

Stroke Priority Setting Partnership

Steering Group Terms of Reference

Version 4.1: January 29 2020

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

In keeping with JLA principles, the Steering Group must include representatives of patients, carers¹ and clinicians^{2 3}. 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 Stroke 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.

¹ In this PSP, we refer to patients as stroke survivors, and carers and stroke survivors collectively as people affected by stroke.

² The term clinician is interpreted in this PSP as meaning health and social care professionals. In keeping with the JLA's mission, in order to contribute questions and/or take part in prioritisation activities, professionals – whether Steering Group members or not – need to have an active practice.

³ Some Steering Group members may have dual roles i.e. be both affected by stroke and a health or social care professional.

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 stroke. 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>.

The Stroke Priority Setting Partnership

Membership of the Steering Group

The Steering Group membership must be a balance of stroke survivors, carers and health and social care professionals⁴.

Following discussion at the First Steering Group meeting on October 24 2019, it is agreed that for the Stroke PSP, a minimum of 50% of members must be present in order for most Steering Group meetings to go ahead and for decisions to be made. For key meetings, which includes those held face-to-face, this rises to 75%. There should be a satisfactory mix of representation.

As meeting dates have been set in advance, and some organisations are sharing representation between two members, it should be possible for most people/bodies to attend most of the time. Where professional bodies are being represented, should

⁴ Some professionals may have an active practice, some may not. Where this is the case, in keeping with previous footnotes, only those that have an active practice can contribute questions or participate in prioritisation exercises.

members consistently be disengaged, it the PSP reserves the right to alert the organisation.

Role of Steering Group members

Steering Group members are asked to contribute, as a minimum, their expertise and their time, be prepared to approach their established contacts and networks, and to establish new contacts as may benefit the PSP.

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 people affected by stroke and health and social care professional stakeholders are involved in the PSP process;
- *Equality*: people affected by stroke and professionals, 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 stroke 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 resources⁵ (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:

- Represent the views of others, where appropriate, as well as their own;

⁵ The Stroke Association is covering most of the costs of this PSP. *These include*: reasonable expenses for individuals affected by stroke to join meetings; meeting room and refreshment costs (unless they can be provided as an in-kind contribution from PSP partners or under the Corporate Social Responsibility element of an external body); the services of the PSP Manager; and reasonable costs of the JLA Adviser and freelance Information Specialist. *Not included* are the expenses of representatives of organisations and professional bodies who sit on the Steering Group, as it is anticipated that these will be available from those organisations. The Cochrane Stroke Group is contributing the time of their Information Specialist in an advisory capacity.

- Publicise the initiative to potential partners. This includes advising on membership of the PSP (to ensure a wide and representative group of stroke survivors, carers and health and social care professionals), emailing contacts to invite them to participate and working through the communication channels of the organisations they represent, where applicable;
- 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;
- Respond promptly with feedback on project materials – within the timeframe for each task – by responding to emails;
- Have oversight of the collection of evidence uncertainties from stroke survivors, carers, health and social care professionals and existing literature (if applicable);
- 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(s);
- Oversee the planning for the final priority-setting workshop(s), and help to publicise it/them. This is usually a one-day workshop that brings patients, carers and clinicians together to debate, rank and agree a final Top 10. It will only be attended by stroke survivors, carers and the health and social care professionals 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(s) 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.

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 people affected by stroke, health and social care professionals, and their representatives.

Lead: Sarah Belson is the lead for the PSP on behalf of the Stroke Association. The Lead works closely with the JLA Adviser and the PSP coordinator to champion the PSP and ensure it is successfully promoted, completed and disseminated to funders.

Manager: Sandra Regan is responsible for the coordination and administration of the PSP on behalf of the Stroke Association. This includes arranging all meetings and workshops, and ensuring that:

- requests for agenda items are discussed with the group;
- papers are available at least two weeks before meetings;
- meeting notes are reviewed by the Chair, circulated within two weeks, and reviewed and agreed at the next meeting.

Information Specialist: Ann Daly, is the Information Specialist for the PSP, contracted on a freelance basis by the Stroke Association to carry out the bulk of the work. She is a Clinical Librarian and has worked with a number of PSPs in this role.

In addition, Joshua Cheyne, Information Specialist for the Cochrane Stroke Group, will provide expertise and advice.

Their role is to advise the Steering Group on data management and analysis strategies and agree these with the group. Ann will also 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.

The outputs delivered by the Information Specialist will be approved by the Steering Group.

Declaring interests

Steering Group members are asked to declare any interests relevant to the Stroke 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 Stroke PSP first Steering Group meeting will be on October 24 2019. We propose that the final priority-setting workshop(s) takes place in October 2020 (TBC).

An overview of the Timeline is appended to the Protocol. Steering Group meeting dates have been set as follows:

2019

- **December:** Tues 10th, teleconference, 0930-1100

2020

- **January:** Thursday 9th teleconference, 0930-1100
- **February:** Wednesday 5th teleconference, 0930-1100
- **March:** Thursday 5th teleconference, 0930-1100
- **April:** Weds 8th teleconference, 0930-1100
- **May:** Thursday 7th teleconference, 0930-1100
- **June:** Thursday 11 all day, face-to-face
- **July:** Thursday 16th teleconference, 0930-1100
- **Aug:** Thursday 13th, teleconference, 0930-1100
- **Sept:** Thursday 17th all day, face-to-face
- **Oct:** Wednesday 7th teleconference, 0930-1100
- **Nov:** Thursday 12th teleconference, 0930-1100
- **Dec:** Wednesday 2nd teleconference, 0930-1100

Steering Group members⁶

Organisation:	Represented by:
Association of Chartered Physiotherapists in Neurology	Ulrike Hammerbeck/ Sally Davenport
British Association of Stroke Physicians	Rustam Al-Shahi Salman/ Nick Evans
British Neurovascular Group	Diederik Bulters
British Psychological Society	Eirini Kontou/ Shirley Thomas
Chest, Heart & Stroke Scotland	Dianne Haley
Cochrane Stroke Group	Gillian Mead
Different Strokes	Brinton Helliwell
National Institute for Health Research Clinical Research Network: Stroke	Christine Roffe
National Stroke Nursing Forum	Clare Gordon/Liz Lightbody
Northern Ireland Multidisciplinary Association of Stroke Teams (NIMAST)	Niamh Kennedy
Royal College of General Practitioners	Jenny Lund
Royal College of Occupational Therapist Specialist Section – Neurological Practice	Jennifer Crow

⁶ Notes:

- It is assumed that, where members represent an organisation, they have permission to do so in an official capacity, and their expenses to attend meetings are covered by that organisation (c.f. footnote 5).
- Where places are being shared by 2 representatives from one organisation in order for them to manage the commitment effectively, it is their responsibility to inform the PSP Manager who will attend which meeting, and to provide one response to requests for feedback etc. between meetings.
- Some members may represent more than one organisation, which helps to keep the membership to a more manageable size.
- It may, from time to time, be necessary to invite other individuals to Steering Group meetings to provide useful information/advice (e.g. regarding communications).
- Steering Group members may occasionally wish to nominate another member of the organisation they represent to attend in their place, although it would be preferable if this were kept to a minimum. If unable to attend a meeting, views may be provided through another Steering Group member or the PSP Manager.

Organisation:	Represented by:
Royal College of Physicians & National Institute for Health Research Stroke National Specialty Group	Thompson Robinson
Stroke Association	Sarah Belson
Stroke Implementation Group, Wales	Jonathan Hewitt
Royal College of Speech & Language Therapists	Marian Brady/Katie Chadd
Nursing, Midwifery and Allied Health Professions Research Unit	Marian Brady/Alex Pollock
UK Neurointerventional Group	Phil White

Individual members affected by stroke⁷:

Ade Adebajo
Jenny Hylands
Ruth Lyle
Sandra Edgington

Supporting members:

Organisation	Name	Role
Cochrane Stroke Group	Joshua Cheyne	Advisory Information Specialist
James Lind Alliance	Suzannah Kinsella	PSP Chair
N/A	Ann Daly	PSP Information Specialist
Stroke Association	Sandra Regan	PSP Manager

⁷ Additional members are being sought to represent the view of carers.