

## Seniors Health Priority Setting Partnership (PSP)

### PROTOCOL

#### 1. Purpose of the PSP and Background

The purpose of this protocol is to set out the aims, objectives, and commitments of the Seniors' Health Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein. It is recommended that the Protocol is reviewed by the Steering Group and updated on at least a quarterly basis.

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004 and based in the United Kingdom. It brings patients, caregivers, and clinicians together in Priority Setting Partnerships (PSPs). These partnerships identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians. The National Institute for Health Research (NIHR – [www.nihr.ac.uk](http://www.nihr.ac.uk)) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton.

The Seniors Health Strategic Clinical Network™ (SCN) is a province-wide network of stakeholders charged with reshaping and improving health care services and practices to enable seniors living in Alberta, Canada to optimize their health, well-being and independence.

Since its inception, the Scientific Office of the Seniors Health SCN has worked to build partnerships to engage in, promote, and advance the use of knowledge to improve care and health outcomes for older adults. The collaboration and capacity building activities undertaken by the SCN have benefited from the broad nature of the SCN's three priority areas: "Aging Brain Care", "Frailty, Resilience, Aging-well: Late-life Transitions Initiative", and "Anticipating an Aging Alberta." However, with the foundation of our Research Community and in-flight research projects, we now believe the time is right to undertake an innovative research prioritization process to refine the key issues within the 3 broad priority areas, and use the process as a catalyst for wide and comprehensive stakeholder engagement.

## 2. Aims and Objectives of the Seniors Health PSP

The aim of the Seniors Health PSP is to identify the unanswered questions about seniors' health and healthcare from patient, caregiver, and clinical perspectives and then prioritise those that patients, caregivers, and clinicians agree are the most important.

The objectives of the Seniors Health PSP are to:

- Work with patients, caregivers, and clinicians to identify unanswered questions within seniors' health.
- To agree by consensus a prioritized list of those unanswered questions, for research.
- To publicize the results of the PSP and process.
- To take the results to research commissioning bodies to be considered for funding.

## 3. The Steering Group

The Steering Group includes representation of patient/carer groups and clinicians<sup>1</sup>.

The Seniors Health PSP will be led and managed by the following:

- Representatives of agencies/groups serving patients/caregivers/clinicians:
  - Jessica Spence [Senior Patient Engagement Consultant, SCNs]
  - Navjot Virk [Brenda Strafford Foundation]
  - Nicole Smith [SAGE (Seniors' Association of Greater Edmonton)]
- Patients:
  - Sandy McMeekin
  - Fran Jamison

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<sup>1</sup> In some cases, it has been suggested that researchers are represented at this level, to advise on the shaping of research questions. However, researchers cannot participate in the prioritisation exercise. This is to ensure that the final prioritised research questions are those agreed by patients, caregivers and clinicians only, in line with the JLA's mission.

- Caregivers:
  - Pat Fonstad
  - Leslie Saunders
  - Lisa Poole
- Clinicians:
  - Katie Churchill [Occupational Therapist]
  - Suzanne Nichol [Nurse]
  - Karen Leung [Physician]

The Partnership and the priority setting process will be supported and guided by:

- The James Lind Alliance (JLA):
  - Katherine Cowan
- Alberta's Seniors Health Strategic Clinical Network™:
  - Dr. Adrian Wagg, Scientific Director and Principal Investigator
  - Dr. Heather Hanson, Assistant Scientific Director and PSP Chair
  - Billy Zhao, PSP Coordinator

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will advise on this.

#### 4. The Wider Partners

Organizations and individuals will be invited to be involved with the PSP as partners. Partners are groups or individuals who will commit to supporting the PSP by disseminating the PSP survey and helping the PSP to gather questions and uncertainties of practical clinical importance relating to the treatment and management of the health problem in question. Partners represent the following groups:

- Older adults, 65 years of age and older, living in Alberta.
- Caregivers of older adults.
- Medical doctors, nurses, and allied health professionals with clinical experience of caring for older adults.

It is important that all organizations which can reach and advocate for these groups should be invited to become involved in the PSP. The JLA Adviser will take responsibility for ensuring the various stakeholder groups are able to contribute equally to the process.

### **Exclusion criteria**

Some organizations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organizations will not be invited to participate. It is possible, however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.

## **5. The Methods the PSP will Use**

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. More details can be found in the Guidebook section of the JLA website at [www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk) where examples of the work of other JLA PSPs can also be seen.

### **Step 1: Identification and invitation of potential partners**

Potential partner organizations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks. Potential partners will be contacted and informed of the establishment and aims of the Seniors Health PSP and may be invited to support and/or participate in the PSP.

### **Step 2: Initial awareness raising**

The initial awareness raising will have several key objectives:

- To invite potential members to participate in the Seniors Health PSP Steering Group and protocol activities.
- To present the proposed plan for the PSP.
- To initiate discussion, answer questions, and address concerns.
- To identify partner organizations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts.

- To establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting, and recording the work and progress of the PSP.

Awareness raising will be fostered through a variety of mechanisms. Announcement and communication of the PSP will be circulated through the Seniors Health SCN Newsletter. The newsletter, along with a parallel short report under the 'what's new' section, was posted on the SCN website. The launch of the PSP was announced at the in-person Seniors Health SCN core committee meeting. Finally, awareness raising and stakeholder identification will be supported by individualized emails to contacts at identified stakeholder groups/agencies/organizations.

### **Step 3: Identifying unanswered questions**

Each partner will identify a method for soliciting from its members questions and uncertainties of practical importance relating to seniors health. A period of three months will be given to complete this exercise.

The methods may be designed according to the nature and membership of each organization, but must be as transparent, inclusive and representative as practicable. Methods may include membership meetings, email consultation, postal or web-based questionnaires, Internet message boards, and focus group work.

Existing sources of information about unanswered questions for patients and clinicians will be searched. These can include question/answering services for patients and caregivers and for clinicians; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared, and registers of ongoing research.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: [www.evidence.nhs.uk](http://www.evidence.nhs.uk).

### **Step 4: Refining questions and uncertainties**

The Steering Group will need to have agreed exactly who will be responsible for this stage – the JLA can advise on the amount of time likely to be required for its execution. The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce “raw” unanswered questions about all aspects related to seniors health. These raw questions will be assembled and categorized and refined by the PSP Coordinator into “collated indicative questions” which are clear, addressable by research, and understandable to all. Similar or duplicate questions will be combined where appropriate.

Systematic reviews and guidelines will be identified and checked by the PSP Coordinator, with support of library scientist(s), to see to what extent these refined questions have, or have not, been answered by previous research. Sometimes, unanswered questions are expressed that can in fact be resolved with reference to existing research evidence - i.e. they are "unrecognized knows" and not unanswered questions. If a question about treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. Accordingly, a separate record of these 'answerable questions' will be kept treated as knowledge translation opportunities by the Seniors Health SCN.

Uncertainties which are not adequately addressed by previous research will be collated and recorded on a template supplied by the JLA) by the PSP Coordinator. This will demonstrate the checking undertaken to make sure that the uncertainties have not already been answered. The data should be submitted to the JLA for publication on its website on completion of the priority setting exercise, taking into account any changes made at the final workshop, in order to ensure that PSP results are publicly available.

### **Step 5: Prioritization – interim and final stages**

The aim of the final stage of the priority setting process is to prioritize through consensus the identified uncertainties relating to the treatment or management of seniors’ health. This will be carried out by members of the Steering Group and the wider partnership that represents patients, caregivers, and clinicians.

- The interim stage, to proceed from a long list of uncertainties to a shorter list to be discussed at the final priority setting workshop (e.g. up to 30), may be carried out in-person or online, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties. There are examples of how other PSPs have achieved this at [www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk) in the Key Documents of the [Anaesthesia and Perioperative Care PSP](#) section and the [Childhood Disability PSP](#) section.
- The final stage, to reach, for example, 10 prioritized uncertainties, will be conducted in a face-to-face meeting, using group discussions and plenary sessions.

- The methods used for this prioritization process will be determined by consultation with the partner organizations and with the advice of the JLA Adviser. Methods which have been identified as potentially useful in this process include: adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

The JLA will facilitate this process and ensure transparency, accountability, and fairness. Participants will be expected to declare their interests in advance of this meeting.

## 6. Dissemination of Findings and Research

### Findings and research

It is anticipated that the findings of the Seniors Health PSP will be reported to funding and research agenda setting organizations such as the Canadian Institutes of Health Research (national funding body for health research), Alberta Innovates (the provincial funding body for health research), Canadian Frailty Network (national research funding of catalyst and trainee grants) and major research funding charities and external partner organizations (Alzheimer Society of Alberta and Northwest Territories). The findings will also be shared with university institutes and centres (leveraging partnership funding opportunities) and will be used internally by the Scientific Office of the Seniors Health SCN (small-scale studentships or catalyst opportunities).

Steering Group members and partners are expected to develop the prioritized uncertainties into research questions, and to work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable.

### Publicity

As well as alerting funders, partners and Steering Group members are encouraged to publish the findings of the Seniors Health PSP using both internal and external communication mechanisms. The Steering Group may capture and publicize the results through descriptive reports of the process itself in plain English. This exercise will be distinct from the production of an academic paper, which the partners are also encouraged to do. However, production of an academic paper should not take precedence over publicizing of the final results.

## 7. Agreement of the Steering Group

Agreement on the Seniors Health Priority Setting Protocol was reached by the Steering Group on November 03, 2017.