

Seniors' health in Alberta: Asking the right questions of future research



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Alberta Seniors' Health Research Priority Setting Partnership

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This report has been prepared by the Seniors' Health Research Priority Setting Partnership Steering Group, in partnership with the Seniors Health Strategic Clinical Network™, Alberta Health Services, and the James Lind Alliance, National Institute for Health Research.

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Executive Summary

What matters most for seniors' health in Alberta?

The AHS Seniors Health Strategic Clinical Network™ brought together patients, caregivers, and clinicians on equal footing to shape the health research agenda.

Working with our partners and guided by our steering group, we identified and prioritized the questions about seniors' health and healthcare that seniors, caregivers, and health/social care providers most want future research to answer.

The Process:



Gathering the questions:

670 people provided over
3000 survey responses
97 summary questions were identified and found to be unanswered by current evidence



Reviewing common trends:

232 people then took part in a second survey to review the summary questions and select the questions they saw as being most important
22 questions were shortlisted as greatest priority



Final prioritization:

22 participants discussed and ranked the shortlisted questions. The result is a "Top 10" list of questions for future research to address.



Introduction

In this final report, we describe the process and outcome of the Alberta Seniors' Health Research Priority Setting Partnership conducted in Alberta, Canada. This project was led by the Alberta Health Services Seniors Health Strategic Clinical Network™ (SCN). The mission of the Seniors Health SCN is to make improvements to healthcare services and practices that enable Alberta's seniors to optimize their health, well-being, and independence.

Since its inception, the Seniors Health SCN has worked to build partnerships to engage in, promote, and advance the use of knowledge to achieve the SCN's mission. We have supported and led a variety of research activities aligned with the platforms of the SCN. However, how topics across seniors' health weigh against one another in terms of greatest priority is not known. Therefore, we embarked on a wide public engagement and prioritization process to understand the knowledge needs of research end-users, and to prioritize those needs. The well-established James Lind Alliance (JLA) method was selected and a Priority Setting Partnership (PSP) was launched in 2017.

Utilizing the PSP process, we sought to create an agreed upon prioritized list of unmet knowledge needs according to participating members of the public, caregivers, and health and social care providers. The product of this undertaking, the "Top 10 List", will be widely disseminated in an effort to promote uptake of research in the prioritized areas. In the next section, we describe the process utilized in this PSP. Further information about the James Lind Alliance or PSPs can be found on the JLA website (www.jla.nihr.ac.uk/).

Process

Establishing the PSP

After working with the JLA on initial readiness to launch the PSP, we identified and invited agencies, organizations, and individuals who shared in our goal and would help us promote this work and the outcome to their groups. Invited partners were those that comprised, represented, or served one or more of the PSPs target groups:

- Older adults (65 years of age and over),

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- Caregivers / partners of older adults (such as a spouse, family member, friend, or neighbour), and
- Clinicians or health/social care providers (such as a doctor, nurse, care aide, allied health provider, pharmacist, or social worker) working with older adults.

Over 40 groups, committees, associations, or organizations agreed to join the partnership and assisted us by promoting the PSP and our recruitment phases.

Simultaneously, we put out an Expression of Interest to recruit a Steering Group. The Steering Group met approximately monthly and guided the conduct and timeline of the PSP, supported by the project team and the JLA. The group represented the constituent groups of older adults, caregivers, and clinicians, and included representatives of agencies/organizations serving these groups. We targeted membership from 2-3 people representing each of these groups plus the JLA advisor and the project team.

Initial Survey

The first data collection phase was a survey to identify unanswered questions about seniors' health. The JLA uses language of 'treatment uncertainties', but for this PSP the Steering Group decided to use the language of "unanswered questions". This decision was made so that the scope of the PSP was not limited to clinical care and treatment, acknowledging that there are issues important to seniors' health that do not arise directly from clinical healthcare encounters.

The survey utilized open-ended questions to ask respondents what mattered most to them about seniors' health. Six topic areas guided respondents:

- Aging well
- Healthcare practices or services for older adults
- Preventing illness or disease
- The diagnosis or treatment of illness or disease
- Managing symptoms or conditions, or supporting someone with health conditions
- Maintaining mental health and social participation in older age

The final section included demographic information to assess our recruitment efforts and categorize responses. The survey was pilot tested with Steering Group members and their known associates prior to finalization.

Target participants were older adults, caregivers of older adults, and clinicians or health/social care providers working with older adults who either lived or worked in Alberta. We also included representatives of agencies or organizations serving these

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groups. The invitation to participate was circulated to our partners, posted on the Seniors Health SCN website, tweeted on social media, and advertised by word-of-mouth through the Steering Group.

Responses were accepted from January to May, 2018 through an online survey and by hard copy submissions. We received 88 pen-and-paper surveys (13%) and 592 submitted electronically (87%), resulting in 670 surveys included in data generation (10 surveys were returned with demographic information only, and were therefore excluded). The respondent demographic characteristics can be found in Tables 1 to 3. Approximately half of participants were older adults and caregivers (52.4%).

Table 1

Sample Description for Initial Survey to Identify Unanswered Questions Affecting Seniors' Health

Respondent Group	N	%
Older Adults	219	32.7
Caregivers	132	19.7
Health and Social Care Workers	314	46.9
Representatives from Related Agencies/ Organizations	5	0.7
Total	670	100

Survey responses were reviewed and categorized by theme to generate an initial taxonomy. Similar and duplicate questions were merged and rephrased where necessary to create a summary question that represented the underlying responses. The taxonomy and example questions were reviewed by the Steering Group, including potential out-of-scope submissions for decision-making. Summary topics were considered to be outside of the scope of this PSP if assessed as likely to have limited evidence available in published synthesis-level literature (clinical guidelines, systematic reviews, and/or meta-analyses) and/or limited relevance to potential health research funders.

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Table 2

Initial Survey Older Adult and Caregiver Respondents' Age, Sex, and Ethnicity

Variable	Older Adults	Caregivers
Age, mean (SD)	73.5yrs (6.4yrs)	57.5yrs (9.4yrs)
Female ^a , n (%)	155 (70.8%)	116 (87.9%)
Ethnicity, n (%)		
North American Indigenous (e.g., First Nations, Metis, or Inuk [Inuit])	3 (1.4%)	4 (3.0%)
Other North American (e.g., Canadian, American, Quebecois)	110 (50.2%)	61 (46.2%)
European	120 (54.8%)	68 (51.5)
Asian (e.g., Middle Eastern, South, East, and Southeast Asian)	15 (6.8%)	8 (6.1%)
Other (Caribbean; Latin, Central, or South American; African; Oceania [e.g., Australian])	3 (1.4%)	0
Prefer not to say	3 (1.4%)	4 (3.0%)

^aOne individual responded as not identifying as male or female and 4 individuals responded as preferring not to answer.

All final summary questions were reviewed by the Steering Group members working in pairs to ensure that the summary questions accurately captured the underlying raw data. A total of 101 within scope summary questions were produced from over 3000 responses submitted to the initial survey.

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Table 3

Initial Survey Health and Social Care Worker Respondents' Professional Backgrounds and Work Settings

Category	N	%
<i>Professional Background</i>		
Aide (HCA, NA, TA)	7	2.2
Nurse (RN, RPN, LPN)	92	28.8
Nurse Practitioner	2	0.6
Social Worker	44	13.8
Allied Health Professional (PT, OT, RT, SLP, Rec.T)	112	35.1
Physician	11	3.4
Pharmacist	2	0.6
Dietician	15	4.7
Manager/Administrator	9	2.8
Other	11	3.4
No Answer	14	4.4
<i>Work Setting</i>		
Primary and Community Care	132	42.0
Acute Care	81	25.8
Continuing Care	118	37.6
Other	32	10.2

Assessment of Uncertainty

The summary questions were assessed against published scientific literature to determine whether or not the questions were unanswered and represented a knowledge gap. Working with a library sciences team from Knowledge Resource Services, Alberta Health Services, we reviewed each summary question against systematic reviews and clinical guidelines through the following resources:

- The Cochrane Database of Systematic Reviews
- NICE guidelines
- SIGN clinical guidelines

The search was limited to English language evidence published in the past 10 years. Where evidence was identified, we reviewed the content to determine the degree to which the evidence answered the summary question. This process produced three

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potential outcomes for each summary question. Questions were determined to be completely answered, partially answered, or completely unanswered. We elected to maintain any partially answered questions in the process as they represented some degree of uncertainty. The majority of summary questions were determined to be unanswered (Table 4).

Table 4

Outcome of the Literature Review Evidence Checking for 101
Summary Questions

Summary Question Outcome	N	%
Fully answered question	4	4
Partially answered question	30	30
Unanswered question	67	66
Total	101	100

Interim Prioritization Survey

Due to the broad nature of this PSP, we anticipated that the majority of the summary questions would be unanswered or partially answered. As such, and to achieve the project timelines, we ran the interim prioritization stage in parallel with the assessment of uncertainty, and sought prioritization of 101 summary questions by respondents to a second survey. This was conducted to reduce the amount of data brought forward to final prioritization workshop.

We utilized the same recruitment strategy as the initial survey, seeking assistance from our partners to circulate the survey to our three target respondent groups. The survey asked respondents to review the summary questions and select the 10 questions that they felt to be of greatest importance. The survey concluded with basic demographic questions to categorize respondents.

We received 232 completed surveys within the 4-week data collection period. The respondent demographic characteristics can be found in Tables 5 to 7. The distribution of respondents across the three constituent groups was approximately the same as the initial survey (53.0% older adults and caregivers).

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Table 5

Sample Description for the Interim Prioritization Survey

Respondent Group	N	%
Older Adults	66	28.4
Caregivers	57	24.6
Health and Social Care Workers	109	47.0
Total	232	100

Table 6

Interim Prioritization Survey Older Adult and Caregiver Respondents' Age, Sex, and Ethnicity

Variable	Older Adults	Caregivers
Age, mean (SD)	72.7yrs (5.8yrs)	60.3yrs (9.9yrs)
Female ^a , n (%)	50 (75.8%)	47 (82.5%)
Ethnicity, n (%)		
North American Indigenous (e.g., First Nations, Metis, or Inuk [Inuit])	0	1 (1.8%)
Other North American (e.g., Canadian, American, Quebecois)	29 (43.9%)	26 (45.6%)
European	41 (62.1%)	32 (56.1%)
Asian (e.g., Middle Eastern, South, East, and Southeast Asian)	1 (1.5%)	3 (5.3%)
Other (Caribbean; Latin, Central, or South American; African; Oceania [e.g., Australian])	1 (1.5%)	0
Prefer not to say/No Answer	0	0

^a One caregiver responded as preferring not to answer.

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Table 7

Interim Prioritization Survey Health and Social Care Worker Respondents' Professional Backgrounds and Work Settings

Category	N	%
<i>Professional Background</i>		
Aide (HCA, NA, TA)	1	0.9
Nurse (RN, RPN, LPN)	35	32.1
Nurse Practitioner	4	3.7
Social Worker	18	16.5
Allied Health Professional (PT, OT, RT, SLP, Rec.T)	22	20.2
Physician	12	11.0
Pharmacist	0	0
Dietician	2	1.9
Manager/Administrator	6	5.5
Other	7	6.4
No Answer	2	1.8
<i>Work Setting</i>		
Primary and Community Care	55	50.5
Acute Care	36	33.0
Continuing Care	35	32.1
Other	10	9.2

The outcome of the assessment of uncertainty was then applied to the interim prioritization list, removing the 4 summary questions assessed as completely answered before assessing the prioritization rankings.

Submissions were analyzed within respondent groups to identify the top 10 questions according to each group in order to ensure equal weighting of the high priority questions. Some questions were ranked as high priority by more than one constituent group, identifying potential areas of shared priority (Table 8). This resulted in 22 questions shortlisted and brought forward to the final prioritization workshop.

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Table 8

Prioritization of Shortlisted Questions by
Number of Respondent Groups

Question Prioritization	Count
Prioritized by 1 group	15
Prioritized by 2 groups	5
Prioritized by all 3 groups	2
Total	22

Final Prioritization Workshop

As the final stage in identifying the top areas for future research on seniors' health we held a final prioritization workshop. An expression of interest call was circulated to identify a diverse mix of attendees interested in participating in the one-day, in-person event. The objective of the workshop was to facilitate reflection and discussion on the short list of summary questions and reach agreement on the top 10 most important questions.

Workshop attendees were individuals representing at least one of the constituent groups, although the majority of attendees identified with more than one group (such as a clinician who is also a caregiver of an aging parent). In total, 22 people participated in the one day, in-person workshop. Clinician perspectives were well represented, including nursing, allied health, nutrition, and medicine. Also present were attendees bringing the lens of health administration, nursing regulatory, housing, and seniors' advocacy. Although older adults and caregivers were in the minority, many clinicians also held this perspective and were encouraged to draw upon their professional and personal experiences while participating in the day.

In advance of the workshop, attendees were provided the shortlist of summary questions and asked to review and rank the questions according to their perspective. The workshop began with an overview of the day, and a brief presentation of the method and results of the work leading to the shortlisted priorities. Attendees then broke into small groups and began an initial round of review and ranking of the summary questions (Figure 1). Each of the three small groups was led by a facilitator familiar with the JLA approach and employed a modified Nominal Group Technique. Attendees then reviewed the aggregate ranked list as a large group and then broke into a second round of small group discussions with new group designations. Attendees returned to the large group for review and discussion of the second aggregate ranked

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list. The large group was facilitated by the JLA Advisor, who supported the discussion and decision-making as the group came to agreement on the final rankings of the summary questions (Figure 2). The workshop concluded with consensus reached on the rank order of the top 10 list of summary questions (below).



Figure 1: Final workshop attendees participating in small group discussion to sort the 22 shortlisted summary questions into an initial list by shared rankings.

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Figure 2. Final workshop attendees participating in large group discussion and decision-making to determine the final list of top questions for future research to address.

Top 10 List

The Alberta Seniors' Health PSP led to the following list of the top 10 topics for future research to address:

1. What strategies best allow older adults to remain independent for as long as possible?
2. In what ways can the healthcare system become more proactive, instead of reactive, in addressing and encouraging prevention of disease/disability?

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3. In what ways can healthcare service accessibility for older adults living in a rural community be improved?
4. How can geriatric-related knowledge among healthcare providers be improved and applied when caring for older adults?
5. What are the optimal ways to ensure healthcare providers take into consideration the goals and wishes of the older adult during care/treatment?
6. What can be done to increase availability of dementia-related care and services for older adults?
7. What interventions and programs best enable older adults to more easily navigate the healthcare system?
8. What are the most effective programs and services which can be provided to caregivers to combat burnout and stress when caring for older adults?
9. What is the most effective strategy to ensure an optimal transition between care settings for older adults?
10. How can healthcare encounters be restructured to allow older adults sufficient time with providers to discuss complex concerns in one appointment?

Next Steps

This PSP produced a list of the top 10 questions for research on seniors' health in Alberta. This list will be used to inform future SCN activities. It will also be used to assess requests for letters of support and decisions on the opportunities we offer to the research community. Our intent is to use this list to drive research forward in the top areas identified as being of greatest importance for seniors' health.

Call to Action

We now seek assistance from stakeholders to champion uptake of the Top 10 List. All stakeholders can assist by promoting the Top 10 List and advocating for research in the identified areas. Patients, caregivers, and clinicians can participate in research studies producing new knowledge. Researchers can conduct research to generate evidence on one of the top 10 questions. Research funding bodies, including both traditional and non-traditional health research funders, can prioritize research grants addressing projects identified to be of importance to knowledge users, such as the topics identified in the Top 10 List produced by this PSP. Together, we can make great strides to meet

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the informational needs of end-users of seniors' health and healthcare knowledge – patients, caregivers, and the health and social care providers who serve them.

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Members of the Alberta Seniors' Health Research PSP Steering Group included:

Fran Jamison, Patient Member
Sandy McMeekin, Patient Member
Pat Fonstad, Caregiver Member
Lisa Poole, Caregiver Member
Leslie Saunders, Caregiver Member
Katie Churchill, Clinician Member
Karen Leung, Clinician Member
Suzanne Nichol, Clinician Member
Jessica Lamb, Representative Member
Nicole Smith, Representative Member
Navjot Virk, Representative Member
Katherine Cowan, JLA Advisor
Billy Zhao, PSP Coordinator
Dr. Heather Hanson, PSP Lead and Chair
Dr. Adrian Wagg, PSP Lead and PI

Appendix

Through discussion and shared decision-making, the final workshop attendees ranked the shortlisted summary questions in order of priority. The summary questions were ranked as follows:

1. What strategies best allow older adults to remain independent for as long as possible?
2. In what ways can the healthcare system become more proactive, instead of reactive, in addressing and encouraging prevention of disease/disability?
3. In what ways can healthcare service accessibility for older adults living in a rural community be improved?
4. How can geriatric-related knowledge among healthcare providers be improved and applied when caring for older adults?
5. What are the optimal ways to ensure healthcare providers take into consideration the goals and wishes of the older adult during care/treatment?
6. What can be done to increase availability of dementia-related care and services for older adults?
7. What interventions and programs best enable older adults to more easily navigate the healthcare system?
8. What are the most effective programs and services which can be provided to caregivers to combat burnout and stress when caring for older adults?
9. What is the most effective strategy to ensure an optimal transition between care settings for older adults?
10. How can healthcare encounters be restructured to allow older adults sufficient time with providers to discuss complex concerns in one appointment?

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11. In what ways can quality of care in continuing care settings best be improved?
12. What strategies best allow older adults to remain in their own homes for as long as possible?
13. What is the most effective strategy for information sharing and collaboration between healthcare providers of different disciplines and/or at different facilities in order to ensure continuity of care?
14. What can be done to increase the availability of services to support older adults to live in their own homes?
15. In what ways can seniors with dementia be better supported by hospital staff when visiting the emergency department?
16. What information should healthcare providers provide to and discuss with older adults and their families to best improve end-of-life care?
17. How can behaviours associated with dementia (e.g., aggression) be most effectively managed through non-pharmacological approaches?
18. What educational strategies are most effective in improving the knowledge of staff working in continuing care setting?
19. What are the most effective strategies to allow people to die on their own terms?
20. What strategies are most effective for improving the environment of continuing care to make it feel more home-like for residents?
21. What strategies are most effective in preventing and/or delaying the onset of dementia?
22. What are the optimal ways for caregivers of older adults to have time away from employment in order to provide care?