



Public Health
Agency of Canada

Agence de la santé
publique du Canada

Understanding Canadians' attitudes and knowledge to promote safe and supportive dementia-inclusive communities

Executive Summary

Prepared for The Public Health Agency of Canada

Supplier name: Earnscliffe Strategy Group

Contract number: CW2273819

Contract value: \$216,770.95

Award date: February 17, 2023

Delivery date: August 28, 2023

Registration number: POR # 133-22

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Canada

Understanding Canadians' attitudes and knowledge to promote safe and supportive dementia-inclusive communities

Prepared for The Public Health Agency of Canada

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August 2023

This public opinion research report presents the results of focus groups and an online survey, conducted by Earnscliffe Strategy Group on behalf of The Public Health Agency of Canada. The qualitative research was conducted in April 2023 and the quantitative research was conducted from March to May 2023.

Cette publication est aussi disponible en français sous le titre : Comprendre les attitudes et les connaissances des Canadiens pour promouvoir des collectivités inclusives à l'égard des personnes atteintes de démence qui sont sécuritaires et solidaires

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Catalogue Number: H14-458/2023E-PDF

International Standard Book Number (ISBN): 978-0-660-68022-4

Related publications (registration number: POR 133-22)

Comprendre les attitudes et les connaissances des Canadiens pour promouvoir des collectivités inclusives à l'égard des personnes atteintes de démence qui sont sécuritaires et solidaires (Final Report, French) ISBN 978-0-660-68023-1

Executive summary

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to the Public Health Agency of Canada (PHAC) summarizing the results of a two-phased qualitative and quantitative research project exploring Canadians’ attitudes and knowledge in promoting safe and supportive dementia-inclusive communities.

Released in 2019 and required under the *National Strategy for Alzheimer’s Disease and Other Dementias Act*, Canada’s national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, supports the vision of a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated. The strategy identifies three national objectives: prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers.

The national dementia strategy recognizes the importance of creating dementia-inclusive communities across Canada that maximize quality of life while being supportive, safe, and inclusive for people living with dementia and their caregivers. In dementia-inclusive communities the participation and contribution of people living with dementia is encouraged, supported, and valued. As well, the care and support provided within the community is culturally safe, culturally appropriate, and mindful of diversity. These communities also help to reduce and eliminate barriers, including those resulting from stigma that can lead to social isolation.

This research will assist in supporting the development and implementation of Canada’s first national dementia strategy, *A Dementia Strategy for Canada: Together we Aspire*. Understanding attitudes, knowledge, and experiences related to dementia-inclusive communities in Canada is critical for government and departmental priorities on dementia by informing efforts and prioritizing options for investments intended to support healthy aging and quality of life through such communities. This research will also deepen understanding of the infrastructure, physical and social environments, and programs and policies available to support dementia-inclusive communities.

The primary objective of this research is to provide the Government of Canada with insights into Canadians’ attitudes, knowledge and experiences related to dementia-inclusive communities. The contract value for this project was \$216,770.95 including HST.

To meet the objectives of the research, Earnscliffe conducted a two-phased qualitative and quantitative research approach.

The first phase of the research was qualitative and involved sixteen (16) online focus groups between April 3-5, 2023 (using the Discussion Guide found in Appendix C). Four focus groups (segmented by region, across Canada, including one group in each region in communities with older populations) took place with each of the four target employment industries (i.e., retail and food services; transportation and public safety; recreation, fitness, community and religious organizations; and financial services – each of which have been identified as professions likely to have encountered people living with dementia now or in the future). Information about the

interview design, methodology, and sampling approach has been provided in the Qualitative Methodology Report in Appendix A.

The second phase of research was quantitative and involved a survey, conducted online or by telephone according to the respondent’s preference in English or in French, of 6,049 Canadian adults between April 21st and May 24th, 2023. The survey took an average of 10 minutes to complete online and 20 minutes to complete on the telephone. The robust sample size was used to obtain sufficient completed surveys across multiple target audiences (i.e., specific industry sectors, ethnic and cultural minorities, unpaid caregivers and those who identify as 2SLGBTQI+). A full description of the sample frame, data cleaning process, and weighting are outlined in the Quantitative Methodology Report (Appendix E) and the questionnaire has been provided in Appendix E. Since a sample drawn from an Internet panel is non-probabilistic in nature, the margin of error cannot be calculated for this survey.

It is important to note that qualitative research is a valid form of scientific, social, policy, and public opinion research. However, focus group research is not designed to help a group reach a consensus or to make decisions, but rather to elicit the full range of ideas, attitudes, experiences and opinions of a selected sample of participants on a defined topic, as was done in this research. Because of the small numbers involved the participants cannot be expected to be thoroughly representative in a statistical sense of the larger population from which they are drawn and findings cannot reliably be generalized beyond their number.

The key findings of this research are presented below. Please note a glossary of terms can be found in the Qualitative Methodology Report in Appendix A that explains the generalizations and interpretations of qualitative terms used throughout the report.

Personal experience, general understanding, and perceptions of dementia

- A strong majority of survey respondents (63%) say they know a person that is living/lived with dementia; most commonly an extended family member (32%) or a parent (19%).
- Nearly one-third (32%) of survey respondents have been an unpaid caregiver of a person living with dementia in the past 5 years, and assisting with errands is the most common task done by unpaid caregivers.
- The majority of participants in the focus groups knew someone who is currently or has lived with dementia and few have acted as unpaid caregiver.
- The most common experiences related to dementia-inclusive communities faced by survey respondents who have provided unpaid care while they were with the person with dementia is having people talk to them instead of the person living with dementia (42%) and encountering people who focus on what the person with dementia cannot do rather than what they can (40%).
- Over one-third (37%) of survey respondents who are or have been an unpaid caregiver say they have not experienced any challenges when accessing/using dementia recommendations or advice compared to 54% who have experienced challenges. In terms of those challenges, one in five say that the advice was too complicated (20%), too expensive (19%) or did not reflect important cultural context (19%).

- More survey respondents rate their knowledge of dementia as one or two (27%) (on a five-point knowledge scale, where one is 'not at all knowledgeable' and five is 'very knowledgeable'; than a four or five (22%). The remaining respondents (49%) say their knowledge of dementia is 'moderate' (a rating of three).
- Almost all focus group participants were aware of the term dementia. When asked to define dementia, many used medical descriptions or symptoms, but there were also many who used terms that described the tragic loss feared or felt by the person living with dementia or the impact of the illness.
- Nearly half (49%) of survey respondents believe that dementia is having a large or very large impact in Canada today, while one-third (33%) say it is having a moderate impact. Fewer (8%) believe dementia is having little or no impact in Canada today.
- A majority of survey respondents agree or strongly agree that people living with dementia are sometimes able to continue being active in their communities (70%), live in their own homes (68%) and continue to work (50%) for years following their diagnosis.
- A strong majority of survey respondents agree or strongly agree that people living with dementia generally face a lower quality of life than people without dementia (68%).
- The quality of life for persons living with dementia was rarely described in positive terms among focus group participants. Participants spoke of a life of mild frustration, confusion, or limitation, and a life where a person may need to live a very controlled life.
- In addition to a perceived diminished quality of life for the person living with dementia, many focus group participants questioned the feasibility of accommodating people living with dementia in the workplace and in their communities.
- When asked about interacting with someone living with dementia, a similar proportion of survey respondents say they are comfortable or very comfortable (41%) or moderately comfortable (39%), while 13% say they are not comfortable.
- When asked to select what they believe to be recommended tips on how to communicate with people living with dementia, many select non-recommended approaches such as physical contact (e.g., hand shakes) (46%) and providing plenty of information (40%).
- Few focus group participants were able to offer, on an unaided basis, any recommendations for interacting with people living with dementia. Once shown a list of recommendations provided by PHAC, most felt these tips were intuitive and helpful, and expressed gratitude for seeing them.

Interactions with people living with dementia in workplace or volunteer settings

- A majority of survey respondents (69%) say that they believe they have never had a role in which they have interacted or may have needed to interact with people living with dementia. However, almost one in ten say that they used to work (9%) or volunteer (8%), and fewer say that they currently work (6%) or volunteer (4%) in such a role.

- Among those who do or may have had a role that may have required them to interact with people living with dementia, nearly half (49%) did/do more than weekly, 30% did/do a few times a month to weekly, and 18% did/do so once a month or less.
- Over half (57%) of survey respondents who have experience interacting with people living with dementia did so in the healthcare field. Fewer do/did in retail and food services (16%), recreation, fitness, community and religious organizations (14%), transportation and public safety (8%), or financial services (6%).
- Mirroring qualitative findings, the most common issues faced by clients or customers that survey respondents felt were related to dementia are confusion (73%) and issues with communication (65%).
- Some focus group participants noted that the behaviours or symptoms they would associate with dementia would depend on the stage of dementia, and others were not confident they know the barriers and challenges a person living with dementia might experience.

Workplace and volunteer setting measures and training to support clients living with dementia

- Roughly half of survey respondents who currently have a work (53%) or volunteer (50%) role or who had a work role (51%) that required them to interact with people living with dementia say their organization provided relevant training; fewer who used to have a volunteer role say the same of their organization (40%).
- Among survey respondents who are from organizations that provide this type of training, the majority (68%) say that they have personally received training on how to interact with people living with dementia.
- General knowledge (78%), communication/interaction tips (72%) and instructions on how to assist those who are confused/lost (66%) are all common topics of training received by survey respondents.
- Within the focus groups, when asked about the training in place for employees at their organizations to assist in recognizing and supporting people who may be living with dementia, the majority of focus group participants said there is none.
- Among those who have/had a work or volunteer role that required them to interact with people living with dementia, nearly half of survey respondents (45%) agree their organization provides/provided enough training for proper interaction with people living with dementia.
- Many focus group participants felt that education or training on how to interact with people living with dementia, and disabilities more broadly, would be of value.
- Approximately half of survey respondents (between 49% and 54%) who have/had a work or volunteer role that required them to interact with people living with dementia say their organization has/had measures or policies specifically to ensure positive and helpful interactions with people living with dementia.
- When asked what they would do if they encountered someone visiting their workplace as a client or customer who appeared to be searching, wandering, or confused, most focus group

participants indicated that they would approach the situation with care and would approach the individual to see how they could assist them.

- Over one-fifth of survey respondents (22%) say that their organization takes/took steps to make online interactions more accessible for those with cognitive impairment, while almost half (47%) say they do/did not.

Efforts to support healthy aging and dementia-inclusive communities

- Over one-third of survey respondents (36%) would give their community a good rating as a place that supports healthy aging, while a slightly fewer (29%) would rate it as neither good nor poor.
- Among those who gave their community a positive rating, the most common reason is due to the activities available (37%). Fewer survey respondents (20%) would say their community is geared towards supporting older individuals. The most common reason for a negative rating is due a lack of resources and supports (51%).
- Among the focus group participants, virtually none felt their community was well-suited for people living with dementia and some balked at the notion that was even plausible. The most common reasons were lack of safety due to natural neighbourhood features (busy streets), outdoor characteristic (wooded areas and waterways), and in some cases, crime.
- The vast majority (75%) of survey respondents say they have not heard of the concept of dementia-inclusive communities, while 17% say they have.
- Very few focus groups participants claimed or demonstrated awareness of the term “dementia-inclusive community”. Assumptions that were made about the term almost always meant something more akin to a long-term care community tailored to serve residents who were living with dementia.
- The majority of survey respondents (54%) believe it is a high priority for their community to become more dementia-inclusive, while 30% would classify the priority as “moderate.” A handful (7%) do not believe it is a priority.
- While several were unsure of the feasibility for their community to become more dementia-inclusive, the majority of focus group participants felt it was important.
- Most survey respondents (82%) are not sure if their community has a guide or plan in place to be more dementia-inclusive; 13% say it does not, while 5% say it does.
- A strong majority of survey respondents (66%) are unable to/do not name any measures a dementia-inclusive community might provide on an unaided basis. The same was found for focus group participants.
- Among the dementia-inclusive measures included in the questionnaire, one-third or more say that their community has inclusive crosswalks (37%), well-maintained pathways (34%) and easily recognizable transit signs (33%).
- Over two in five (41%) survey respondents say they are unsure if their community offers any of the dementia-inclusive activities included in the questionnaire, though a similar proportion (37%) say their community centre provides dementia-inclusive activities.

- A handful of responses offered by focus group participants as activities in place within their community to support the inclusion of people living with dementia were the Alzheimer’s Society, long-term care facilities, seniors’ groups, community centres, and home and community support services, though awareness of these types of activities was generally low.

Research firm: Earncliffe Strategy Group (Earncliffe)
Contract number: CW2273819
Contract value: \$216,770.95
Contract award date: February 17, 2023

I hereby certify as a representative of Earncliffe Strategy Group that the final deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Communications Policy of the Government of Canada and Procedures for Planning and Contracting Public Opinion Research. 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:

Date: August 28, 2023



Stephanie Constable