



## **Bleeding Disorders 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 Bleeding Disorders. 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 Bleeding Disorders Priority Setting Partnership**

The background and wider aims and responsibilities of the Bleeding Disorder PSP are set out in the JLA Bleeding Disorders 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<sup>1</sup>**

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:

- Attend and participate in telephone conference calls. To be effective in its decision making, each meeting should be represented with 50% of medical and 50% of allied health and patient members are present.
- attend face to face meetings, or 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
- 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 treatment 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 Bleeding Disorder treatment uncertainties 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.

### **Declaring interests**

Steering Group members are asked to declare any interests relevant to the Bleeding Disorders 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 Sheela Upadhyaya, JLA Adviser. Marta Szczot is responsible for the coordination and administration of the PSP. This includes making arrangements for all meetings and workshops, and ensuring that:

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<sup>1</sup> Add and modify as appropriate

**Steering Group**

- organising venue, refreshments
- communication with steering group members
- preparing & circulating agenda and papers for meetings
- preparing/ circulating documents for meetings (ideally 2 weeks in advance)
- taking minutes & monitoring actions and helping to prompt actions

**Partners**

- contacting partners identified by SG members
- engaging in dialogue to encourage partnering
- tracking the status of potential partners to report to SG
- keeping partners updated

**Other**

- support survey development and subsequent activities as necessary
- map routes to survey and promote; prompting partners as necessary
- Monitor and manage budget
- Manage timeline of project

**Timescales**

The Bleeding Disorders PSP first Steering Group meeting will be in October 2016.

**Key contacts**

PSP Chair: Sheela Upadhyaya, JLA adviser

PSP Lead: Mike Laffan

PSP Co-ordinator: Marta Szczot

