once a month; If PAID CAREGIVER, skip to QP14

P6. **[UNPAID CAREGIVER]** What is your relationship with the person or people living with dementia for whom you provide unpaid care or assistance?

I am a family member of that person/those people 1
I am a friend or acquaintance of that person/those people..2
I am a neighbour of that person/those people 3
Other (Specify: _____) 4

INSTRUCTIONS: Recruit a mix in each UNPAID CAREGIVER GROUPS if possible

P7. **[UNPAID CAREGIVER]** In which age group are you?

Less than 18 1
18-29..2
30-39..3
40-49..4
50-59..5
60-64..6
65-69..7
70-74..8
75-79..9
80-85..10
More than 85 years old.....................11

P8. **[UNPAID CAREGIVER]** What is your gender?

Male...1
Female; or...2
Prefer to self-identify (Please specify: ____)...3
Prefer not to answer 4

INSTRUCTIONS: Recruit mix of gender in UNPAID CAREGIVER GROUPS

P9. **[UNPAID CAREGIVER]** What is your current employment status?

Working part-time or full-time, or self-employed..1
Retired...4

Unemployed 5
Student 6
Other (Specify: _____) 7
DK/NR 8

P10. **[IF EMPLOYED AT P9]** In what sector do you work and what is your current occupation?

Sector: ____________________________________
Occupation: ________________________________

INSTRUCTIONS: Thank & Terminate if similar occupations as in QP1

P11. **[IF RETIRED AT P9]** In what sector were you last employed before retirement and what was your occupation?

Sector: ____________________________________
Occupation: ________________________________

P12. **[UNPAID CAREGIVER]** To make sure that we speak to a diversity of people, could you tell me what is your ethnic background? **DO NOT READ – CODE ALL THAT APPLY**

White/European (for example, German, Irish, English, Italian, French, Polish, etc.) 1
Hispanic, Latino, Spanish (for example, Mexican, Cuban, Salvadoran, Columbian, etc.) 2
Black or African Canadian (for example, African Canadian, Jamaican, Haitian, Nigerian, Ethiopian, etc.) 3
East Asian (for example, Chinese, Filipino, Vietnamese, Korean, etc.) 4
South Asian (for example, East Indian, Pakistani, etc.) 5
Middle Eastern or North African (for example, Lebanese, Iranian, Syrian, Moroccan, Algerian, etc.) 6
Indigenous (e.g. First Nations, Métis, Inuit) 7
Other (Specify: ___) 8
Don't know / No response 9

INSTRUCTIONS: Recruit mix in UNPAID CAREGIVER GROUPS; SKIP TO SECTION N: NETFOCUS

P13. **[PAID CAREGIVER]** In which capacity or role do you interact with people living with dementia as part of your work or professional activities; that is what type of work do you do?

[CONSIDER FOR PAID CARE PROVIDER – FIRST RESPONDER GROUPS]
Police officer 1
Firefighter 2
Paramedic 3
Search and rescue 4
Dispatcher 5

[CONSIDER FOR PAID CARE PROVIDER – HEALTHCARE GROUPS]

Physician	6
Specialist (psychologist, psychiatrist)	7
Nurse	8
Geriatric care specialist	9
Pharmacist	10
Continuing Care Assistant (CCA)	11

[CONSIDER FOR PAID CARE PROVIDER – CARE GROUPS]

Social worker	12
Therapist (occupational, physio, massage, etc.)	13
Dietitian/nutritionist	14
Developmental service worker	15
Paid personal care worker	16

[FOR ALL]

Other (Specify: ___)	17

INSTRUCTIONS: If other, please verify validity with supervisor; Consider others based on the categories identified for FIRST RESPONDER GROUPS, HEALTHCARE GROUPS, and CARE GROUPS – recruit mix of employment in each group – limiting the number to 2 for each type of employment identified

SECTION P: Profiling Questions – ASK IF EITHER YES, SELF (CODE 1) AT QA1 OR NO AT QA2 – NOT A CARE PROVIDER

P14. In which age group are you?

Less than 18	1
18-29	2
30-39	3
40-49	4
50-59	5
60-64	6
65-69	7
70-74	8
75-79	9
80-85	10
More than 85 years old	11

INSTRUCTIONS: Recruit good diversity across all age categories in GEN POP GROUPS and skew older (40+) in HIGHER RISK GROUPS

P15. What is your gender?

Male	1

Female; or..........2
Prefer to self-identify (Please specify: ___)..........3
Prefer not to answer..........4

INSTRUCTIONS: Recruit mix of gender in GEN POP GROUPS and PEOPLE LIVING WITH DEMENTIA GROUPS; skew female in HIGHER RISK GROUPS

P16. Are you a member of the LGBTQ2+ community?

Yes..........1
No..........2
Prefer not to say..........3

INSTRUCTIONS: If yes, consider for HIGHER RISK GROUPS - aim to recruit 4 per group

P17. What is your current employment status?

Working part-time or full-time, or self-employed..........1
Retired..........2
Unemployed..........3
Student..........4
Other (Specify: ______)..........5
DK/NR..........6

P18. **[IF EMPLOYED AT QP18]** In what sector do you work and what is your current occupation?

Sector: ______________________________________
Occupation: __________________________________

INSTRUCTIONS: Thank & Terminate if similar occupations as in QP1

P19. **[IF RETIRED AT QP18]** In what sector were you last employed before retirement and what was your occupation?

Sector: ______________________________________
Occupation: __________________________________

INSTRUCTIONS: Thank & Terminate if similar occupations as in QP1

P20. To make sure that we speak to a diversity of people, could you tell me what is your ethnic background? **DO NOT READ – CODE ALL THAT APPLY**

White/European (for example, German, Irish, English, Italian, French, Polish, etc.)..........1
Hispanic, Latino, Spanish (for example, Mexican, Cuban, Salvadoran, Columbian, etc.)..........2
Black or African Canadian (for example, African Canadian, Jamaican, Haitian, Nigerian, Ethiopian, etc.)..........3

East Asian (for example, Chinese, Filipino, Vietnamese, Korean, etc.) 4
South Asian (for example, East Indian, Pakistani, etc.) 5
Middle Eastern or North African (for example, Lebanese, Iranian, Syrian, Moroccan, Algerian, etc.)..6
Indigenous (e.g. First Nations, Métis, Inuit) 7
Other (Specify: ___)...8
Don't know / No response 9

INSTRUCTIONS: Recruit 2 Indigenous and 5 non-Caucasians for each HIGHER RISK GROUPS; Recruit 2-4 in each GEN POP groups; Recruit mix of PEOPLE LIVING WITH DEMENTIA groups

P21. Do you currently have one of the following condition or illnesses?

Hypertension 1
Diabetes...2
High cholesterol 3
Obesity 4

INSTRUCTIONS: Recruit min 5 who at least one illness or condition, for each HIGHER RISK GROUPS

P22. Do you have a physical, intellectual or psychological disability?

Yes...1
No..2
Prefer not to say...............................3

INSTRUCTIONS: If yes, continue; if no or prefer not to say, skip to QP25

P23. Do you feel comfortable telling us about your disability to help us create diverse focus groups?

RECORD VERBATIM COMMENT: _______
No, I don’t feel comfortable 97

INSTRUCTIONS: Recruit min 3 who have one or more of the following disabilities in each HIGHER RISK GROUPS: mental health conditions, acquired brain injuries, hearing impairment, intellectual disabilities, physical disabilities, autism; If code 97 (do not want to disclose), consider for other groups

P24. Do you live alone or with other people? **SINGLE RESPONSE**

I live alone...1
I live with other people 2

INSTRUCTIONS: Recruit mix for each GEN POP GROUPS and HIGHER RISK GROUPS; If answer is live with others (code 2), ask QP26. If answer is alone (code 1), skip to Section N: Netfocus Questions

P25. **IF CODE 1 IN QP25, ASK** Is there someone in your household who has a chronic illness or health condition? **SINGLE RESPONSE**

Yes..1
No...2

INSTRUCTIONS: Recruit min 2 and max 3 who answered yes (code 1) for each GEN POP GROUPS and HIGHER RISK GROUPS. Examples of chronic illnesses or health conditions include (but are not limited to): hypertension, high cholesterol, diabetes, stroke, cancer, mental illnesses, kidney diseases, lung disease, etc.

SECTION N: Net*focus* Questions

The discussion groups for this project will be conducted over the phone and online simultaneously and will require the use of a laptop or desktop computer and a telephone line (landline or cell phone) for the duration of the focus group session. Note that you cannot use a computer tablet or smartphone to access the online session.

NF1. Do you have access to a laptop or desktop computer with high-speed Internet to take part in this focus group?

Yes, laptop or desktop computer 1
Yes, computer tablet..2
No..3

INSTRUCTIONS: If yes, computer tablet, or no, thank & terminate

NF2. The session will be held online using Adobe Connect which requires the installation of a free and secure plug in. Will you, or your system's administrator, be able to install this application before the focus group discussion? We will send you the installation instructions at least two days prior to the session.

Yes..1
No...2

INSTRUCTIONS: If no, thank & terminate

NF3. Once you are online for the session you will also be required to join a separate telephone conference call to be connected to the discussion with the rest of the group. You will need to use a telephone line and **NOT** your computer audio. Will you have access to a dedicated telephone (either landline or cellular) located near your computer? Note that you will not incur long-distance charges.

Yes 1
No...2

INSTRUCTIONS: If no, thank & terminate

INSTRUCTIONS FOR NF1-NF3 THANK & TERMINATE: Based on your responses, we are unable to invite you to take part in this online focus group, as you do not meet the technical requirements. We thank you for your interest in this research.

SECTION R: Previous Focus Group Experience Questions

I just have a few more questions…

R1. Have you ever attended a group discussion or interview for which you received a sum of money?

Yes……………………………………………………1
No ……………………………………………………2

INSTRUCTIONS: If yes, max of 5 recruits per group; If no, skip to SECTION I: INVITATION

R2. When was the last time you attended a group discussion or interview? _____________

R3. How many groups or interviews have you attended in the past 5 years? ____________ MAX 4

R4. What was the subject(s) of the focus group(s) or interview? ___________________________

THANK AND TERMINATE IF THEY HAVE…
- been to 5 or more groups in the past 5 years (max 4 groups/interviews attended)
- attended a focus group in the past six months.
- ever attended a group discussion on dementia

SECTION I: Invitation

NET*FOCUS* INVITE:
Based on your responses so far, we would like to invite you to participate in a small group discussion that will be conducted simultaneously over the telephone and online at <INSERT TIME> on <INSERT DATE>. The session will bring together [4 to 6/6 to 8] people and it will last about [one hour/two hours]. The purpose is to gather feedback and suggestions to assist the Government of Canada in developing an online portal that provides information on dementia. You will receive [$100/$125/$150/$200] in appreciation for your time. To take part, you would simply log on to a secure website from your computer and at the same time join in a group discussion on the phone via conference call.

I1. Are you available and interested in taking part in this focus group?

Yes……………………………………………………1
No ……………………………………………………2 THANK AND TERMINATE

I2. The discussion in which you will be participating will be audio/video recorded for research purposes only. Be assured that your comments and responses are strictly confidential and that your name will not be included in the research report. Are you comfortable with the discussion being audio/video recorded?

Yes..1
No 2

INSTRUCTIONS: If no, thank & terminate

I3. There may also be employees from the Government of Canada who will be listening in on the discussion. They will not be given the last names of participants. Are you comfortable with having observers?

Yes..1
No 2

INSTRUCTIONS: If no, thank & terminate

I4. The group discussion will be held **[GROUPS A, B: in English] [GROUPS C, D: in French].** Participants may also be asked to read text, write responses and/or review images during the session. Are you able to take part in these activities **[GROUPS A, B: in English] [GROUPS C, D: in French]** on your own, without assistance?

Yes..1
No...2

INSTRUCTIONS: If no, thank & terminate

I5. **[FOR PEOPLE LIVING WITH DEMENTIA GROUPS]** There will be someone available to assist you with the login process to join the online session. We will also provide you with the list of topics and questions that will be discussed during the focus group ahead of time. There will be a professional facilitator conducting the focus groups, and they will provide ample response time during the session for participants to share their opinions. Are there any other accommodations you may require to ensure you are able to participate in this focus group?

RECORD VERBATIM COMMENT: _______

I6. Could we please confirm the email address where we can send you the detailed conference call instructions for logging in to the group?

Record email address (and verify): ____

We will send you the instructions by email at least 2 days in advance of the group. The group discussion will begin promptly at **<TIME>** and will end at **<TIME>**, lasting up to **[1 hour/2 hours]**. Please log in at least 15 minutes prior to the start time to ensure that the session is not delayed. **[FOR ALL AUDIENCES EXCEPT**

PEOPLE LIVING WITH DEMENTIA: If you arrive late, we will not be able to include you in the discussion, and will not provide you with the incentive.]

I7. As mentioned, we will be pleased to provide everyone who participates with **[$100/$125/$150/$200]**, provided by e-Transfer or cheque, as you'd prefer. It takes approximately 3 business days to receive an incentive by e-Transfer or approximately 2-3 weeks following your participation to receive an incentive by cheque. Would you prefer to receive your incentive by e-Transfer or cheque?

e-Transfer 1
Cheque 2

I8. **[IF PREFER TO RECEIVE INCENTIVE BY E-TRANSFER] Could** you please confirm the e-mail address where you would like the e-transfer sent after the focus groups?

Email address: ____
And please confirm the spelling of your name: ____

The e-transfer password will be provided to you via email following the group.

I9. **[IF PREFER TO RECEIVE INCENTIVE BY CHEQUE]** Could I have the mailing address where you would like the cheque mailed after the focus groups?

Mailing address: ____
City: ____
Province: _______________________________________Postal Code: ______________________
And please confirm the spelling of your name: ____

I10. As these are very small groups and with even one person missing, the overall success of the group may be affected, I would ask that once you have decided to attend that you make every effort to do so. If you are unable to take part in the study, please call_____ (collect) at ________as soon as possible so a replacement may be found. **Please do not arrange for your own replacement.**

So that we can call you to remind you about the focus group or contact you should there be any changes, can you please confirm your name and contact information for me? **[CONFIRM INFORMATION ALREADY COLLECTED AND CHANGE/COMPLETE AS NECESSARY]**

First Name: ____
Last Name: ____
Email: ____
Cell Phone: ____
Home Phone: ____
Work Phone: ____

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 focus group. If they still refuse THANK & TERMINATE.

Thank you for your interest in our study. We look forward to hearing your thoughts and opinions!

Attention Recruiters

Recruit **6 participants per mini group** & **10 participants per full group**
CHECK QUOTAS
Ensure participant has a good speaking (overall responses) ability-If in doubt, DO NOT INVITE
Do not put names on profile sheet unless you have a firm commitment.
Repeat the date, time and verify email before hanging up.

Confirming – DAY BEFORE GROUP

1. Confirm in person with the participant the day prior to the group – do not leave a message unless necessary
2. Confirm all key qualifying questions
3. Confirm date and time
4. Confirm they have received the login instructions and completed the diagnostic test

Appendix B:
Moderator’s Guides

Moderator’s Guide – Final

Dementia Information Portal Focus Groups - PLWD

Study Objectives (do not share with participants)

- ***Capture awareness of and perceptions about existing dementia information online resources:*** *Sources of dementia information; credibility and quality of content; and core and popular dementia topics;*
- ***Understand current dementia information needs and gaps:*** *Identify dementia topics that lack accessible and credible online resources/information; and assess dementia information/resource gaps and/or barriers by key target audiences;*
- ***Evaluate perceptions of features, tools and information resources that users would expect to see as part of a dementia information portal:*** *Determine elements of a portal that support credibility, accessibility and visibility; Assess perceptions of sample approaches to dementia information portal; and*
- ***Determine whether additional tools are needed to effectively meet information needs related to dementia.***

Introduction *10 minutes*

Provide visual cues on the screen during the introduction

- **Welcome:** Introduce self & research firm & role as moderator (keep on time/on topic). Apart from me, there are X people on the call. I will start by explaining what we will do in this session and then you will have an opportunity to introduce yourself before we continue with our discussion.
- **Sponsor & Topic:** Groups on behalf of the Public Health Agency of Canada; Federal government is looking to develop an online information tool – or information website – relating to dementia; your assistance today will help to ensure that once developed, that tool meets the needs of those who want to learn about dementia and dementia resources
- **Length:** Our discussion should last about 60 min. Excuse yourself if needed during the session
- **Your Role:** Share your opinions freely and honestly; no prep needed; not testing your knowledge; participation is voluntary
- **Process:** All opinions are important; looking to understand minority/majority of opinions; Interested in hearing from everyone;
- **Logistic:** Recording discussion for reporting (the recording can be paused during the session if you feel more comfortable sharing your opinion on something without it being recorded – just let me know when this is the case); observation from government (listening in but not part of discussion)
- **Confidentiality:** Your comments are anonymous; no names in reports; answers will not affect dealings with Government of Canada; Once finalized, the report can be accessed through Library and Archives Canada.
- **Agenda:** We will begin with a short introduction from everyone; then we will discuss what information on dementia you have seen and used and where the information came from. For those familiar with the Internet, we will talk about what makes a website easy or difficult to use. And finally, we will discuss the idea of a Canadian website on dementia and what it should include.
- **Participant Introduction:** First name, where you live; and if you live alone or with someone else; if someone else, who lives with you

Information Sources / Needs *30 minutes*

THROUGHOUT THE SESSION, MODERATOR ASKING REPETITIVE NATURE QUESTIONS (IN BRACKET AND ITALICS) AS NEEDED BASED ON THE GROUP DYNAMIC; VISUAL CUES SHOWN ON THE SCREEN WHERE POSSIBLE TO AID WITH THE DISCUSSION.

One thing all of you have in common is that you are living with dementia. I'd like to begin our discussion by better understanding the kind of information you may want about dementia

Information Needs and Sources:

Since you've been diagnosed with dementia…

- What type of information on dementia have you received or looked for? (*What have you learned about dementia?*)
- What did you do with the information you found? (*How was the information useful to you?*)
    - Was this information useful to you? Why/why not?
- Where did you get this information? (*Where have you looked for information? Who provided you with information*?)
    - ***If online, ask:*** Where online did you look? (*What specific websites?*)
- Which sources do you trust the most for information on dementia? Why do you trust those? *(Which sources do you believe? Which sources provided information you trust? Which sources are evidence-based?)*
- What else would you like to know about dementia? (*What more do you need to know about dementia? What is missing? What other information would you like to know? What questions do you still have about dementia? Anything that you would like to know, but have not been able to find*?)

Internet Usage (ask questions where relevant based on Internet usage)

The Internet is often a source of information. For those of you who use the Internet, I would like to understand your experience.

- What makes a website easy to use? (*When you are looking for information on the Internet, regardless of what you are looking for, what makes it a positive experience?*)
    - Are there any websites that are really easy to use? [probe for sites] What makes them easy to use?
- What makes a website difficult to use? (*What are some of the problems you've experienced when looking for information online?*)

Information is available online in different ways: [show visual icons and brief words on screen] You can read it on your computer screen; sometimes you can save documents to your computer; and sometimes you can watch short videos or listen to recordings to get information. These are a few examples of how information can be shared.

- What way do you find is easiest to get information from the Internet? (*probe – videos, podcasts, documents you can print, documents you read online…*

Online Portal Content/Functionality *20 minutes*

We've got about 20 minutes left in our session. As mentioned at the beginning of our call, the Public Health Agency of Canada is working on a website that would provide information on dementia. There is a lot of information that could be included on this website – some of which you have already identified. I'd like to show you some of the things the website might include. Let's read what is on the screen together.

Share listing of information on the screen [moderator to read]

- Signs and symptoms of dementia
- Prevention / how to reduce risks of developing dementia symptoms
- Tools that help with diagnosis
- Dementia care such as management of symptoms
- How to reduce stigma (negative stereotypes) and make communities more inclusive and supportive for people living with dementia
- Government policies and strategies about dementia
- Current dementia research projects and results
- Information needed by care providers
- Dementia information adapted to specific populations
- Dementia service organizations (listings / links to organizations / support groups available for those living with dementia)
- Caregiver resources (services / self-care / groups)
- Online forum (ability to ask questions / have discussion online with other people using the website)

- What items from this list should be included on a dementia information website? (*Which of those would you like to see on the website?*)
    - Which ones are most important? Why?
- Is there anything that should not be included on a dementia information website? If so, what / why?
- Is there anything missing from the list? (*Apart from what is listed, what other information or resources should be included on the website?*)
- Do you have any advice to ensure that the website is easy to use and helpful to all Canadians? (*What would ensure that the website is accessible to everyone, regardless of age or disabilities?*)

Today you've shared with me: what you have learned about dementia, where you got this information and some of the questions you still have. You have also told me what information and resources you thought the Public Health Agency of Canada should consider having on the website they are developing.

- Now that you have had a few minutes to think about this, what do you think are the most important things to keep in mind when creating this type of portal?
- In addition to a website or online resource, what tools and supports would you like to see available about dementia?
    - ***Probe if not mentioned: print outs, national support line, local community support groups***
- Any final suggestions for the Public Health Agency of Canada as it looks to develop such a website?

Thanks & Closure

That concludes our discussion. On behalf of the Government of Canada, thank you for your time and input. Your feedback will be used by the Government of Canada to help in the development of a website on dementia.

Moderator's Guide – Final

Paid and Unpaid Care Providers; General Population; Higher Risks Population

Dementia Information Portal Focus Groups

Study Objectives (do not share with participants)

- ***Capture awareness of and perceptions about existing dementia information online resources:*** *Sources of dementia information; credibility and quality of content; and core and popular dementia topics;*
- ***Understand current dementia information needs and gaps:*** *Identify dementia topics that lack accessible and credible online resources/information; and assess dementia information/resource gaps and/or barriers by key target audiences;*
- ***Evaluate perceptions of features, tools and information resources that users would expect to see as part of a dementia information portal:*** *Determine elements of a portal that support credibility, accessibility and visibility; Assess perceptions of sample approaches to dementia information portal; and*
- ***Determine whether additional tools are needed to effectively meet information needs related to dementia.***

Introduction 10 minutes

- **Welcome:** Introduce self & research firm & role as moderator (keep on time/on topic)
- **Sponsor & Topic:** Groups on behalf of the Public Health Agency of Canada; Federal government is looking to develop an online information tool – or information portal – relating to dementia; your assistance today will help to ensure that once developed, that tool meets the needs of those who want to learn about dementia and dementia resources
- **Length:** Our discussion should last about [**PLWD:** 60 min. Excuse yourself if needed during the session] [**ALL OTHERS:** 90 minutes.]
- **Your Role:** Share your opinions freely and honestly; no prep needed; not testing your knowledge; participation is voluntary
- **Process:** All opinions are important; looking to understand minority/majority of opinions; talk one at a time; interested in hearing from everyone; participation is voluntary
- **Logistic:** Recording discussion for reporting (the recording can be paused during the session if you feel more comfortable sharing your opinion on something without it being recorded – just let me know when this is the case); observation from government (listening in but not part of discussion)
- **Confidentiality:** Your comments are anonymous; no names in reports; answers will not affect dealings with Government of Canada; Once finalized, the report can be accessed through the Library and Archives Canada.
- **Participant Introduction:** First name:
    - [**Unpaid Care Provider**]; in which community do you live; how long you have been providing care to someone living with dementia?
    - [**PCP Care**]; in which community you work; nature of job; how long you have been providing care to someone living with dementia?
    - [**PCP Healthcare**]; in which community you work; nature of your job; how long you have been interacting with people who are living with dementia?
    - [**PCP First Responder**]; in which community you work; nature of your job; how long you have been doing this type of work?

Information Sources / Needs *30 minutes*

[Unpaid Care Provider] You all have one thing in common today: you care for someone living with dementia without financial compensation – for example, that could be a family member, a friend, a neighbour, or someone else you know. Today, I am interested in your opinions as a person providing such a support role.
[Paid Care Provider] You all have one thing in common today: as part of your work, you interact or are likely to interact with people living with dementia. Today, I am interested in your opinions as someone who interacts with people living with dementia.

I'd like to begin our discussion by better understanding your information needs as it relates to dementia.

- **[Unpaid and Paid Care Providers]** In your role as a care provider to people living with dementia, what information do you personally need about dementia?
    - And what type of information do you think people living with dementia need to know about dementia?
- **[GP/Higher Risk]** This may not be a subject matter you are interested in right now, but I'd like to know if there is information about dementia you are interested in or could imagine you might be interested in in the future?
- What types of information have you specifically looked for, if any? Why that?

    <u>IF LOOKED:</u>
    - Where or from whom have you looked for that information? Why there?
        - ***If online, ask:*** Where online did you look; what specific websites?
    - Did you find what you were looking for?
    - What did you think of the quality of information you found? ***PROBE IF NOT MENTIONED:*** Was it credible? Comprehensive? Trustworthy?
    - In your experience, what information about dementia is easy to find/is easily available?
    - Anything / certain topics that you have not been able to access or have had problems finding?
        - What challenges did you encounter while looking for this information?
    - What other information would you like to know?
    - What is the greatest gap in information about dementia – information you need but that you have not been able to find?
    - ***ASK IF TIME PERMITS:*** And of the information you came across, is there any you were not interested in? Which ones and why?
    - Is there anything that made it difficult for you to access information on dementia?
- Regardless of whether you have looked for information or not, which sources do you or would you trust the most for information about dementia? Why those?
    - Where would you go first for this information? Why there?

As you mentioned, the Internet is one of the sources of information on dementia.

- Are there websites you have used or are aware of that provide information about dementia?
    - Why did you go there for information?
- How did you find out about the websites on dementia – regardless of whether or not you use those sites?
- How do you know that a website is trustworthy or that online information is credible?
    - Which websites do you trust more for information or assistance about dementia?
    - And for medical information in general?

There are lots of ways information can be made available online. Information can be accessed by reading text on a website, downloading files, seeing listings or libraries of information or resources – with or without links to various other online sources, using assessment tools or questionnaires, reviewing videos or audio files (podcasts) or taking part in an online forum. These are just examples and there could be more formats available. Most likely, the formats available will depend on the type of information and what it is used for.

Show listing of formats on the screen

Let's chat about that…

- When looking online, in what formats do you prefer to access information about dementia?
- How might the format be different based on the type of information you are interested in and what you would use it for?
    - ***Probe if not mentioned: research for academic/work purposes; personal use and interest; share with family and friends; share with healthcare providers, share with patients***

Online portal content and functionality *20 minutes*

As mentioned, the Public Health Agency of Canada is currently working on developing an online resource or information portal, with a goal of ensuring information needs related to dementia are fully addressed.

- What type of dementia-related information should this website include?

There are many different types of information or resources that could be included on such a site, some of which you have already identified.

Share listing of information on the screen

- ➢ Signs and symptoms of dementia
- ➢ Prevention / how to reduce risks of developing dementia symptoms

- Tools that help with diagnosis
- Dementia care such as management of symptoms
- How to reduce stigma (negative stereotypes) and make communities more inclusive and supportive for people living with dementia
- Government policies and strategies about dementia
- Current dementia research projects and results
- Information needed by care providers
- Dementia information adapted to specific populations
- Dementia service organizations (listings / links to organizations / support groups available for those living with dementia)
- Caregiver resources (services / self-care / groups)
- Online forum (ability to ask questions / have discussion online with other people using the website)

ONLINE INDIVIDUAL POLL: How important do you think each of those themes would be to include on the site? Please check all the items that you think are a 'must have'.

share online poll – check all that apply; share poll results with everyone once exercise is completed

Now let's talk about this together…

- What items from this list should be included on a dementia information website?
  - Which ones are most important? Why?
- Is there anything that should not be included? If so, what / why?
- If there was a forum on the website, is this something you might use?
  - ***If yes:*** How would you use the online forum? Would you participate in the discussion or simply review the comments that were posted by others? What information would you be looking for on the forum? Who would you expect to access in a forum?
- Have you seen interesting tools or functionalities used on other websites – not necessarily about dementia – that could be considered?
- What, if anything, might help to ensure that the portal is easy to use and has relevant content for all Canadians?
- In addition to a website or online resource, what additional tools and supports would you like to see available about dementia?
  - ***Probe if not mentioned: printed materials, national support line, local community support groups***

Examples of online portals on dementia *20 minutes*

To finish up, I want to briefly get your thoughts on an existing website that provides information on dementia. This is an Australian website. I'm just interested in getting your initial reactions to each, not a detailed site review or evaluation of its content.

If possible, moderator to show the site on their screen; alternatively, review static images for the site: dementia.org.au

This site features human interest stories related to dementia, a banner where you can find information about dementia, support, education, how to get involved, research, a calendar of events, and details about the organization. When you click on any of the banner points there is a drop down menu of available items, and also visual icons on each item. These will give you an idea of what the site includes. I am going to show you a few pictures / screen shots of the site. [walk thru different images].

Web Pages to Be Shown by Audience						
	General Population	Higher Risk	Care Providers (Unpaid)	Care (Paid)	First Responders (Paid)	Healthcare (Paid)
Home Page (https://www.dementia.org.au/)	✓	✓	✓	✓	✓	✓
Information – What is dementia? (https://www.dementia.org.au/about-dementia/what-is-dementia)	✓	✓			✓	
Information – I am a health professional (https://www.dementia.org.au/resources/health-professionals)				✓	If time permits	✓
Information – I am a carer, family member, or friend (https://www.dementia.org.au/information/about-you/i-am-a-carer-family-member-or-friend)			✓			

<u>After reviewing each site, ask:</u>

- Overall impressions of this site?
- What do you think about the overall "look & feel" – colours, use of graphics, general layout?
- At a glance, how do you feel about the way the information is organized?
- How easy do you think it would be to find what you are looking for on this site?
- Have you noticed the accessibility features on the site? What could be done to improve accessibility? ***Note to moderator: examples of accessibility features include a feature that reads the information on the website for you, email support, helpline webchat, National Dementia Helpline, colour contrast, information in different languages (this may not be obvious unless you navigate to specific sections of the website)***
- At a glance, would you trust the information on this site? Why/why not?

Today you've shared details on where you turn for information on dementia, what type of information you would like to have available on dementia, and what the Public Health Agency of Canada should consider as it develops an information portal or online resource on dementia.

- Now that you have had a few minutes to think about this, what do you think are the most important things to keep in mind when creating this type of portal?
- To allow for more options on how the portal is designed, it may be hosted through an organization outside of government even though it is funded by the government – specifically the Public Health Agency of Canada. This means that the URL would not include

“Canada.gc.ca”. If this is the case, what should the website include to ensure users have trust in the information?
    - ***Probe for: evidence-based information, easy to determine the source of information, indication that the website is funded by the Public Health Agency of Canada, information about how the material on the website is reviewed and approved***
    - ***If government website perceived as more trusted, probe to understand why.***
- Any final suggestions for the Public Health Agency of Canada as it looks to develop such a portal?

Thanks & Closure

That concludes our discussion. On behalf of the Government of Canada, thank you for your time and input.

Appendix C:

Materials Shared During the Focus Groups

NARRATIVE
RESEARCH

Welcome!

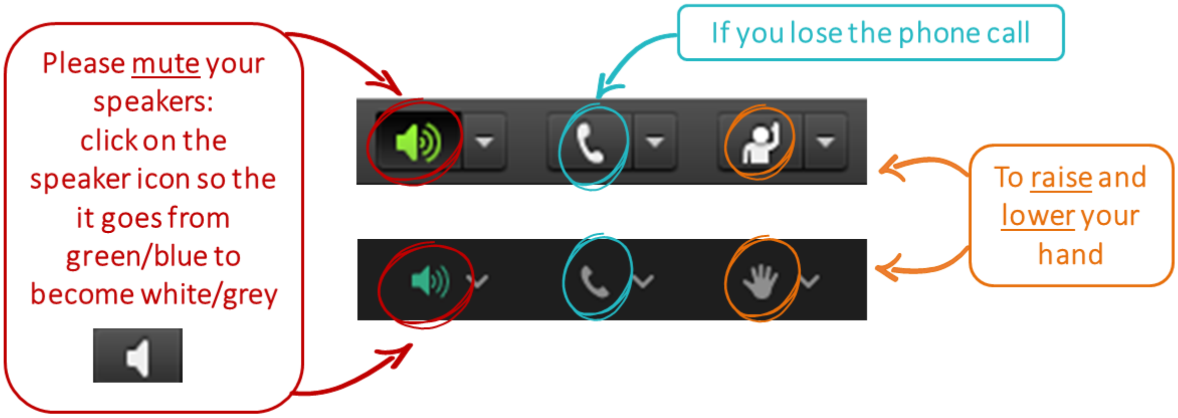
You are now connected to the session

We will begin the discussion when everyone has logged on.

Please make sure you are using a __desktop__ or __laptop__ computer.

Introduction

- Let me explain what we will do today…



Please mute your speakers: click on the speaker icon so the it goes from green/blue to become white/grey

If you lose the phone call

To raise and lower your hand

Introductions

- In which community do you live?
- Who lives in your home?

Introductions

- In which community do you live?
- How long have you been providing care to someone living with dementia?

Introductions

- In which community do you work?
- What is the nature of your work?
- How long have you been providing care to people living with dementia?

Introductions

- In which community do you work?
- What is the nature of your work?
- How long have you been interacting with people who are living with dementia?

Introductions

- In which community do you work?
- What is the nature of your work?
- How long have you been doing this type of work?

Information Needs / Sources

- Information about dementia
- Sources of information

Information Formats Online

- Reading text on a website
- Downloading files
- Seeing listings or libraries of information or resources (with or without links to other online sources)
- Using assessment tools or questionnaires
- Reviewing videos or audio files (podcasts)
- Taking part in an online forum

Online Portal on Dementia

Online Portal on Dementia

- Signs and symptoms of dementia
- Prevention / how to reduce risks of developing dementia symptoms
- Tools that help with diagnosis
- Dementia care such as management of symptoms
- How to reduce stigma (negative stereotypes) and make communities more inclusive and supportive for people living with dementia
- Government policies and strategies about dementia
- Current dementia research projects and results
- Information needed by care providers
- Dementia information adapted to specific populations
- Dementia service organizations (listings / links to organizations / support groups available for those living with dementia)
- Caregiver resources (services / self-care / groups)
- Online forum (ability to ask questions / have discussion online with other people using the website)

Online Portal on Dementia

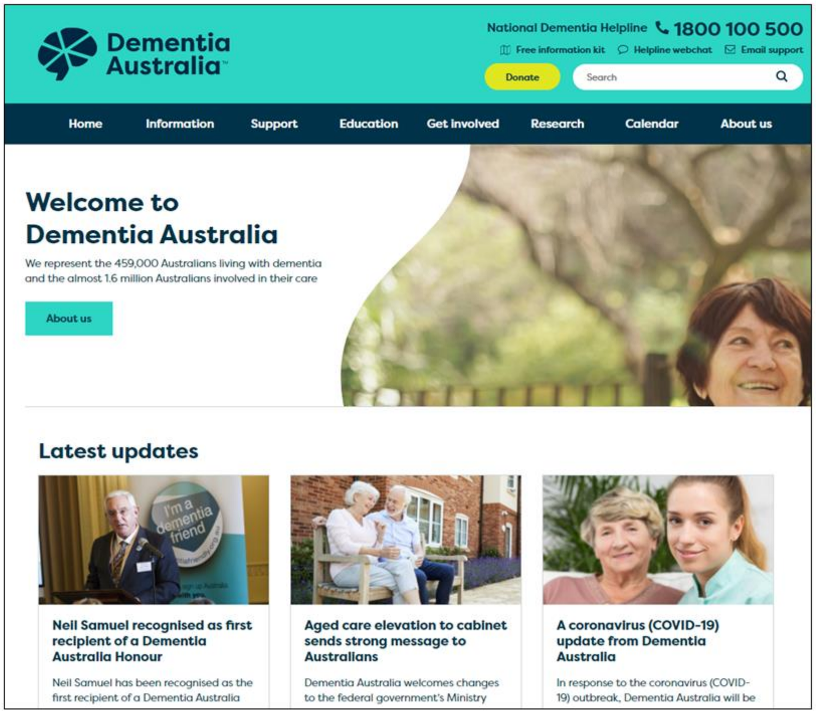
Online Portal on Dementia

Example of a Website on Dementia

Let’s have a look at an example of a website on dementia:

www.dementia.org.au

We will look at the screenshots of the website **from the Home screen to the Information section.**



Welcome to Dementia Australia

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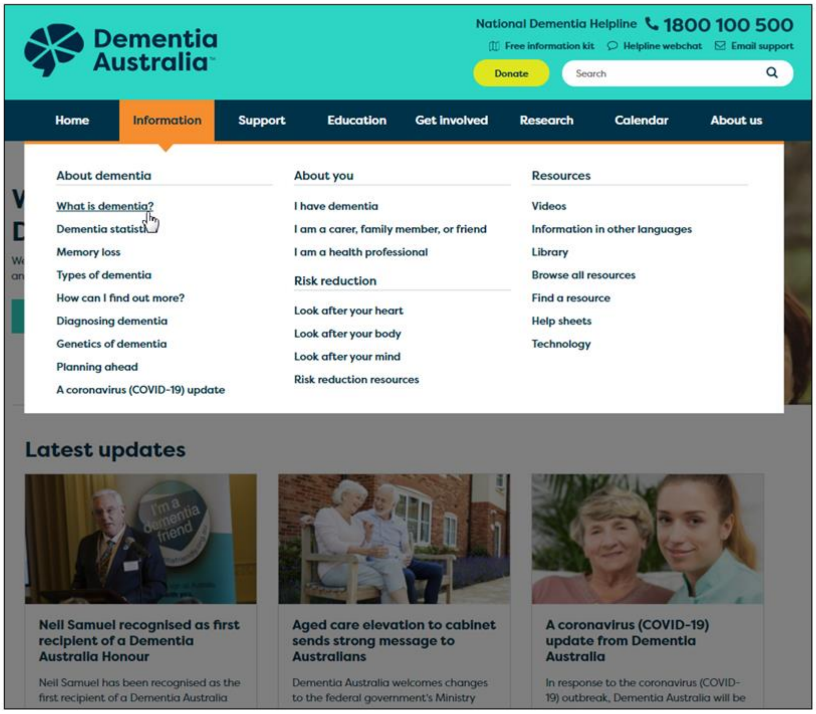

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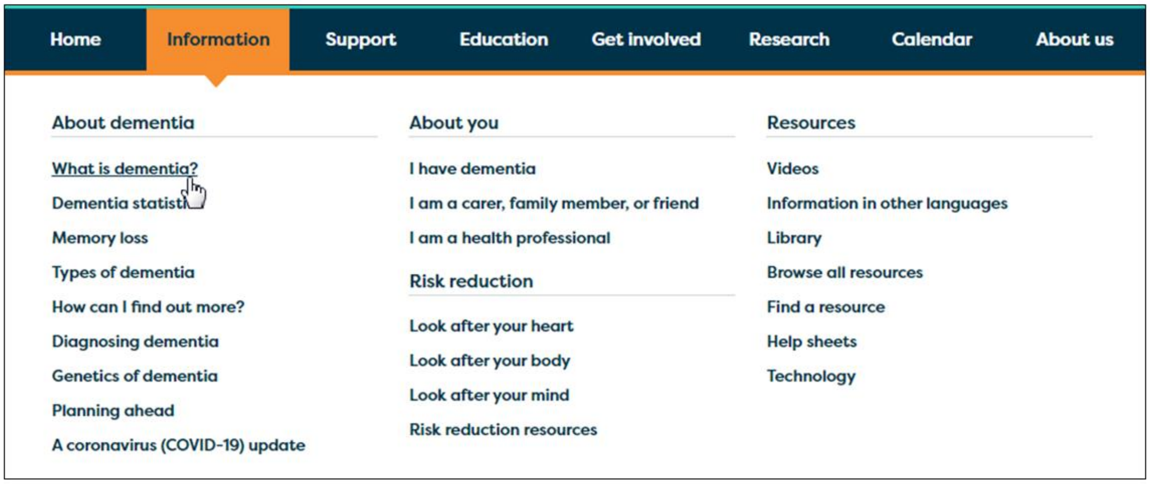
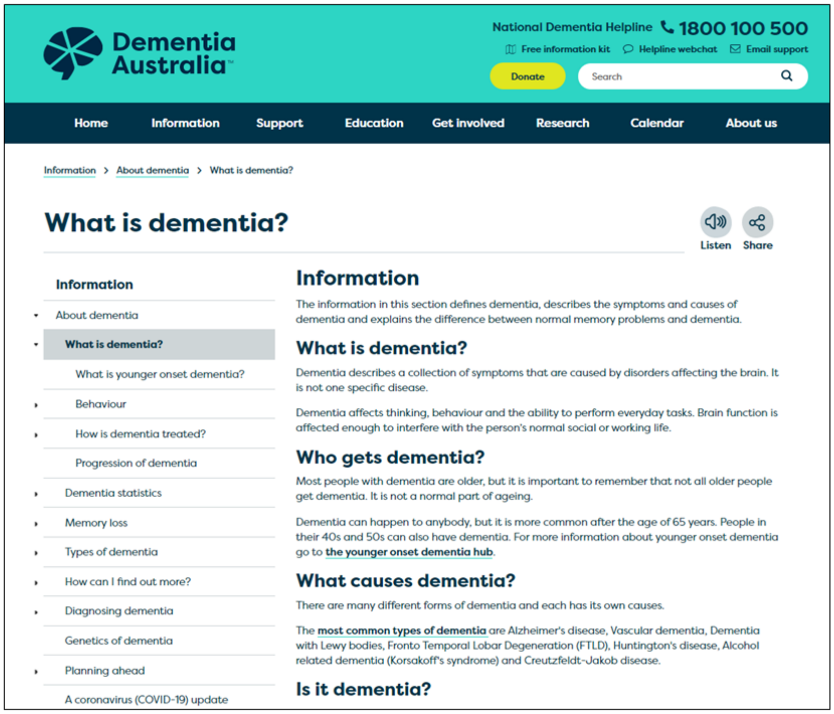




What is dementia?

Information

The information in this section defines dementia, describes the symptoms and causes of dementia and explains the difference between normal memory problems and dementia.

What is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease.

Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life.

Who gets dementia?

Most people with dementia are older, but it is important to remember that not all older people get dementia. It is not a normal part of ageing.

Dementia can happen to anybody, but it is more common after the age of 65 years. People in their 40s and 50s can also have dementia. For more information about younger onset dementia go to **the younger onset dementia hub**.

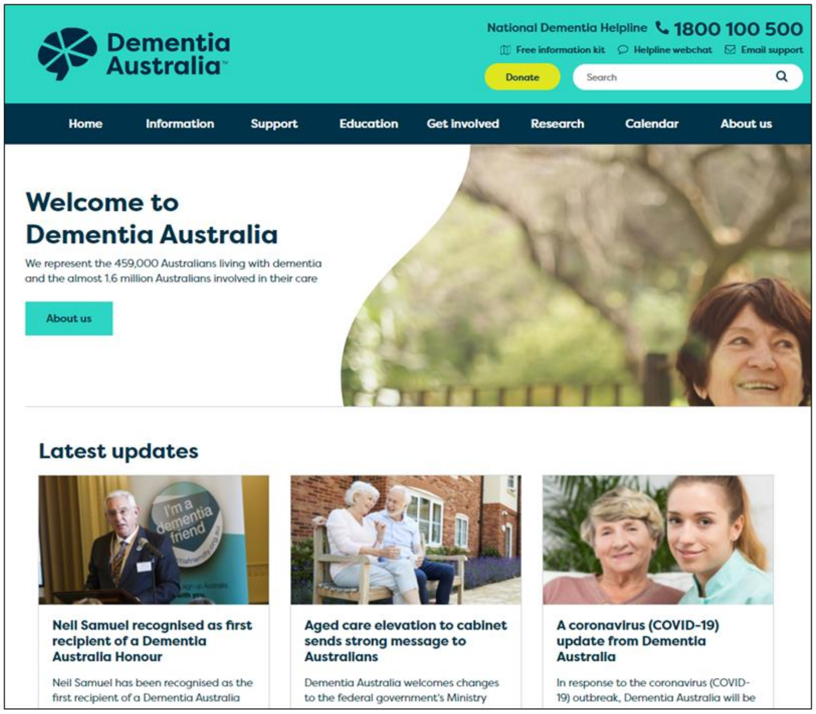
What causes dementia?

There are many different forms of dementia and each has its own causes.

The **most common types of dementia** are Alzheimer's disease, Vascular dementia, Dementia with Lewy bodies, Fronto Temporal Lobar Degeneration (FTLD), Huntington's disease, Alcohol related dementia (Korsakoff's syndrome) and Creutzfeldt-Jakob disease.

Is it dementia?

We will look at the screenshots of the website **from the Home screen to the Information section for health professionals.**



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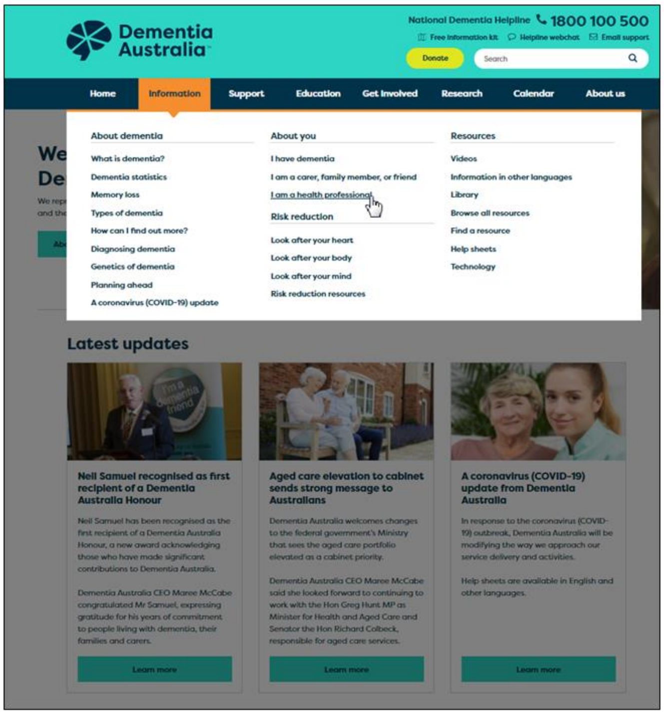

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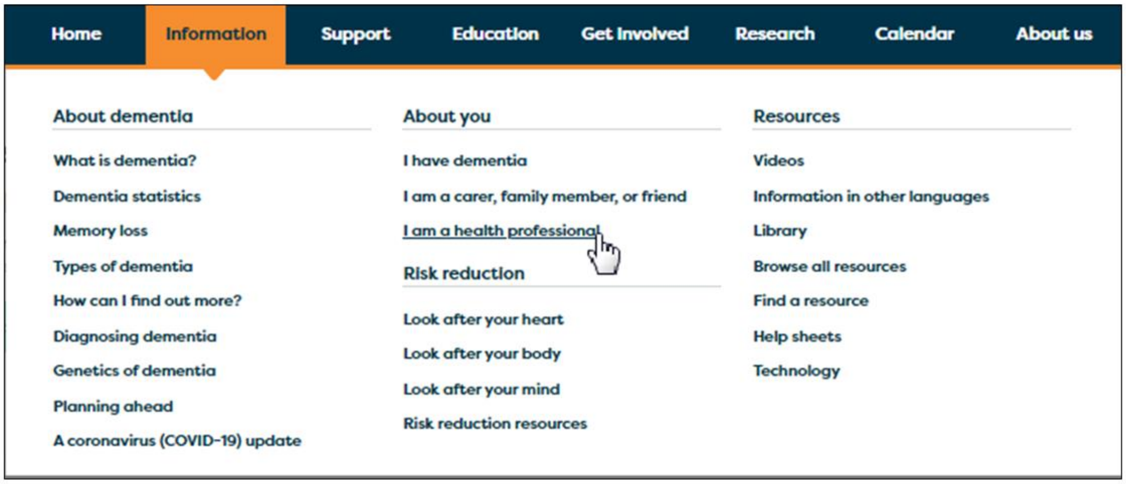

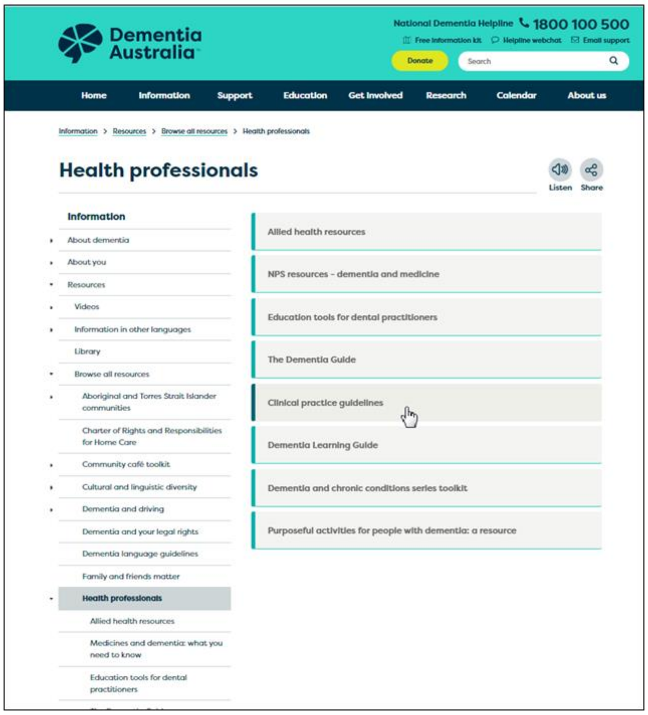

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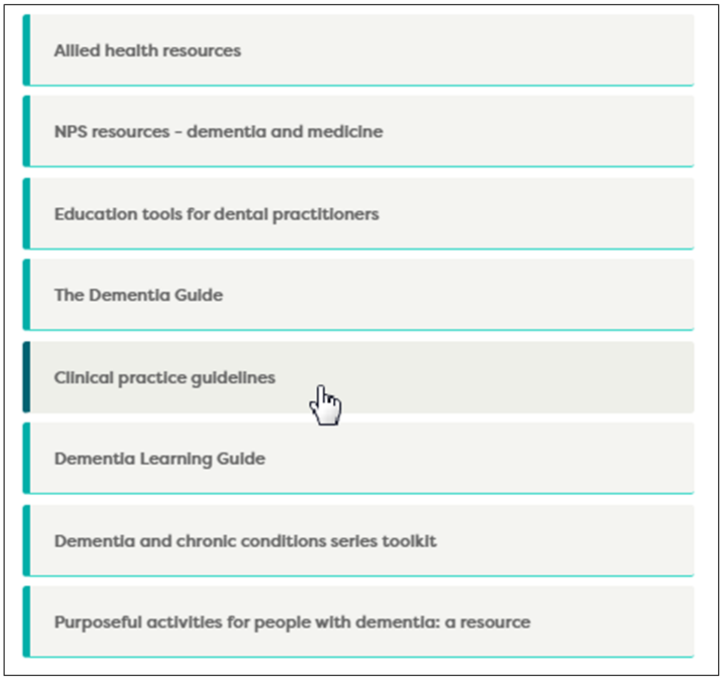

Allied health resources

NPS resources - dementia and medicine

Education tools for dental practitioners

The Dementia Guide

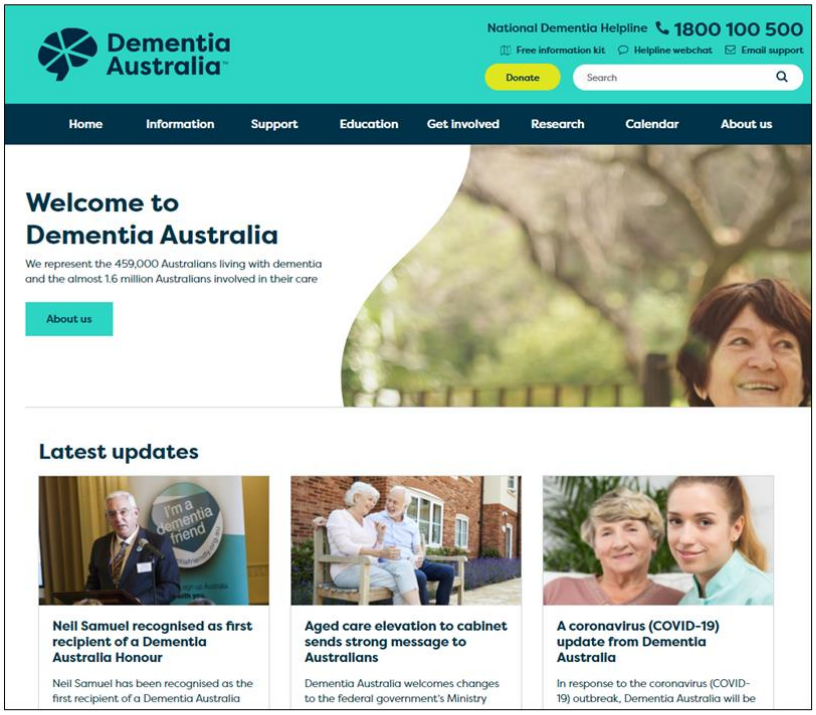
Clinical practice guidelines

Dementia Learning Guide

Dementia and chronic conditions series toolkit

Purposeful activities for people with dementia: a resource

We will look at the screenshots of the website **from the Home screen to the Information section for carers, family members, or friends.**


Dementia Australia

National Dementia Helpline 1800 100 500

Free information kit Helpline webchat Email support

Donate

Search

Home Information Support Education Get involved Research Calendar About us

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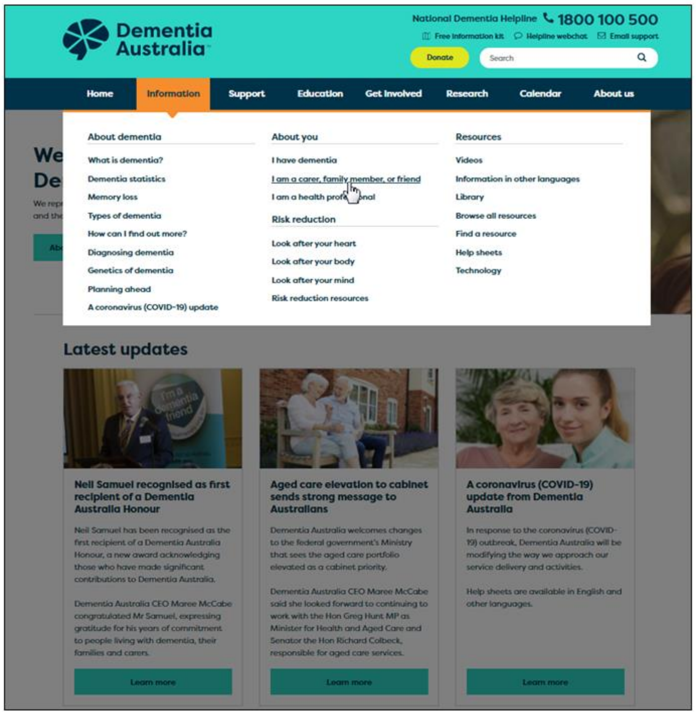

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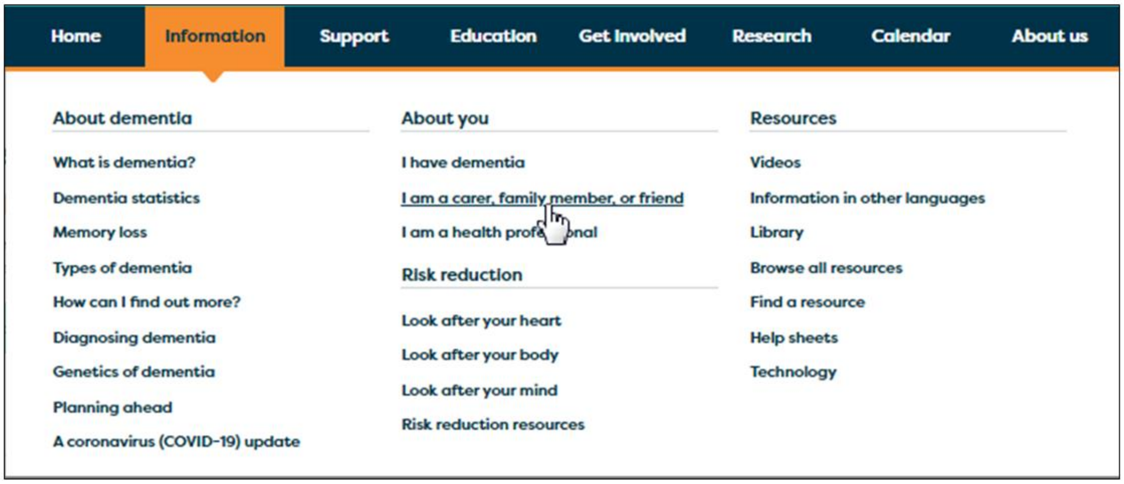

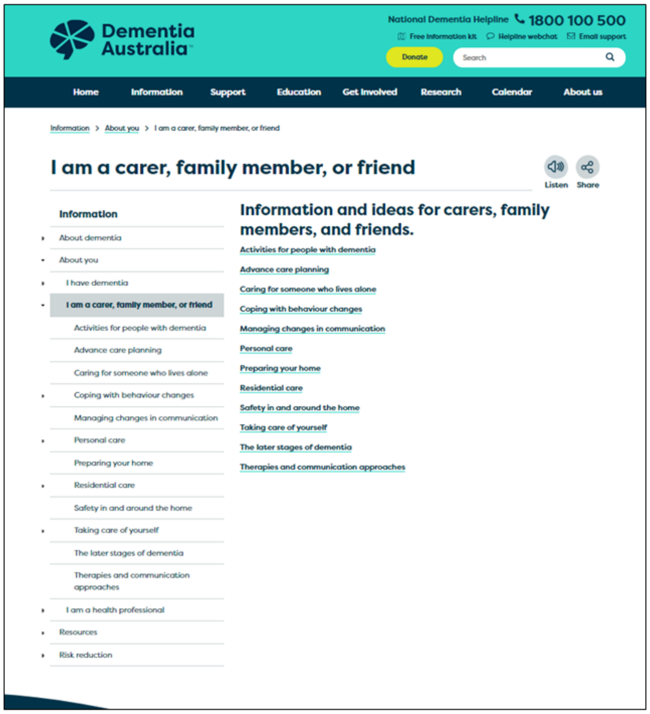

I am a carer, family member, or friend

Information and ideas for carers, family members, and friends.

Activities for people with dementia

Advance care planning

Caring for someone who lives alone

Coping with behaviour changes

Managing changes in communication

Personal care

Preparing your home

Residential care

Safety in and around the home

Taking care of yourself

The later stages of dementia

Therapies and communication approaches

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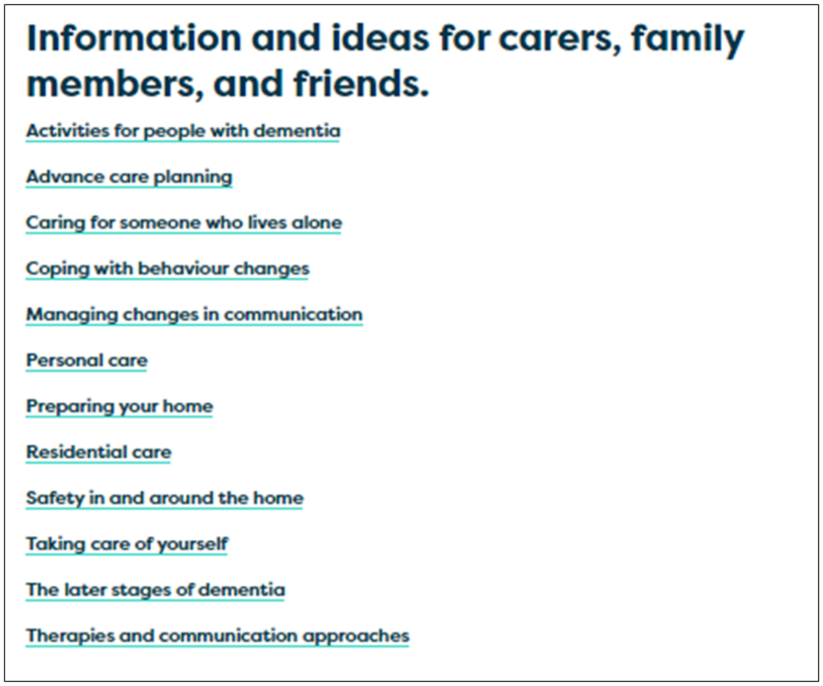

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Conclusion

NARRATIVE
RESEARCH

Thank you!