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Qualitative Research on Dementia Awareness, Knowledge, and Behaviours for Public Education Campaigns Final Report

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Supplier name: Earnscliffe Strategy Group
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.

Research Firm:

Earnscliffe Strategy Group Inc. (Earnscliffe)
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I hereby certify as a Representative of Earnscliffe 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: March 31, 2020

Stephanie Constable
Principal, Earnscliffe

INTRODUCTION

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 overall objectives of the research were to assess awareness, knowledge, attitudes, and behaviours of the Canadian population about dementia, risks and preventative measures, and stigma associated with dementia. The specific objectives of the research were to:

- Assess general knowledge, attitudes, perceptions, and behaviours towards dementia, including:
 - Knowledge and perception of dementia, including its signs and symptoms;
 - Attitude and perception on the challenges associated with dementia;
 - Perception of risk and protective factors for dementia, risk reduction actions and/or lifestyle behaviours/brain health; and,
 - Attitudes/Perceptions/Behaviours towards taking action to reduce various risks and/or change lifestyle behaviours.

- Assess attitudes, perceptions and behaviours of stigma, including:
 - Perceptions/Attitudes about aging;
 - Perception of the causes of stigma;
 - Perception of people living with dementia;
 - Attitudes/Behaviours/Feelings toward someone living with dementia;
 - Perception on how to best interact with someone who may be living with dementia in the community; and,
 - Beliefs/Perceptions about what is needed to live well with dementia in the community.

- Gather information on how best to inform and communicate with target audiences (such as those identified for this research), including:
 - Preferred and trusted resources to discuss dementia-related concerns;
 - Preferred and trusted sources of information about dementia; and,
 - Determine if the approach and possible messages are meaningful and credible.

The research will be used to inform a multi-faceted approach to dementia public education campaigns.

Research Approach

To meet these objectives, Earncliffe 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 with each 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 conditions or criteria that put them at higher risk of developing dementia (hypertension, high cholesterol, obesity [if 45-65 years old], or diabetes [if 65 and older]).

The groups in Montreal were conducted in French; in all other locations, they were conducted in English. The sessions were approximately two hours in length. Most focus group participants received an honorarium of \$100 as a token of appreciation for their time. Given the lower incidence and demands of their time, informal caregivers received an honorarium of \$125.

The table below depicts the number of participants in each group in each location:

Exhibit 1

Group audience	Toronto	Charlottetown	Vancouver	Montreal	Red Deer	TOTAL
18-24	8	8	7	7	9	39
25-34	8	8	8	9	8	41
35-64	8	8	8	8	10	42
65 and older	7	8	8	8	7	38
Higher risk of developing dementia	8	7	8	8	9	40
Informal caregivers	8	8	8	8	9	41
TOTAL	47	47	47	48	52	241

Appended to this report are the screener, discussion guide, and messages.

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.

DETAILED FINDINGS

This qualitative report is divided into four sections: context, awareness, and understanding; attitudes, perceptions, and behaviours relating to stigma; message testing; and, communications needs.

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.

Except where specifically identified, the findings represent the combined results regardless of audience, location or language (English and French).

Please refer to Appendix A: Methodology Report for a glossary of terms used throughout the report.

Context, Awareness, and Understanding

The focus groups began with an initial warm-up exercise and discussion to gauge participants' awareness and understanding of, as well as, their level of concern related to dementia.

Thoughts on Aging

Initially, participants were asked how often they thought about aging, what they thought about, and the feelings they had when they thought about aging.

Most participants across all audiences indicated that they think about aging at least sometimes. Middle aged participants (35-64) and younger participants (25-34) seemed to be the most preoccupied about aging. Younger participants (18-24) were more preoccupied with aging in the context of their aging parents and relatives. Interestingly, most older participants (65 and older) in all locations said they deliberately try not to think about aging. They talked about aging as being a state of mind and argued they prefer to live in the moment, which in and of itself, implies a certain bias about aging.

"It doesn't cross my mind at all. Life is busy. My wife still works. I'm active. Age is but a number. I don't feel any different." Charlottetown, 65 and older

"I don't think about it very often. It surprises me when I think of my age. I still feel young." Montreal, 65 and older

"I try not to think about aging. Four years ago, I told myself it was time to lose a bit of weight. I did and I feel better now. You have to do what you can to stay healthy." Charlottetown, Informal caregivers

What participants thought about in the context of aging varied widely and often by life stage or circumstance. Younger participants seemed to be thinking about aging as it relates to their career path, finances, settling down/having a family or, for some (more often those who identify as female) losing their youthful appearance. Middle-aged participants, and older participants who were thinking about

aging, were often thinking about it in the context of their own personal health, especially as they reflected on more frequent aches and pains, rather than their stage of life.

Not surprisingly given this context, when asked how they feel about aging, those who tended to be worried about it often conveyed a sense of anxiety. Younger participants were anxious about societal norms and pressure to establish themselves (in the ways mentioned above), whereas middle-aged and older participants were anxious about health concerns related to loss of quality of life (e.g., the ability to do all the activities they enjoy, the loss of mobility, etc.) or family history that suggested there may be a condition awaiting them in their future.

“I think about where I am going to be in terms of my career and how do I achieve my goals for a family, children, lifestyle, etc.” Toronto, 18-24

“I think about aging around my birthday. I feel a bit sad and a little anxious. Mostly I’m sad about my skin [wrinkles], using more sunscreen, getting more sleep. I’m anxious about my financial situation.” Toronto, 25-34

“I think about aging every day. I have more aches. My body is changing.” Montreal, 35-64

“I think about how many more years I’ll be able to work.” Red Deer, 35-64

“My main concern is I don’t have any kids. I will be on my own.” Charlottetown, Higher risk of developing dementia

When thinking about aging relatives or friends, what participants thought about varied by age. The oldest participants often thought in comparative terms and thought of the ones who were struggling with health conditions. The youngest participants were typically thinking of elderly grandparents although some thought of their own parents. They tended to cite noticing that these people were either facing health challenges or were less able to do all the things they enjoyed in the past. Middle-aged participants often talked about aging parents and grandparents and the challenges those people faced, as well as the challenges they faced, personally, caring for them.

Top Health Concern

Participants were tasked with writing down the single most concerning health issue or illness facing society today. It is worth noting that it is difficult to gauge whether the mentions of dementia and/or Alzheimer’s were completely unaided especially as there were two questions asked as part of the screening process that specified dementia. That being said, the response list of health issues and illnesses was rather short, and for the most part included a number of illnesses that one would expect, especially among these audiences.

- Cancer was among the most frequently mentioned illnesses and common across all audiences.
- Dementia and/or Alzheimer’s was raised in most groups, and especially among middle-aged or older participants, as well as informal caregivers. In most locations, participants raised either condition equally; however, in Montreal, Alzheimer’s was raised most often across all audiences. As we will see later in terms of participants’ understanding of these conditions, dementia was perceived to be more of a mental disorder than a neurocognitive disorder; and, not as serious as Alzheimer’s.

- Other degenerative diseases like ALS (or Lou Gehrig’s Disease) and Parkinson’s were also raised quite often by middle-aged and older participants.
- And, finally, heart disease, stroke, and other cardiovascular conditions were raised across a number of groups, but especially among those at higher risk of developing dementia (as these illnesses often relate to conditions they are currently dealing with).

Regardless of whether they had any experience witnessing dementia (or Alzheimer’s) or if they had written either down as the health issue of greatest concern, virtually all agreed that dementia (and Alzheimer’s) was a serious illness and usually at least as serious as the one they did write down. Some younger participants did not think dementia was as serious as cancer in the sense that they perceived dementia as a disease that affects older people, whereas cancer affects people of all ages. And, interestingly, some participants over 65 also felt the same way, arguing that they were not yet able to detect any signs or symptoms and felt they would have displayed some at this point if they were susceptible to it. Among those at higher risk of developing dementia, a few who cited the illness that they face as the top health concern, reasoned that dementia (and Alzheimer’s) could be more serious because they were aware of things they could do to prevent and treat their illnesses but were not aware what one could do to prevent or treat dementia. Perhaps, not surprisingly, a number of caregivers felt that dementia (or Alzheimer’s) was of equal concern to cancer; arguing that one ravages the body while the other ravages the brain.

“Once you’ve seen dementia firsthand, it’s very scary.” Toronto, 18-24

“Dementia is equally as serious. It affects everything.” Charlottetown, 35-64

“It’s terrible. You lose a person twice. First, you lose them to the disease because they forget who you are. Then, you lose them when they actually pass away.” Red Deer, 35-64

“I think dementia is less serious. It’s not in my family and I play a lot of mind games to keep my brain active.” Charlottetown, 65 and older

Awareness and Knowledge of Dementia and Alzheimer’s

However, despite general awareness of the terms (dementia and Alzheimer’s), knowledge of these illnesses, including the differences and/or similarities, seemed to be fairly limited. Younger participants seemed to have more limited knowledge as compared to those over 65. In many groups, and especially the groups among informal caregivers, there were a few participants with fairly extensive knowledge, though no one described themselves as experts.

As evidenced in the previous discussion, many participants used the term Alzheimer’s to describe the condition; dementia was not top of mind. Indeed, when asked, virtually all indicated having a sense that they were connected in some way and assumed the difference was a subtle enough nuance that the terms may be used interchangeably or were interpreted as meaning the same thing.

Upon reflection and in response to probing, most assumed that there must be differences although few were particularly confident (or accurate) in describing those differences. In Montreal, Alzheimer’s was the term used most often to describe this condition whereas the term dementia was often used to describe a state of lunacy or insanity. As we will see later, this perception influenced their thinking on (and the significance of schizophrenia as a) possible risk factors of dementia.

There were, however, some older participants (over 65) and informal caregivers who felt they were more knowledgeable. Among these participants, one common way of describing the difference was to describe dementia as “the umbrella” and Alzheimer’s as falling under that umbrella. Some also felt that Alzheimer’s was something for which you could be diagnosed, and conjectured that dementia was not a specific medical condition. There were also some who felt that the two may have different prognoses, with a few indicating feeling that Alzheimer’s was a more debilitating disease that advanced fairly rapidly, compared to dementia which may not be as physically debilitating and could progress either slowly or rapidly.

When asked what it was about dementia or Alzheimer’s 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. 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.

*“You lose all function, who you were as a person. You lose your memories. It’s really sad.”
Charlottetown, 18-24*

“It’s tough for everyone involved. There is memory loss, loss of quality of life. You’re not who you were and you’re not able to do things for yourself.” Charlottetown, 25-34

*“I think it’s actually a bigger burden to the people around them. It’s painful to have someone forget you and the amount of support you have to provide is overwhelming.”
Vancouver, Informal caregivers*

In fact, when asked to describe dementia, there tended to be two general interpretations: one was what might be described as clinical in nature, with participants describing the disease, its symptoms, or its prognosis; the other interpretation was more visceral, with participants describing it in terms of emotion or impact on the patient and loved ones. Notably, descriptions offered on either interpretation tended to resonate with most other participants.

Those who replied in more clinical terms tended to describe dementia as a disease that progressively affects the brain, causing memory loss (particularly short-term), confusion, and erosion of one’s mental or physical capabilities.

When probed to provide a more visceral feeling or sentiment, participants tended to describe dementia as scary, sad, difficult, heartbreaking, confusing, bad, or terrible. As more than one participant described it, dementia causes you to lose someone twice – first to dementia and then ultimately a second time when they pass away. Discussions indicated that there was strong empathy for the person with the disease, but often these visceral answers related to the perceived feelings of the loved ones.

restricted, and possibly patronized. Most had the sense that those in the later stages of dementia were often unaware of the challenges.

“I think when it starts, they’re very scared. They probably feel like a burden.” Toronto, 18-24

“I have to think it’s pretty scary if they’re aware of what’s going on.” Montreal, 25-34

“Initially their confidence goes. They lose their self-worth. I think it is frustrating for them. I think some go in denial initially.” Charlottetown, 65 and older

“I think some are unaware of the challenges.” Charlottetown, Informal caregivers

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 estimate 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 living with/have lived with dementia. As a result, responses ranged widely. Almost no one put their odds at either 0% or 100%; overall, estimates ranged from 5% to 80%. Those with family members who are living with/have lived with dementia were fairly consistently providing higher probabilities (50% or higher) and citing that as the reason. For those who offered the lower estimated probabilities (10% or lower), they often began with the rationale that there was no history of dementia in their family. What was very interesting, however, was that very few, if any, of those at a higher risk of developing dementia (due to their current health condition) estimated their likelihood any higher. Participants’ estimated likelihood of developing dementia seemed to be more correlated with family history of the disease instead of their other current health conditions (that put them at higher risk).

Beyond genetics, other possible risk factors that were raised spontaneously included: head injuries, stroke, stress, isolation or inactivity (both mental and physical). A few other factors were mentioned rather uniquely by a very small number of participants, typically based upon learning from a case of dementia in their life such as alcohol abuse and medications.

Provided with a list and asked to check those they think are possible risk factors of dementia and to put an asterisk beside the one they think is the highest risk, participants consistently identified some far more often than others.

As illustrated in the table below, the identification of risk factors ranged from as few as 6 participants to as many as 198 of the 241 participants. The most commonly identified risk factors were often described as being interrelated and included stress, social isolation, harmful alcohol consumption, anxiety, depression, lack of physical activity, lack of sleep, poor diet and schizophrenia. Schizophrenia was also a possible risk factor that was identified often, especially in Montreal where this risk factor seemed to highly correlate with their perception of dementia as a state of lunacy or insanity.

Exhibit 3 - Please take a moment to review this list and check (✓) the ones you think are possible risk factors of dementia. Please indicate the one you think is the highest risk by placing an asterisk (*) beside your choice. Exhibit 4 has the breakdowns by target group.

Risk Factors	✓	*
Stress	198	51
Social isolation	185	50
Harmful alcohol consumption	170	21
Anxiety	170	20
Depression	162	21
Lack of physical activity	154	13
Lack of sleep	150	13
Poor diet	147	17
Smoking	111	10
Schizophrenia	106	22
Cannabis consumption	77	6
High blood pressure	76	9
Obesity	65	1
High cholesterol levels	65	1
Diabetes	41	5
Autism	33	1
Dyslexia	18	1
Asthma	6	0

Exhibit 4 - Please take a moment to review this list and check (✓) the ones you think are possible risk factors of dementia. Please indicate the one you think is the highest risk by placing an asterisk (*) beside your choice.

Risk Factors	18-24		25-34		35-64		65+		Higher risk of developing dementia		Informal caregivers	
	✓	*	✓	*	✓	*	✓	*	✓	*	✓	*
Stress	36	14	35	8	31	8	32	7	28	4	36	10
Social isolation	32	7	35	9	31	9	24	5	31	11	32	9
Harmful alcohol consumption	28	2	29	3	30	6	29	2	29	7	25	1
Anxiety	30	5	29	4	29	3	28	6	23	0	31	2
Depression	27	5	27	3	29	2	24	3	26	3	29	5
Lack of physical activity	23	2	23	2	29	1	22	2	26	4	31	2
Lack of sleep	30	6	28	3	19	0	24	0	24	2	25	2
Poor diet	21	3	27	3	23	3	20	1	24	1	32	6
Smoking	18	0	16	2	21	1	15	3	21	2	20	2
Schizophrenia	23	5	24	4	12	2	20	9	15	2	12	0
Cannabis consumption	14	4	18	0	10	0	16	2	14	0	5	0
High blood pressure	5	0	12	0	17	4	17	1	16	4	9	0
Obesity	8	0	13	0	11	0	11	0	13	1	9	0
High cholesterol levels	8	0	10	0	17	0	8	0	14	0	8	1
Diabetes	5	0	6	0	7	1	9	3	9	1	5	0
Autism	5	0	7	0	2	0	6	0	9	1	4	0
Dyslexia	0	0	4	0	2	0	4	0	4	1	4	0
Asthma	1	0	3	0	0	0	0	0	1	0	1	0

Although some said they believe (or hope) dementia is preventable, most participants were reluctant to say they felt it was truly preventable; certainly no one felt it was curable. There were several behaviours that participants in most groups raised (unaided) 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 list of healthy behaviours and asked to indicate which, if any, they think could help prevent or delay the onset of dementia and to put an asterisk beside the one they think is the most important, participants felt that most or all of these behaviours could potentially help. Indeed, typically at least four participants in each group indicated they had put a checkmark beside all of the behaviours on the list. Not surprisingly, the behaviours that were more widely acknowledged as beneficial were consistent with the suggestions offered spontaneously (as outlined above) and often complementary to the risk factors identified (i.e., social isolation and socializing; alcohol consumption and limiting alcohol consumption). Further, 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.

Exhibit 5 - *Now please take a moment to review the second list and check (✓) the ones you think are possible healthy lifestyle behaviours that can help prevent or delay the start of dementia. Please indicate the one you think is the most important by placing an asterisk (*) beside your choice. Exhibit 6 has the breakdowns by target group.*

Healthy Lifestyle Behaviours	✓	*
Doing regular exercise	210	43
Socializing	198	56
Eating healthy foods	197	35
Doing puzzles	194	18
Reading	184	11
Taking a class in something new	171	8
Being active in the community	167	17
Playing a musical instrument	164	8
Playing chess	163	6
Meditating	162	17
Limiting alcohol consumption	162	16
Learning a new language	162	10
Listening to music	154	6
Not smoking	145	3
Painting/Drawing	141	1
Doing yoga	136	4
Speaking two languages	128	5

Exhibit 6 - Now please take a moment to review the second list and check (✓) the ones you think are possible healthy lifestyle behaviours that can help prevent or delay the start of dementia. Please indicate the one you think is the most important by placing an asterisk (*) beside your choice.

Healthy Lifestyle Behaviours	18-24		25-34		35-64		65+		Higher risk of developing dementia		Informal caregivers	
	✓	*	✓	*	✓	*	✓	*	✓	*	✓	*
Doing regular exercise	34	6	35	3	34	8	35	10	36	6	36	10
Socializing	30	11	36	8	34	11	29	5	33	11	36	10
Eating healthy foods	30	6	32	4	35	7	36	10	32	3	32	5
Doing puzzles	34	3	32	4	31	1	31	5	33	2	33	3
Reading	30	5	30	3	33	1	30	2	29	0	32	0
Taking a class in something new	33	2	31	1	26	2	23	2	30	1	28	0
Being active in the community	25	5	30	4	33	2	24	0	27	3	28	3
Playing a musical instrument	21	2	28	2	27	0	27	0	29	2	32	2
Playing chess	28	1	26	1	29	3	24	0	28	1	28	0
Meditating	27	2	25	2	31	1	26	5	26	3	27	4
Limiting alcohol consumption	26	4	27	0	28	3	29	5	29	4	23	0
Learning a new language	27	0	30	1	26	2	20	1	31	3	28	3
Listening to music	19	1	24	1	29	0	25	0	26	1	31	3
Not smoking	22	0	22	1	27	0	27	1	23	1	24	0
Painting/Drawing	20	0	27	0	26	0	24	1	19	0	25	0
Doing yoga	22	2	25	1	23	1	21	0	23	0	22	0
Speaking two languages	20	1	20	3	22	0	21	0	24	0	21	1

In every group, all participants said there was at least one preventative behaviour listed that they were currently doing, and many indicated they were already doing several of them such as socializing, trying to exercise regularly, eating healthier, reading, doing puzzles or playing games. Asked if there was a preventative behaviour on the list that they were not currently doing that they would find easy to adopt, nearly all were able to say there was. Some behaviours that participants thought they could easily adopt often included yoga and meditation. Of those who said there was not, most often the reason was because the few they were not doing were ones they felt would be a little more difficult to start (e.g., learning a new language or learning to play a musical instrument).

Attitudes, Perceptions, and Behaviours Relating to Stigma

The focus groups included several lines of enquiry designed to learn about how people living with dementia are perceived and treated by society.

The opinions expressed during this part of the discussions demonstrated that participants themselves universally expressed feelings of empathy and a desire to be supportive of those living with dementia and those who support them. At the same time, there was widespread recognition that there are likely times when those living with dementia are not treated appropriately.

When asked to describe a person living with dementia, there were elements that were offered commonly across all groups. Participants reiterated signs or symptoms discussed previously, but also offered some additional descriptions often:

- Senior citizens, often those over 70;
- Not working, but usually due to their age and the fact they were retired;
- Having a vacant, blank or lost look on their face;
- Being frail (often because they are no longer able to cook or have lost their appetite or ability to eat); and,
- Spend their time watching TV or sitting alone.

In terms of the adjectives used to describe people living with dementia, as illustrated below, most tended to be negative, such as forgetful, confused, frustrated, and, lost. However, there were positive descriptions provided as well, more often than not by older participants. These included funny, caring, content, sweet, social, normal, nice, loving, and strong.

Exhibit 7 - On the paper in front of you, I want you to think about a person with dementia. Please describe that person for me – how old are they, what do they look like, what are their personality traits, how do they behave, do they have a job, hobbies/interests, what do they do every day, etc.?

Note: For ease of use, the font size corresponds with the frequency of mentions of each word (i.e., words that appear in a larger font size depict words that were mentioned more often than those in a smaller font size). There is no significance with respect to the colour of the font used.



Of note, when asked to identify a gender, the majority of participants felt that dementia could affect anyone. Informal caregivers tended to characterize someone living with dementia as a female, whereas participants 65+ tended to say a male.

After the first night of groups, a question was added to gauge whether those who know or have known someone living with dementia have any positive post-diagnosis memories of them. In most groups, at least one participant provided a positive memory or anecdote, including:

- An increase in levity and the ability to laugh more easily and/or more robustly;
- The loved one's forgetting things they disliked such as food or things they would criticize of others; and,
- The ability to enjoy things in a less inhibited manner than would have been normal (i.e., sometimes relating more easily with grandchildren and sharing their activity).

"She had an almost childlike joyful innocence. My memories were positive." Montreal, 25-34

"I remember he really loved music. In the beginning he was very agreeable and funny. Very funny. He had really good one liners." Montreal, 65 and older

"She forgot all the things she hated and would complain about and that made it easier to spend time with her." Vancouver, Higher risk of developing dementia

"If you listen to what they are saying when they are lost in time, you can learn about some great memories and stories you never knew." Red Deer, Informal caregivers

While some seemed to believe that society was empathetic and compassionate towards people living with dementia, many indicated feeling that people living with dementia are probably not consistently treated well. Most participants were more likely to feel that family members of people living with dementia treated them well and there was a mixed sense as to whether friends were always maintaining contact. When asked about health care providers, opinions ranged widely, with some feeling these professionals treated people living with dementia very well, while others felt quite the opposite. There was a similar range of impressions for how other services providers (e.g., salesclerks, bus drivers, bank tellers) treat people living with dementia. In discussing this particular category of people, participants suggested that such service providers are probably often unaware of whether a person they are dealing with has dementia and even if they are, they are probably not trained on how best to treat a person living with dementia.

When asked how people living with dementia are treated by people in the workplace, most participants indicated assuming that people living with dementia would not have a workplace. This was primarily because the assumption was that dementia occurs post-retirement, but some also indicated wondering whether someone living with dementia could even have a job.

There was a fair degree of consensus over how people who wonder or have concerns that they are developing dementia might feel. Participants often pointed out the feelings must include fear, anxiety, and sadness, and perhaps depression, anger, and a reluctance to share.

Participants were typically able to offer suggestions for how best to interact with people living with dementia and by far, the single most common response offered was “with patience.” Only positive, supportive suggestions were offered, although some participants struggled to come up with anything beyond patience and kindness. Other suggestions included providing support with daily living, avoiding the temptation to correct them, being friendly and agreeable, and watching out for their safety.

“First and foremost, with patience and understanding.” Toronto, 18-24

“Treat them with compassion and patience. Put on a happy face. Try to be positive. Redirect. And, don’t try to tell them they said something already. Just play along.” Charlottetown, 25-34

“Don’t try to correct them. It can make them confused and angry.” Vancouver, 35-64

“Guide them. Play by their rules. Don’t come with your own agenda.” Charlottetown, Informal caregivers

“Be patient and answer every time when they ask you the same question six times in 10 minutes.” Red Deer, Informal caregivers

It was widely expected that people living with dementia need a lot of support, assistance, and care 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. Some pointed out that availability may not be as significant a challenge as the cost of these things, characterizing it as a lack of affordable services and care facilities.

Participants often pointed out that people living with dementia, and particularly those in more advanced stages of dementia, face a lot of barriers to living well in their communities. They were perceived as needing assistance with daily tasks such as feeding, dressing, and hygiene; transportation to appointments, activities or shopping; monitoring to ensure they are taking medication appropriately; and, living safely (e.g., neither wandering off nor leaving the stove on).

In terms of addressing these barriers, other than wanting to see more support and care facilities made available, there was no clear consensus as to how to make that happen, nor on what specific solutions should be implemented. A range of suggestions were offered, including providing assistance to the informal caregivers to help them give the care that may be required; providing more financial support or tax credits for the cost of services, programs and care facilities; and, building more dementia-friendly facilities such as small, secure replica communities that provide people living with dementia the ability to feel they are independent even while being fully supervised and protected.

Message testing

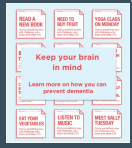




Participants were shown five creative concepts that combined text with either illustrations or photography and were asked to rank them according to their preferences and to identify what they liked and disliked about each one.

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. Regardless of the specific concept, participants felt that the tone was appropriate and that the information was credible.


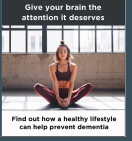

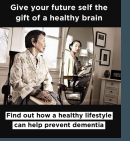

The following tables illustrate the overall rankings of each concept by the number of participants and the number of times each concept was ranked in the Top 3 for each audience. Please note that the Concept names provided in parentheses below are for reporting purposes only and were not shown to or discussed with participants as part of the focus groups.

Exhibit 8 - *I am going to pass out a sheet with some visuals and messages. Please rate them by overall preference (#1 being your favourite and #5 your least favourite) and add what you like most and least about each one.* Exhibit 9 has the breakdowns of the Top 3 concepts by target group.

Concepts	Concept #1 (Post-it Note)	Concept #2 (Meditation)	Concept #3 (Statistic)	Concept #4* (Reflection)	Concept #5 (Labyrinth)
Ratings for each concept					
1 st	41	33	80	55	33
2 nd	33	56	48	39	63
3 rd	34	59	41	45	58
4 th	33	71	34	47	55
5 th	100	22	38	39	32

*Ratings for Toronto with participants 18-24 and 25-34 are not included as they viewed a different version of this concept.

Exhibit 9 - I am going to pass out a sheet with some visuals and messages. Please rate them by overall preference (#1 being your favourite and #5 your least favourite) and add what you like most and least about each one.

Concepts	Concept #1 (Post-it Note)	Concept #2 (Meditation)	Concept #3 (Statistic)	Concept #4* (Reflection)	Concept #5 (Labyrinth)
					
Top 3 rankings for each concept					
Overall	108	148	169	139	154
18-24 (n = 116)	19	23	33	23	18
25-34 (n = 119)	16	25	31	19	28
35-64 (n = 114)	20	22	27	26	19
65 and older (n = 126)	20	31	26	16	33
Higher risk of developing dementia (n = 120)	17	21	27	26	29
Informal caregivers (n = 123)	16	26	25	29	27
Toronto	23	28	40	17	28
Charlottetown	25	24	28	31	33
Vancouver	20	26	32	27	36
Montreal	24	36	31	20	33
Red Deer	16	34	38	44	24

*Ratings for Toronto with participants 18-24 and 25-34 are not included as they viewed a different version of this concept.

Each of the concepts will be reviewed in the following order based on the Top 3 Overall rankings for each concept: Concept #3 (Statistic), Concept #4 (Reflection), Concept #5 (Labyrinth), Concept #2 (Meditation), and Concept #1 (Post-it Note). Please note that while Concept #4 (Reflection) had fewer Top 3 rankings, it was not tested in this final form the first night in Toronto. Based on qualitative reactions and the fact it received the second highest Number 1 ratings, we felt it should be reviewed as the second preferred concept.

Concept #3 (Statistic)

This concept seemed to appeal to the majority of participants. It was by far the concept that received the most #1 rankings across most audiences except among those 35-64 and 65 and older, and participants in Vancouver although it still figured highly in their respective Top 3 rankings. Worth noting, slightly more participants who identify as female preferred this concept over those who identify as male.

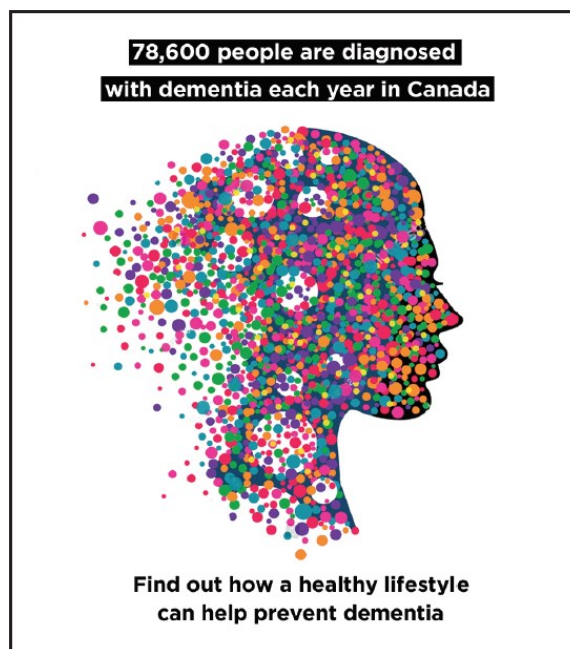


Exhibit 10 – Ratings for Concept #3 (Statistic).

Rating	1 st	2 nd	3 rd	4 th	5 th
Overall	80	48	41	34	38
18-24	16	8	9	3	3
25-34	22	5	4	4	6
35-64	7	10	10	6	5
65 and older	8	10	8	7	9
Higher risk of developing dementia	15	6	6	7	6
Informal caregivers	12	9	4	7	9
Toronto	22	12	6	6	1
Charlottetown	8	11	9	4	15
Vancouver	8	16	8	6	9
Montreal	23	2	6	9	8
Red Deer	19	7	12	9	5

What stood out for most were the statistic and the visual.

When asked which of the concepts provided new information that stood out, participants overwhelmingly selected this concept. It was the only concept to provide concrete, statistical information about the prevalence of the disease, which most found impactful. Indeed, many participants volunteered that they thought this would be an effective initial advertisement that would inform Canadians about the prevalence of dementia, upon which other ads could build to inform Canadians about how to prevent or prolong onset.

Participants also described the artwork as eye-catching and many specifically appreciated the colours and that the depiction of the dots leaving the back of the silhouette was a metaphor for the way memories drift from those living with dementia.

Having said that, some felt that the information (statistic) was a little scary and alarming; it was felt to be a too accurate depiction of dementia. Also, some participants in Red Deer, mentioned feeling the visual looked like it may be depicting physical violence.

“The colours are vibrant and grab your attention. It speaks to everyone.” Montreal, 25-34

“I like the artwork. It’s suggestive of the brain slowly drifting away.” Charlottetown, 35-64

“It looks like someone getting the back of their head blown off.” Red Deer, 65 and older

“The statistic shocks you. It’s a big number. This information needs to get out there.” Charlottetown, Higher risk of developing dementia

“The brain is falling apart, and I like the messaging about that.” – Vancouver, Higher risk of developing dementia

Concept #4 (Reflection)

While initial reactions to this concept were at times mixed, according to the ratings below, it was particularly effective with younger participants (18-24), residents of Charlottetown, Vancouver, and Red Deer, as well as with those who identify as female.



Exhibit 11 – Ratings for Concept #4 (Reflection).

Rating	1 st	2 nd	3 rd	4 th	5 th
Overall	55	39	45	47	39
18-24**	13	4	6	6	2
25-34**	10	6	3	8	6
35-64	8	9	9	8	4
65 and older	9	2	5	14	12
Higher risk of developing dementia	6	8	12	5	9
Informal caregivers	9	10	10	6	6
Toronto**	3	5	9	8	6
Charlottetown	18	6	7	4	12
Vancouver	12	5	10	14	6
Montreal	4	11	5	15	13
Red Deer	18	12	14	6	2

**Ratings for Toronto with participants 18-24 and 25-34 were not included as they did not review the final version of this concept.

Despite initial mixed reactions, most felt that the message communicated by this concept was quite powerful. The message that some participants understood was that one needed to start when they were young to prevent dementia.

Those who ranked this concept less tended to be confused and did not immediately understand or make the connection between the two images of the woman (and starting early to prevent dementia). They often only understood the message with explanation from others around the table and wondered whether they would notice this ad. They thought the concept might be more effective if the women were reversed (i.e., the younger woman seeing her older self in reflection).

Worth noting, while many really liked the message, “give yourself the gift of a healthy brain”, it was much less effective in French, “Offrez à votre futur vous un cerveau en santé”. Participants in every group in Montreal questioned this language and felt that the reference to “votre futur vous” did not appear to be grammatically correct.

“I rated this my number one. The pictures makes one think about aging. The message is about preparing for the future. Start healthy habits for the brain now so your future self can reap the benefits.” Charlottetown, 18-24

“It shows it can happen to anyone. Just looking into a mirror, seeing what you used to be. It’s very real.” Vancouver, 18-24

“I just really like the perspective of the older woman looking into the mirror and seeing her younger self. For me, if I were to see this at a bus shelter, I would look at it.” Vancouver, 25-34

“I was confused by this one. What’s it telling us? She looks regretful and sad. It’s almost as if she’s thinking ‘I wish I was young.’” Charlottetown, 35-64

“This one was the only one that focussed on a younger person and what you could have done to prevent dementia. It was hopeful.” Charlottetown, Higher risk of developing dementia

Concept #5 (Labyrinth)

This concept was met with generally favourable reactions and was especially well received by those 65 and older and residents of Vancouver. With respect to gender, more of those who identify as female ranked this as their preferred concept than those who identify as male.



Exhibit 12 – Ratings for Concept #5 (Labyrinth).

Rating	1 st	2 nd	3 rd	4 th	5 th
Overall	33	63	58	55	32
18-24	1	9	8	13	8
25-34	4	11	13	8	5
35-64	8	4	7	11	8
65 and older	10	13	10	5	4
Higher risk of developing dementia	6	17	6	9	2
Informal caregivers	4	9	14	9	5
Toronto	8	9	11	12	7
Charlottetown	3	14	16	11	3
Vancouver	12	11	13	5	6
Montreal	7	15	11	11	4
Red Deer	3	14	7	16	12

Most described it as simple, eye-catching, and to the point. Participants appreciated the vibrant colours and the connection of the illustration (labyrinth) to the importance of mental exercise as a preventative behaviour.

Those critical of this concept often cited the graphic design (including the colour scheme) as something they found unappealing or the message being too narrow or uninteresting.

“It’s Ok. Nothing special. All it has going for it is vibrant colours.” Vancouver, 18-24

“I like that it gives you a way you can exercise your brain.” Toronto, 25-34

“This one was very simple and to the point. I liked the colours. The message was positive.” Montreal, 25-34

“This was my number one because keeping your brain active is one way to prevent dementia.” Montreal, 65 and older

“I really liked the association between the text and the visual and both very clearly communicated the importance of keeping the brain active.” Montreal, 65 and older

“It resembles the brain the most. The mental exercise helps your brain stay fit and it has a puzzle.” Vancouver, Higher risk of developing dementia

Concept #2 (Meditation)

Reactions to this concept were generally mixed though it was rated number 1 most by Informal caregivers. In terms of the overall Top 3 rankings (please refer to Exhibit 6) it also figured prominently for those 65 and older. Worth noting, this was the only concept that those who identify as male ranked higher than those who identify as female.

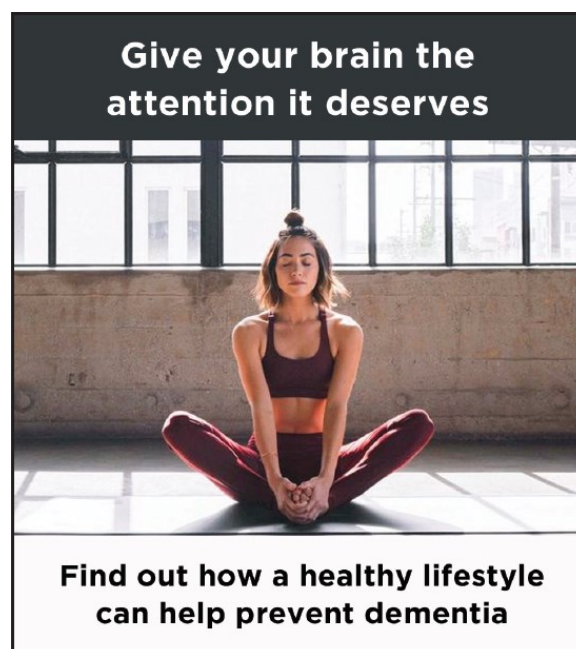


Exhibit 13 – Ratings for Concept #2 (Meditation).

Rating	1 st	2 nd	3 rd	4 th	5 th
Overall	33	56	59	71	22
18-24	3	8	12	11	5
25-34	1	14	10	10	6
35-64	8	10	4	10	6
65 and older	7	10	14	10	1
Higher risk of developing dementia	4	7	10	16	3
Informal caregivers	10	7	9	14	1
Toronto	6	11	11	16	3
Charlottetown	8	9	7	20	3
Vancouver	6	12	8	13	8
Montreal	9	10	17	8	4
Red Deer	4	14	16	14	4

The aspects participants liked about this concept was the sense of calm and warmth it conveyed. They also liked that it depicted a young woman, for whom positive preventative behaviours were most relevant.

The aspects participants were critical of were a sense that the audience for this concept was narrow (i.e. young women); some participants did not relate to it personally. They also thought the focus on one specific preventative behaviour, yoga, was too narrow; the link to dementia was not obvious.

“I like that it had someone my age.” Vancouver, 25-34

“It looks like an ad for a yoga studio.” Red Deer, 35-64

“It represents someone who is very zen. If one could achieve this, that helps.” Montreal, Higher risk of developing dementia

“I didn’t get the connection to dementia at first and if I weren’t in this group, I don’t know if I would have. I would have just ignored it.” Red Deer, Higher risk of developing dementia

“This had a clear, concise message. She’s looking after her body and mind. It’s all there.” Charlottetown, Informal caregivers

“I really liked the tagline. It’s interesting and clever. It speaks to me.” Montreal, Informal caregivers

Concept #1 (Post-it Note)

This concept seemed to be the most widely criticized. It was by far the concept that received the most #5 rankings, although it was in the Top 3 for residents of Charlottetown. Across gender, slightly more of those who identify as female preferred this concept over those who identify as male.

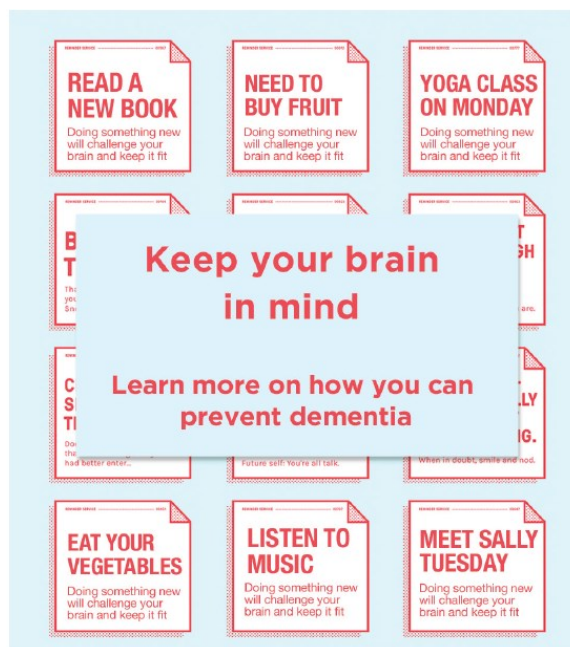


Exhibit 14 – Ratings for Concept #1 (Post-it Note).

Rating	1 st	2 nd	3 rd	4 th	5 th
Overall	41	33	34	33	100
18-24	7	9	3	5	15
25-34	4	4	8	11	14
35-64	7	5	8	3	15
65 and older	8	7	5	6	16
Higher risk of developing dementia	9	2	6	3	20
Informal caregivers	6	6	4	5	20
Toronto	8	8	7	4	20
Charlottetown	11	6	8	8	14
Vancouver	9	4	7	9	18
Montreal	5	10	9	5	19
Red Deer	8	5	3	7	29

The most effective element of this concept was the slogan, “Keep your brain in mind”. The majority of participants described it as an interesting play on words and particularly relevant in the context of dementia.

Those who liked this concept really liked that, unlike all of the other concepts, without having to click for more information, one received a variety of practical suggestions for preventing dementia.

Those who did not like it generally did not like it for one primary reason: the design and a sense that the amount of information was a little overwhelming. The colours were described as drab and not attention-

grabbing, the layout was felt to be busy, and many were not comfortable with six of the suggestions being covered up by the message box.

“I don’t like looking at photos of people. I see hundreds of those every day, but I really like ads with words on it. And I like the colour of this one. Lists? There’s colour? It pops to me! I’ll learn more about how to prevent dementia. Vancouver, 18-24

“This one actually had information. It was more engaging.” Toronto, 25-34

“I really liked the tagline. It was witty and creative.” Toronto, 25-34

“I found this one too busy and cluttered. I would never stop and read it.” Charlottetown, 25-34

“It bothers me that you can’t see six of the notes. It’s frustrating.” Charlottetown, 25-34

“I gave it a three because it was a little bland and mono-chromatic.” Charlottetown, 65 and older

Communications Needs

The focus groups culminated with a discussion about who participants would confide in or seek advice from if they were symptomatic of or diagnosed with dementia. The discussions also investigated trusted sources of information.

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 related to the life stage and, thus, answers varied somewhat by target segment. Those who were older tended to say they would confide in their spouse and possibly their adult children. Those who were middle-aged tended to say their spouse, sibling, friend or possibly parent. The youngest participants tended to say their parents or their spouse (assuming they had one at the time).

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. Beyond their doctor, a few offered that they may seek advice from others who have dealt with dementia, people in support groups, or the Alzheimer’s Society.

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. Asked whether there were people they would not tell or be reluctant to tell, most participants felt there were people in that category. Often, participants reflected on the question and said that they may tell various groups of people in stages. The most common answer for who would not be told was one’s employer or work colleagues. A few said they would find it very difficult to tell their children. The reasons were often that they would not want to be treated differently or have people distance themselves, but some also said they would not want people to worry about them.

“I’d have a hard time telling my mom because it would make her sad. I could see myself not doing that.” Vancouver, 18-24

“I would not tell my boss; you may lose your job. In fact, I wouldn’t tell coworkers either. They might think you’re not as capable.” Toronto, 25-34

“I would tell my spouse so that they could keep an eye on me.” Charlottetown, 25-34

“I’d be ok telling anyone, but it’s not like I’d advertise it.” Vancouver, 25-34

“I would tell my doctor first. I wouldn’t want to worry everyone.” Montreal, 35-64

“It would depend on the stage. At first, I’d only tell my sister and mother.” Red Deer, 35-64

“I’d tell the people in my life so they could know what to expect or so they could understand why I’m acting differently.” Red Deer, Informal caregivers

Participants felt their immediate concerns would often be about how long they had to live and what the path ahead would involve. They expected a lot of fear, particularly about losing memories and relationships, and causing pain for, and being a burden on, those they love.

Virtually all said they would seek out information about dementia either from their doctors or on the Internet. Probed as to the Internet sources they would most trust for medical information, participants suggested (in order of importance): 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.

Social media was not raised unprompted as a reliable Internet source of information. When specifically asked, social media did not tend to be regarded by many as a place they would turn to find information about dementia and a few openly scoffed at the idea of gathering information on such a serious topic over a social media platform. However, further probing demonstrated that the source of the information on social media would influence their impression. For many, a Health Canada message on dementia, such as the concepts reviewed in the groups, would be much more acceptable than their default assumption of what was meant in the initial question on trusting information on social media. Worth noting, some participants suggested that there is a need to try to distinguish communications concepts from the norm. They explained that they often scroll quickly through ads on their social media feeds and worried that they might dismiss an ad sponsored by Health Canada given their perspectives on social media as a trusted source of information.

While there are some who felt that there was no social media platform that they would say could be good for credibly communicating information on dementia, most could offer that one platform or another would probably make sense for them, but it did vary by audience.

- The social media platforms that younger participants (18-24 and 25-34) suggested included (in order of preference): Reddit, Instagram, Twitter, Facebook, Snapchat, and LinkedIn. Worth noting, participants felt that there were specific medical user boards on Reddit that are monitored and that

they would find quite helpful if they were interested in information about dementia. Where Facebook was concerned, a number of younger participants mentioned that they would rely on it as a resource for testimonials and the lived experiences of those with dementia. They felt it was a useful platform for finding groups with shared experiences. Finally, with respect to LinkedIn, there was a sense that it was a more “professional” platform as compared to other platforms like Facebook, Twitter and Instagram.

- With respect to middle-aged (35-64) and older participants (65 and older), there appeared to be more limited use of various social media platforms. The platforms that they suggested they use more often included: Facebook and Twitter; some middle-aged participants also mentioning Instagram. In fact, older participants suggested that it would be more efficient to reach them through other channels than social media. When asked which channels would be best to communicate with participants, most felt that the reach needed to be broad. Some suggested advertising via mass media in newspapers, on television and radio; others suggested advertisements in public transportation (i.e., subways, buses, bus shelters, etc.); and, information in pharmacies and doctor’s offices.

CONCLUSIONS

Regardless of age or exposure, awareness of dementia was extremely broad. Participants in every group in every location expressed a shared perspective that dementia was a serious illness that has highly undesirable effects. It was consistently described as a condition that deprives those who suffer from it of their memories, independence, and, to some degree, their identities. Most felt that perhaps equally tragic was the impact dementia has on the loved ones of the person living with dementia, as they are witness to a decline and subjected to being forgotten by those they hold most dear.

Beyond the consensus around the sad and frightening nature of the condition, knowledge and understanding of dementia was strikingly varied, with some knowing little more than the name and the most commonly known symptoms. Most, even among those who demonstrated greater understanding of dementia, were not entirely sure how dementia and Alzheimer's differed from each other, often struggling to correctly explain the difference.

Those with more exposure to the disease – usually as a result of aging friends and relatives having developed it – were typically more able to offer specifics on how the disease manifests itself and how best to interact with those suffering from dementia. However, even those with little or no exposure offered that demonstrating compassion and patience would be constructive. Those with a deeper understanding of the disease spoke of having to protect the safety of those living with dementia. Further, those who know the disease better than others described mood swings and outbursts that would have been unthought-of for that individual pre-diagnosis.

In terms of risk factors associated with dementia, participants almost universally assumed that genetics was strongly at play and that, if one had dementia in their family history, they had a much higher likelihood of receiving a diagnosis at some point in their lifetime. Conversely, those with no family history had a tendency to discount their own likelihood of a diagnosis, including those at a higher risk of developing dementia. Beyond that, smaller numbers of participants were convinced that a range of other risk factors existed, like those provided in the risk factor exercise (see Appendix C). And, interestingly, those at a higher risk of developing dementia did not estimate their likelihood of developing dementia any higher due to their current health condition.

When discussing preventative behaviours, few appeared comfortable with the notion that dementia could be prevented, but virtually all were of the view that there were healthy behaviours that one could adopt that might help delay the onset of dementia. Despite feeling that genetics was the primary risk factor, participants did demonstrate consensus that a number of behaviours were helpful for at least delaying the onset of dementia. These included doing puzzles, socializing, and generally taking care of one's health (i.e., regular exercise, proper diet, etc.).

The consensus about how people living with dementia are treated by society was that inexperienced, untrained or uninformed individuals almost certainly do not treat people living with dementia as well as they would if they knew that the person they were dealing with was living with dementia or were equipped with some basic guidance on how best to behave.

There was no clear consensus on whether there were characteristics that distinguished those suffering from dementia from everyone else, but it was clearly the case that the default assumption was that these individuals are old (perhaps elderly) and post-retirement. The notion that someone living with

dementia might actually be employed was counterintuitive for nearly all. Instead, the sense was much more often that a person living with dementia either lacked independence and required support – perhaps even 24-hour supervision – or were heading towards that eventuality.

Relatedly, participants tended to feel that people living with dementia – and the people who care for people living with dementia – require a lot of support. It may be light at the early stages, but participants agreed that eventually, dementia can be particularly debilitating and lead to the loss of independence. There was a widespread sense that this support is lacking, or at least that good support may be available but is inaccessible due to the high cost of good care and facilities.

In terms of advice, the majority of participants would consult their doctor initially, at the very least to confirm what they were sensing or to receive a diagnosis. Most participants indicated that there were people in whom they would confide if they were worried they were developing dementia or if they had received a diagnosis. However, there were some participants who thought they might keep the information a little closer to their chest for fear of worrying people unnecessarily. That being said, nearly all agreed there would be some people with whom they would have more difficulty confiding, often out of fear of being judged, treated differently, or just because they would not want to make others worry.

Taken together, the focus groups demonstrated that although participants uniformly demonstrated empathy toward people living with dementia, there was clearly a degree of stereotyping and fear that may sometimes result in stigmatizing behaviours and there was also certainly an acceptance that because of their disease, people living with dementia undoubtedly sometimes face stigma in one aspect of their life or another.

Participants often organically brought up the suggestion of a public education campaign to inform Canadians about what dementia is; that it is more common than they might assume; and, prepare them to better recognize and deal with individuals living with dementia whenever and wherever that might occur. Along these lines, the concepts tested in the groups offered some of the kinds of messaging and encouragement that most participants felt was necessary at this time. The concepts were met with both favourable and unfavourable reactions and seemed to appeal to different participants for different reasons, which suggests this may be a multi-faceted campaign.

Most participants felt that the campaign could begin with Concept #3 (Statistic) that provided a compelling statistic to inform Canadians about the prevalence of dementia. While not initially understood, Concept #4 (Reflection) seemed to have one of the stronger messages about starting young to prevent dementia. Concept #5 (Labyrinth) was commended for its vibrancy and clear connection with a commonly accepted preventative behaviour. Concept #2 (Meditation) appealed to informal caregivers and those who appreciated seeing a young person in a calm state. Concept #1 (Post-it Note) appealed to those who wanted immediate access to tips and advice.

In summary, the spirit of participants was quite sympathetic with, and supportive of, those living with dementia and their loved ones who bear that inevitable burden and share in the emotional pain. Providing support, particularly by at least educating Canadians about the disease, how to cope with it, how to prevent it, and how best to interact with those living with dementia, was widely endorsed as a step worth taking.

APPENDIX A: METHODOLOGY REPORT

Methodology

The research program included a series of thirty (30) qualitative discussions in five locations across Canada: Toronto, ON (March 2-4); Charlottetown, PE (March 3-5); Vancouver, BC (March 5-7); Montreal, QC (March 9-11); and, Red Deer, AB (March 9-11). These cities were selected as they represented a good cross section of large and smaller urban centres across the country.

In each city, separate groups were held with each 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 conditions or criteria (hypertension, high cholesterol, obesity [if 45-65 years old], or diabetes [if 65 and older]) that put them at higher risk of developing dementia.

The groups in Montreal were conducted in French; in all other locations, they were conducted in English. The sessions were approximately two hours in length.

Schedule and composition of the focus groups

City	Group	Gender		Date/Time
		F	M	
Toronto, ON	18-24	4	4	Monday, March 2, 5:30 pm
	25-34	5	3	Monday, March 2, 7:30 pm
	65 and older	4	3	Tuesday, March 3, 5:30 pm
	35-64	4	4	Tuesday, March 3, 7:30 pm
	Higher risk of developing dementia	3	5	Wednesday, March 4, 5:30 pm
	Informal caregivers	4	4	Wednesday, March 4, 7:30 pm
Charlottetown, PE	18-24	6	2	Tuesday, March 3, 5:30 pm
	25-34	6	2	Tuesday, March 3, 7:30 pm
	65 and older	5	3	Wednesday, March 4, 5:30 pm
	35-64	4	4	Wednesday, March 4, 7:30 pm
	Higher risk of developing dementia	4	3	Thursday, March 5, 5:30 pm
	Informal caregivers	4	4	Thursday March 5, 7:30 pm
Vancouver, BC	18-24	3	4	Thursday, March 5, 5:30 pm
	25-34	5	3	Thursday, March 5, 7:30 pm
	Higher risk of developing dementia	5	3	Friday, March 6, 5:30 pm
	Informal caregivers	4	4	Friday, March 6, 7:30 pm
	65 and older	4	4	Saturday, March 7, 10:00 am
	35-64	4	4	Saturday, March 7, 12:00 pm
Montreal, QC	18-24	5	2	Monday, March 9, 5:30 pm
	25-34	6	3	Monday, March 9, 7:30 pm
	65+	4	4	Tuesday, March 10, 5:30 pm
	35-64	6	2	Tuesday, March 10, 7:30 pm
	Higher risk of developing dementia	4	4	Wednesday, March 11, 5:30 pm
	Informal caregivers	4	4	Wednesday, March 11, 7:30 pm
Red Deer, AB	18-24	5	4	Monday, March 9, 5:00 pm
	25-34	4	4	Monday, March 9, 7:30 pm
	65 and older	5	2	Tuesday, March 10, 5:00 pm
	35-64	6	4	Tuesday, March 10, 7:30 pm
	Higher risk of developing dementia	4	5	Wednesday, March 11, 5:00 pm
	Informal caregivers	7	2	Wednesday, March 11, 7:30 pm

Recruitment

Participants were recruited using a screening questionnaire (included in Appendix D).

The target audiences were members of the general population, 18 years and older. The screener contained a series of standard screening questions to ensure participants qualified based on their ages and whether they were informal caregivers or at higher risk of developing dementia. Additionally, we screened participants to ensure we aimed for a good mix of gender (aiming for slightly more women than men), household income, ethnicity, etc.

Quality Response and their selected suppliers reached out to members of their respective databases first via email and followed up with telephone calls to pre-qualify participants for speed and economies. All participants were contacted pre-group to confirm attendance. We also included a re-screening service for the focus groups with informal caregivers and those at higher risk of developing dementia in Toronto, Vancouver and Montreal to ensure the quality of participants.

For groups in the Toronto area, Quality Response relied on their own proprietary database of Canadians. Quality Response's database includes approximately 35,000 Canadians with profiling on a range of attributes including standard personal demographics, household composition, medical background, technology usage, financial services, health and wellness, business profiles, and other relevant criteria.

For groups in Charlottetown, PEI, and Red Deer, AB, Quality Response relied on Metroline. Metroline's database includes approximately 2,500 Canadians in Charlottetown and 4,500 in Red Deer. Metroline profiles their database for a variety of characteristics including but not limited to: location; marital status; occupation; income; and, other lifestyle behaviours, etc.

For groups in Montreal, QC, Quality Response relied on MBA Recherche. Their vast database includes approximately 35,000 Canadians across Quebec. In addition to a variety of demographics, MBA Recherche's profiling includes automobile types, substance use, and mobile phone attributes.

For groups in Vancouver, BC, Quality Response relied on Walmsley Research's database which is comprised of approximately 5,500 residents of Vancouver. In addition to a variety of demographics, their database is profiled for: age of children, occupation, spouse's occupation, health issues, etc.

Moderation

Given the accelerated timeline, two moderators were used to conduct the focus groups. Both moderators attended the first night of groups in Toronto to ensure both were aware of the flow of the focus groups and involved in any conversation about potential changes to the discussion guide or flow of conversation for each subsequent night/day.

Each moderator takes notes and summarizes their groups and, after each night of groups, the moderators each provide the other with a debrief on the groups including the functionality of the discussion guide; any issues relating to recruitment, turnout, technology or the facility; and, key findings including noting instances that were unique and that were similar to previous sessions. Together, they discuss the findings on an ongoing basis in order to allow for probing of areas that require further investigation in subsequent groups and before the final results are reported.

A note about interpreting qualitative research results

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.

Glossary of terms

The following is a glossary of terms used throughout the report. These phrases are used when groups of participants share a specific point of view. Unless otherwise stated, it should not be taken to mean that the rest of participants disagreed with the point; rather others either did not comment or did not have a strong opinion on the question. In cases where there was a significant difference of opinion, it was noted in the report. This applies to all of the terms defined below.

Term	Definition
Few	<i>Few</i> is used when less than 10% of participants have responded with similar answers.
Several	<i>Several</i> is used when fewer than 20% of the participants responded with similar answers.
Some	<i>Some</i> is used when more than 20% but significantly fewer than 50% of participants responded with similar answers.
Many	<i>Many</i> is used when nearly 50% of participants responded with similar answers.
Majority/Plurality	<i>Majority</i> or <i>plurality</i> are used when more than 50% but fewer than 75% of the participants responded with similar answers.
Most	<i>Most</i> is used when more than 75% of the participants responded with similar answers.
Vast majority	<i>Vast majority</i> is used when nearly all participants responded with similar answers, but several had differing views.
Unanimous/Almost all	<i>Unanimous</i> or <i>almost all</i> are used when all participants gave similar answers or when the vast majority of participants gave similar answers and the remaining few declined to comment on the issue in question.

APPENDIX B: DISCUSSION GUIDE

Introduction

10 min 10 min

Moderator introduces herself/himself and her/his role: role of moderator is to ask questions, make sure everyone has a chance to express themselves, keep track of the time, be objective/no special interest.

- The name of the firm the moderator works for, and the type of firm that employs them (i.e. an independent marketing research firm)
- Role of participants: speak openly and frankly about opinions, remember that there are no right or wrong answers and no need to agree with each other.
- Results are confidential and reported all together/individuals are not identified/participation is voluntary.
- The length of the session (2 hours).
- The presence of any observers, their role and purpose, and the means of observation (one-way mirror, teleconference/webstreaming; colleagues viewing in the back room and listening in remotely).
- The presence and purpose of any recording being made of the session (audio and video taping of the discussion).
- Turn off cell phones for the duration of the discussion.

- Moderator to explain the research purpose and disclose the research sponsor, described, at a minimum. We are conducting these sessions on behalf of the Government of Canada; the Public Health Agency of Canada, specifically.

Moderator will go around the table and ask participants to introduce themselves. Please tell us your first name, what you do during the day, and what you like to do in your spare time.

General Knowledge and Awareness

40 min 50 min

- How often would you say you think about aging – would you say never, sometimes, often? (And, when I use that term, I'm thinking of getting older or your future self later in life)?
 - What do you normally think about?
 - What feelings do you have when you think about aging? Why?
- When it comes to health, how do you feel about your older relatives and friends aging? What do you think about?
 - [IF YES] What aspects of aging would you say worry you the most? Why?
- When you think of the various health issues or illnesses that we face today, what do you think is the most serious health issue or illness – in other words, what is the health issue, disease or illness that concerns you most. Please write it down on the paper in front of you. Please do so in silence; we will discuss what everyone wrote down as a group once everyone is done.

[MODERATOR TO GO AROUND THE ROOM AND HAVE PARTICIPANTS VOICE WHAT THEY WROTE DOWN]

– *[IF MENTION DEMENTIA/ALZHEIMERS]* What specifically is of concern to you? Why?

- Thinking back about the health issue you wrote down, for those who did not identify dementia, how does dementia compare to the health issue that you raised – equally serious, more serious, less serious? Why?

[IF NOT CAREGIVER GROUP]

- What about dementia? *[HANDS UP]* How many of you are aware of the term dementia?
- What about Alzheimer’s disease? Is it the same as dementia or different? How so?
- *[HANDS UP]* How many of you know someone with dementia? Can you tell us what your relationship is with that person?

[IF CAREGIVER GROUP]

- Each one of you is caring for someone living with dementia correct?
 - Can you tell us what your relationship is with that person?
 - How long have you been caring for that person?
 - What is their stage of dementia? (early/mid/Advanced)
- *[PROJECTION ACTIVITY]* On the paper in front of you, fill in the blank. Dementia is...?
 - What comes to mind when you think about dementia? How would you describe it?
- Can anyone name any possible signs or symptoms of dementia?
 - *[IF ANY SIGNS/SYMPTOMS ARE OUT OF THE ORDINARY]* Why do you say that?
- If you had to name challenges associated with dementia what would they be? Why do you say that?
 - How would you say people with dementia are affected by those challenges?
- If you had to guess, what would you say your likelihood of being diagnosed with dementia in your lifetime is? Why do you say that?

For the purposes of our conversation this evening, dementia is a set of symptoms that can affect memory, judgment, language, mood and behaviour. It may also appear as a decline in cognitive (thinking) abilities. Alzheimer’s disease is the most common cause of dementia.

Now let’s talk about risks and prevention.

- *[HANDS UP]* Do you think that dementia is preventable? Why or why not?
 - What are some things you think could help prevent dementia? Why do you say that?
- Do you think there are any risk factors that would make someone more likely to develop dementia? (A risk factor is something that increases a person's chances of developing a disease). Why or why not?
 - To the best of your knowledge, what are they?
- I would like to show you 2 lists. Please take a moment to review the first list and check the ones you think are possible risk factors of dementia. Please indicate the one you think is the highest risk by placing an asterisk (*) beside your choice. Why do you feel that that is the highest risk?
- Now please take a moment to review the second list and check the ones you think are possible healthy lifestyle behaviours that can help prevent or delay the start of dementia. Please indicate the one you think is the most important by placing an asterisk (*) beside your choice.

- Which one did you select as the most important? Why?
- Do you currently do any of these healthy lifestyle behaviours? Which one(s)?
- Out of the ones you do not do, which one would be the easiest for you to adopt?

Attitudes, Perceptions and Behaviours of Stigma

20 min

70 min

Now, let's explore your perceptions of people with dementia.

- [PROJECTION ACTIVITY] On the paper in front of you, I want you to think about a person with dementia. Please describe that person for me – how old are they, what do they look like, what are their personality traits, how do they behave, do they have a job, hobbies/interests, what do they do every day, etc.?

[MODERATOR TO GO AROUND THE ROOM AND HAVE PARTICIPANTS VOICE WHAT THEY WROTE DOWN]

- Why did you describe them this way?
- For those that know (or knew) someone living with dementia, do you have any positive memories of them?
- In general, how do you think people with dementia are treated by society? Why?
 - How about by close friends and/or family?
 - How about by health care providers?
 - How about by other service providers (i.e., bank teller, bus driver, retail workers)?
 - How about in the work place?
- How do you think people that might wonder or have concerns that they are developing dementia, might feel?
- To the best of your knowledge, what are the best ways to interact with people with dementia? Why?
 - Can you name any ways to help people with dementia?
- What do you think people with dementia need in order to live well in their communities?
 - Do you think there is currently enough support available in the community to help persons living with dementia have the best possible quality of life? Why or why not?
 - What barriers, within the community, would you say exist for persons living with dementia that reduce their quality of life?
 - How should we, or could we, address these barriers?

Message Testing

25 min

95 min

I am going to pass out a sheet with some visuals and messages. Please rate them by overall preference (#1 being your favourite and #5 your least favourite) and add what you like most and least about each one. Please add a “?” beside anything that is confusing or unclear and circle any information that is new to you.

VISUALS WITH MESSAGES TO COME FROM HC

MODERATOR TO PROBE:

- Which message really stood out for you? Which one has a stronger impact than others?
- Overall, are the messages relevant to you? Which ones are the most relevant? Why?
- Was anything confusing or unclear/put a “?” beside?
- What information is new? Is it credible? Believable? Why or why not?
- What do you think about the tone? Are any inappropriate? Why?

Communications Needs

10 min

115 min

- If you had concerns about starting to show symptoms of dementia, who would you confide in and/or seek advice? Why?
 - How does this source compare to a [IF NOT MENTIONNED] to close friends, a family members, health care professionals, co-workers?
 - If you were diagnosed with dementia (you’ve been to the doctor and received a diagnosis), would you tell anyone? Who would you tell? Who would you not tell or be reluctant to tell?
 - What would be your first concern and what would be your first step (action)?
- Where would you go to learn about dementia, to get more information? Why?
 - Are there any specific sources you trust more than others, why?
- Would you trust information you saw on the internet or on social media about dementia? Why or why not?
- Which one social media platform in particular would you say could be trustworthy for this type of health information?

Conclusion

5 min

120 min

MODERATOR TO CHECK IN THE BACK ROOM AND THE ONLINE CHAT TO SEE IF THERE ARE ANY ADDITIONAL QUESTIONS OR AREAS OF PROBING.

- This concludes what we needed to cover tonight. We really appreciate you taking the time to come down here to share your views. Your input is very important.
- Reminder to those in the first group about reserving comments so as not to influence those waiting at reception for the next group.

APPENDIX C: HANDOUTS

Please take a moment to review this list and check all those that you think are possible risk factors of dementia. Please identify the one you think is the highest risk by placing an asterisk (*) beside your choice.

- | | |
|------------------------------------------------------|----------------------------------------------------|
| <input type="checkbox"/> Smoking | <input type="checkbox"/> High cholesterol levels |
| <input type="checkbox"/> Stress | <input type="checkbox"/> Dyslexia |
| <input type="checkbox"/> Obesity | <input type="checkbox"/> Poor diet |
| <input type="checkbox"/> Autism | <input type="checkbox"/> Asthma |
| <input type="checkbox"/> Lack of sleep | <input type="checkbox"/> Schizophrenia |
| <input type="checkbox"/> Harmful alcohol consumption | <input type="checkbox"/> Social isolation |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Diabetes |
| <input type="checkbox"/> High blood pressure | <input type="checkbox"/> Cannabis consumption |
| <input type="checkbox"/> Anxiety | <input type="checkbox"/> Lack of physical activity |

Please take a moment to review this list and check all those that you consider to be healthy behaviours that can help prevent dementia or delay onset. Please identify the one you think is the most important by placing an asterisk (*) beside your choice.

- Eating healthy foods
- Socializing
- Doing puzzles
- Doing yoga
- Doing regular exercise
- Reading
- Listening to music
- Not smoking
- Playing chess
- Learning a new language
- Speaking 2 languages
- Painting/Drawing
- Limiting alcohol consumption
- Meditating
- Taking a class in something new
- Being active in the community
- Playing a musical instrument

READ A NEW BOOK
Doing something new will challenge your brain and keep it fit.

NEED TO BUY FRUIT
Doing something new will challenge your brain and keep it fit.

YOGA CLASS ON MONDAY
Doing something new will challenge your brain and keep it fit.

Keep your brain in mind

Learn more on how you can prevent dementia

EAT YOUR VEGETABLES
Doing something new will challenge your brain and keep it fit.

LISTEN TO MUSIC
Doing something new will challenge your brain and keep it fit.

MEET SALLY TUESDAY
Doing something new will challenge your brain and keep it fit.

Give your brain the attention it deserves

Find out how a healthy lifestyle can help prevent dementia

Mental exercise helps your brain stay fit

Learn more on how to prevent dementia

78,600 people are diagnosed with dementia each year in Canada

Find out how a healthy lifestyle can help prevent dementia

Give your future self the gift of a healthy brain

Find out how a healthy lifestyle can help prevent dementia

APPENDIX D: SCREENER

TORONTO (NIGHT 1) Monday, March 2, 2020

GROUP 1: Adults 18-24	5:30 pm
GROUP 2: Adults 25-34	7:30 pm

TORONTO (NIGHT 2) Tuesday, March 3, 2020

GROUP 3: Adults 65 and older	5:30 pm
GROUP 4: Adults 35-64	7:30 pm

TORONTO (NIGHT 3) Wednesday, March 4, 2020

GROUP 5: Those at higher risk of developing dementia	5:30 pm
GROUP 6: Informal caregivers	7:30 pm

CHARLOTTETOWN (NIGHT 1) Tuesday, March 3, 2020

GROUP 1: Adults 18-24	5:30 pm
GROUP 2: Adults 25-34	7:30 pm

CHARLOTTETOWN (NIGHT 2) Wednesday, March 4, 2020

GROUP 3: Adults 65 and older	5:30 pm
GROUP 4: Adults 35-64	7:30 pm

CHARLOTTETOWN (NIGHT 3) Thursday, March 5, 2020

GROUP 5: Those at higher risk of developing dementia	5:30 pm
GROUP 6: Informal caregivers	7:30 pm

VANCOUVER (NIGHT 1) Thursday, March 5, 2020

GROUP 1: Adults 18-24	5:30 pm
GROUP 2: Adults 25-34	7:30 pm

VANCOUVER (NIGHT 2) Friday, March 6, 2020

GROUP 5: Those at higher risk of developing dementia	5:30 pm
GROUP 6: Informal caregivers	7:30 pm

VANCOUVER (DAY 3) Saturday, March 7, 2020

GROUP 3: Adults 65 and older	10:00 am
GROUP 4: Adults 35-64	12:00 pm

MONTREAL (NIGHT 1) Monday, March 9, 2020

GROUP 1: Adults 18-24	5:30 pm
GROUP 2: Adults 25-34	7:30 pm

MONTREAL (NIGHT 2) Tuesday, March 10, 2020

GROUP 3: Adults 65 and older	5:30 pm
GROUP 4: Adults 35-64	7:30 pm

MONTREAL (NIGHT 3) Wednesday, March 11, 2020

GROUP 5: Those at higher risk of developing dementia	5:30 pm
GROUP 6: Informal caregivers	7:30 pm

RED DEER (NIGHT 1) Monday, March 9, 2020

GROUP 1: Adults 18-24	5:00 pm
GROUP 2: Adults 25-34	7:30 pm

RED DEER (NIGHT 2) Tuesday, March 10, 2020

GROUP 3: Adults 65 and older	5:00 pm
GROUP 4: Adults 35-64	7:30 pm

RED DEER (NIGHT 3) Wednesday, March 11, 2020

GROUP 5: Those at higher risk of developing dementia	5:00 pm
GROUP 6: Informal caregivers	7:30 pm

Respondent's name:

Interviewer:

Respondent's phone number:

Date:

Respondent's phone number:

Validated:

Respondent's email:

On quotas:

Hello/Bonjour, my name is _____ and I'm calling on behalf of Earncliffe, a national public opinion research firm. We are organizing a series of discussion groups on issues of importance to Canadians, on behalf of the Public Health Agency of Canada. We are looking for people 18+ who would be willing to participate in a discussion group. Can you please confirm you are 18 years or older?

Yes CONTINUE

No PLEASE ASK TO SPEAK TO SOMEONE 18+, GO BACK TO BEGINNING ONCE ON THE LINE

Participation is voluntary. We are interested in hearing your opinions; no attempt will be made to sell you anything or change your point of view. The format is a 'round table' discussion led by a research professional. All opinions expressed will remain anonymous and views will be grouped together to ensure no particular individual can be identified. Participants will receive an honorarium for their participation.

But before we invite you to attend, we need to ask you a few questions to ensure that we get a good mix and variety of people. May I ask you a few questions?

Yes CONTINUE

No THANK AND TERMINATE

READ TO ALL: "This call may be monitored or audio taped for quality control and evaluation purposes."

ADDITIONAL CLARIFICATION IF NEEDED:

- To ensure that I (the interviewer) am reading the questions correctly and collecting your answers accurately;
- To assess my (the interviewer) work for performance evaluation;
- To ensure that the questionnaire is accurate/correct (i.e. evaluation of CATI programming and methodology – we're asking the right questions to meet our clients' research requirements – kind of like pre-testing)
- If the call is audio taped, it is only for the purposes of playback to the interviewer for a performance evaluation immediately after the interview is conducted or it can be used by the Project Manager/client to evaluate the questionnaire if they are unavailable at the time of the interview – all audio tapes are destroyed after the evaluation.

READ TO ALL: "The information collected will be used for research purposes only and handled according to the Privacy Act of Canada.*"

***IF ASKED:**

- The personal information you provide is protected in accordance with the Privacy Act and is being collected under the authority of section 4 of the Department of Health Act. The information you provide will not be linked with your name on any document including the consent form or the discussion form. In addition to protecting your personal information, the Privacy Act gives you the right to request access to and correction of your personal information. You also have the right to file a complaint with the Office of the Privacy Commissioner if you feel your personal information has been handled improperly. For more information about these rights, or about our privacy practices, please contact Health Canada's Privacy Coordinator at 613-948-1219 or hc.privacy-vie.privee.sc@canada.ca.

S1. Could you please tell me which of the following age categories you fall into? Are you...
(ENSURE A GOOD MIX)

18-24	1	
25-34	2	
35-44	3	
45-54	4	
55-64	5	
65 and older	6	
Prefer not to say	9	THANK AND TERMINATE

S2. **DO NOT ASK – NOTE GENDER**

Male	1
Female	2

FOR EACH GROUP EXCEPT GROUP 5 IN EACH MARKET, PLEASE RECRUIT AT LEAST 5 TO 6 WOMEN. FOR GROUP 5, AIM FOR A MIX.

S3. Do you normally (at least half the year) reside in the [INSERT CITY] area?

Yes	1	CONTINUE
No	2	THANK AND TERMINATE

S4. Do you or any member of your household work for...

	Yes	No
A marketing research firm	1	2
A magazine or newspaper, online or print	1	2
A radio or television station	1	2
A public relations company	1	2
An advertising agency or graphic design firm	1	2
An online media company or as a blog writer	1	2
An organization involved in caring for or advocating for persons living with dementia	1	2
The federal, provincial or municipal government in marketing, advertising, public opinion research, media relations, and/or communications	1	2

IF “YES” TO ANY OF THE ABOVE, THANK AND TERMINATE.

S5. Do you provide care and/or assistance to a family member or friend with dementia? This can range from being their primary caregiver to checking in with them to make sure they are ok at least once a week, taking them to appointments, running errands for them, etc.?

Yes	1	CONTINUE FOR GROUP 6
No	2	CONTINUE FOR ALL OTHER GROUPS
DK/NR	9	THANK AND TERMINATE

S6. Are you currently living with and/or are you prone to the following health conditions?

	Yes	No	DK/NR
Hypertension	1	2	9
Obesity (45-65 years old)	1	2	9
Diabetes (65 and over)	1	2	9
High cholesterol	1	2	9

IF YES TO ANY OF THE ABOVE, QUALIFIES FOR GROUP 5 (THOSE AT HIGHER RISK OF DEVELOPING DEMENTIA). CONTINUE TO ENSURE A GOOD MIX.

S7. What is your current employment status? *ENSURE GOOD MIX*

Working full-time	1	
Working part-time	2	
Self-employed	3	
Retired	4	
Unemployed/home maker	5	
Student	6	
Other	7	
DK/NR	9	THANK AND TERMINATE

S8. Which of the following categories best describes your total household income? That is, the total income of all persons in your household combined, before taxes [READ LIST]? *ENSURE GOOD MIX*

Under \$20,000	1	
\$20,000 to under \$40,000	2	
\$40,000 to under \$60,000	3	
\$60,000 to under \$80,000	4	
\$80,000 to under \$100,000	5	
\$100,000 to under \$150,000	6	
\$150,000 or more	7	
DK/NR	9	THANK AND TERMINATE

S9. What is the highest level of education that you have completed? *ENSURE GOOD MIX*

Some high school	1
High school diploma or equivalent	2
Registered apprenticeship or other trades certificate or diploma	3
College, CEGEP or other non-university certificate or diploma	4
University certificate or diploma below bachelor's level	5
Bachelor's degree	6
Post graduate degree above bachelor's level	7

S10. And, what is your ethnic background? [DO NOT READ] *[ENSURE GOOD MIX]*

Caucasian	1	
Chinese	2	
South Asian (i.e., East Indian, Pakistani, etc.)	3	
Black	4	
Filipino	5	
Latin American	6	
East or Southeast Asian (i.e., Vietnamese, etc.)	7	
Arab	8	
West Asian (i.e. Iranian, Afghan, etc.)	9	
Korean	10	
Japanese	11	
Indigenous (First Nations, Métis, or Inuit)	12	
Other (please specify)	13	
DK/NR	14	THANK AND TERMINATE

S11. Have you participated in a discussion or focus group before? A discussion group brings together a few people in order to know their opinion about a given subject.

Yes	1	
No	2	SKIP TO S15
DK/NR	9	THANK AND TERMINATE

S12. When was the last time you attended a discussion or focus group?

If within the last 6 months	1	THANK AND TERMINATE
If not within the last 6 months	2	CONTINUE
DK/NR	9	THANK AND TERMINATE

S13. How many of these sessions have you attended in the last five years?

If 4 or less	1	CONTINUE
If 5 or more	2	THANK AND TERMINATE
DK/NR	9	THANK AND TERMINATE

S14. And what was/were the main topic(s) of discussion in those groups?

IF RELATED TO DEMENTIA OR ALZHEIMERS, THANK AND TERMINATE

S15. Participants in discussion groups are asked to voice their opinions and thoughts. How comfortable are you in voicing your opinions in front of others? Are you... (READ LIST)

Very comfortable	1	MINIMUM 4 PER GROUP
Comfortable to somewhat comfortable	2	CONTINUE
Not very comfortable	3	THANK AND TERMINATE
Not at all comfortable	4	THANK AND TERMINATE
DK/NR	9	THANK AND TERMINATE

S16. Participants will be asked to read text, write and review images during the discussion. Is there any reason why you could not participate?

Yes	1	THANK AND TERMINATE
No	2	CONTINUE
DK/NR	9	THANK AND TERMINATE

S17. The discussion group will take place on [INSERT DATE @ TIME] for up to two hours and participants will receive [INSERT AMOUNT] for their time. Would you be willing to attend?

Yes	1	RECRUIT
No	2	THANK AND TERMINATE
DK/NR	9	THANK AND TERMINATE

PRIVACY QUESTIONS

Now I have a few questions that relate to privacy, your personal information and the research process. We will need your consent on a few issues that enable us to conduct our research. As I run through these questions, please feel free to ask me any questions you would like clarified.

P1) First, we will be providing the hosting facility and session moderator with a list of respondents' names and profiles (screener responses) so that they can sign you into the group. This information will not be shared with the Public Health Agency of Canada organizing this research. Do we have your permission to do this? I assure you it will be kept strictly confidential.

Yes	1	GO TO P2
No	2	READ RESPONDENT INFO BELOW & GO TO P1A

We need to provide the facility hosting the session and the moderator with the names and background of the people attending the focus group because only the individuals invited are allowed in the session and the facility and moderator must have this information for verification purposes. Please be assured that this information will be kept strictly confidential. GO TO P1A

P1a) Now that I've explained this, do I have your permission to provide your name and profile to the facility?

Yes	1	GO TO P2
No	2	THANK & TERMINATE

P2) A recording of the group session will be produced for research purposes. The recordings will be used only by the research professional to assist in preparing a report on the research findings and will be destroyed once the report is completed.

Do you agree to be recorded for research purposes only?

Yes	1	THANK & GO TO P3
No	2	READ RESPONDENT INFO BELOW & GO TO P2A

It is necessary for the research process for us to record the session as the researcher needs this material to complete the report.

P2a) Now that I've explained this, do I have your permission for recording?

Yes	1	THANK & GO TO P3
No	2	THANK & TERMINATE

P3) Employees from the Public Health Agency of Canada may be onsite to observe the groups in-person from behind a one-way mirror or online via webcasting.

Do you agree to be observed by employees of the Public Health Agency of Canada?

Yes	1	THANK & GO TO INVITATION
No	2	GO TO P3A

P3a) It is standard qualitative procedure to invite clients, in this case, Public Health Agency of Canada employees, to observe the groups in person and online. They will be seated in a separate room and observe from behind a one-way mirror or will stream the session live online. They will be there simply to hear your opinions first hand although they may take their own notes and confer with the moderator on occasion to discuss whether there are any additional questions to ask the group.

Do you agree to be observed by Public Health Agency of Canada employees?

Yes	1	THANK & GO TO INVITATION
No	2	THANK & TERMINATE

INVITATION:

Wonderful, you qualify to participate in one of our discussion sessions. As I mentioned earlier, the group discussion will take place on [INSERT DATE AND TIME] for up to 2 hours. You will receive an honorarium of \$[INSERT AMOUNT] for your time.

Do you have a pen handy so that I can give you the address where the group will be held? It will be held at: [PROVIDE FACILITY NAME AND ADDRESS].

<p>TORONTO</p> <p>Monday, March 2, 2020 Tuesday, March 3, 2020 Wednesday, March 4, 2020</p> <p>CRC Research 2 Bloor Street West, 3rd Floor Toronto, ON M4W 3E2 T: 416.967.1596</p>
<p>CHARLOTTETOWN</p> <p>Tuesday, March 3, 2020 Wednesday, March 4, 2020 Thursday, March 5, 2020</p> <p>MQO Research 119 Kent Street, Suite 550 Charlottetown, PE C1A 1N3 T: 902.422.9264</p>
<p>VANCOUVER</p> <p>Thursday, March 5, 2020 Friday, March 6, 2020 Saturday, March 7, 2020</p> <p>Vancouver Focus 503-1080 Howe Street Vancouver, BC V6Z 2T1 T: 604.682.4292</p>
<p>MONTREAL</p> <p>Monday, March 9, 2020 Tuesday, March 10, 2020 Wednesday, March 11, 2020</p> <p>CRC Research 1610 Saint-Catherine Street West, Suite 411 Montreal, QC H3H 2S2</p>

T: 514.932.7511

RED DEER

Monday, March 9, 2020

Tuesday, March 10, 2020

Wednesday, March 11, 2020

Radisson Hotel Red Deer

6500 67 Street

Red Deer, AB T4P1A2

T: 1.800.661.4961

We ask that you arrive fifteen minutes early to be sure you find parking, locate the facility and have time to check-in with the hosts. The hosts may be checking respondents' identification prior to the group, so please be sure to bring some personal identification with you (for example, a health card, a student card, or a driver's license). If you require glasses for reading make sure you bring them with you as well.

As we are only inviting a small number of people, your participation is very important to us. If for some reason you are unable to attend, please call us so that we may get someone to replace you. You can reach us at **[INSERT PHONE NUMBER]** at our office. Please ask for **[NAME]**. Someone will call you in the days leading up to the discussion to remind you.

So that we can call you to remind you about the discussion group or contact you should there be any changes, can you please confirm your name and contact information for me?

First name

Last Name

Email

Daytime phone number

Evening phone number

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 discussion group. If they still refuse THANK & TERMINATE.