

Identifying what matters most for seniors' health

RESEARCH

Short running header: Identifying what matters most for seniors' health

## Identifying what matters most for seniors' health in Alberta: Results from a James Lind Alliance Research Priority Setting Partnership

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12 Group for their contributions guiding this initiative.  
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## Abstract

**Background:** Older adults, their caregivers, and front line clinicians are often underrepresented in research priority-setting. James Lind Alliance (JLA) Priority Setting Partnerships (PSPs) actively engage these groups to determine research questions that matter to them as end-users of research findings. We conducted a PSP to bring these groups together to identify and prioritize the most important topics on seniors' health in Alberta that should be addressed by future research.

**Methods:** We followed the JLA method. We conducted an initial survey to identify what respondents saw as being most important for seniors' health in Alberta. Responses were formed into summary questions and checked against existing evidence. A second survey shortlisted the summary questions and an in-person workshop was held to rank the list through discussion and shared decision-making.

**Results:** We recruited 670 participants to tell us what mattered most to them for seniors' health. Over 3000 responses generated 101 summary questions, of which only 4 were completely answered by existing evidence. The interim prioritization survey was completed by 232 participants to produce a shortlist of 22 high priority questions. Twenty-two attendees participated in a summary workshop to create a prioritized list of questions for future research on seniors' health. Questions within the Top 10 list addressed aspects of the health system, provision of care, and living well in older adulthood.

**Interpretation:** Seniors, caregivers, and clinicians co-produced a prioritized list of questions that matter most to seniors' health in Alberta. Researchers and research funders should address these unmet end-user knowledge needs.

Identifying what matters most for seniors' health

**Keywords:** geriatrics; priority setting; research decision-making; health; wellbeing

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## Introduction

As the number and proportion of older adults (65+y) continues to increase(1, 2), seniors' health will be increasingly important for individuals and the healthcare system. Research is needed to uncover new approaches to improve health outcomes and system sustainability. Alberta's Seniors Health Strategic Clinical Network™ (SCN) aims to improve healthcare services and practices for older Albertans through health system transformation(3). With the fiscal constraints of a publicly funded health system and limited availability of research dollars, identifying and pursuing health research questions of greatest priority is vital to maximizing impact.

There is growing emphasis on the need to conduct research that is patient-oriented, guided by and conducted with meaningful engagement with patients (4, 5). A compelling outcome of patient-oriented approaches is the improved fit between knowledge needs and knowledge production. Research that meets a clear need of end-users decreases the risk of wasting valuable public resources on findings with low relevance, impact, or real-world application(6). Patient-oriented clinical research also aligns with the provincial commitment to patient and family centred care, which views patients as integral members of the health care team(7).

One method for purposefully engaging research end-users is the James Lind Alliance (JLA) Priority Setting Partnership (PSP) approach. The JLA is a non-profit initiative whose infrastructure is supported by the UK's National Institute for Health Research. PSPs bring together those often under-represented at the priority-setting table—patients, caregivers, and clinicians—to identify and prioritize questions of greatest importance(8), shaping the health research agenda and ultimately bringing awareness to researchers and funders of what matters

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3 most to the people who use research evidence(9). PSPs have been successfully conducted across  
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5 a range of topics, including dementia, urinary incontinence, Parkinson's disease, and fragility  
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7 fractures(10-13). Given the strengths of this approach, we sought to conduct a PSP. Unlike the  
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9 majority of single condition PSP, we purposefully aimed to produce a broader themed exercise  
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11 inclusive of the range of seniors' health concerns. Therefore, the goal of this PSP was to bring  
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13 older adults, caregivers, clinicians, and their representative organisations together in a wide  
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15 engagement exercise to identify and prioritize the most important questions on seniors' health  
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17 that future research should address.  
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## 22 **Methods**

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25 We followed the JLA method for PSPs(9). This work was overseen by an independent  
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27 JLA Advisor(9). We partnered with agencies, organizations, and individuals who shared in our  
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29 goal and would help us promote this work and the outcome to their groups. Partners comprised,  
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31 represented, or served one or more of the PSPs target groups:  
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- 35 • Older adults (65+ years of age),
- 36 • Caregivers/partners of older adults (e.g., spouse, family member, friend, neighbour),  
37 and
- 38 • Front line clinicians or social care providers (e.g., doctor, nurse, care aide, allied  
39 health provider, pharmacist, social worker, community/social service provider)  
40 working with older adults.  
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43 Simultaneously, we recruited a Steering Group by an Expression of Interest. The group  
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45 met monthly to guide the process and represented our three constituent groups (above) including  
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47 representatives of agencies/organizations serving these groups. We targeted membership from 2-  
48  
49 3 people representing each group plus the JLA advisor and the project team.  
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52 Initial data were collected by a survey to identify unanswered questions about seniors'  
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54 health. Acknowledging that there are issues important to seniors' health that do not arise directly  
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3 from clinical healthcare encounters, the Steering Group decided to use the language of  
4  
5 “unanswered questions” rather than the JLA language of “treatment uncertainties”. The survey  
6  
7 utilized open-ended questions to ask respondents what mattered most to them about seniors’  
8  
9 health within 6 topic areas:

- 12 • Aging well
- 13 • Healthcare practices or services
- 14 • Preventing illness or disease
- 15 • Diagnosis or treatment of illness or disease
- 16 • Managing symptoms or conditions, or supporting someone with health conditions
- 17 • Maintaining mental health and social participation

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20 The final section included demographic information to assess our recruitment efforts and  
21  
22 categorize responses. The survey was pilot tested and refined by minor edits for clarity prior to  
23  
24 distribution.

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26  
27 Target participants were older adults, their caregivers, and clinicians or social care  
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29 providers working with older adults who either lived or worked in Alberta, including  
30  
31 representatives of agencies/organizations serving these groups. The invitation to participate was  
32  
33 circulated through our partners, the Seniors Health SCN website, social media, and by word-of-  
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35 mouth. The survey was completed online or by hard copy submissions returned in postage  
36  
37 prepaid reply envelopes.

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40 Survey responses were reviewed and categorized by content area to generate an initial  
41  
42 taxonomy (Figure 1). Similar and duplicate questions were merged and rephrased where  
43  
44 necessary to create a summary question that represented the underlying responses. The taxonomy  
45  
46 and example questions were reviewed by the Steering Group, including potential out-of-scope  
47  
48 submissions for decision-making. Submissions falling outside of the scope of the PSP were  
49  
50 removed: procedures or protocols relating to regulations/policies, advocacy on seniors’ issues,  
51  
52 and housing and transportation when not framed in connection to health. All final summary  
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3 questions were reviewed by Steering Group members working in pairs to ensure that the wording  
4  
5 accurately captured the underlying raw data.  
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8 The summary questions were assessed against published evidence to determine if  
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10 questions represented a knowledge gap. Working with a library sciences team, each summary  
11  
12 question was assessed against systematic reviews (The Cochrane Database of Systematic  
13  
14 Reviews) and clinical guidelines (NICE guidelines and SIGN clinical guidelines) limited to  
15  
16 English language published in the past 10 years. Where evidence was identified, the content was  
17  
18 reviewed to determine the degree to which it answered the summary question (completely  
19  
20 answered, partially answered, or completely unanswered). Partially answered questions were  
21  
22 retained as they represented some degree of uncertainty. Questions identified as completely or  
23  
24 partially answered were critically appraised to assess the quality of the evidence using the A  
25  
26 MeaSurement Tool to Assess systematic Reviews (AMSTAR 2) tool(14).  
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31 Due to the broad nature of this PSP, we anticipated that the majority of the summary  
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33 questions would be partially or completely unanswered. As such, and to achieve the project  
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35 timelines, we made the case to the JLA for adapting the process and running an interim  
36  
37 prioritization survey in parallel with the assessment of uncertainty. The interim survey reduced  
38  
39 the list of questions to take forward to the final prioritization workshop. It utilized the same  
40  
41 recruitment strategy as the initial survey. Respondents were asked to review the summary  
42  
43 questions and select the 10 questions that they felt to be of greatest importance. Basic  
44  
45 demographic questions were included to categorize respondents. The outcome of the assessment  
46  
47 of uncertainty was then applied to the interim prioritization list to remove the completely  
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49 answered questions before assessing the prioritization rankings. Submissions were analyzed  
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3 within respondent groups in order to ensure equal weighting of the high priority questions, which  
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5 were brought forward to the final workshop.  
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8           The final prioritization workshop ranked the top areas for future research. An expression  
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10 of interest was circulated to identify a diverse mix of attendees from our three groups interested  
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12 in participating in the one-day, in-person event. The workshop objective was to facilitate  
13  
14 reflection and discussion on the short list of summary questions and reach agreement on the top  
15  
16 10 felt to be most important. The JLA Advisor chaired the workshop. Attendees participated in  
17  
18 rounds of mixed composition, small and large group conversations to discuss and prioritize the  
19  
20 summary questions. Each of three small groups was led by a facilitator familiar with the JLA  
21  
22 approach and employed a modified Nominal Group Technique(9). Small group question  
23  
24 rankings were aggregated across the three groups after each of two rounds (comprising different  
25  
26 group compositions for both rounds) and then presented to the large group for a final round of  
27  
28 discussion and rank ordering. The workshop concluded when participants had reached consensus  
29  
30 through discussion and shared decision-making on the final ranked list of summary questions.  
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32 The PSP received research ethics board approval from the University of Alberta (Pro00070878)  
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34 and all participants provided informed consent.  
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## 41 **Results**

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44           Over 40 groups, committees, associations, or organizations agreed to join the partnership.  
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46 The initial survey was actively promoted by our partners and steering group over a 14.5 week  
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48 period. We received 88 pen-and-paper surveys (13%) and 592 online surveys (87%), resulting in  
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50 670 surveys included in data generation (10 surveys were returned with demographic  
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52 information only, and were therefore excluded). The respondent demographic characteristics can  
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54 be found in Tables 1-3. Approximately half of participants were older adults and caregivers  
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3 (52.4%). In total, 101 within scope summary questions were produced from over 3000 responses.  
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5 Although there was some overlap, the summary questions represented 24 content areas (Figure  
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10 The majority (67%) of summary questions were determined to be unanswered, with one-  
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12 third assessed as partially answered (Table 4). The 4 completely answered questions related to  
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14 symptom management in older adults with multiple diseases(15), effective diagnosis of  
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16 delirium(16), timely and accurate diagnosis of dementia(17, 18), and prevention of isolation and  
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18 loneliness in continuing care settings(19). Following the AMSTAR 2 review, no evidence in  
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20 support of the partially or completely answered questions was assessed as low/critically low  
21  
22 quality(14).  
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26 The 101 summary questions formed the basis of the interim prioritization survey. We  
27  
28 received 232 completed surveys within a 4-week online data collection period. The distribution  
29  
30 of respondents across the three groups was approximately the same as the initial survey (53.0%  
31  
32 older adults and caregivers; Tables 1-3). The highest priority unanswered summary questions  
33  
34 ( $n=97$ ) were identified for each respondent group; some questions were ranked as high priority  
35  
36 by more than one group (Table 5). This resulted in 22 questions shortlisted and brought forward  
37  
38 to the final prioritization workshop.  
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42 Final workshop attendees were individuals representing at least one constituent group,  
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44 although the majority identified with more than one group (such as a clinician who was also a  
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46 caregiver of an aging parent). In total, 22 people participated in the workshop. Attendee  
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48 perspectives included health administration, nursing regulatory, housing, seniors' advocacy, and  
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50 clinical care (nursing, allied health, nutrition, and medicine). Although older adults and  
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3 caregivers were in the minority, many clinicians also identified as representing this perspective  
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5 and were encouraged to draw upon both their professional and personal experiences.  
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8 Small group discussions led to a preliminarily rank ordering of summary questions  
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10 (Figure 2). This aggregated rank order was provided back to attendees to consider and modify in  
11  
12 a second round of small group discussions with new group membership. The final prioritized list,  
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14 the “Top 10 List”, resulted from large group discussions facilitated by the JLA Advisor (Figure  
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17 3, Table 6).  
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## 23 **Interpretation**

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26 Utilizing the well-established JLA approach, we engaged older adults, caregivers,  
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28 clinicians, and organizational representatives serving these groups to identify and prioritize the  
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30 most important issues for future research in seniors' health to address. The Top 10 list address  
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32 aspects of the health system (navigation; rural accessibility; culture), provision of informal  
33  
34 (caregiving) and formal care (senior-friendly care; provider availability; continuity), and living  
35  
36 well in older adulthood (dementia; daily living). A central theme within the summary questions  
37  
38 was independence, with the maintenance of independence ranked first within the final Top 10  
39  
40 list. Other questions within the Top 10, if addressed, can be viewed as supporting this primary  
41  
42 aim. Improving continuity of care (ninth) across care transitions may well decrease the  
43  
44 opportunities for errors and poor outcomes that occur when unwell older adults are transferred  
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46 between healthcare settings(20). The desire for the health system to proactively support health,  
47  
48 rather than reacting to disease and disability (second) also aids in maintaining independence. The  
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50 PSP places a greater emphasis on preventive care and public health which would allow people to  
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52 maintain health and prevent avoidable illness(21), delaying the onset of disability and preserving  
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3 independence for as long as possible(22). The Top 10 List largely supports the objective of  
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5 improving the quality of care and health outcomes for older adults as well as calling for means to  
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7 improve the health literacy for people to gain most benefit from the healthcare system (seventh  
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9 and tenth).

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12 The interim survey identified areas of shared importance, with 7 of the 22 shortlisted  
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14 questions brought forward by 2+ groups. For example, programs and services to combat burnout  
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16 and stress of those caring for older adults was identified by each respondent group as being of  
17  
18 high importance, ranked as fourth, eighth, and tenth by health/social care workers, older adults,  
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20 and caregivers, respectively. At the conclusion of the in-person workshop, it was ranked as  
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22 eighth within the final prioritized list. This and two other priority questions remained in the final  
23  
24 Top 10 List, the others being strategies to allow older adults to remain independent (first  
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26 position), and strategies to ensure optimal transitions between care settings (ninth position).  
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28 Workshop attendees used the interim rankings by respondent groups in their discussions which  
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30 served to ground conversations in a wider pool of perspectives.  
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36 To our knowledge, this is the first PSP to weigh the issues, conditions, and diseases  
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38 affecting the health of seniors together. Although recently conducted Canadian PSPs include the  
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40 national dementia PSP(10) and the frailty PSP(23), we purposefully spanned issues affecting the  
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42 lives of seniors and their caregivers to assess how such questions compared to each other in  
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44 terms of priority. This is not to say that there is not value in condition-specific PSPs for older  
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46 adults. In fact, the dementia and frailty PSPs both provide researchers and funders aligned with  
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48 those content areas prioritized lists for targeted research in those areas. However, for  
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50 organizations that advocate for and fund research related to seniors' health and wellbeing more  
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3 broadly, this PSP adds considerable value by highlighting the questions that lay outside  
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5 disease/condition areas and how these issues rank against one another.  
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8         There is a knowledge translation opportunity related to the summary questions assessed  
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10 as completely answered. Although evidence is available, it has not yet reached knowledge users.  
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12 A knowledge translation product would assist in moving evidence toward use of that knowledge  
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14 by end-users(24). There is thus an opportunity to close the knowledge gap by translating and  
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16 disseminating information on the answered summary questions. It would be a natural extension  
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18 of PSPs to share what is known about a topic that was generated by the process but removed as it  
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20 did not represent an uncertainty or knowledge gap. Future PSPs should consider at the outset the  
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22 steps that might be taken to close knowledge gaps when identified by their projects.  
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26         Despite the significant strength of this project in weighing issues affecting seniors' health  
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28 together for prioritization, the work is not without limitation. We note the low number of older  
29  
30 adults participating in the final workshop, the underrepresentation of Indigenous older people  
31  
32 and those either over 80 years of age or residing in long term care in responding to the surveys.  
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34 We made great efforts with the steering group, and the seniors' centres and care facilities to  
35  
36 which they were connected, to invite such participation. We highlighted this at the start of the  
37  
38 workshop to encourage participants to consider these groups. Recognition of who is, and is not,  
39  
40 at the prioritization table is needed for balanced conversations.  
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44         The Alberta Seniors' Health PSP engaged knowledge end-users in identifying and  
45  
46 prioritizing the issues that should be addressed by future research. We call upon seniors' health  
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48 stakeholders to advocate for uptake of the Top 10 List. Patients, caregivers, and clinicians can  
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50 participate in studies producing new knowledge. Researchers can generate evidence on one of  
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52 the Top 10 questions. Research funders can prioritize grants addressing projects prioritized by  
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3 end-users. Together, we can make great strides to meet the informational needs of end-users of  
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5 seniors' health and healthcare knowledge – patients, caregivers, and the health and social care  
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7 providers who serve them.  
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## Tables and Figures

Table 1  
Sample Description for Initial Survey to Identify Unanswered Questions Affecting Seniors' Health and Interim Prioritization Survey

Respondent Group	Initial Survey		Interim Prioritization Survey	
	N	%	N	%
Older Adults	219	32.7	66	28.4
Caregivers	132	19.7	57	24.6
Health and Social Care Workers	314	46.9	109	47.0
Representatives from Related Agencies/ Organizations	5	0.7	0	0
<b>Total</b>	<b>670</b>	<b>100</b>	<b>232</b>	<b>100</b>

Table 2  
Initial and Interim Prioritization Survey Older Adult and Caregiver Respondents' Age, Sex, and Ethnicity

Variable	Initial Survey		Interim Prioritization Survey	
	Older Adults	Caregivers	Older Adults	Caregivers
Age in years, mean (SD)	73.5y (6.4y)	57.5y (9.4y)	72.7y (5.8y)	60.3y (9.9y)
Female <sup>a</sup> , n (%)	155 (70.8%)	116 (87.9%)	50 (75.8%)	47 (82.5%)
Ethnicity, n (%)				
North American Indigenous (e.g., First Nations, Metis, or Inuk [Inuit])	3 (1.4%)	4 (3.0%)	0	1 (1.8%)
Other North American (e.g., Canadian, American, Quebecois)	110 (50.2%)	61 (46.2%)	29 (43.9%)	26 (45.6%)
European	120 (54.8%)	68 (51.5)	41 (62.1%)	32 (56.1%)
Asian (e.g., Middle Eastern, South, East, and Southeast Asian)	15 (6.8%)	8 (6.1%)	1 (1.5%)	3 (5.3%)
Other (Caribbean; Latin, Central, or South American; African; Oceania [e.g., Australian])	3 (1.4%)	0	1 (1.5%)	0
Prefer not to say	3 (1.4%)	4 (3.0%)	0	0

<sup>a</sup>One individual responded as not identifying as male or female and 5 individuals responded as preferring not to answer.

Table 3  
Initial and Interim Prioritization Survey Health and Social Care Worker Respondents' Professional Backgrounds and Work Settings

Category	Initial Survey		Interim Prioritization Survey	
	N	%	N	%
<b>Professional Background</b>				
Aide (HCA, NA, TA)	7	2.2	1	0.9
Nurse (RN, RPN, LPN)	92	28.8	35	32.1
Nurse Practitioner	2	0.6	4	3.7
Social Worker	44	13.8	18	16.5
Allied Health Professional (PT, OT, RT, SLP, Rec.T)	112	35.1	22	20.2
Physician	11	3.4	12	11.0
Pharmacist	2	0.6	0	0
Dietician	15	4.7	2	1.9
Manager/Administrator	9	2.8	6	5.5
Other	11	3.4	7	6.4
No Answer	14	4.4	2	1.8
<b>Work Setting</b>				
Primary and Community Care	132	42.0	55	50.5
Acute Care	81	25.8	36	33.0
Continuing Care	118	37.6	35	32.1
Other	32	10.2	10	9.2

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
<b>Total</b>	<b>101</b>	<b>100</b>

Table 5  
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
<b>Total</b>	<b>22</b>

Table 6  
 Alberta Seniors' Health Top 10 List of Priority Areas for Future Research

- 
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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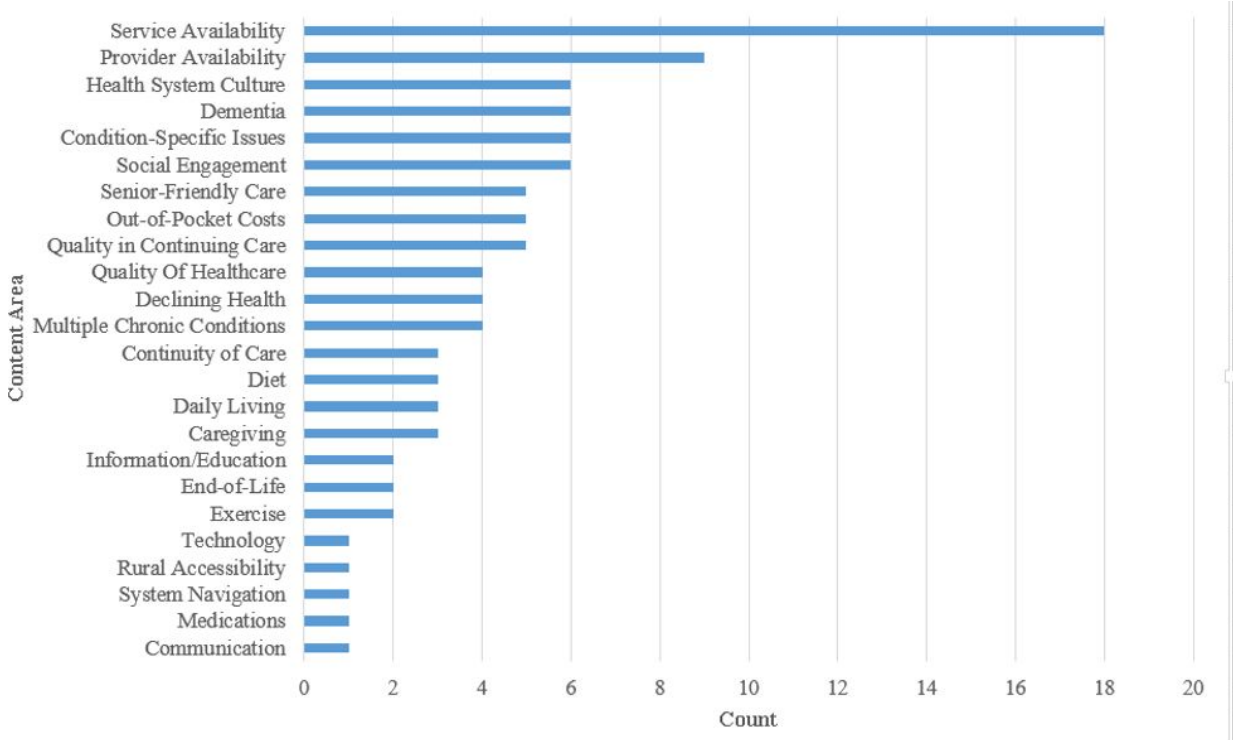


Figure 1: Content area taxonomy represented by the 101 summary questions.

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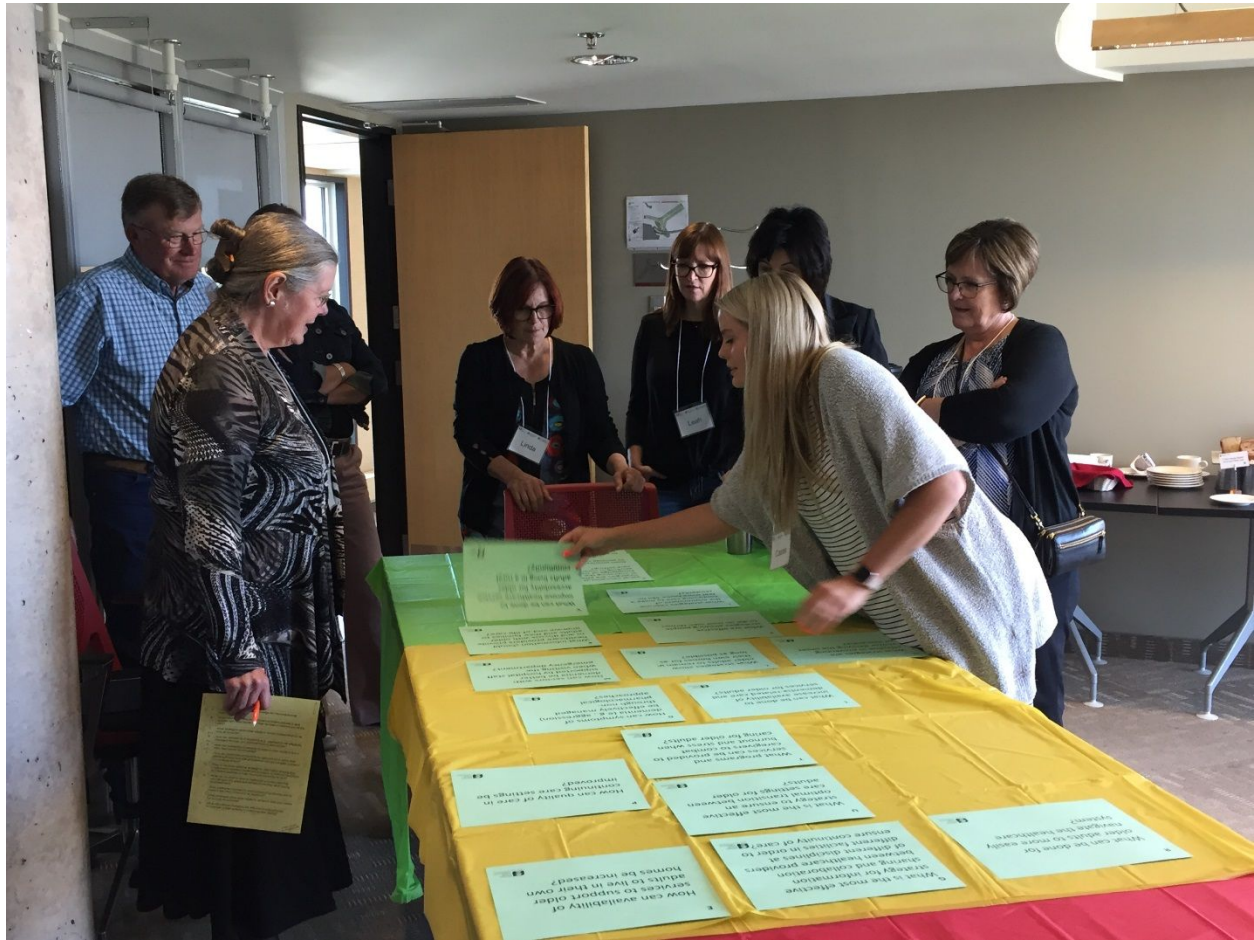


Figure 2: Final workshop attendees participating in small group discussion to sort the 22 shortlisted summary questions into an initial list by shared rankings.

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Figure 3. Final workshop attendees participating in large group discussion and decision-making to determine the final list of top questions for future research to address.