Knowledge, Perspectives and Experience of Dementia Care Providers

Executive Summary

Prepared for the Public Health Agency of Canada

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This public opinion research report presents the results of an online survey conducted by EKOS

Research Associates Inc. on behalf of the Public Health Agency of Canada. The research study included a survey with 1,500 paid and unpaid care providers of people living with dementia, as

well as 50 in-depth interviews conducted between February and March 2021 with those

providing dementia care or support.

Cette publication est aussi disponible en français sous le titre Connaissances, perspectives et

expériences de fournisseurs de soins dans le domaine de la démence au Canada.

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EXECUTIVE SUMMARY

A. BACKGROUND AND OBJECTIVES

Dementia is characterized by a decline in cognitive abilities, including memory; awareness of person, place and time; language; basic math skills; judgment; and planning. Dementia can also affect mood and behaviour. Prevention of dementia, eliminating stigma, and enabling dementia-inclusive communities are critical objectives. Growing evidence supports recent guidance that around 40% of worldwide dementia cases could be prevented by addressing 12 risk factors: lower levels of early life education; hypertension; obesity; hearing loss; smoking; depression; physical inactivity; diabetes; social isolation; excessive alcohol consumption; traumatic brain injury; and air pollution¹. In addition, stigma and a lack of understanding about dementia have been identified as significant barriers to receiving early and timely diagnosis, quality care, and the ability to engage meaningfully in one's community. Given Canada's growing and aging population, the number of Canadians living with dementia is expected to increase in future decades². Creating safe, supportive, and inclusive communities across Canada for people living with dementia and family and friend caregivers is essential to improving quality of life.

Care providers play an integral role in supporting people living with dementia. They require sufficient knowledge and skills to be well-equipped and contribute to an improved quality of life for people living with dementia and caregivers. Professional care providers working with people living with dementia include:

- developmental service workers who support those with disabilities;
- health care professionals (e.g., physicians, nurses, and social workers);
- personal care workers;
- first responders; and
- family and friend caregivers who support those living with dementia, often in an unpaid role.

Livingston, G et al. Dementia prevention, intervention, and care. The Lancet Commissions. 2017; Reference: https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext

Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian chronic disease surveillance system. Government of Canada. 2017; publications.gc.ca/collections/collection_2018/aspc-phac/ HP35-84-2017-eng.pdf

Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, released in June 2019, identifies three national objectives: prevent dementia; advance therapies and find a cure, and improve the quality of life of people living with dementia and caregivers. The strategy sets out a vision of a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated. The current research is intended to address "several areas of focus noted in the strategy including: (a) address the importance of access to quality care, from diagnosis through end of life; (b) build the capacity of care providers, including through improved access to and adoption of evidence-based and culturally appropriate guidelines for standards of care; and (c) improve support for family and friend caregivers, including through access to resources and supports".

The primary objective of the research is to understand the perspectives, experiences, and knowledge of care providers in Canada. Care providers are critical information sources regarding:

- risk factors and prevention related to dementia, dementia diagnosis, screening, and perceptions including stigma;
- treatment and advance care planning for people living with dementia, and in particular for specialized and higher risk populations, as well as those with co-morbidities;
- available dementia supports, education and training;
- the priorities and needs to improve the quality of life of those living with dementia; and,
- the impact of greater systemic pressures, such as exerted during the COVID-19 pandemic, on ability to provide care to those living with dementia

The information will be used to inform dementia-related initiatives and support annual reporting to Parliament on Canada's dementia strategy and international reporting obligations related to the Global Dementia Observatory.

2 • EKOS RESEARCH ASSOCIATES, 2021

B. METHODOLOGY

The study included a national survey of 1,593 paid care providers and unpaid family and friend caregivers, largely collected online, but with some completed by telephone, complemented by a series of 51 in-depth interviews with those providing dementia care or support.

Survey

The study included a national survey of paid care providers and family and friend caregivers of people living with dementia. The survey sample was randomly selected from a probability-based panel. The Probit panel, which is assembled using a random digit dial (RDD) process for sampling from a blended land-line cell-phone frame, provides full coverage of Canadians with telephone access. The distribution of the panel is meant to mirror the actual population in Canada (as defined by Statistics Canada). As such, our more than 100,000 member panel can be considered representative of the general public in Canada (meaning that the incidence of a given target population within our panel very closely resembles the public at large) and margins of error can be applied. Twenty percent of surveys were collected by trained, bilingual interviewers, while the rest were collected through online survey self-administration.

The survey was conducted online and by telephone from February 27 to March 30, 2021, in both official languages. This followed testing to make sure public understanding was clear and consistent. The survey length averaged 17 minutes online and 28 minutes by telephone. The overall rate of participation was 25% (27% online and 15% by telephone). Details on the rate of participation can be found in Appendix A, and the full questionnaire is provided in Appendix B.

Interviews

Using the Probit panel to recruit paid care providers and family and friend caregivers, a total of 51 interviews were conducted³, each lasting roughly 60 minutes. On average, 10 participants were interviewed in each paid care provider category (health care professionals, developmental service workers, personal care workers), as well as among unpaid family and friend caregivers. Interview participants were included from each provincial region of the country⁴.

Participants in the interviews were asked to describe their experiences with and the nature of support or care they provide to those living with dementia, factors affecting care as well as

³ Eight were conducted with providers in the Atlantic, and 8 in Quebec, with 7 completed in the Prairies and Alberta, and 6 in BC. 15 were completed in Ontario.

challenges and rewards, impact on care during COVID, their views on the ability of people living with dementia to live independently, stigma encountered in dementia care, culturally appropriate tools, and any training and dementia guidance they have received that has helped them to provide dementia care. Paid care providers were provided with an incentive for their time. The interview guide can be found in Appendix C.

C. KEY FINDINGS

Role of Care Providers

Frequency of Care

Among family and friend caregivers in the survey, nearly half (47%) provide daily care for someone living with dementia, and 36% do so at least once per week. For paid care providers, personal care workers provide care more regularly than developmental service workers or health care professionals; 61% provide support each day. Among health care professionals, 36% provide daily care, 35% at least once weekly. The pattern is similar among developmental service workers. First responders are less likely to provide support or care for people living with dementia on a regular basis, although nearly half (46%) provide care at least once a month (20%) or less often (26%).

Type of Care

Among health care professionals, many play multiple roles in the care of those living with dementia. Nearly half (49%) complete comprehensive history for those living with dementia, while 42% provide counselling or emotional support. One-third (33%) assist with daily living. Roughly, two in ten health care professionals administer medication (27%), provide non-pharmacological therapy (23%) or provide emergency treatment (20%).

Over half of developmental service workers provide counselling or emotional support (54%), and nearly half assist with daily living (46%). Nearly one-third of developmental support workers help complete comprehensive health history and assess patients (31%). One-quarter administer medication (25%) and slightly fewer provide first aid or emergency response (22%).

Most personal care workers (86%) assist with activities of daily living such as movement, bathing, dressing, meal preparation, and assistance with eating. Nonetheless, one-quarter said they administer medication (25%) or provide counselling and emotional support (25%).

Two in three first responders (67%) provide first aid to those living with dementia. Just less than half provide emergency treatment (47%) or rescue and locate missing persons (47%).

The role of family and friend caregivers is multipronged. About two in three family and friend caregivers currently or have in the past assisted with general health care and health monitoring such as overseeing medication usage, helping to administer medication or setting up appointments (68%) or assisting with financial affairs (66%). Over half assist with activities of daily living such as cooking, cleaning, bathing, or dressing (59%), or with transportation (56%). Over four in ten (43%) provide support with house maintenance or outdoor work. Fewer help with general social and mental health, social engagement, and outings (21%). In interviews, most family and friend caregivers said they provide care for a family member, most often a parent.

Comfort, Perceptions, Stigma

Comfort

Paid care providers who care for people living with dementia are much more likely than family and friend caregivers to say they are comfortable with their ability to provide quality care and support (i.e., indicating a 4 or 5 on a 5-point scale from uncomfortable to very comfortable). Personal care workers reported the highest level of comfort, with nine in ten (91%) indicating they are comfortable providing quality care or support to someone living with dementia. Two-thirds (64%) of family and friend caregivers reported being comfortable. Fewer first responders (58%) said they are comfortable in their ability to support care for someone living with dementia. In the presence of co-morbidities, health professionals reported the highest comfort (85%) of the four paid care provider groups in providing care for people living with dementia.

Perceptions

Survey respondents said they are relatively confident about the ongoing capabilities of people living with dementia in the years following diagnosis. Most health care professionals (81%) agree or strongly agree (4 or 5 on 5-point scale) that someone living with dementia can **sometimes continue to live in their own homes for years following diagnosis**; as do 75% of family and friend caregivers. About two-thirds of developmental service workers, personal care workers, or first responders agree.

Most also believe that people living with dementia can **sometimes continue to be active in the community for years after the diagnosis**, again with health care professionals most likely to agree (85%), followed by about three-quarters of developmental service workers, personal support workers and first responders, as well as family and friend caregivers saying the same. Just over half of developmental service workers (57%), health care professionals (53%) and first responders (53%) agree that people living with dementia can **sometimes continue to work for**

years following diagnosis. A lower proportion of personal care workers (41%) and family and friend caregivers (35%) agree.

Although few interview participants said they believe that dementia is a normal part of aging, many perceive that there are an increasing number of individuals living with dementia. These participants feel that increasing vascular issues and other illnesses such as diabetes are driving up the incidence of dementia. Some participants, however, feel that the increase in dementia can be attributed to both an increase in the diagnosis of dementia and greater life expectancy.

Interview participants perceive that people living with dementia can have a good quality of life; although, there were nuanced views of what contributes to quality of life. Many participants feel that contributors to quality of life can vary greatly depending on stages of dementia. For those who are in the early stages, for example, quality of life might come from a continued degree of activity and social connection. During later stages, most suggested that a higher quality of life might come from living among familiar surroundings and remaining in their home as long as possible.

Stigma

Over half of care providers agree or strongly agree that **negative stereotypes about dementia are common within the health care system**. This includes 53% of family and friend caregivers, and 56% to 57% of developmental service workers and health care professionals. Slightly fewer personal care workers (48%) and first responders (39%) agree. Notably, 65% of developmental service workers and 59% of health care professionals have witnessed a reduction in the quality of health care received by people living with dementia due to stigma.

Over half of health care professionals and developmental service workers (56%) feel they are knowledgeable about **stigma related to dementia and how to reduce it**. This is also the case among 47% of personal care workers. Among family and friend caregivers, 37% feel knowledgeable, although nearly as many (31%) said they feel less knowledgeable in this area. Only 28% of first responders rated themselves as knowledgeable in this area.

The majority of interview participants also identified stigma as a pervasive issue affecting the care received by people living with dementia. Stigma was often described in terms of misunderstanding or misjudging the abilities of people living with dementia. Interview participants feel that many paid care providers do not adequately understand how to assess the abilities of people living with dementia and are not adequately trained in how to communicate with people living with dementia.

6 • EKOS RESEARCH ASSOCIATES, 2021

Knowledge, Training and Resources

Knowledge of Risk and Protective Factors

Among the dementia prevention interventions presented in the survey, **social Isolation** is seen as the most important risk or protective factor to be prioritized, according to family and friend caregivers (66%), personal care workers (60%), first responders (59%), health care professionals (55%), and developmental service workers (51%). **Physical inactivity** was noted by 51% of family and friend caregivers as an important risk factor that should be prioritized. **Depression** was noted as a priority by developmental service workers and personal care workers (41% each), but less so by health care professionals (28%). **Higher levels of formal education** were reported by about one-quarter of all care providers (22 to 27%) as an important risk or protective factor that should be prioritized in dementia prevention interventions.

Among interview participants, most believe social isolation is a key contributor to cognitive decline, and that continuing social connections, not living alone, and joining social groups could help delay the development of dementia symptoms. Many participants also said that keeping the mind active can help mitigate the onset or progression of dementia.

Overall, many interview participants pointed to a mixture of risks that can contribute to cognitive decline; most believing that there is not just one factor that determines the propensity to develop dementia. These participants identified a combination of genetics, lifestyle choices, social connection, and mental stimulation as contributors to the development of dementia.

Dementia Knowledge

Survey respondents rated their knowledge in a variety of areas related to dementia prevention, diagnosis, care, and treatment on a 5-point scale, from least knowledgeable to most knowledgeable. For reporting purposes, we refer to scores of 1 or 2 on the sale as less knowledgeable, a score of 3 as moderately knowledgeable and scores of 4 or 5 as more knowledgeable. Less than half of developmental services workers (43%), health care professionals (41%), and personal care workers (36%) said they feel more knowledgeable about dementia prevention and reducing risk. First responders and family and friend caregivers more often said they feel less knowledgeable in this area.

In terms of knowledge of screening for dementia or making a diagnosis, 41% of health care professionals, 32% of developmental service workers, and 31% of family and friend caregivers said they feel more knowledgeable; in each case a similar number of respondents rated themselves as less knowledgeable. Only 22% of personal care workers and 11% of first responders said they feel more knowledgeable in this area.

In terms of knowledge of **treatments and care** for those living with dementia, nearly three-quarters of personal care workers (72%) said they feel more knowledgeable. Health professionals (68%), developmental service workers (57%), and family and friend caregivers (46%) also rated themselves as more knowledgeable in this area. First responders more often said they are less knowledgeable in this area.

Regarding advance care planning and end-of-life care for those living with dementia, a higher proportion of health care professionals rated themselves as more knowledgeable (52%), compared with personal care workers (45%), developmental service workers (41%) and family and friend caregivers (39%). Among first responders, 63% said they feel less knowledgeable and only 15% said they are more knowledgeable in this area.

Training in Dementia Care

Survey respondents rated the extent to which they felt they could use more preparation/training in a variety of areas related to dementia prevention, diagnosis, care, and treatment on a 5-point scale, from 1 (needing the least additional preparation/training) to 5 (the most additional preparation/training). For reporting purposes, we refer to scores of 1 or 2 on the scale as needing minimal additional preparation/training, a score of 3 as needing a moderate amount of additional preparation/training and scores of 4 or 5 as needing much more preparation/training. The majority of developmental service workers (60%) and personal care workers (52%) feel they could use much more preparation or training in **dementia prevention and reducing risk**. Less than half of health care professionals (46%) and over one-third of first responders (38%) said they could use much more training in dementia prevention and reducing the risk.

Over half of developmental service workers (55%) reported that they could use much more preparation or training in **screening for dementia or making a dementia diagnosis**. Less than half of personal care workers (46%) and health care professionals (42%) said the same, as did more than one-third of first responders (35%).

Personal care workers (54%) are most likely to feel they could use much more training on the **treatment and care** of someone living with dementia. About four in ten developmental service workers (47%), first responders (41%), and health care professionals (40%) reported the same.

There is greater variation across care providers regarding their perceived need for much more training on **advance care planning and end-of-life care** for those living with dementia. This ranges from 56% among developmental service workers, and 52% among personal care workers, to 41% among health care professionals, and 31% among first responders.

8 • EKOS RESEARCH ASSOCIATES, 2021

Many developmental service workers (56%) feel they could use much more training on **how to make interactions with care providers feel safer and more supportive**. Just under half of personal care workers (49%), health care professionals (42%), and first responders (42%) also feel this is the case for them.

In interviews, few paid care providers reported receiving formal training on providing care for those living with dementia. Many shared that they have become capable of caring for those living with dementia as a result of on-the-job training. Among family and friend caregivers, many said they are not well trained to provide care for someone living with dementia. A few friends and family caregivers have asked for information during their doctor's appointments on how to care for the individual living with dementia, or consulted with other friends or acquaintances who are health care providers or who have experience caring for their own loved one living with dementia.

Dementia Guidance Resources

Two-thirds of health care professionals (68%) said they know where to find resources related to **dementia prevention and reducing risk**. About six in ten developmental service workers (60%) or personal care workers (59%) reported that they know where to find this information. A minority of friend and family caregivers (41%) and first responders (35%) said the same.

Nearly three-quarters of health care professionals (73%) know where to find information on **dementia screening and diagnosis**. Fewer developmental support workers (64%), family and friend caregivers (59%), and personal care workers (50%) said this, as did a minority of first responders (36%).

Most health care professionals (83%), personal care workers (79%), and developmental service workers (76%) know where to find resources on the **treatment and care** of someone living with dementia. Family and friend caregivers (65%) and first responders (53%) are least likely to have said this.

The majority of developmental service workers (58%) and health care professionals (55%) reported they would know where to find **resources related to stigma reduction**. Less than half of personal care workers (49%), family and friend caregivers (31%), and first responders (30%) said they would know where to find this information.

Health care professionals and developmental service workers (69% each) are more likely than other care providers to have said they know where to find information on **advance care planning and end-of-life care**. Nearly two-thirds of personal care workers (61%) also know where to find this information. Fewer family and friend caregivers (48%) and first responders (32%) said this.

In interviews, some participants said they try to stay current on the latest advice to provide care for people living with dementia. Aside from formal workshops and training, a few care providers identified resources from their employer or discussions with colleagues as ways to stay current. Some paid care providers pointed to non-profit organizations with a specific focus on dementia as a primary source of information.

Culturally Appropriate Care and Tools

Culturally appropriate care involves considering a patient's cultural background, personal experiences, and norms. Over half of developmental service workers (59%) and personal care workers (54%) said they would know where to find **culturally appropriate tools**. Nearly half of health care professionals (48%) and about one-quarter of first responders (26%) or family and friend caregivers (24%) said the same.

Culturally appropriate tools were reported to be available to provide care or support for specific segments of the population living with dementia, to varying degrees. These populations include:

- People from **ethnic and cultural minority communities** Less than half of paid care providers said that necessary tools are available to provide care for those living with dementia from ethnic and cultural minority communities.
- People with intellectual/developmental disabilities Two in three developmental service workers, and half of personal care workers and health care professionals and just over onethird of first responders reported that tools are available;
- Rural and remote communities About four in 10 the personal care workers, health care
 professionals, and developmental service workers reported that tools are available,
 although fewer first responders said this;
- Those living with young onset dementia About four in 10 personal care workers, health
 care professionals, and developmental service workers reported that tools are available,
 although fewer first responders said this is the case;
- LGBTQ2+ community Just over one in three care providers reported that tools are available;
- Indigenous People Roughly one in three care providers reported that tools are available;
 and.
- Official language minority communities About one in three developmental service workers, personal care workers, and health care professionals reported that tools are available, although fewer first responders said the same.

40 FWOC DECEMBER ACCOUNTED 2024

Among the one-on-one interviews, a few participants said they are aware of culturally appropriate guidance, or have received culturally appropriate training, specifically designed for those living with dementia.

Factors Impacting Quality of Care and Challenges to Care

Quality of Care

Many challenges can affect the ability to provide quality dementia care or support. Mitigation strategies noted include better sharing of information across care providers or in care settings (57%) and more dementia care training (54%). Health care professionals reported the sharing of information as a key area for change (63%) that would improve quality of care.

Having more time to spend with those with dementia is another area where many care providers feel change is needed, particularly personal care workers (48%) and health care professionals (40%). Increased mental health supports is also considered a key area for positive change, particularly among family and friend caregivers (50%), but also among 39% of developmental service workers, 32% of first responders and 31% of health care professionals.

Having an advance care plan in place is also believed to have a positive impact on quality of care, particularly among family and friend caregivers (39%). Knowing the medical history of the individual is a key area for positive change, notably among personal care workers (33%) and first responders (32%). Better access to culturally appropriate information resources is also seen as having the potential to improve quality of care according to care providers (24%), particularly health care professionals (33%).

In interviews, family and friend caregivers said that improved access to programs that provide respite and information, such as day programs and support groups, would be valuable in providing care. Several said that they had to find dementia guidance on their own, and would welcome any communication of sources for dementia guidance. Improved access to paid care providers including doctors, psychologists, and home care (including consistency in home care staff) were noted by family and friend caregivers as necessary to support the overall care available for the person living with dementia.

According to interviews with personal care workers and health care professionals, adequate staffing and time to provide care, along with training specific to dementia care, are critical elements of providing quality care for persons living with dementia. Developmental service workers emphasized the need for training and dementia guidance to ensure well-informed and consistent approaches to care. Emergency responders noted fear and confusion experienced by

those living with dementia in emergency situations and the difficulty of gaining compliance and gathering information on the scene.

Impact of COVID on Quality of Care

Care providers were asked about the impact of COVID-19 on ability to provide care. Results indicate that restrictions due to the COVID-19 pandemic negatively impacted communication methods and access to in-person care for those living with dementia. Among survey respondents, half of health care professionals and developmental service workers said they had to change how they communicate with patients when providing care, typically communicating through virtual methods. This was also noted by 30% of family and friend caregivers. Reducing in-person care because of concerns about transmission was similarly identified by higher proportions of health care providers (32%) and family and friend caregivers (30%) compared with other care providers. Health care professionals said they had less time to spend with people because of increased caseload and staffing issues (36%), also noted by 29% of developmental service workers. Not being able to provide in-person care because of visitation restrictions was reported by 33% of developmental service workers, 32% of family and friend caregivers, and 27% of health care professionals. Disruption of appointments was also noted by 30% of developmental service workers and 26% of family and friend caregivers.

Challenging Aspects of Providing Care

A systemic lack of resources was noted as a barrier to providing or receiving adequate care for those living with dementia. Both paid care providers and family and friend caregivers identified a lack of staff and adequate training to engage with and provide stimulation to people living with dementia as problematic. Access to specialists and physicians, and long wait times for some resources and programs were cited as barriers. Limited access to home care and other respite options for caregivers was also described as an area for improvement in supporting people living with dementia in the home. Finally, lack of coordination and sharing information were noted as other areas for improvement; with many highlighting interdisciplinary, holistic, approaches as the most desirable way to address the complex needs of people living with dementia, particularly those with co-morbidities.

D. NOTE TO READERS

Detailed findings are presented in the sections that follow under the headings of Survey Findings and Interview Findings. Overall survey results are presented in the main portion of the narrative and are typically supported by graphic or tabular presentation of results. Bulleted text is used to point out any statistically significant and meaningful differences between sub-groups of respondents. If differences are not noted in the report, it can be assumed that they are either

not statistically significant⁴ in their variation from the overall result or that the difference was deemed to be too small to be noteworthy (e.g., less than 5% above or below the overall average).

Survey results for the proportion of respondents in the sample who either said "don't know" or did not provide a response may not be indicated in the graphic representation of the results in all cases, particularly where they are not sizable (e.g., 10% or less). These responses were, however, included in the calculations. Results may not total to 100% for this reason, and also due to rounding.

Overall themes are also described for interview responses, followed by anonymized, illustrative quotes. Quotes from participants are included first in the language of the speaker and then translated to the other language as needed. It should be noted that the results of the interviews are qualitative in nature. These results should not be used to estimate numeric proportion or number of individuals in the population who hold a particular opinion as they are not generalizable. That is, results should not be assumed to be representative of the experiences of the wider population of dementia care providers or family and friend caregivers in Canada. Responses from the interviews are meant to provide more detailed illustrations of experiences and perspectives. For this reason, terms such as "a few," "some" and "most" are used to broadly indicate views, rather than using specific percentages. To ensure a common understanding of the terms used in the analysis, the following guidelines were used in analysing and reporting on participant results:

- "A few participants" = less than 25 per cent;
- "Some participants" = 25 to 49 per cent;
- "Many participants" = 50 to 75 per cent;
- "Most participants" = over 75 per cent; and
- "Almost all participants" = 95 per cent or more.

It should also be understood that the information provided by participants is subjective in nature, based on their own recollection, and perceptions and should not be interpreted as factual in nature.

E. CONTRACT VALUE

The contract value for the POR project is \$142,317.74 (including HST).

Supplier Name: EKOS Research Associates

PWGSC Contract Number: 6D016-203931/001/CY

⁴ Chi-square and standard t-tests were applied as applicable. Differences noted were significant at the 95% level.

Contract Award Date: November 24, 2020

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

F. POLITICAL NEUTRALITY CERTIFICATION

I hereby certify as Senior Officer of EKOS Research Associates Inc. that the deliverables fully comply with the Government of Canada political neutrality requirements outlined in the Communications Policy of the Government of Canada and Procedures for Planning and Contracting Public Opinion Research. Specifically, the deliverables do not include information on electoral voting intentions, political party preferences, standings with the electorate, or ratings of the performance of a political party or its leaders.

Signed by:

Susan Galley (Vice President)