

James Lind Alliance Multiple Conditions in Later Life Priority Setting Partnership Steering Group – background and Terms of Reference

Introduction to the James Lind Alliance and priority setting

The James Lind Alliance (JLA) is non-profit making initiative which was established in 2004 with the aim of enabling groups of patients, carers and clinicians to work together to agree priorities for health research. The JLA facilitates Priority Setting Partnerships (PSPs) in particular health areas.

Each PSP consists of patients, carers and their representatives, and clinicians, and is led by a Steering Group. Collaboration between patients, carers and clinicians to set the research agenda is extremely rare, but vital in drawing issues to the attention of research funders which might not otherwise be suggested or prioritised.

The role of the PSP is to identify questions about interventions (i.e. treatment, management, care and support) to enable older people to live well with multiple conditions in later life, which have not been answered by research to date, and to then prioritise these. The first stage is an online survey, along with focus groups and one to one interviews to patients, carers and clinicians. These questions will then be assessed to check they are in scope for the PSP and checked and verified as true uncertainties. An interim prioritisation exercise then takes place to shortlist the uncertainties, before a priority setting workshop is then convened where participants debate and finally arrive at a Top 10 list of shared unanswered questions, or uncertainties, which are most important to them. The aim is then to turn these uncertainties into research questions and for members of the Steering Group to work with researchers and research funders to obtain funding for that research. All uncertainties are displayed on the JLA website. Further details about the JLA and PSPs are at <http://www.jla.nihr.ac.uk/>

JLA Multiple Conditions in Later Life PSP

The background and wider aims and responsibilities of the JLA Multiple Conditions in Later Life PSP are set out in the PSP's Protocol.

About the Steering Group

The Steering Group is responsible for overseeing and guiding the activity of the PSP. Drawing on members' expertise and networks, the Steering Group will help encourage membership to the wider PSP and, where capacity permits, will carry out the practical work needed to collate the interim and final priority setting exercises. The Steering Group is also responsible for helping raise awareness of the final Top 10 uncertainties, including among research funders.

Membership of the Steering Group includes individuals and representatives of organisations which can reach and advocate for patients and clinicians, as well as the JLA Adviser. Steering Group members with direct relevant experience as patients, carers or healthcare professionals are invited to participate in the priority setting exercise.

Role of Steering Group meetings

Steering Group members are asked to contribute, as a minimum, their expertise and their time. Steering Group members are asked to adhere to the following principles:

- an interest in the initiative and outcomes being pursued in the project
- a broad understanding of project management issues and the approach being adopted
- commitment to working with other members respectfully and constructively
- advocacy for the project's outcomes.

Specifically, Steering Group members will:

- participate in Steering Group meetings and/or teleconferences. To be effective in its decision making, each meeting should be represented with at least a clinical, patient and research element
- submit comments ahead of the meeting if unable to attend. Where a Steering Group member is unable to attend a meeting, decisions made at the meeting will be respected
- respond promptly with feedback on project materials by responding to emails
- share networks and contacts for membership of the PSP
- publicise the initiative to potential partners to encourage them to join the PSP. This includes advising on membership of the PSP (to ensure a wide and representative group of patients, carers and clinicians) and emailing contacts to invite them to participate
- have oversight of the collection of intervention (i.e. treatment, management, care and support) uncertainties from patients, carers, clinicians and existing literature
- oversee and lend expertise to the data management process, including agreeing the scope and process for data-checking
- have oversight of the interim priority setting stage
- verify the shortlisted questions to be taken to the final priority setting workshop
- participate in the final priority setting exercise (if job role qualifies them to represent the views of patients, carers or clinicians). This is the one-day workshop which brings patients, carers and clinicians together to debate, rank and agree a final Top 10. It is only attended by patients, carers and the healthcare professionals or support workers who actively work with them be involved in the development of the Top 10 uncertainties about interventions (i.e. treatment, management, care and support) to enable older people to live well with multiple conditions in later life into research questions for funders
- work with the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC) and other research funders to develop the priorities into research questions.

Reference group

This group will be formed of patients, family members and carers and includes members of Voice North. It is anticipated that there will be circa 15 members and two nominees from this group will be selected to feed in to the Steering Group. The reference group is a mechanism to enable patients and carers to be actively involved in the management of the PSP.

Declaring interests

Steering Group members are asked to declare any interests relevant to the Multiple Conditions in Later Life PSP. The JLA provides an example form, and the interests of each member will be listed and shared among the group. This is to encourage a culture of openness and transparency. Relevant interests may be professional, personal or related to an interest in or involvement in clinical research.

PSP Coordination

The PSP will be chaired by Katherine Cowan, JLA Adviser. The Newcastle University Engagement Project Manager and Engagement Team are responsible for the coordination and administration of the PSP. This includes making arrangements for all meetings and workshops, and ensuring that:

- requests for agenda items are discussed with the group
- papers are available at least a week before meetings
- meeting notes are circulated within two weeks.

Timescales

The first Steering Group meeting for the JLA Multiple Conditions in Later Life PSP will be in October 2016. We would like to aim to complete the project with the final meeting prioritisation approximately 18 months later.

Key contacts

PSP Chair: Katharine Cowan, JLA adviser

PSP Leads: Prof Stuart Parker & Dr Lynne Corner

PSP Co-ordinator: Newcastle University Engagement Project Manager