



James Lind Alliance

Priority Setting Partnerships

Neurodevelopmental Disorder 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 a 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 which have not been answered by research to date, and to then prioritise these. The first stage is an online survey to patients, carers and clinicians, asking for unanswered questions about [healthcare area]. 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/>

The Neurodevelopmental Disorders Priority Setting Partnership

The background and wider aims and responsibilities of the Neurodevelopmental Disorder PSP are set out in the JLA Neurodevelopmental Disorder PSP 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 monthly telephone conference calls. To be effective in its decision making, each meeting should be represented with at least a clinical, patient and research element
- respond promptly with feedback on project materials by responding to emails
- share networks and contacts for membership of the PSP
- help publicize the initiative to potential partners to encourage them to join the PSP. This includes emailing contacts to invite them to participate
- oversee collection of uncertainties from patients, carers, clinicians and existing literature
- have oversight of 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. This is the one-day workshop which brings patients, carers and clinicians together to debate, rank and agree on a final Top 10.
- be involved in the development of the Top 10 Neurodevelopmental Disorder uncertainties into research questions for funders
- work with the Province of Ontario Neurodevelopmental Network (POND) and other researchers and organizations to develop the priorities into research questions.
- Publicizing the final top 10 uncertainties

It is agreed that for this Neurodevelopmental Disorder PSP, two patient/carer representatives and two healthcare professionals will need to be present in order for Steering Group meetings to go ahead and for decisions to be made.

Declaring interests

Steering Group members are asked to declare any interests relevant to the Neurodevelopmental Disorder 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 Evdokia Anagnostou. Carla Arasanz and Jessica Jordao 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 Neurodevelopmental Disorder PSP first Steering Group meeting will be in February 2016. We propose that the final meeting prioritisation takes place in February 2017.

Key contacts

Carla Arasanz, Knowledge Translation Lead, Ontario Brain Institute

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