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Dementia Guidance and Indigenous Populations in Canada

Summary

Prepared for Public Health Agency of Canada

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Canada 

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This public opinion research report presents the results of an online survey conducted by EKOS Research Associates Inc. on behalf of the Public Health Agency of Canada. The research study was conducted between April 7 and June 21, 2021 with 1,008 Indigenous respondents or Non-Indigenous respondents who have provided care to an Indigenous person living with dementia.

Cette publication est aussi disponible en français sous le titre : *Conseils en matière de démence et populations autochtones au Canada*.

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EXECUTIVE SUMMARY

A. BACKGROUND AND OBJECTIVES

Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, released in June 2019, 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 strategy also identifies that Indigenous Peoples are a population at higher risk of developing dementia and may face barriers to diagnosis and care. Higher incidence of chronic conditions that are risk factors to dementia are prevalent in the Indigenous population¹. Although dementia research in Indigenous populations is limited, some findings document a higher incidence of dementia among First Nations populations².

The primary objective of the research is to gather Indigenous perspectives on dementia guidance, including guidelines and best practices on prevention, diagnosis, treatment and management, stigma reduction, creating dementia inclusive communities, and emergency preparedness and response. Gathering Indigenous perspectives and experiences with dementia guidance is essential to move closer towards ensuring dementia guidance is culturally appropriate and culturally safe and reflects the distinctiveness across Indigenous Peoples, including geographic and other differences, as well as varying barriers and challenges

This research is intended to inform PHAC programs and initiatives, along with supporting information needs of others working on guidance. Results will also support annual reporting on the national dementia strategy to Parliament as required by the *National Strategy for Alzheimer's Disease and Other Dementias Act*.

¹ National Collaborating Centre for Aboriginal Health. *Alzheimer's Disease and Related Dementias in Indigenous populations in Canada: Prevalence and Risk Factors*. 2018.

² Jacklin K, Walker J, Shawande M. The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. *Canadian Journal of Public Health*. 2013.

B. METHODOLOGY

The survey is comprised of 1,008 completed cases of respondents, 18 years of age and older, including 111 paid care providers that have cared for an Indigenous person living with dementia in the last 10 years. These paid care providers may or may not be Indigenous themselves. Another 176 are unpaid care providers, defined as someone who provides unpaid care and support to an Indigenous person living with dementia, within the last 10 years. These unpaid care providers may or may not be Indigenous themselves. There is also a small sample of 28 individuals who reported themselves to be an Indigenous person living with dementia. The remaining 693 are Indigenous respondents who have identified themselves as not living with dementia and have not cared for an Indigenous person living with dementia in a paid or unpaid capacity in the last 10 years. This segment of respondents is referred to as Indigenous Peoples (Other) throughout the report.

The survey sample was drawn from multiple sources, including from the *Probit* panel, which is assembled using a random digit dial (RDD) process for sampling from a blended land-line cell-phone frame, which provides full coverage of Canadians with telephone access. The distribution of the recruitment process is meant to mirror the actual population in Canada (as defined by Statistics Canada). As such, our more than 120,000-member panel can be considered representative of the general public in Canada (meaning that the incidence of a given target population within our panel very closely resembles the public at large) and margins of error can be applied. We also relied on RDD of land and cell phones associated with geographic areas that include First Nation reserve communities. Respondents who had previously completed a survey of the general public in the spring of 2020, also participated if they were providing paid or unpaid care to an Indigenous person living with dementia. Further, a subset of respondents to a survey of dementia care providers, conducted in February-March 2021, also participated if they were providing care to an Indigenous person living with dementia. A small number of records were also completed as a result of referrals from other respondents within the sample.

The majority of the sample (76%) was collected by telephone, although 245 cases were completed online and mostly concentrated among those who are not individuals living with dementia. The interview length averaged 15 minutes online and 23 minutes by telephone. Cases were collected between April 7 and June 21, 2021, following extensive testing online and by telephone, in both English and French³. The rate of participation was 11% (14% online and 10%

³ Interviews were not offered in Indigenous languages, therefore 212 individuals contacted were unable to participate in the survey. This was more concentrated in Nunavut and Northern Quebec than elsewhere in the country.

by telephone). Details on the rate of participation can be found in Appendix A and the questionnaire is provided in Appendix B.

This randomly recruited probability sample carries with it a margin of error of +/-3.1%. The margin of error for most target groups is between 5% and 10%. Results for those Indigenous respondents who are not living with dementia and have not provided paid or unpaid care to someone with dementia (i.e., “Indigenous Peoples (Other)”) have been weighted to Indigenous population proportions for region, age, and Indigenous identity groupings (i.e., First Nations, Métis, Inuit). Chi-square tests were used to compare subgroups to the remaining sample. Where there was a sizable degree of association between sub-groups, multivariate analysis was used to further explore which independent variable (i.e., sub-group) was most likely the strongest association and possible explanation for other associations. For scaled items linear regression was used and where the responses were not linear (i.e., response categories), logistic regression was used.

C. KEY FINDINGS

Most Indigenous Peoples (Other)⁴ in the survey know someone who is living with or has lived with dementia (66%); only 30% do not. Among this group, 42% said that they know an extended family member with dementia. Fewer said they know a friend, neighbour or colleague (19%), a community member (14%), Elder or Knowledge Keeper (12%) or parent (11%) living with dementia.

Survey respondents rated their knowledge regarding a variety of dementia topics, such as signs and symptoms, prevention, and dementia inclusive communities, on a 5-point scale, from not at all knowledgeable to very knowledgeable. Those who are paid to provide care to Indigenous Peoples living with dementia (i.e., paid care providers) tended to report higher knowledge on dementia topics than unpaid care providers. Those respondents who are Indigenous Peoples not living with dementia or providing paid or unpaid dementia care (i.e., Indigenous Peoples (Other)) self-reported the lowest levels of knowledge. Over three-quarters (77%) of paid care providers said they are moderately or very knowledgeable about the signs and symptoms of dementia. Over half of paid care providers said they are moderately or very knowledgeable of the ways to reduce the risk of developing dementia (54%) and how to make a community more welcoming and supportive of people living with dementia (52%). Over half (52%) of those respondents who are providing care to Indigenous Peoples living with dementia in an unpaid capacity (i.e., unpaid

⁴ Indigenous respondents who are not living with dementia, nor providing paid or unpaid care or support to a person living with dementia.

care providers) said they are moderately or very knowledgeable of the signs and symptoms of dementia. Nearly one-third (32%) of unpaid care providers felt knowledgeable about how to make the community more welcoming and supportive of people living with dementia and over one-quarter (28%) of unpaid care providers reported that they are moderately or very knowledgeable about the ways to reduce the risk of developing dementia. Among the Indigenous Peoples (Other) group, only about one-quarter (26%) felt moderately or very knowledgeable about the signs and symptoms of dementia. Fewer reported they were moderately or very knowledgeable about how to make a community more welcoming and supportive of people living with dementia (19%) or the ways to reduce the risk of developing dementia (14%).

Paid care providers are more likely than both the unpaid care providers and the Indigenous Peoples (Other) respondent groups to have selected harmful alcohol use (39%) more often as a key factor for an increased risk of developing dementia. The next most commonly identified factors, reported by all three respondent groups, are a diet lacking in healthy foods, lack of physical activity, and loneliness and social isolation.

Over half (59%) of unpaid care providers said they have taken steps to reduce their own risk of developing dementia, while two-thirds (66%) of paid care providers have done so. Only 39% of respondents within the Indigenous Peoples (Other) group said that they have taken steps to reduce their risk. The strongest barrier to reducing risk reported by unpaid care providers and Indigenous Peoples (Other) is a lack of awareness of what steps to take.

Paid care providers are less likely than unpaid care providers or the respondents from the Indigenous Peoples (Other) group to worry about the possibility of personally developing dementia (38%, compared to 56% and 50% respectively). Respondents were more concerned about someone close to them developing dementia than their own personal risk (55% of paid care providers, 68% of unpaid, and 67% of the general population).

Care provider respondents, including 70% of unpaid- and 69% of paid-, demonstrated a stronger preference than the general population for printed material such as brochures and pamphlets when looking for health recommendations or advice. Among Indigenous Peoples (Other), most indicated online resources as their preferred format (70%, compared to 57% of unpaid care providers and 62% of paid care providers).

Most paid care providers (77%) said they have used guidance on treatment and management of dementia. Half or more have used guidance on prevention (56%) or screening and diagnosis (50%). Overall, paid care providers would use primarily the websites of advocacy organizations (74%) for dementia guidance available online, followed by health care expert websites (68%)

when looking for dementia guidance and recommendations. About half of paid care providers said they would be moderately or very likely to seek information online from the federal or provincial governments, or from regional or local Indigenous health authority websites. This is also the case for about four in ten unpaid care providers and the Indigenous Peoples (Other) group.

One-third of Indigenous Peoples (Other) living with dementia (32%) said they found or received dementia recommendations or advice. This respondent group indicated a need for dementia-related recommendations or advice on the different types of dementia, pharmacological and non-pharmacological treatments and therapies, and supports and services for people living with dementia.

Unpaid care provider respondents identified the strongest need for recommendations and advice on day-to-day care for people living with dementia (76%). About two-thirds reported the need for advice on screening and diagnosis of dementia (69%), ways to reduce the risk of developing dementia (68%), transitions in care (65%), or dementia-inclusive communities and negative stereotypes (64%).

About seven in ten paid care providers reported gaps or barriers in dementia guidance on the treatment and management of dementia (70%), how to make interactions feel safe and more supportive (69%), ways to reduce the risk of developing dementia (68%), or transitions in care (68%).

Less than half (47%) of paid care providers felt that the dementia guidance and related tools they use to provide care and support to Indigenous Peoples living with dementia are culturally appropriate and culturally safe. There is a strong consensus among paid and unpaid care providers as well as respondents in the Indigenous Peoples (Other) group that the development of dementia guidance should involve Indigenous communities and Elders in order to be culturally appropriate, and that training for care providers should be specific to Indigenous Peoples. Specifically, 81% of unpaid care providers, 79% of paid care providers, and 75% of respondents in the Indigenous Peoples (Other) group felt that in order to ensure that recommendations or advice about dementia are culturally appropriate and culturally safe for Indigenous Peoples, training for care providers should be specific to Indigenous Peoples living with dementia. Most respondents also felt that it is important to involve Indigenous Peoples in the development of recommendations or advice to ensure the material is culturally appropriate and safe for Indigenous populations (84% of paid care providers, 82% of the Indigenous Peoples (Other) group and 79% of unpaid care providers). About three-quarters said that material should involve

Indigenous Elders, Healers, and Knowledge Keepers (79% of paid care providers, 77% of respondents in the Indigenous Peoples (Other) group and 75% among unpaid care providers).

D. NOTE TO READERS

Detailed findings are presented in the sections that follow. Overall results are presented in the main portion of the narrative and are typically supported by graphic or tabular presentation of results. Results are presented separately for each of the four types of respondents:

- Indigenous Peoples living with dementia – caution should be used in interpreting the findings because of relatively small sample size; (n=28);
- Paid care providers – Indigenous and non-Indigenous individuals providing paid care to an Indigenous person living with dementia;
- Unpaid care providers – Indigenous and non-Indigenous individuals providing unpaid care to an Indigenous person living with dementia; and,
- Indigenous Peoples (Other)⁵ – Indigenous respondents (including First Nations, Métis, Inuit and those who identified otherwise as Indigenous)⁶ who are not living with dementia, nor providing paid or unpaid care to Indigenous Peoples living with dementia.

It should be noted that results are presented separately for each respondent group⁷ in the charts, tables and introductory text. Results for the proportion of respondents in the sample who either said “don’t know” or did not provide a response (i.e., DK/NR) may not be indicated in the graphic representation of the results in all cases, particularly where they are not sizable (e.g., 10% or less). Results may also not total to 100% due to rounding. Some questions invited respondents to indicate “other” and provide their own response. In some cases, these “other” responses were coded into existing response categories or new categories were added. In the case of the latter, these are indicated in the chart or table through the use of “(unprompted)” following the new category label.

⁵ Note using this title throughout the report to distinguish these respondents from the other three groups.

⁶ 19 Indigenous respondents did not specify or indicate identifying with two Indigenous populations.

⁷ Where relevant (i.e., to the extent that each was asked specific survey items).

Bulleted text presented below charts and/or tables is also used to point out any statistically and substantively significant differences between regional and demographic sub-groups of respondents. Regional and demographic sub-groups results are pooled for all respondents, across the four respondent types. Sub-groups include:

- Three separate Indigenous identity groups (First Nations, Métis and Inuit) among the 88% of respondents who are Indigenous.
- Results based on region, and urban/rural location⁸;
- Key demographic patterns of interest which are described based on gender, age, education, and sexual orientation. Since education is strongly correlated with type of respondent, with paid and unpaid care providers reporting higher levels of education than the other two respondent groups, results are only described for education where they do not seem to be explained by other differences among the main respondent groups.

Only differences that are statistically and substantively different (e.g., five percentage points from the overall mean) are presented, where there are at least 10 responses in a given cell.

Details of the methodology and sample characteristics can be found in Appendix A. The programmed survey instrument can be found in Appendix B.

E. CONTRACT VALUE

The contract value for the POR project is \$99,980.65 (including HST).

Supplier Name: EKOS Research Associates

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To obtain more information on this study, please e-mail hc.cpab.por-rop.dgcap.sc@canada.ca.

⁸ Respondents were assumed to live in urban settings unless the second digit of the postal code is 0, indicating a rural or remote location, or First Nation respondents who said they live on a reserve for at least six months of the year.

F. POLITICAL NEUTRALITY CERTIFICATION

I hereby certify as Senior Officer of EKOS Research Associates Inc. that the 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 by:



Susan Galley (Vice President)