

Article details: 2019-0225	
Title	Identifying what matters most for seniors' health in Alberta: results from a James Lind Alliance Research Priority Setting Partnership
Authors	Heather M. Hanson XX XX, Katherine Cowan XX XX, Adrian Wagg XX XX
Reviewer 1	Dr. Larry W. Chambers
Institution	Elisabeth Bruyere Research Institute, Ottawa, Ont.
General comments (author response in bold)	<p>In the last two years, a dementia prioritizing project and a frailty prioritizing project were reported in Canada. This is the third project which focuses on health services for older adults (I recommend the authors refer to 'older adults' rather than 'seniors') in Alberta. Specific topics in this priority setting exercise were framed to ask what could health services do to improve the following: age well; improve healthcare practices or services; prevent illness or disease; diagnosis or treat illness or disease; manage symptoms or conditions, or support someone with health conditions; and maintain mental health and social participation.</p> <p>Thank you for this comment – we have altered the text as requested by the editor – we acknowledge the disease specific JLA PSP in our manuscript and note how ours is different and original.</p> <p>It may be too much to expect health services to take the lead and be effective with all the determinants of the health of older adults. As the project's focus was on health services, other approaches to improving the health of seniors were excluded including housing and transportation, as the authors state "...were not framed in connection to health". According to a recent critique of WHO's proposal for a decade of healthy ageing (Lloyd-Sherlock et al Lancet November 26, 2019), this approach of distinguishing between health service and social support reflects "...fixed notions about how things are done – settings where care is provided, and the types of people who provide it – rather than the intrinsic differences in user needs." The paradigm used in the project supports continuation of the status quo and does little to overcome professional, cultural, and institutional disconnects across health services and social support. The project provides little guidance on how the reader should think about the spectrum of needs (from acute episodes to more complex, chronic conditions) and a spectrum of responses (from single treatments to more continuous support) where distinctions between health needs and social support needs are largely meaningless.</p> <p>We thank the reviewer for this opinion, we feel that our PSP reflects a health systems perspective whilst acknowledging the interconnectedness of health and social care for older people and reflecting the perspective noted by the reviewer – we have made alterations to the discussion section in response to this comment and that below.</p> <p>In terms of methods used in the project, the investigators have adhered to the now well-established James Lind Alliance protocols for such studies. They recruited 670 participants to report on what mattered most to them for the health of older adults. With the help of 40 partner organizations in Alberta, they received responses from 3000 individuals that generated 101 summary questions, for which only four could be said to be research questions that were already answered when examined against a review of the 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 the health of older adults.</p>

	<p>Questions within the Top 10 list addressed aspects of the health system, provision of care, and living well in older adulthood.</p> <p>The paper should be published but there should be discussion about the problems with focusing only of the health services to improve the health of older adults. We have attempted to address this using the perspective the reviewer notes above and incorporating the provided reference – see the discussion.</p> <p>The health services treatment of older adults contracts differ from social support contracts. The interaction of the health services with other services and the interface is what gives the most difficulty; that is, the tension between acute care hospitals and long-term care homes, sometimes referred to as ‘hallway medicine’. This difficulty plays out when an older person, often with dementia, is deemed to require institutional care by both the community and institutionally based workers so must remain at home because each institution maintains the person is the responsibility of the other. This type of person has been referred to as “too fit and too frail” – that is, she is too fit for hospital and too frail for a long-term care home, so must remain at home with her very elderly disabled spouse, or an elderly child, or alone.</p> <p>We thank the reviewer for this perspective but have made no change to the paper in this regard, for what it is worth, Alberta has an integrated health and social service provision for older people, including the provision of continuing care services, from community to long term care.</p> <p>Health services personnel are typically involved in the time-consuming case conferences to resolve these disputed decisions and more funds will not prevent these interface problems. The fundamental difference in the objectives of health and social services – the health service perspective being that for patient the “glass is half empty” whereas the social service perspective for the resident is that the “glass is half full”. Health services personnel using treatment principle are able to say to older adults “I know your knees hurt, but you have got to keep walking if you want to get better”. There is a degree of control over the individual older adult who become patients which is not acceptable to those providing social services. Although those who work in social services, for example, long term care homes, are keen to encourage independence among their residents, the people in the homes are not patients. There is a belief among many members of the public that “care” for older adults means doing things for old people and this may nullify these efforts of staff and make rehabilitation very difficult.</p> <p>Again, whilst this discourse is of interest we have made no change to the paper.</p>
Reviewer 2	Dr. Kathryn A. Birnie
Institution	Hospital for Sick Children, Toronto, Ont.
General comments (author response in bold)	<p>This paper presents the undertaking and results from a James Lind Alliance Priority Setting Partnership to identify the top 10 priorities for seniors’ health in Alberta per older adults/seniors, caregivers, health and social care workers, and representatives from related agencies/organizations. This is important work; however, there are several necessary details currently missing from the manuscript that are critical to include to appreciate the scope, rigour, and impact of the presented work. These can very likely be addressed by the authors.</p> <p>1. A JLA Priority Setting Partnership emphasizes the empowered voice of</p>

people with lived experience in its methodology. Why are no patient partners or people with lived experience included as authors on the paper? For example, why are not all members of the steering committee authors on the papers. As per JLA methodology, this group of people is critical for overseeing the PSP and providing critical insight, decision-making, and direction. Quite likely they would meet criteria warranting authorship if given the chance to review and provide comment on the manuscript. (<http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>). At the very least, there should be people recognized in the acknowledgements.

We agree, whilst no member of the steering group would meet the criteria for authorship, we have included them in our acknowledgements.

2. There are two relevant reporting guidelines that the authors should adhere to in this paper as both are clearly relevant here. GRIPP/GRIPP-2 to report patient and public involvement in research (<https://www.bmj.com/content/358/bmj.j3453>) and REPRISE to report priority setting in health research (<https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0889-3>).

We have included reference to the REPRISE reporting framework and have included the checklist with the manuscript.

3. Please include the names of the partner agencies and organizations who were part of this PSP. These could be listed in the acknowledgements, table, supplementary material, etc.

This list has been appended as supplementary material.

4. Did “caregivers” include adult children of seniors? (not currently listed on p. 4, lines 36-38).

We did not collect this information, although it is highly likely that some participants belonged to this category.

5. Include how the 6 topic areas pre-determined and who identified them. Was this a limitation to the work? Is it possible that some areas were missed?

The 6 topic areas were determined by the steering committee – these were determined to be as inclusive as possible although conceivably some areas could have been missed. We have included the method of determination in the paper methods section.

6. Include who the survey pilot tested with. (p. 5, line 22-23).

This has been done, as noted above.

7. Include who reviewed and categorized the survey responses? (p.5, line 41). Was this done in duplicate?

This has been added, as noted above.

8. More information is needed about the steering committee members in terms of composition.

We have included a list as supplementary information, as I’m sure the reviewer is aware, the word limit does rather constrain our ability to include this level of detail in the main manuscript.

9. List who reviewed the identified evidence and what criteria was used to determine whether an identified question was “completely answered”, “partially answered”, or “completely unanswered”. p. 6

This has been added to the relevant section.

10. Include who critically appraised the identified evidence using the AMSTAR 2 (p.6, line 26-28).

This has been added to the relevant section.

11. Include the total number of summary questions that respondents were asked to review (p.6, lines 43-45).

This has been added.

12. The respondents were restricted to those who lived in Alberta. Do the authors think that there are some specific geographical characteristics to the findings? Do they think the top 10 questions are directly generalizable to seniors living in other provinces in Canada or internationally?

This is an interesting question but one which we are unable to answer, there may be for example, urban – rural differences but we did not trace the origin of each respondent. Whilst the Top 10 items may be generic, the external validity of these cannot be assessed; there are no data from other provinces or territories nor yet from other countries.

13. Include some detail about who the “expression of interest” was circulated to. (p.7, line 10).

This has been done.

14. Include the city in which the final workshop was held and the date (p.7, line 31).

Whilst I have done this, I must say that this additional information appears to have limited utility for the reader – to what end is this request made?

15. Were all stages of the PSP given REB approval? As a single study? PSP are considered quality improvement by the JLA in the UK, and do not require research ethics approval. It would be beneficial to others for the authors to include some more detail or comment about ethics approval for this PSP in their paper.

Yes, for all stages. We sought ethical approval as our institution felt that this was warranted. We have made no alteration to the paper in this regard, given the lack of space to do so.

16. Add “lived experience” as one of the listed attendee perspectives at the workshop. (p.8, lines 48-52).

We have made this change.

17. It is very interesting that the authors state that all of the top 10 priorities support the primary aim of “maintenance of independence” (p. 9, line 42-44). It would be helpful to the reader if they could provide some more elaboration about what they mean by this, how this impression was made, etc.

This statement is purely the opinion of the authors, it appears to make sense and to link some of the prioritized topics – the maintenance of independence, or autonomy, is clearly important to the seniors constituency.

	<p>We have made some edits to this section for ease of reading.</p> <p>18. The authors should identify that patients, caregivers, and clinicians can help CO-DESIGN studies to produce new knowledge, not just participate in them. (p. 11, lines 51-53). Adjusting this wording is critical to acknowledge the true spirit of patient engagement/partnership/involvement more generally, and consistent with the JLA PSP.</p> <p>We have added in this point.</p> <p>19. Presumably the authors believe that their findings can have a greater impact that merely to “meet the informational needs of end users”. Suggest rewording to acknowledge larger benefit.</p> <p>Minor edit made – thank you for this point.</p> <p>20. The authors should consider combining Tables 1-3, or alternatively including the total sample size for each group in the columns in Tables 2 and 3.</p> <p>We have added in the totals in the columns.</p> <p>21. Table 4 would benefit from references to the questions and corresponding systematic reviews/clinical practice guidelines for the fully answered and partially answered questions.</p> <p>We have made no change to the table – to add in this level of detail would make the table unwieldy. The 4 fully answered questions and the associated evidence are provided in the Results section.</p> <p>22. Table 5 would benefit from listing which groups of respondents, and which questions; otherwise consider removing the table. It does not add much benefit or information as is.</p> <p>We have removed the table as suggested by the reviewer, as these details are presented in the text.</p>
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