

# CANADIAN DEMENTIA PRIORITY SETTING PARTNERSHIP



## 1. GATHERING QUESTIONS ABOUT DEMENTIA

**1217** People from across Canada – persons with dementia, friends, family and caregivers, as well as health and social care providers – completed a survey asking for their questions about living with dementia as well as prevention, treatment and diagnosis of dementia.

## 2. WORKING WITH THE DATA

**5924** Questions were categorized, merged and summarized, then checked against existing research evidence.



## 3. INTERIM PRIORITY-SETTING

**249** Individuals and groups from across Canada completed a second survey to shortlist the 79 questions.



## 4. FINAL PRIORITY-SETTING

**28** People from across Canada – persons with dementia, friends, family and caregivers, as well as health and social care providers – participated in a 2 day workshop to review and rank the 23 shortlisted questions.

## QUESTIONS ABOUT DEMENTIA

**8203**  
SUBMISSIONS

**2279**  
SUBMISSIONS  
were out of scope or  
could not be turned  
into a question

**5924**  
QUESTIONS

**79**  
SUMMARY  
QUESTIONS

**23**  
SHORTLISTED  
QUESTIONS

**TOP  
10**

**PRIORITIZED  
QUESTIONS**



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## Top 10 Priorities for Dementia Research

### 1 ADDRESSING STIGMA

What is the impact of stigmas associated with dementia and mental health issues on persons with dementia and their families?

What are effective ways of reducing the stigma experienced by persons with dementia and their friends, family and caregivers/care partners?

### 2 EMOTIONAL WELLBEING

What can be done to support emotional wellbeing, including maintaining a sense of dignity, for persons with dementia?

### 3 IMPACT OF EARLY TREATMENT

Among persons with dementia, what is the impact of early treatment on quality of life, disease progression and cognitive symptoms?

### 4 HEALTH SYSTEM CAPACITY

How can the health system build and sustain the capacity to meet the health and social care needs of persons with dementia and their friend or family caregivers/care partners?

### 5 CAREGIVER SUPPORT

What services, supports and therapies for friends or family caregivers/care partners of persons with dementia would improve or maintain health, wellbeing and quality of life for persons with dementia and their friends or family caregivers/care partners?

### 6 ACCESS TO INFORMATION AND SERVICES POST-DIAGNOSIS

After dementia is diagnosed, what would help persons with dementia and their friends, family and caregivers/care partners get the information, treatment, care and services they may need?

### 7 CARE PROVIDER EDUCATION

What dementia-related skills and knowledge should health and social care providers have? What are effective ways of providing them with these skills and this knowledge?

How can the number of health and social care providers who have these skills and this knowledge be increased?

### 8 DEMENTIA-FRIENDLY COMMUNITIES

What enables the creation of dementia-friendly communities? What impact do dementia-friendly initiatives have on persons with dementia and their friends, families and caregivers/care partners?

### 9 IMPLEMENTATION OF BEST PRACTICES FOR CARE

What would ensure implementation and sustainability of best practices for dementia care within and across health care settings, including effective approaches to providing person-centred care?

### 10 NON-DRUG APPROACHES TO MANAGING SYMPTOMS

Among persons with dementia, what are the effects of non-pharmacological treatments compared to pharmacological treatments on behavioural and psychological symptoms of dementia?

Can non-pharmacological treatments replace, reduce or be used in conjunction with pharmacological treatments for managing behavioural and psychological symptoms of dementia?