

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

Executive Summary

Prepared for Health Canada and the Public Health Agency of Canada

Prepared by Narrative Research
PSPC Contract Number: 6D016-203943/001/CY
Contracted Value: \$108,835.95
Contract Date: December 8, 2020
Delivery Date: March 2021
POR number: 078-20

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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).