

## **Childhood Neurological Conditions Priority Setting Partnership**

### **Steering Group – Terms of Reference**

**1<sup>st</sup> October 2019**

This document sets out the Terms of Reference for the Steering Group of the James Lind Alliance Childhood Neurological Conditions Priority Setting Partnership. The Steering Group coordinates the Priority Setting Partnership (PSP) and organises its activities.

The Steering Group must include representatives of patients, carers and clinicians. These may be members of a charity or professional organisation within the area of the PSP. Members will bring with them knowledge of the condition, an understanding of the patient, carer and clinician populations and access to networks of patients, carers and clinicians. Members will need to be fully engaged in the process and have the time to carry out the work involved.

The background and wider aims and responsibilities of the Childhood Neurological Conditions PSP are set out in its Protocol.

#### **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 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 that might not otherwise be suggested or prioritised.

The role of the PSP is to identify questions that have not been answered by research to date, and then to prioritise these. The first stage is to ask patients, carers and clinicians, often via an online survey, for unanswered questions about the area focussing on ways to improve the health and/or wellbeing of children with neurological conditions about which there is uncertainty of the effectiveness of the intervention, therapy or procedure. These questions are then assessed to check they are in scope for the PSP and are checked and verified as true uncertainties. An interim prioritisation exercise then takes place, before a priority-setting workshop is convened where participants debate and finally arrive at a Top 10 list of research priorities.

The eventual aim is to turn these priorities into research questions, and for members of the Steering Group to work with researchers and research funders to obtain funding for that research.

The JLA will display all priorities on the JLA website. Further details about the JLA and PSPs are at <http://www.jla.nihr.ac.uk/>. A flowchart of the PSP process can be seen in the Templates and useful documents section of the JLA website at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm>.

#### **Introduction to the BPNA**

The British Paediatric Neurology Association is a registered charity (number 1159115) and is the professional organisation for doctors who specialise in the care of children with neurological disorders.

The BPNA is the principle supporter of the PSP.

BPNA charitable aims:

To promote the health and well-being of children with neurological disorders through:

- The training and education of professionals working in the field of paediatric neurosciences
- The promotion of research into the causes, effects and treatments of neurological disorders affecting children and young people
- The improvement of knowledge of professionals, the public and patients and their families through scientific and educational meetings
- The provision of professional support to members to facilitate the delivery of the above objectives and work with health service planners and providers to achieve this aim.

BPNA ethics values and principles:

Everyone involved with BPNA projects are responsible for ensuring their activities are run in accordance with the BPNA's ethics, values and principles. As members and staff of the BPNA, we aim to:

- Place patients and their families at the heart of our activities
- Promote an ethos of multidisciplinary working with fellow healthcare and related professionals
- Demonstrate through our actions that we place a high value on education and training
- Expect integrity and honesty in all our conduct
- Empower individuals to bring about positive change
- Seek excellence in all our endeavours

Responsibilities of the BPNA to the PSP

- The BPNA trustee with oversight of this project is Professor Manju Kurian, BPNA Chair of Research
- BPNA trustees have awarded a fixed amount of £50,000 for the PSP project; this is an allocated reserve within the BPNA accounts. All costs will be paid in accordance with BPNA accounting procedures.
- Provide administrative support (Professional Support Administrator is allocated to the PSP 10 hours per week until 31 March 2021).
- Host a webpage

Responsibilities of the PSP to BPNA Trustees

- Ensure the group's activities contribute to the BPNA's charitable aims and meet the BPNA ethics values and principles
- Provide an annual report of activities for inclusion in the Trustees' report for 2019-20 and 2020-21
- To update the BPNA Trustees of planned activities and budget spend for the 2020-21 BPNA operating plan
- Provide quarterly update reports to the BPNA Trustees including budget spend and how the PSP is developing

## **The Childhood Neurological Conditions Priority Setting Partnership**

### **Membership of the Steering Group**

The Steering Group membership must be a balance of patients, carers and professionals.

It is agreed that for the Childhood Neurological Conditions PSP, the aim will be for 5 patient/carer representatives and 9 healthcare professionals will be on and invited to Steering Group meetings. All members will be asked for their input for decisions to be made.

### **Role of Steering Group members**

Steering Group members are asked to contribute, as a minimum, their expertise and their time, and to be prepared to approach their established contacts and networks.

All Steering Group members are asked to commit to working according to the JLA principles:

- **Inclusivity:** working with other members respectfully and constructively and ensuring the full range of patient, carer and clinical stakeholder are involved in the PSP process
- **Equality:** patients, carers and clinicians, and the knowledge and experience they bring, are of equal value to the PSP
- **Fairness and transparency:** declaring any personal interests, and ensuring decisions and activities are documented openly
- **Evidence based:** ensuring the work of the PSP recognises the existing knowledge base for Paediatric Neurology and contributes to this through the PSP's evidence checking and open publication of information from the PSP

Members of the Steering Group will need to agree the resources (including time and expertise) that they will contribute to ensure that each stage of the process is completed. Members of the Steering Group may spend in the region of 1 day/month on PSP activities and will:

- Publicise the initiative to potential partners. 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
- Publicise and participate in an initial awareness meeting if this takes place
- Take part in monthly Steering Group meetings/teleconferences. It is usual for a Steering Group to meet either by teleconference or face to face on an approximately monthly basis in order to keep momentum around the PSP and to maintain their relationship as a team
- If unable to attend, submit comments ahead of the meeting. 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
- Have oversight of the collection of evidence 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
- Agree the final shortlist of questions to be taken to the final priority setting workshop
- Oversee the planning for the final priority-setting workshop and help to publicise it. This is the one-day workshop that 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. Typically, not all members of the Steering Group attend, allowing space for new participants
- Ensure that the PSP's working spreadsheet of uncertainties and the final prioritised list of questions are supplied to the JLA, for publication on the JLA website
- Help publicise the final top 10 uncertainties to the research community
- Be involved in the development of research questions from the agreed priorities, and work with research funders where necessary to provide any extra information they need

**NB:** In addition, an Expert Panel will serve as a designated subspecialty expertise resource with the key role to make sure all aspects of the area of expertise is represented to support steering group members who will provide unbiased input. In this “expert” group role you will not directly contribute to the shortlisting stages and do not need to attend all face to face meeting but will be kept up to date via emails of the entire process.

### **Specific Roles**

**Chair:** The PSP will be chaired by Suzannah Kinsella, a JLA Adviser. The JLA Adviser also Chairs and runs the final priority-setting workshop. The JLA Adviser’s role is to support and guide the PSP, as a neutral facilitator, ensuring that the process is followed in a fair, transparent way, with equal input from patients, carers and clinicians and their representatives.

**Lead:** Ming Lim and Helen Cross will lead the PSP. The leads work closely with the JLA Adviser and the PSP coordinator to champion the PSP and ensure it is successfully promoted, completed and disseminated to funders.

**Coordinator:** Philip Levine who works for the BPNA is responsible for the coordination and administration of the PSP. This includes arranging 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 reviewed by the Chair, circulated within two weeks, and reviewed and agreed at the next meeting.

**Information Specialist:** Up to 5 members identified from steering group will share the information specialist role for the PSP. They are: Ming Lim, Jill Cadwgan, Daniel Lumsden, Jane Goodwin (co-opted) and another member TBC. Their role is to advise the Steering Group on data management and analysis strategies and agree these with the group. They will review and analyse the data collected, review existing evidence, and help develop the long list of questions, under the guidance and assurance of the Steering Group and Expert Panel. Additional support for the information specialist members will be provided by designated members of the research teams of PSP co-leads (Ming Lim and Helen Cross) who will perform literature reviews and assimilate existing evidence.

### **Declaring interests**

Steering Group members are asked to declare any interests relevant to the Childhood Neurological Conditions PSP. The JLA provides an example form, and the interests of each member will be 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. The same form asks Steering Group members to consider their agreement to being named in publicity about the PSP.

Researchers may sit on the Steering Group if the group feels this is appropriate and useful – the JLA Adviser will ensure that they do not have an undue influence on the outcome. Researchers who are currently clinically active may participate in the priority setting if they declare their interests.

### **Timescales**

The Childhood Neurological Conditions PSP first Steering Group meeting will be on 9 October 2019. We propose that the PSP will be fully completed no later than 31<sup>st</sup> March 2021.

### Priority Setting Project Steering Committee

Name	Role
Suzannah Kinsella	James Lind Alliance, External Chair to the PSP
Dr Ming Lim	PSP Chair/Lead
Philip Levine	PSP Secretary/Administrator
Professor Helen Cross	PSP Co-Lead
Professor Manju Kurian	BPNA Chair of Research
Dr Sam Amin	Consultant Paediatric Neurologist
Dr Richard Chin	Reader in Paediatric Neurosciences
Dr Ava Easton	CEO, The Encephalitis Society
Barbara Babcock	Past Chair Transverse Myelitis Society (Patient reported outcome measures)
Siobhan Hannan	Patient Representative
Molly Brick	Young Adult Representative
Rhys Inward	Young Adult Representative
Harriet Pollard	Young Adult Representative
Carol-Anne Partridge	Patient Representative
Ben Green	Lay Representative, Co-opted
Dr Andrew Mallick	Consultant Paediatric Neurologist
Professor Jeremy Parr	Senior Lecturer Paediatric Neurodisability
Dr Jill Cadwgan	Neurorehabilitation

### Priority Setting Project Expert Panel

Name	Expertise
Professor Robert McFarland	Muscle and mitochondrial
Dr Ruth Williams	neurodegenerative disorders and epilepsy
Dr William Whitehouse	Headache and acute neurology
Dr Evangeline Wassmer	Inflammation and inherited white mater disorder
Dr Vijeya Ganesan	Stroke
Dr Rachel Kneen	Neuro Infectious diseases
Dr Daniel E Lumsden	Movement disorder
Dr Anne-Marie Childs	Neuromuscular
Dr Anthony Hart	Neonatal Neurology

