

The Canadian Frailty Priority Setting Partnership: Research Priorities for Older Adults Living with Frailty

Bethell et al. (2019)
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For which topic were research priorities identified?

frailty

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Research on frailty presents challenges, including that older adults living with frailty may not self-identify and people with lived or clinical experience of frailty (i.e., older adults, friends, family and caregivers, and care providers) are typically not involved in the research process, leaving important gaps in current knowledge. For research priority-setting, involving those with lived or clinical experience has the potential advantages of democratizing allocation of research resources and increasing impact.

What was the objective?

to engage people with lived or clinical experience of frailty, and produce a list of research priorities related to care, support, and treatment of older adults living with frailty, to stimulate more research in these priority areas and, in doing so, improve the health and care of older adults living with frailty

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

Establishing steering group: October 2016. Survey: March 2017 - June 2017. Interim ranking: July 2017 - September 2017. Workshop: September 2017.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: establishing steering group and inviting partner organizations. Step 2: collecting research questions: survey: inviting people with lived or clinical experience of frailty to submit their questions about care, support, and treatment of older adults living with frailty, 799 questions submitted. Step 3: processing data: out-of-scope submissions and submission that could not be formulated into a question were excluded, remaining questions categorized, merged, and summarized as indicative questions, questions that asked only once excluded, indicative questions checked against research evidence, list of 41 indicative questions generated. Step 4: interim ranking: via survey, participants identified their own unranked top 10 priorities (unranked), then frequency each question was selected was tabulated, stratified ranked lists were created to ensure both groups' priorities were brought forward, questions narrowed down to 22. Step 5: final prioritization: workshop: small group discussions with nominal group technique, discussing and ranking the shortlisted questions

Which stakeholders took part?

Survey: 389 individuals and groups (older adults concerned about frailty, older adults with no direct experience of frailty but interested in it, partners, relatives or friends of a frail older adult, caregivers or former caregivers of a frail older adult, health and/or social care providers). Interim ranking: 146 individuals and groups (older adults concerned about frailty, older adults with no direct experience of frailty but interested in it, partners, relatives or friends of a frail older adult, caregivers or former caregivers of a frail older adult, health and/or social care providers). Workshop: 21 participants: 9 represented lived experience and 12 represented clinical experience

How were stakeholders recruited?

Partner organizations assisted by promoting surveys, identifying workshop participants, and disseminating results. In addition to assistance from partner organizations, Steering Group members assisted with distributing the survey, community newspaper ads were run in Canadian cities. Paper surveys were mailed to older adults in the Seniors Helping Advance Research Excellence group. Partner organizations were encouraged to promote the survey. Interim prioritization: Individuals who provided their contact information in the first survey were contacted and others were invited to join through partner organizations.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process. They were part of a steering group. The steering group consisted of 17 members: people with lived or clinical experience of frailty, researchers, 1 JLA adviser. The members met monthly, oversaw and advised on project, identified partner organizations, and helped to distribute survey. Some members participated in the workshop.

