CANADIAN DEMENTIA RESEARCH PRIORITIES

Report of the Canadian Dementia Priority Setting Partnership

ACKNOWLEDGEMENTS

We are grateful for the many contributions of our Steering Group (see Appendix A), our partner organizations (see Appendix B) and the people from across Canada who shared their experiences and opinions with the Canadian Dementia Priority Setting Partnership.

We are especially thankful to the 28 individuals from across Canada – persons with dementia, friends, family and care partners, and health and social care providers – who participated in the final prioritization workshop. The diversity of their experiences and their enthusiasm to share and learn from one another were instrumental in creating this list of shared research priorities.

We also thank the organizations that made this work possible through their support:

The **Alzheimer Society** is the leading not-for-profit health organization working nationwide to improve the quality of life for Canadians affected by Alzheimer's disease and other dementias and advance the search for the cause and cure. **For more information about the Alzheimer Society, go to:** http://www.alzheimer.ca

The **Canadian Consortium on Neurodegeneration in Aging (CCNA)** provides the infrastructure and support that facilitates collaboration amongst Canada's top dementia researchers. By accelerating the discovery, innovation, and the adoption of new knowledge, the CCNA positions Canada as a global leader in increasing understanding of neurodegenerative diseases, working towards prevention, and improving the quality of life of those living with dementia. **For more information about the CCNA, go to:** http://ccna-ccnv.ca/en/

The **Toronto Rehabilitation Institute (TRI) – University Health Network** is Canada's largest academic hospital dedicated to adult rehabilitation and complex continuing care. The research program at TRI is dedicated to improving the lives of people living with the effects of disability, illness, and age-related health conditions. **For more information about research at TRI, go to:** http://www.uhn.ca/Research/Research_Institutes/Pages/TRI.aspx

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A MESSAGE FROM THE CHAIR OF THE CANADIAN DEMENTIA PRIORITY SETTING PARTNERSHIP STEERING COMMITTEE

Dementia, in all of its manifestations, has been with us for centuries but received little research attention until this century. Fortunately, dementia is now the focus of much research activity. Families who have been personally touched by the disease, Alzheimer societies across the world, and health care providers who have cared for people with the disease have all pressured governments and funding bodies to support research into the causes, treatment, prevention, care, and course of the different types of dementia. But this research has been driven by the scientists in the field. There is no question of the value of these studies and programs of research but they leave out a critical element: the questions that people with the disease, their family members, frontline health care providers, and the public have about dementia. This is what James Lind Alliance projects aim to correct.

The James Lind Alliance (JLA), which is based in the United Kingdom, provides a methodology for identifying the questions that the above groups want answers to about a given health condition and result in a list of their top 10 questions. The Canadian research team, led by Dr. Katherine McGilton, partnered with the JLA group to undertake this project under the management of Dr. Jennifer Bethell. The Alzheimer Society of Canada funded the project and the Alzheimer societies across the country were critical to the success of the project by recruiting project participants from among people with dementia and their care partners, who received services from their societies. The project was assisted enormously by the Ontario Dementia Advisory Group comprised of individuals who are living with dementia. They reviewed all materials that were distributed including the questionnaire, to ensure they were accessible to people with dementia.

The Steering Group – with representatives of persons with dementia, care partners, and professional care providers – oversaw every element of the development, conduct, and analysis of the results of the data collection.

The final 10 questions represent the collective wisdom of all the people who contributed to the project. They deserve the attention of the research community, because they reflect the day-to-day and year-to-year experiences of those who live with dementia. Responding to these questions, as well as all the other questions presented in the longer list (see Appendix D), will directly impact the quality of care, services, and experiences of those living with and those who are impacted by dementia.

Dorothy Pringle

Dorothy Pringle, OC RN PhD FCAH
Chair, Canadian Dementia Priority Setting Partnership Steering Committee

1. INTRODUCTION AND BACKGROUND

Historically, in health research, scientists have set the research priorities and identified research questions. Increasingly, there is recognition of the need for research to incorporate the experiences and insights gained from living with a condition, including in the research priority-setting process.

By involving “patients” (individuals with personal experience of a health issue and informal caregivers, including family and friends)[1], it is thought that research will not only be more democratic, but also more relevant and impactful. In turn, this improves the health system and health outcomes for these groups and individuals.

In 2014, the Canadian Consortium on Neurodegeneration in Aging (CCNA) was funded by the Canadian Institutes of Health Research (CIHR) and 18 partner organizations, including the Alzheimer Society of Canada, to address three areas of research: primary prevention, secondary prevention and quality of life. As part of this partnership, the Alzheimer Society was asked by CIHR to develop a forum for the voices of Canadians affected by dementia to inform the CCNA’s research agenda. The Canadian Dementia Priority Setting Partnership was devised as part of the Alzheimer Society’s effort to support the CCNA in meeting this need. In doing so, the Alzheimer Society recognized an opportunity for a unique contribution: to connect people from across the country, who are affected by dementia, to influence the direction of dementia research in Canada.

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[1] Government of Canada, Canadian Institutes of Health Research, Research and Knowledge Translation. “Strategy for Patient-Oriented Research – Patient Engagement Framework.”, 2 July 2014, www.cihr-irsc.gc.ca/e/48413.html.

2. TOP 10 PRIORITIES FOR DEMENTIA RESEARCH

The Canadian Dementia Priority Setting Partnership asked Canadians affected by dementia about their unanswered questions related to living with dementia, and dementia prevention, treatment, and diagnosis. These questions were identified as the top 10 priorities for dementia research in Canada by persons with dementia, their friends, family and care partners, as well as health and social care providers.

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?

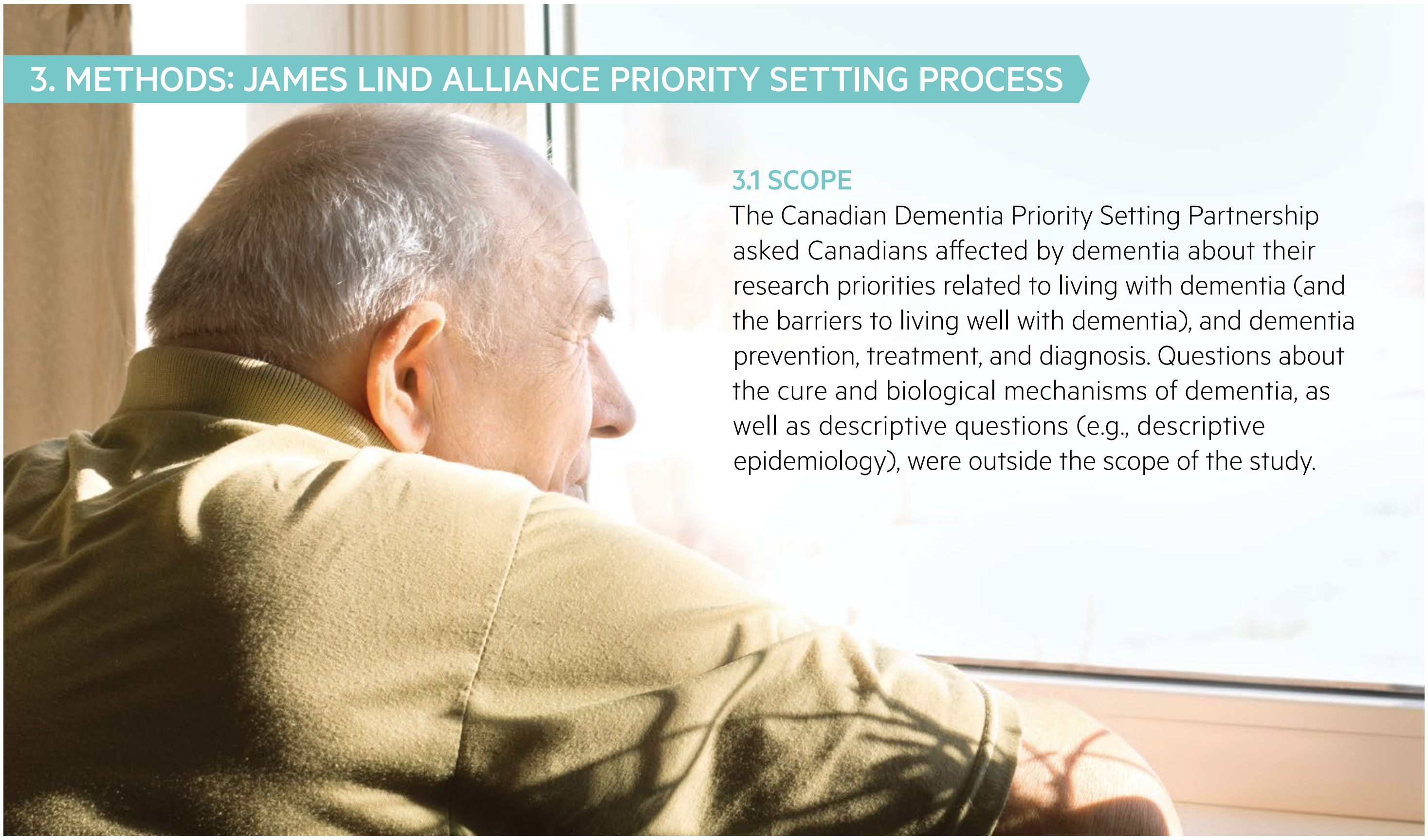
9 IMPLEMENTATION OF BEST PRACTICES FOR CARE

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?



3. METHODS: JAMES LIND ALLIANCE PRIORITY SETTING PROCESS

3.1 SCOPE

The Canadian Dementia Priority Setting Partnership asked Canadians affected by dementia about their research priorities related to living with dementia (and the barriers to living well with dementia), and dementia prevention, treatment, and diagnosis. Questions about the cure and biological mechanisms of dementia, as well as descriptive questions (e.g., descriptive epidemiology), were outside the scope of the study.

3.2 METHODS

The Canadian Dementia Priority Setting Partnership followed the methods of the James Lind Alliance[2]. The James Lind Alliance is a non-profit initiative, supported by the National Institute for Health Research (UK), which has facilitated over 50 priority setting partnerships to develop shared research priorities for an array of health conditions. **For more information about the James Lind Alliance, see:** http://www.jla.nihr.ac.uk/

The Canadian Dementia Priority Setting Partnership process is summarized in figures 1 and 2 and described in sections 3.2.1 to 3.2.7.

> "The work we did in Toronto was amazing. The process of breaking down the types of projects and the numbers made a project of this size and magnitude so easy. In spite of the fact each of us probably had our own pet project that we would have liked to put forward, or a private agenda, there was none of that."
>
> *Canadian Dementia Priority Setting Partnership workshop participant, person with lived experience of dementia*

Figure 1: *Stages of the Canadian Dementia Priority Setting Partnership.*

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[2] "JLA Guidebook." JLA Guidebook | James Lind Alliance, www.jla.nihr.ac.uk/jla-guidebook/.

Research Ethics Board (REB) approval was granted by the University Health Network. Support and guidance was provided by Katherine Cowan, Senior Adviser to the James Lind Alliance, to assist the Canadian Dementia Priority Setting Partnership to follow the James Lind Alliance methodology and uphold the key principles of transparency, inclusion, and equal involvement.

> “It was a very interesting process, including learning to compromise for the greater good”
>
> *Canadian Dementia Priority Setting Partnership workshop participant, person with lived experience of dementia*

3.2.1 ESTABLISH STEERING GROUP

A Steering Group was established to oversee and advise the Canadian Dementia Priority Setting Partnership. Steering Group members included those with personal or professional experience of dementia (see Appendix A). Their knowledge and understanding of dementia, as well as their extended networks of Canadians with an interest in dementia, were integral to the Canadian Dementia Priority Setting Partnership. Steering Group members participated in each step of the process, including inviting partner organizations, data processing, priority setting (as workshop participants), and disseminating the results. The Steering Group met monthly-in-person and by teleconference or videoconference – from November 2015 to April 2017.

3.2.2 INVITE PARTNER ORGANIZATIONS

Organizations that can reach or advocate for persons with dementia, their friends, family and care partners, and the health and social care providers who work with them were identified and invited to join the Canadian Dementia Priority Setting Partnership. Partner organizations included Alzheimer Societies across Canada, as well as professional associations and societies (see Appendix B). Partner organizations were directly involved in several aspects of the study, including promoting surveys within their communities, nominating workshop participants, and disseminating the study results.

3.2.3 GATHER QUESTIONS

An open, cross-Canada survey was conducted so that Canadians affected by dementia could submit their questions about dementia. The survey was available in English and French, and in both paper and online formats. The survey was open for roughly three months, from May to August 2016. **For a copy of the survey, see:** http://www.jla.nihr.ac.uk/priority-setting-partnerships/dementia-canada/.

Persons with dementia, friends, family, and care partners of persons with dementia, health and social care providers, and people not yet affected by dementia but who are interested in the topic were all invited to take part. The survey asked people to list the questions they would like to see answered by research and related to:

- Living with dementia
- Barriers to living well with dementia
- Preventing dementia
- Treatments for symptoms of dementia
- Diagnosing or being diagnosed with dementia

Demographic information was also collected from individuals and groups that participated in the initial survey for descriptive purposes (see Appendix E). Some Alzheimer Societies also submitted research questions from group discussions, including from persons with dementia and friends, family and care partners. This was very helpful in reaching out to individuals with a personal connection to dementia and who may not have otherwise accessed the survey. **For example, for more details on some of the Alzheimer Society of Manitoba’s contributions to the Canadian Dementia Priority Setting Partnership, see:** http://www.jla.nihr.ac.uk/news/gathering-input-for-the-canadian-dementia-priority-setting-partnership-from-people-with-dementia/3731.

CANADIAN DEMENTIAPRIORITY SETTING PARTNERSHIP

Figure 2: *Summary of Canadian Dementia Priority Setting Partnership*

1. GATHERING QUESTIONS ABOUT DEMENTIA

1217 People from across Canada – persons with dementia, friends, family and care partners, 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 care partners, 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

> "It was an honour to be part of the Dementia Research Priorities workshop. I interacted with people from across the country who have been impacted by dementia personally and professionally. Over two days, I saw more faces, heard more voices, and felt more passion than I've ever had in my volunteer work with Alzheimer advocacy."
>
> *Canadian Dementia Priority Setting Partnership workshop participant, person with lived experience of dementia*

3.2.4 WORK WITH THE DATA

The responses were downloaded into a spreadsheet. Questions were disaggregated (i.e. lines with multiple questions were separated into distinct lines) and categorized. Wherever possible, Population, Intervention/exposure, Control and Outcome (PICO) elements were extracted from the question. Responses that were out of scope, requesting information, expressing experiences or opinions (without any discernible question), or that did not provide enough information to understand the intent were excluded. Questions were analysed within categories, by two reviewers working together, and similar questions were summarized and combined into indicative questions. To keep the list to a manageable size, questions that were asked only once were excluded.

The list of indicative questions was then reviewed by the Steering Group and checked against current research reviews on dementia to ensure they had not already been answered; the literature search was conducted by an Information Specialist at the University Health Network – Toronto Rehabilitation Institute, who searched Medline (including Medline in Process and other non-indexed citations, ePubs and Medline Daily), the Cochrane Database of Systematic Reviews and Database of Abstracts of Reviews of Effects to identify any reviews related to dementia published between January 2014 and February 2017. The search was also limited to only identify reviews written in English or French (for complete search strategies, see Appendix C). This created a list of 79 indicative questions (see Appendix D).

3.2.5 INTERIM PRIORITY SETTING

The list of 79 indicative questions was then reduced to a short-list of questions for discussion and prioritization at the final priority setting workshop. For this, survey respondents who indicated an interest in being involved in this subsequent phase of the project were contacted by mail or email, according to their stated preference. Partner organizations were also contacted to invite others to join the project at this stage. The survey was open for roughly one month, from April to May 2017.

Interim prioritization survey respondents were presented with the list of 79 questions and asked to identify their top 10 priority questions. The 20 most highly ranked questions (i.e. the questions that were selected by the most respondents) were short-listed for the workshop. Demographic information was also collected from individuals and groups that participated in the interim prioritization for descriptive purposes (see Appendix F).

After reviewing the responses to the interim prioritization survey, additional input from persons with dementia was sought. Specifically, a support group for persons with dementia, held by a provincial Alzheimer Society, discussed the questions and themes, and while most of their priorities had appeared in the overall prioritized list, three further questions that were uniquely important to persons with dementia were added to the short list. In total, 23 questions were identified for discussion and priortization at the final priority setting workshop.

3.2.6 FINAL PRIORITY SETTING

The final priority setting workshop was held in Toronto, Ontario on June 8 – 9, 2017 and chaired by the James Lind Alliance Senior Adviser. Using the established JLA approach, based on Nominal Group Technique, it brought together 28 participants – persons with dementia, friends, family and care partners, and health and social care providers – from across Canada. Workshop participants included some Steering Group members, but mainly participants that were nominated by partner organization representatives. Participants were provided with the list of 23 questions and asked to review and rank them in advance of the meeting. Then, at the workshop, they worked in both small and large groups to come to consensus on a shared ranking of the 23 questions (including the "top 10"). Observers attended the workshop in order to gain a better understanding of the process and the research priorities that would emerge from the Canadian Dementia Priority Setting Partnership. The meeting was planned using recommendations for dementia friendly meetings, produced by the Scottish Dementia Working Group.[3]

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[3] "SDWG Publications." Scottish Dementia Working Group, www.sdwg.org.uk/sdwg-publications/.

For more details on the Canadian Dementia Priority Setting Partnership workshop, including the adaptations made to encourage involvement by persons with dementia, see: http://www.jla.nihr.ac.uk/news/adapting-psp-surveys-and-workshops-to-make-sure-everyone-can-get-involved/6635.

For the complete list of the 23 questions ranked, see: http://www.jla.nihr.ac.uk/priority-setting-partnerships/dementia-canada/top-10-priorities.htm.

3.2.7 DISSEMINATE RESULTS

The Canadian Dementia Priority Setting Partnership produced a list of research priorities decided by Canadians affected by dementia. These priorities have been presented to dementia research funders, including (but not limited to) the Alzheimer Society of Canada, and dementia researchers in Canada and internationally with the hope that more research will be conducted in these priority areas.

> "As the list reflected general topics, each one has flexibility for in-depth and targeted research."
>
> *Canadian Dementia Priority Setting Partnership workshop participant, person with lived experience of dementia*

The "Top 10" were reported immediately following the workshop on the Alzheimer Society's blog[4] and the Canadian Consortium on Neurodegeneration in Aging's website[5]. Methods and interim results were also reported at conferences, including the Canadian Consortium on Neurodegeneration in Aging's (CCNA) Science Day (Ottawa, Ontario in 2015; Vancouver, British Columbia in 2016; and Toronto, Canada in 2017), the Alzheimer's Association International Conference (Toronto, Canada in 2016; and London, England in 2017), Canadian Association on Gerontology (Montreal, Quebec in 2016; and Winnipeg, Manitoba in 2017) and the Canadian Conference on Dementia (Ottawa, Ontario in 2015; and Toronto, Ontario in 2017).

3.3 ENGAGING PERSONS WITH DEMENTIA IN THE RESEARCH PROCESS

Persons with dementia were engaged in the governance and conduct of the Canadian Dementia Priority Setting Partnership, as well as in disseminating the results. One person with dementia served on the Steering Group throughout the project to oversee and advise on the study; this participation was defined in a role profile and Steering Group Terms of Reference that were developed at the outset of the project. Through this Steering Group member, the Ontario Dementia Advisory Group (ODAG) was also involved in the study. ODAG is a group of people living with dementia in Ontario, Canada whose objective is to influence policies, practices, and people to ensure that individuals with dementia are included in the decisions that affect their lives. ODAG was consulted for their assistance in making the study materials more accessible to persons with dementia. Several ODAG members met, by videoconference, on multiple occasions to review the survey content at different stages of the process. Based on these discussions, revisions were made to the text and formatting of the surveys. **For more detail on some of ODAG's contributions to the Canadian Dementia Priority Setting Partnership, see:** http://www.jla.nihr.ac.uk/news/nothing-about-them-without-them/3430.

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[4] "Top 10 Dementia Research Priorities." Alzheimer Society Blog, 23 Aug. 2017, alzheimersocietyblog.ca/top-10-research-priorities/.

[5] "Canadian Dementia Priority Setting Partnership's "Top 10" Research Priorities Announced" Canadian Consortium on Neurodegeneration in Aging, 22 June 2017, ccna-ccnv.ca/en/2017/06/19/canadian-dementia-priority-setting-partnerships-top-10-research-priorities-announced/.

A MESSAGE FROM A MEMBER OF THE CANADIAN DEMENTIA PRIORITY SETTING PARTNERSHIP STEERING COMMITTEE

It is of the utmost importance to respond to the "top 10" research questions we've identified. I realize that most researchers remain guided by the medical model, hoping to cure or delay the signs and symptoms of dementia. This certainly has its place, and it's a worthy goal to be the person who discovered the cure for dementia. But it's the social model of research – answering questions concerned with meaning and lived experience – that will help us to live better here and now.

Even though I have early onset Alzheimer's disease, research is still highly important to me. I'm currently sitting on six different research projects, including the James Lind Alliance Canadian Dementia Priority Setting Partnership.

In the past, when I would participate in research, I felt like the 'token' person with Alzheimer's disease, who would lend validity to the project by enabling the research team to say "we had a person with dementia in our study." When I would share an idea or voice an opinion I wasn't heard – at least not in a meaningful way.

This was unacceptable to me. I am still a person. I am still able to contribute and share my experiences. I am still able to help.

The JLA recognized this fully, and welcomed my perspective. I was fully heard, and engaged in every aspect of the project. But it wasn't just me and my voice. The team was more than willing for me to bring in other voices of the community I am part of to help guide us through the process, benefitting from a broad variety of perspectives.

My hope is that our "top 10" questions will help people living with all types of dementia to live longer in their own homes, to live better, and to be able to cope more easily with this disease.

Sincerely,

Phyllis Fehr

Phyllis Fehr
Ontario Dementia Advisory Group
Member, Canadian Dementia Priority Setting Partnership Steering Committee

APPENDIX A: STEERING GROUP AND STUDY TEAM MEMBERSHIP

Canadian Dementia Priority Setting Partnership Steering Group:

DOROTHY PRINGLE (Chair),
Professor Emerita,
Lawrence S. Bloomberg
Faculty of Nursing,
University of Toronto

MOHAMMAD UL-ALAM

DEBBIE BENCZKOWSKI
Alzheimer Society of Canada

JOAN BULLIVANT-WALLACE

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James Lind Alliance (UK)

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Ontario Dementia Advisory Group

MIRANDA FERRIER
Ontario Personal Support Worker
Association & Canadian Support
Worker Association

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Alzheimer Society of Ontario

DAVID HARVEY
Alzheimer Society of Ontario

ANDREAS LAUPACIS
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CHRIS RAGONETTI

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Toronto Rehabilitation Institute –
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ELANA COMMISSO
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APPENDIX B: LIST OF PARTNER ORGANIZATIONS

Canadian Dementia Priority Setting Partnership Partner Organizations

Alberta Continuing Care Association
Alzheimer Society of Canada
Alzheimer Society of Alberta and Northwest Territories
Alzheimer Society of B.C.
Alzheimer Society of Manitoba
Alzheimer Society of New Brunswick
Alzheimer Society of Newfoundland and Labrador
Alzheimer Society of Nova Scotia
Alzheimer Society of Ontario
Alzheimer Society of Prince Edward Island
Alzheimer Society of Saskatchewan
Canadian Academy of Geriatric Psychiatry
Canadian Association of Occupational Therapists
Canadian Association of Social Workers
Canadian Consortium on Neurodegeneration in Aging
Canadian Geriatrics Society
Canadian Gerontological Nursing Association
Canadian Home Care Association
Canadian Hospice Palliative Care Association
Canadian Neurological Society
Canadian Society of Consultant Pharmacists
Canadian Society of Palliative Care Physicians
Canadian Support Workers Association
Canadian Therapeutic Recreation Association
Family Councils Ontario
Federation of Quebec Alzheimer Societies
Huntington Society of Canada
Ontario Association of Non-Profit Homes and Services for Seniors
Ontario Association of Residents' Councils
Ontario Dementia Advisory Group
Ontario Long Term Care Association
Ontario Personal Support Worker Association
Parkinson Canada
Speech-Language and Audiology Canada
Students Against Alzheimer's University of Toronto

APPENDIX C: LITERATURE SEARCH STRATEGY

DATABASE: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

1 exp Dementia/
2 Delirium, Dementia, Amnestic, Cognitive Disorders/
3 dement*.tw,kw.
4 alzheimer*.tw,kw.
5 (lewy* adj2 bod*).tw,kw.
6 or/1-5
7 meta-analysis.pt.
8 meta-analysis/ or systematic review/ or meta-analysis as topic/ or "meta analysis (topic)"/ or "systematic review (topic)"/ or exp technology assessment, biomedical/
9 ((systematic* adj3 (review* or overview*)) or (methodologic* adj3 (review* or overview*)) or (scoping* adj3 (review* or overview*))).tw,kf,kw.
10 ((quantitative adj3 (review* or overview* or synthes*)) or (research adj3 (integrati* or overview*))).tw,kf,kw.
11 ((integrative adj3 (review* or overview*)) or (collaborative adj3 (review* or overview*)) or (pool* adj3 analy*)).tw,kf,kw.
12 (data synthes* or data extraction* or data abstraction*).tw,kf,kw.
13 (handsearch* or hand search*).tw,kf,kw.
14 (met analy* or metanaly*).tw,kf,kw.
15 (meta regression* or metaregression*).tw,kf,kw.
16 (meta-analy* or metaanaly* or systematic review*).mp,hw.
17 (medline or cochrane or pubmed or medlars or embase or cinahl).tw,hw.
18 (cochrane or evidence report).jw.
19 or/7-18
20 6 and 19
21 (eng or fre).lg.
22 20 and 21
23 limit 22 to yr="2014 – Current"

DATABASE: EBM Reviews – Cochrane Database of Systematic Reviews <2005 to February 15, 2017>

1 dement*.ti,ab.
2 alzheimer*.ti,ab.
3 (lewy* adj2 bod*).ti,ab.
4 "dement*".gw.
5 1 or 2 or 3 or 4
6 limit 5 to full systematic reviews
7 limit 6 to last 4 years

DATABASE: EBM Reviews – Database of Abstracts of Reviews of Effects <1st Quarter 2015>

1 dement*.af.
2 alzheimer*.af.
3 (lewy* adj2 bod*).af.
4 1 or 2 or 3
5 "2014".do.
6 4 and 5

APPENDIX D: FULL LIST OF QUESTIONS FOR DEMENTIA RESEARCH

Complete list of questions prioritized in the Canadian Dementia Priority Setting Partnership

CARE

1. What would improve care for persons with dementia in hospital settings, including emergency departments, inpatient units and rehabilitation facilities?

2. What is the effect of care provided by friend or family caregivers/care partners compared to care provided by paid or professional caregivers on persons with dementia?

3. How do the characteristics of paid or professional caregivers, including consistency, ethnic and cultural background and, languages spoken, impact persons with dementia?

4. Which health care providers/specialists are best suited to manage medical care of persons with dementia?

5. What would help health care providers and persons with dementia and their friend or family caregivers/care partners to work together as a team in caring for persons with dementia?

6. 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?

7. What is the impact of staffing models and staff characteristics on the health and quality of life for persons with dementia living in long-term care homes?

8. What design characteristics and environmental adaptations (including of bathrooms) are best suited for persons with dementia living in long-term care homes?

9. What is the impact of living in separate and/or locked/secured units on persons with dementia living in long-term care homes?

10. What is the impact of regulations and regulatory compliance on care, health and quality of life for persons with dementia living in long-term care homes?

11. 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?

12. 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?

13. What are effective ways to prevent and manage physical conditions in persons with dementia, including pain, difficulty swallowing, urinary tract infections, and mobility issues that can lead to falls?

14. How can care, services and treatments for dementia be tailored to meet the needs of persons with young onset dementia and their friend or family caregivers/care partners?

15. How can care, services and treatments for dementia be tailored to meet the needs of diverse individuals and groups of persons with dementia? Including:
    - persons with intellectual disabilities (including Down syndrome)
    - persons with mental illness
    - Indigenous persons
    - persons of different sex and/or gender

16. How can care, services and treatments for dementia be tailored to meet the needs of persons with dementia who are without family support?

17. What would improve access to health and social care services and supports for persons with dementia and their friend or family caregivers/care partners living in rural and remote areas?

18. What is the role for, and effect of, genetic counseling for people with a family history of dementia?

DIAGNOSIS

19. What is the impact of a dementia diagnosis on persons receiving the diagnosis and on their friends, family and caregivers/care partners?

20. What tests and assessment procedures would improve the diagnostic process and enable a more accurate and timely dementia diagnosis (including by type of dementia)?

21. What would make the tests and assessment procedures used to diagnose dementia more acceptable and appropriate for use in different individuals and groups?

22. What would make the process of obtaining a dementia diagnosis more personalized and family-focused?

23. 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?

24. What would enable persons with dementia to obtain an early diagnosis? In what ways does obtaining an early diagnosis benefit persons with dementia and their friends, family and caregivers/care partners?

25. What tests and protocols can improve the ability to predict a person's risk of developing dementia before noticeable signs and symptoms are apparent, including in people with a family history of dementia? What is the impact of obtaining information about one's risk of developing dementia on prevention, treatment and care planning?

26. What information and assessment procedures would improve the ability to determine stages of disease and predict rate of disease progression for different types of dementia?

LIVING WITH DEMENTIA

27. What would help persons with dementia meet their transportation needs?

28. What are the costs and benefits of alternative models of housing, including dementia villages and small group homes? Including costs and benefits to the individual, their family, and society.

29. What are the costs and benefits of remaining at home in the community (with supports) compared to living in other settings such as long-term care and retirement homes? Including costs and benefits to the individual, their family, and society.

30. What would help persons with dementia and/or their friend or family caregivers/care partners recognize when the transition to a more supportive living environment should happen? What would make the transition process easier for persons with dementia and their friend or family caregivers/care partners?

31. What would help persons with dementia to continue living in their own homes or living environments of choice?

32. What services, supports and therapies for friend or family caregivers/care partners of persons with dementia would improve or maintain health, well-being and quality of life for persons with dementia and their friends or family caregivers/care partners?

33. What would improve communication between persons with dementia and their friends, family and caregivers/care partners? Including how to respond to persons with dementia when what they perceive to be happening is not actually happening and whether to remind persons with dementia that they have dementia.

34. What would help friends, family and caregivers/care partners assess awareness and feelings in persons with dementia who have difficulty communicating?

35. What would help increase awareness and acceptance among persons with dementia and their friends and family who are in denial or resistant to care?

36. What would improve the process of driving cessation (transition away from driving) for persons with dementia and their friends, families and care partners, including determining when a person should stop driving?

37. What are effective ways of providing clear, accurate and timely information and education about dementia to persons with dementia, their friends, family and caregivers/care partners?

38. What would help persons with dementia and/or their family, friends and caregivers/care partners plan and execute end of life decisions (including but not limited to medical assistance in dying)?

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

40. Among persons with dementia, what is the impact of diet, specific foods, nutrients or nutritional supplements on quality of life, disease progression and cognitive symptoms?

41. Among persons with dementia living in different settings, what is the impact of physical, mental and social activities, including programmed activities, on quality of life, disease progression and cognitive symptoms?

42. Among persons with dementia, what is the impact of support groups and services on quality of life, disease progression and cognitive symptoms?

43. Among persons with dementia, what is the impact of social connectedness and personal support networks (including involved caregivers/care partners), on quality of life, disease progression and cognitive symptoms?

44. Among persons with dementia, what is the impact of social determinants of health, including income and social status, on quality of life and disease progression?

45. Among persons with dementia, how do other physical and mental health conditions and the management of these conditions (including drug interactions) impact quality of life, disease progression and cognitive symptoms?

46. What would help persons with dementia to maintain their independence and complete activities of daily living (including eating, bathing, dressing, taking medications, managing money and using the telephone) while remaining safe and minimizing risk (including financial)?

47. What can be done in the workplace to enable persons with dementia to continue working?

48. What would improve approaches to determining competency and capacity in persons with dementia? Including competency for medical and legal decision-making and capacity to live alone.

49. What would enable persons with dementia and their friends, family and caregivers/care partners to be more actively involved and engaged in research?

50. What would help persons with dementia and their friends, family and caregivers/care partners plan for different stages of disease progression and future care needs?

PREVENTION

51. Do cognitive stimulation activities prevent or delay the onset of dementia?

52. Do nutritional supplements and remedies prevent or delay the onset of dementia?

53. What lifestyle factors, independently or in combination, prevent or delay development of dementia? Including:
    - Diet, specific foods or nutrients
    - Physical activity
    - Consuming alcohol, tobacco or cannabis
    - Sleep habits, including amount of sleep

54. Do social connections, interactions and activities prevent or delay the onset of dementia?

55. Does multilingualism, being able to use more than one language, prevent or delay the onset of dementia?

56. Is there a causal relationship between physical and mental health conditions and dementia? What is the impact of treatments and therapies (including medications) for these physical and mental health conditions on the risk of developing dementia?

57. Is there a causal relationship between environmental pollutants, food additives and preservatives, and water and soil contaminants and dementia?

58. Is there a causal relationship between exposure to certain digital devices and technologies, including computers, cellular telephones and WIFI, and dementia?

59. Is there a causal relationship between traumatic life events and dementia?

60. Do spirituality or spiritual practices (including meditation) prevent or delay the onset of dementia?

61. What is the impact of social determinants of health, including income, education and employment and working conditions, on the risk of developing dementia?

62. Why is dementia more common in women than men?

63. How can prevention strategies be tailored according to age, sex and/or gender and specific risk factors, including family history of dementia?

SOCIETAL

64. What are effective ways of raising awareness about dementia in the general public and, in particular, among persons working in service and public sectors?

65. 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?

66. What would help reduce social isolation and/or promote social inclusion for persons with dementia and their friends, family and caregivers/care partners?

67. 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?

68. How do media representations of persons with dementia impact stigmas associated with dementia?

69. How can the ethical issues of involving persons with dementia in research, including consent, be better addressed?

TREATMENT

70. What pharmacological treatments (including psychotropic and non-psychotropic drugs and medical marijuana) are effective for managing behavioural and psychological symptoms of dementia?

71. 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?

72. How can drug delivery methods, including pills and patches, be adapted to meet the needs of persons with dementia?

73. What is the effect of current medications for dementia on quality of life, disease progression, and cognitive symptoms? What are the side-effects and safety issues, including drug interactions, of the current medications?

74. What person-level factors (e.g., personality, genetic, psychological, baseline function, stage of disease) influence the response to pharmacological and non-pharmacological treatments for dementia?

75. What are the best outcomes and measures to assess the effect of pharmacological and non-pharmacological treatments for dementia?

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

77. Among persons with dementia, what is the impact of complementary and alternative medicines and therapies on quality of life, disease progression, and cognitive symptoms?

78. Among persons with dementia, what is the impact of brain stimulation procedures, including deep brain stimulation?

79. Among persons with dementia, what are the effects of non-pharmacological treatments compared to pharmacological treatments on quality of life, disease progression, and cognitive symptoms? Can non-pharmacological treatments replace, reduce, or be used in conjunction with pharmacological treatments?

APPENDIX E: DESCRIPTION OF SURVEY RESPONDENTS

Description of responses to the Canadian Dementia Priority Setting Partnership survey to identify research questions, May-August, 2016 (n=1217 individual and group responses)

Are you completing this questionnaire alone, or as a pair or group?	n	%
Alone	1096	90.1%
As a pair or group	67	5.5%
Not specified	54	4.4%
Which of the following best describes you or the members of your pair or group? Check all that apply.		
Person with dementia	44	3.6%
Partner/relative/friend of a person with dementia	642	52.8%
Caregiver/former caregiver of a person with dementia	438	36.0%
Health and/or social care provider, current profession:	333	27.4%
Nurse	70	5.8%
Occupational therapist	23	1.9%
Pharmacist	26	2.1%
Physician	50	4.1%
Physiotherapist	4	0.3
Personal support worker, care aide or community health worker	20	1.6%
Recreation therapist	46	3.8%
Social worker	33	2.7%
Speech language pathologist or audiologist	10	0.8%
Other	87	7.1%
Part of an organization representing people with dementia	110	9.0%
No direct experience of dementia, but interested in it	63	5.2%
Which type of dementia do you or the members of your pair or group have experience with? Check all that apply.		
Alzheimer’s disease	880	72.3%
Vascular dementia	484	39.8%
Dementia with Lewy bodies	320	26.3%
Young onset dementia	266	21.9%
Creutzfeldt-Jakob disease	92	7.6%
Fronto-temporal dementia	296	24.3%
Mild cognitive impairment	389	32.0%
Dementia, but don’t know which type	305	25.1%
Other	59	4.8%
No direct experience of dementia	39	3.2%

Prefer not to say	3	0.2%
Which part of Canada do you or the members of your pair or group live in? Check all that apply.		
Alberta	134	11.0%
British Columbia	165	13.6%
Manitoba	92	7.6%
New Brunswick	16	1.3%
Newfoundland and Labrador	12	1.0%
Northwest Territories	4	0.3%
Nova Scotia	43	3.5%
Nunavut	0	0.0%
Ontario	479	39.4%
Prince Edward Island	6	0.5%
Quebec	164	13.5%
Saskatchewan	75	6.2%
Yukon	1	0.1%
What were the ethnic or cultural origins of your ancestors? Check all that apply.		
North American Aboriginal	43	3.5%
Other North American (e.g. Canadian or American)	508	41.7%
European	696	57.2%
Caribbean	9	0.7%
Latin, Central, or South American	12	1.0%
African	6	0.5%
Oceania (e.g. Australian)	2	0.2%
Asian (e.g. Middle Eastern, South, East, and Southeast Asian)	65	5.3%
Prefer not to say	18	1.5%
How do you identify?		
Male	206	16.9%
Female	871	71.6%
Other	2	0.2%
Prefer not to say/not specified	138	11.3%
In what year were you born?		
1900 – 1919	0	0.0%
1920 – 1939	115	9.4%
1940 – 1959	509	41.8%
1960 – 1979	362	29.7%
1980 – 1999	82	6.7%
Prefer not to say/not specified	149	12.2%

APPENDIX F: DESCRIPTION OF INTERIM PRIORITIZATION RESPONDENTS

Description of responses to the Canadian Dementia Priority Setting Partnership interim prioritization survey, April-May, 2017 (n=249 individual and group responses)

Are you completing this questionnaire alone, or as a pair or group?	n	%
Alone	234	94.0%
As a pair or group	5	2.0%
Not specified	10	4.0%
Which of the following best describes you or the members of your pair or group? Check all that apply.		
Person with dementia	10	4.0%
Partner/relative/friend of a person with dementia	127	51.0%
Caregiver/former caregiver of a person with dementia	87	34.9%
Health and/or social care provider, current profession:	55	22.1%
Nurse	14	5.6%
Occupational therapist	7	2.8%
Pharmacist	0	0.0%
Physician	2	0.8%
Physiotherapist	0	0.0%
Personal support worker, care aide or community health worker	3	1.2%
Recreation therapist	9	3.6%
Social worker	5	2.0%
Speech language pathologist or audiologist	1	0.4%
Other	17	6.8%
Part of an organization representing people with dementia	27	10.8%
No direct experience of dementia, but interested in it	7	2.8%
Which type of dementia do you or the members of your pair or group have experience with? Check all that apply.		
Alzheimer's disease	179	71.9%
Vascular dementia	103	41.4%
Dementia with Lewy bodies	58	23.3%
Young onset dementia	57	22.9%
Creutzfeldt-Jakob disease	19	7.6%
Fronto-temporal dementia	57	22.9%
Mild cognitive impairment	66	26.5%
Dementia, but don't know which type	42	16.9%
Other	9	3.6%
No direct experience of dementia	4	1.6%
Prefer not to say	0	0.0%

APPENDIX F: DESCRIPTION OF INTERIM PRIORITIZATION RESPONDENTS

Which part of Canada do you or the members of your pair or group live in? Check all that apply.		
Alberta	23	9.2%
British Columbia	52	20.9%
Manitoba	20	8.0%
New Brunswick	2	0.8%
Newfoundland and Labrador	3	1.2%
Northwest Territories	0	0.0%
Nova Scotia	6	2.4%
Nunavut	0	0.0%
Ontario	96	38.6%
Prince Edward Island	1	0.4%
Quebec	32	12.9%
Saskatchewan	12	4.8%
Yukon	1	0.4%
What were the ethnic or cultural origins of your ancestors? Check all that apply.		
North American Aboriginal	7	2.8%
Other North American (e.g. Canadian or American)	92	36.9%
European	153	61.4%
Caribbean	3	1.2%
Latin, Central, or South American	4	1.6%
African	2	0.8%
Oceania (e.g. Australian)	0	0.0%
Asian (e.g. Middle Eastern, South, East, and Southeast Asian)	10	4.0%
Prefer not to say	6	2.4%
How do you identify?		
Male	54	21.7%
Female	177	71.1%
Other	0	0.0%
Prefer not to say/not specified	18	7.2%
In what year were you born?		
1900 – 1919	1	0.4%
1920 – 1939	22	8.8%
1940 – 1959	128	51.4%
1960 – 1979	65	26.1%
1980 – 1999	15	6.0%
Prefer not to say/not specified	18	7.2%