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Qualitative Research on Dementia Awareness, Knowledge, and Behaviours for Public Education Campaigns Executive Summary

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March 2020

This public opinion research report presents the results of focus groups conducted by Earnscliffe Strategy Group on behalf of Health Canada. The research was conducted in March 2020.

Cette publication est aussi disponible en français sous le titre : Recherche qualitative sur la sensibilisation, la connaissance et les comportements liés à la démence pour les campagnes de sensibilisation du public.

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EXECUTIVE SUMMARY

Earnscliffe Strategy Group (Earnscliffe) is pleased to present this report to Health Canada summarizing the results of focus group research into dementia awareness, knowledge, and behaviours to inform development of public education campaigns.

The Public Health Agency of Canada (PHAC) has developed, and is now implementing, Canada's first national dementia strategy with the overall objectives to prevent dementia, advanced therapies and find a cure, and improve the quality of life of people living with dementia and caregivers. Health Canada and PHAC will be leading a multi-faceted approach to dementia public education to provide multiple segments of the Canadian population with clear, consistent and evidence-informed information about dementia. As such, Health Canada set out to gather evidence-based data and insights to inform and guide the public education strategy and marketing outreach initiatives to educate Canadians about dementia, encourage the uptake of preventative actions, and to reduce stigmatizing behaviours. Findings will also inform policy requirements.

The objectives of the research were to assess Canadians' awareness, knowledge, attitudes, and behaviours about dementia, risks and preventative measures, and stigma associated with dementia. The contract value for this project was \$209,961.63 including HST.

To meet these objectives, Earnscliffe conducted a comprehensive wave of qualitative research. The research included a series of thirty focus groups across five cities: Toronto (March 2-4), Charlottetown (March 3-5), Vancouver (March 5-7), Montreal (March 9-11), and Red Deer (March 9-11). In each city, separate groups were held, each consisting of six target audiences: those aged 18-24, 25-34, 35-64, 65 and older; those who are informal caregivers for someone living with dementia; and, those who have at least one of four health conditions that put them at higher risk of developing dementia: (hypertension, high cholesterol, obesity [if 45-65 years old], or diabetes [if 65 and older]). Groups in Montreal were conducted in French; in all other locations, they were conducted in English. The sessions were approximately two hours in length.

It is important to note that qualitative research is a form of scientific, social, policy, and public opinion research. 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. 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 from the research are presented below.

- Most participants indicated that they think about aging at least sometimes, but what it is that they think about varies widely and often by life stage or circumstances. Younger participants tended to think about aging in the context of their career path, finances, settling down/having a family, losing their youthful appearance, or their aging relatives. Older participants seemed to think more about aging in the context of their own personal health, although many (mostly those 65 and older) suggested that they deliberately try not to think about aging.

- When asked to reflect on the single most concerning health issue, the resulting list of illnesses was short, although tendencies to focus on specific issues did appear to vary by audience. Cancer was among the most frequently mentioned illnesses and common across all audiences. Dementia and/or Alzheimer’s disease was raised often in most groups, and especially among middle-aged or older participants, as well as informal caregivers. Regardless of whether they had any experience witnessing dementia or if they had written dementia down as their health issue of greatest concern, virtually all agreed that dementia was a serious illness and usually at least as serious as the one they did write down.
- Almost all were aware of dementia and/or Alzheimer’s disease, although levels of knowledge and understanding of these illnesses were quite diverse. For example, younger participants seemed to have more limited knowledge as compared to those over 65. Not surprisingly, those caring for someone living with dementia tended to be a little more knowledgeable, including younger participants of this audience. In many groups, there were a few people with fairly extensive knowledge, though no one described themselves as experts.
- When asked what it was about dementia or Alzheimer’s disease that was of specific concern, most participants generally spoke of their perception (and fear) of loss: losing one’s mind, losing oneself, losing connections, losing control, and losing a sense of reality. However, many spoke of it being an illness that was much more difficult for loved ones rather than for the person suffering with dementia or Alzheimer’s.
- In most groups, participants could easily offer up a list of signs and symptoms of dementia. The signs and symptoms that came up most often included: forgetfulness, memory loss, confusion, inability to recognize loved ones, believing they were in a different time/era, being repetitive, and for some, aggression. Some caregivers went further suggesting loss of motor skills and the inability to complete day-to-day tasks such as dressing or using a restroom.
- Participants in every group recognized that there were challenges associated with dementia for both those living with dementia and those caring for someone living with dementia. The challenges for those living with dementia often included a declining ability to think clearly, be understood, and to live independently. The challenges for those caring for someone living with dementia included the need to ensure their safety, to provide support for day-to-day tasks such as cooking, shopping, cleaning, transportation, and, for those in more advanced stages of dementia, personal support like dressing and hygiene.
- Participants offered a mix of opinions when asked how they felt people living with dementia are affected by these challenges. It was often the case that participants in one group or another offered that how dementia affects those suffering with the disease depends on the person’s stage of dementia.
- The overwhelming majority of participants felt that the most important risk factor that would make someone more likely to develop dementia was genetics and a family predisposition to the illness. In fact, when asked to guess the likelihood of being diagnosed with dementia in their lifetimes, participants invariably reflected on their family history with the illness and the proximity of family members who are living/have lived with dementia. Interestingly, this also included those at a higher risk of developing dementia who invariably linked their probability of developing dementia to family

history and not their current health condition. Beyond genetics, other possible risk factors that were raised spontaneously included head injuries, stroke, stress, isolation or inactivity (both mental and physical).

- Provided with a list of eighteen possible risk factors of dementia, participants consistently identified some far more often than others. The most commonly identified risk factors were often described as being interrelated and included stress, social isolation, anxiety, depression, lack of sleep, harmful alcohol consumption, lack of physical activity, poor diet and schizophrenia.
- Although some said they believe (or hope) dementia is preventable, most participants were reluctant to say they felt it was truly preventable; no one felt it was curable. There were several behaviours that participants in most groups raised to help prevent or prolong onset of the disease, such as keeping the brain active (i.e., doing crosswords, puzzles, sudoku, etc.), maintaining good health by eating well and exercising, and engaging socially.
- Provided with a second list of healthy lifestyle behaviours, the behaviours that were more widely acknowledged as beneficial were consistent with the suggestions offered spontaneously or linked to the risks identified earlier, such as doing regular exercise, socializing, eating healthy foods, doing puzzles, reading, or limiting alcohol consumption. For the most part, most indicated that they try to incorporate a number of these behaviours into their lifestyles currently (i.e., exercise, healthy eating, limiting alcohol consumption). Those more familiar with dementia often spoke of having read that learning a new language, speaking two languages, or playing a musical instrument were uniquely beneficial. When asked what additional behaviours they thought they could add to their lives, there was a sense that adding things like yoga and meditation would be relatively easy to incorporate.
- Most wanted to think that society was empathetic and compassionate towards people living with dementia, but there seemed to be a sense that treatment was very much dependent on the setting and individual. This was consistent whether reflecting on the treatment of people living with dementia by a close friend, family member, health care provider, or other service provider. Some were aware of examples of excellent care while others were aware of examples of consistently poor treatment as well.
- In terms of their needs and the barriers they face, it was widely expected that people living with dementia need a lot of support, assistance, and facilities in order to live well in their communities and, in every group, the tendency was to feel there was a lack of each in the community. Participants often pointed out that people living with dementia, and particularly those with more advanced stages of dementia, face a lot of barriers to living well in their communities. The barriers included addressing some of the challenges mentioned earlier such as assistance with personal hygiene, transportation, shopping, and monitoring; as well as, broader challenges such as addressing a weak health care system (raised more often in Montreal) and the lack of health care facilities and support for those who care for people living with dementia.
- Participants were shown five creative concepts that combined text with either illustrations or photography and were asked to rank them according to their preferences. Regardless of the specific concept, participants felt that the tone was appropriate and that the information was credible.

- All of the concepts received both positive and negative reactions and were preferred by different people (within and across groups) for different reasons, which suggests that there is not necessarily a one-size-fits-all campaign. In terms of preferences for each concept, Concept #3 (Statistic) was the preferred concept (figured in the Top 3) for those 18-24, 25-34 and 35-64. Those 65 and older and at higher risk of developing dementia preferred Concept #5 (Labyrinth), while informal caregivers preferred Concept #4 (Reflection).
- Almost all participants felt they would confide in someone if they had concerns they were starting to show symptoms of dementia. The person in whom they would confide often was related to their life stage. For example, older participants tended to say they would confide in their spouse and possibly their adult children. Those who were middle-aged tended to say they would confide in their spouse, sibling, friend or possibly parent. Younger participants tended to say they would confide in their parents or in the context of them being older if/when impacted by this illness, their spouse.
- In terms of advice, the majority would consult their doctor initially, at the very least to confirm what they were sensing. Interestingly, some felt they might initially consult their doctors before confiding in anyone, especially family, so as not to worry anyone unnecessarily.
- If diagnosed, most, but not all, felt there was someone they would tell. Typically, it was the same person in whom they would confide their fears of showing symptoms.
- Virtually all said they would seek out information about dementia either from their doctors or on the Internet. Internet sources that most would trust for medical information included: medical websites and journals (e.g., WebMD, The Mayo Clinic); expert organizations such as the Alzheimer’s Society and other non-profits/advocates for mental health; government sources (e.g., provincial, federal, other nations) including Health Canada which was more often mentioned unprompted by participants of all ages in Montreal and older audiences (35-64 and 65 and older) in other locations; and, academic sources.

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Signed:



Date: March 31, 2020

Stephanie Constable
Principal, Earnscliffe