



# Dementia priorities survey

Summary Report of Findings

On January 4, 2016, the Alzheimer Society of Ontario released a survey to our community members seeking input on what they view as the most important priorities to the continuing development of the Ontario Dementia Strategy. The survey closed in February, 2016 with an overwhelming 1,141 responses from a variety of community members, including people living with dementia, caregivers, and concerned members of the public, among others. The volume of responses over the course of one month demonstrates a considerable recognition of dementia as a pressing issue and concern needing to be addressed.

The survey asked 26 questions that entailed a mix of quantitative and qualitative responses. Questions focused on four main categories:

- Stigma, Brain Health & Early Diagnosis
- Caregiver Support
- Strengthening the Dementia Workforce
- Research

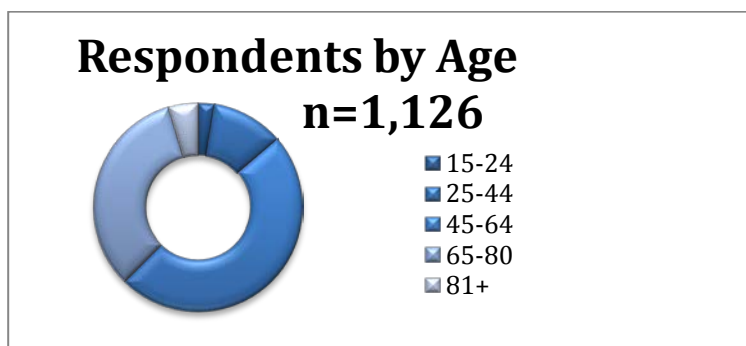
The survey was distributed to 7,100 community members who have indicated an interest in receiving, and participating in the ongoing advocacy work of the Alzheimer Society.

## Participants

Below are demographics of survey respondents. These demographics provide some insight into the profile of the Alzheimer Society of Ontario's community partners.

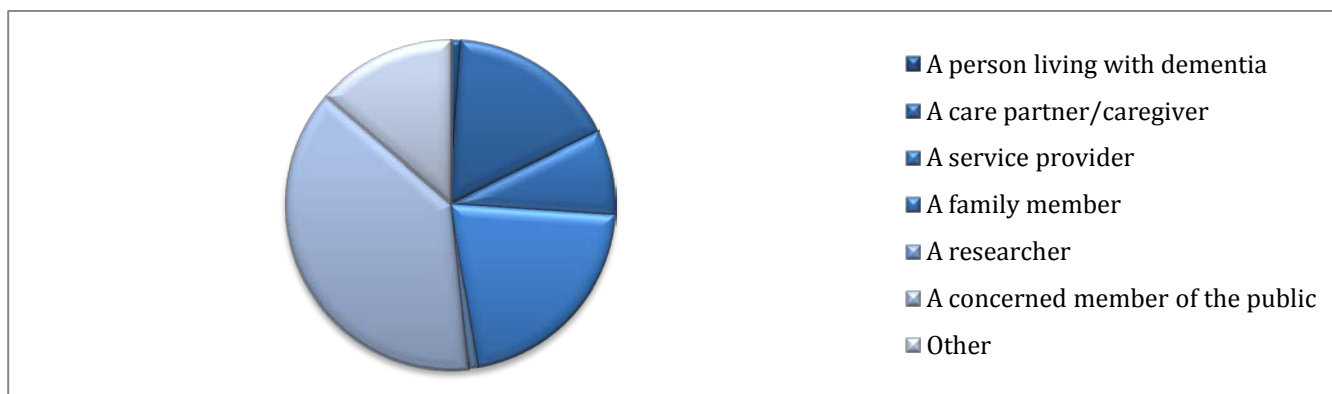
There was a wide range of ages, with respondent ranging between 15-24 years old to persons who were older than 81. Although there were a variety of ages among survey respondents, the majority were between the ages of 45-64 (48.22%) and 65-80 (32.68%) years (shown in Figure 1). This is consistent with the age groups of individuals most likely to be providing care to a loved one, know someone who is providing care, or to provide care within the near future.

**Figure 1: Age of Participants**



There was also a mix in how survey respondents self-identified, with most respondents (38.07%) identifying as “a concerned member of the public” with no direct affiliation to dementia (shown in Figure 2). This demonstrates that the issue of dementia is one that spans beyond the dementia community, effecting the population more broadly.

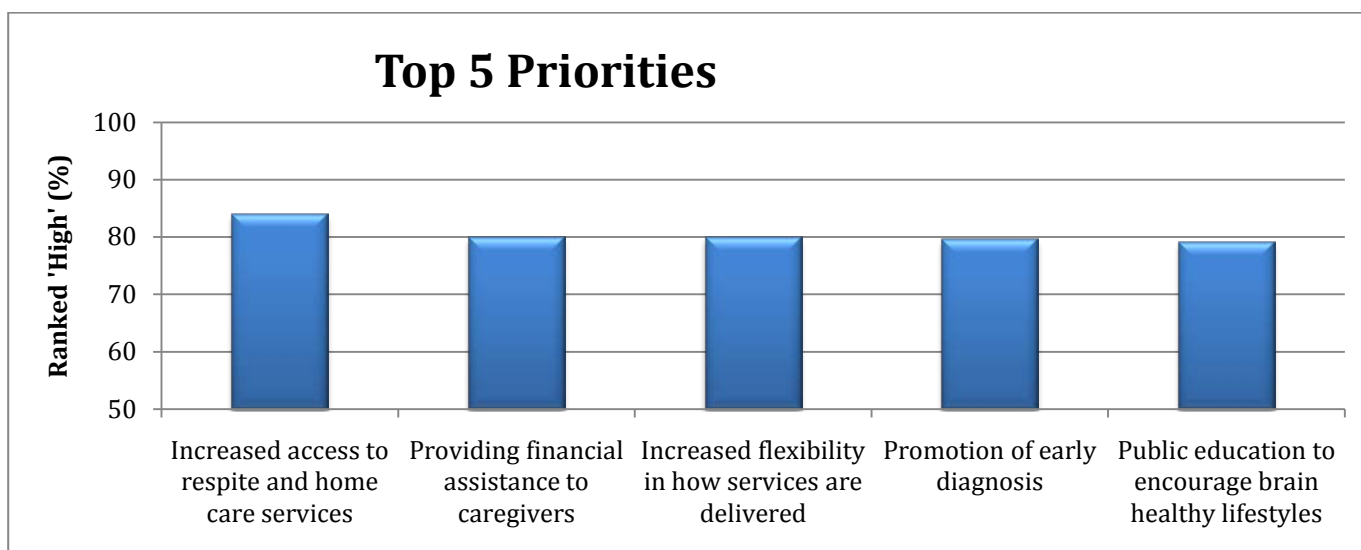
**Figure 2: Identifiers of Participants**



### Overall Results

All potential priorities introduced by the survey were ranked overall as 'high' by survey respondents, signifying that all issues raised are pressing and in need of attention. However, some priorities were ranked as 'high' more consistently among survey respondents. The top three identified priorities all related to caregiver needs, followed closely by issues of education to encourage brain healthy lifestyles and the promotion of early diagnosis (shown in Figure 3).

**Figure 3: Top 5 Priorities of Survey Respondents**



Caring for an individual diagnosed with Alzheimer's or a related dementia, though fulfilling, is particularly challenging. These findings demonstrate that support for the caregivers of people living with dementia is a top concern for many survey respondents and echoes what has been heard time and again in consultations with community partners.

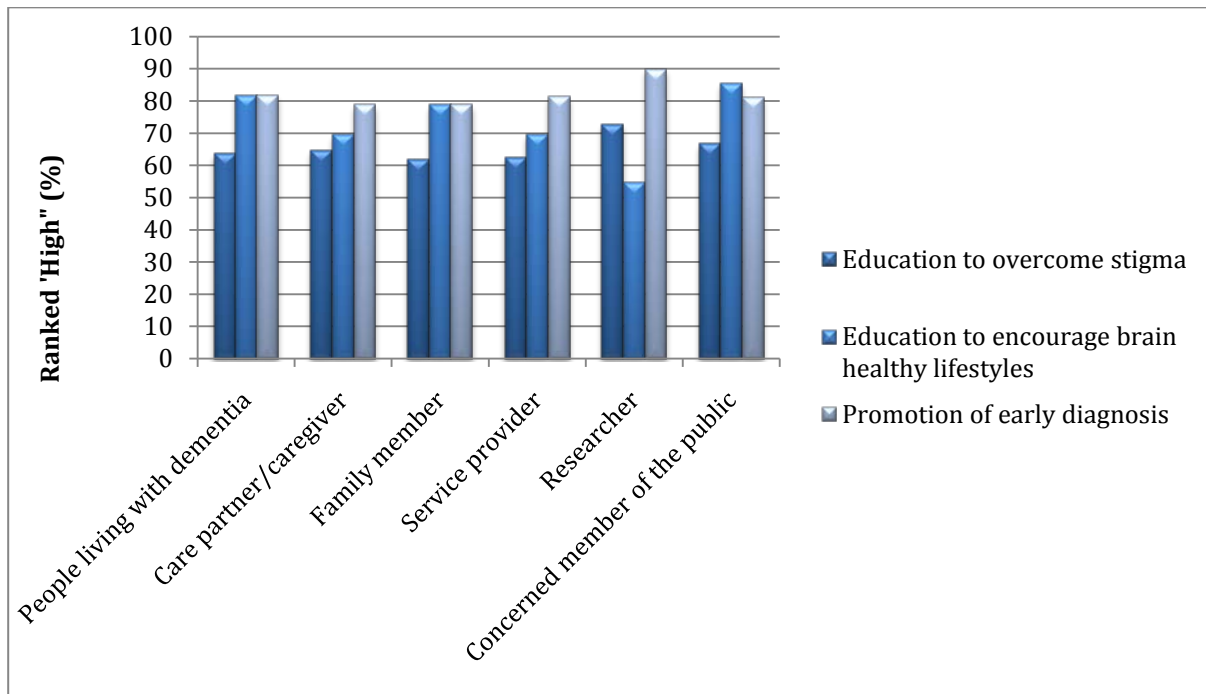
In addition, from these findings it is clear that there is a demand for more information and public education regarding the risk factors associated with Alzheimer's and related dementia's as well as lifestyle factors that can help individuals reduce their risk of developing Alzheimer's or dementia. In relation to this, it is also important that the public is well informed on the early signs and symptoms associated with dementia in order to get a diagnosis as early as possible. Early diagnosis of dementia

helps both the person diagnosed and their families to learn about the disease and access important information and resources that will help them to live well with dementia.

### Stigma, Brain Health & Early Diagnosis

Priorities related to stigma, brain health and early diagnosis included issues of education to overcome stigma and to encourage brain healthy lifestyles to reduce the risk of dementia as well as promoting early diagnosis of the disease. These priorities ranked fairly consistently across all respondent groups. Education to overcome stigma was ranked the lowest priority in this category by all survey respondents, aside from researchers (shown in Figure 4). That is not to say that reducing stigma is a 'low' priority, but merely that, comparatively, it was not identified as requiring as significant of attention as the other issues within this category. This may be a reflection of the gains that have been made in the areas of public awareness and education. However, despite these potential gains, more work on this matter is required and such gains do not negate the need for continued efforts to support inclusion and accessibility for people living with dementia.

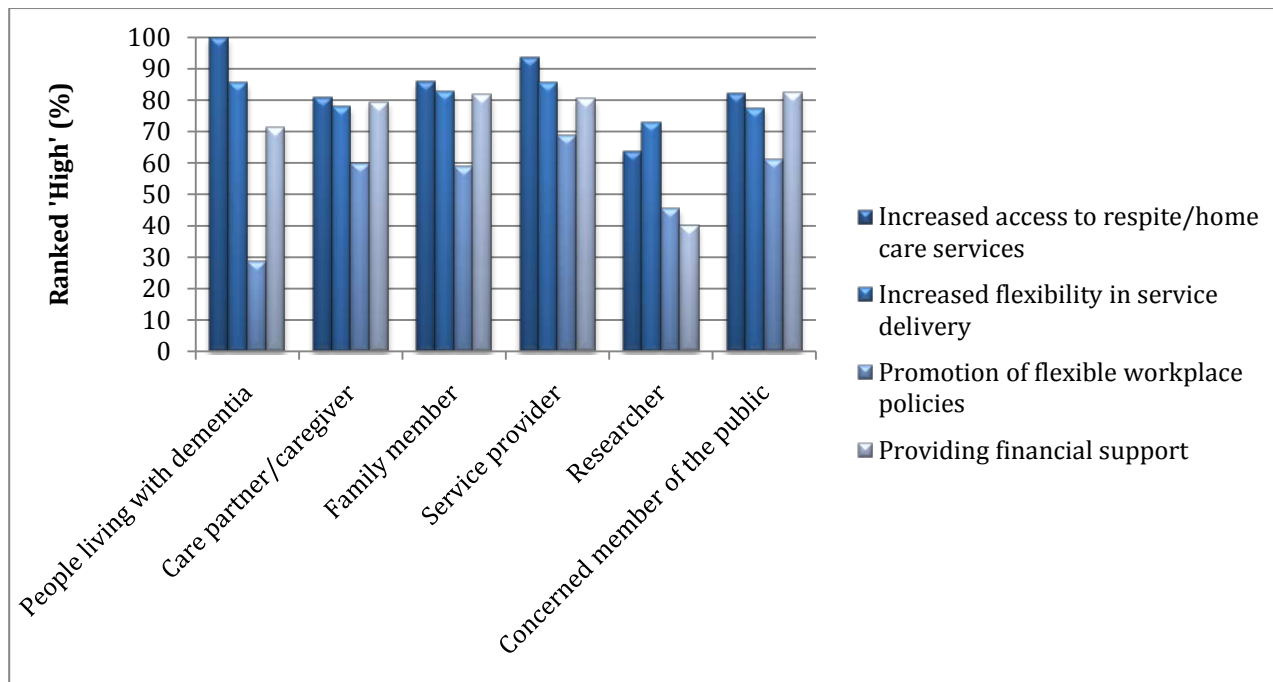
Figure 4: Priorities for 'Stigma, Brain Health & Early Diagnosis'



## Caregiver Support

As previously mentioned, issues relating to caregiver needs and support were among the top ranked priorities of survey respondents. Priorities regarding caregiver support as indicated by survey responses are shown in Figure 5.

Figure 5: Priorities for 'Caregiver Support'

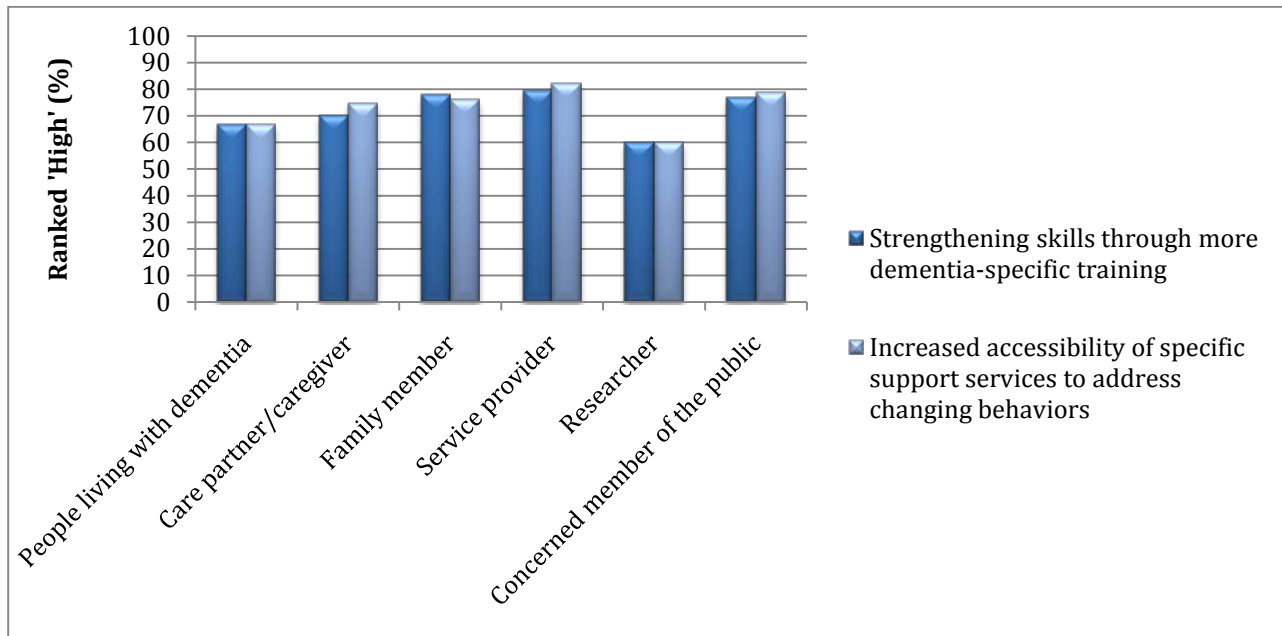


We know that caregivers are struggling to meet the growing demands that have been placed on them as increasingly complex care has been shifted into the community. As evidenced by the Health Quality Ontario (2015) report, 33 per cent of people who care for loved ones at home reported feeling distress, anger or depression in 2013-14, up from 16 per cent in 2008-09. In order to ensure their continued ability to take on this rewarding, but extremely challenging role, we must make certain that caregiver needs are being sufficiently acknowledged and supported as priorities if we are to claim to support a strong dementia strategy for Ontario.

## Strengthening the Dementia Workforce

As the number of people diagnosed with dementia increases, it is important to ensure we have a properly trained and knowledgeable workforce to support the growing demand for care and services. Priorities relating to the dementia workforce were ranked relatively lower overall by the majority of survey respondents, which, when considered in relation to priorities of caregiver support, may indicate that barriers to support and caregiver relief are issues of quantity rather than quality of available support services. However, it is interesting to note that, compared to other respondent groups for this category, service providers ranked both priorities most favorably (shown in Figure 6). This finding may suggest that service providers, themselves, recognize the value in enhancing the skills and knowledge necessary to provide high quality care to people living with dementia.

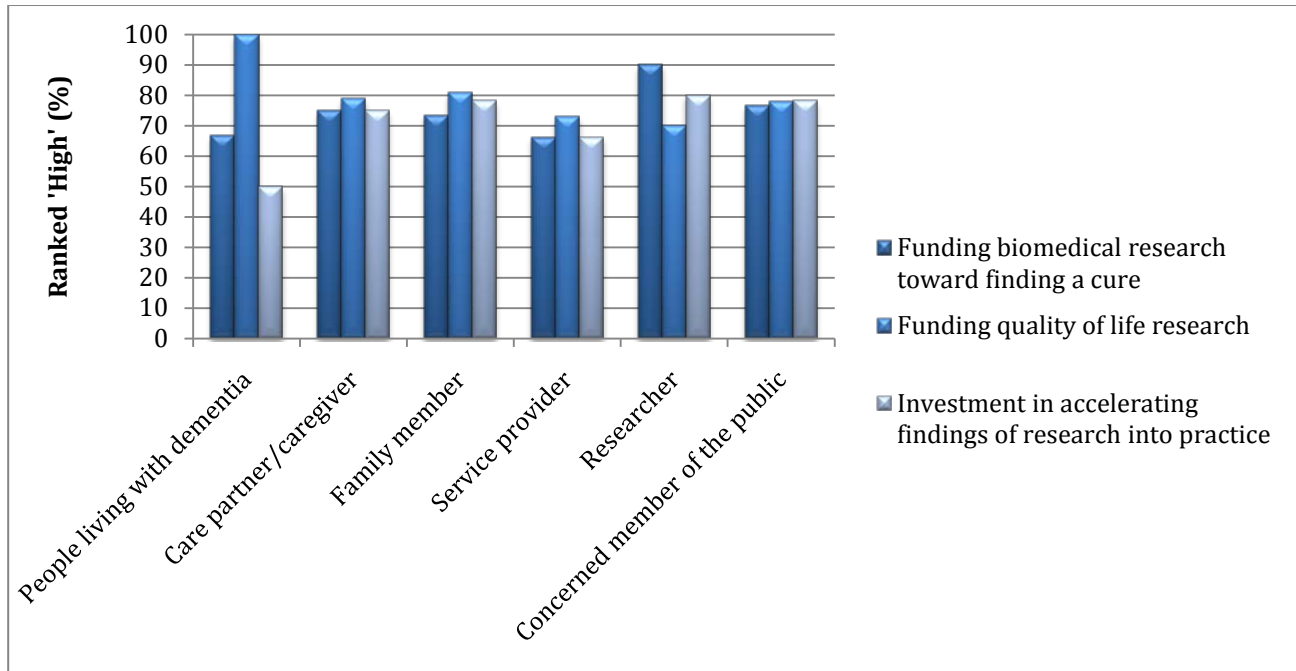
Figure 6: Priorities for 'Strengthening the Dementia Workforce'



## Research

Priorities relating to research ranked relatively low among survey respondents compared to other potential priority issues. Funding quality of life research was ranked most favorably of research priorities, both within the research category (shown in Figure 7) as well as in the overall findings of the survey. Investment in biomedical research toward finding a cure for dementia, somewhat surprisingly, ranked among the bottom three overall priorities.

**Figure 7: Priorities for 'Research'**



Findings in this category demonstrate that, among those with a personal or familial connection to the disease, ensuring that people living with dementia are afforded the best possible quality of life is of the most significant value.