

Spinal Cord Injury in Sweden Priority Setting Partnership

Expert Group – Terms of Reference

25-26 November 2020

This document sets out the Terms of Reference for the Expert Group of the James Lind Alliance (JLA)¹ Spinal Cord Injury (SCI) in Sweden Priority Setting Partnership (PSP).

In line with JLA principles, this Expert Group will include representatives of persons living with SCI (PLEx), their relatives, carers and health professionals working with PLEx in Sweden. Members will bring with them knowledge of the condition, an understanding of the populations of PLEx, their relatives, carers and health professionals and access to networks of PLEx, their relatives, carers and health professionals working with PLEx in Sweden.

The role of the PSP is to identify and prioritise needs and matters of importance and to identify questions that have not been answered by research to date, and then to agree which of these are the most important. The background and wider aims and responsibilities of the SCI in Sweden PSP are set out in its Protocol.

Membership of the Expert Group

The Expert Group membership includes PLEx, carers and health professionals working with PLEx in Sweden. Quorum is agreed to be $\frac{2}{3}$ of the expert group membership.

Role of Expert Group members

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

- Inclusivity: working with other members supportively, respectfully and constructively and aiming to ensure the full range of PLEx, their relatives, carers and health professionals working with PLEx in Sweden are involved in the PSP process
- Equality: PLEx, their relatives, carers and health professionals working with PLEx in Sweden, and the knowledge and experience they bring, are of equal value to the PSP. Their opinions are treated equally and differences in opinions are respected
- 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 based for SCI and contributes to this through the PSP's evidence checking and open publication of information from the PSP.

¹ For more information about JLA, please visit www.jla.nihr.ac.uk

Members of the Expert Group will:

- Agree the resources (including time and expertise) that they will contribute
- Ensure that each stage of the process, described in the “SCI in Sweden PSP protocol”, is completed.
- Publicise the PSP to potential partners. This includes advising on contacts for the PSP (to ensure a wide and representative group of patients, carers and clinicians) and emailing contacts to invite them to participate
- Take part in approx. 8 Expert Group meetings during the 18–20 month long PSP
- If unable to attend, submit comments ahead of the meeting
- Respond promptly with feedback on project materials by responding to emails
- Ensure that the PSP’s working spreadsheet of needs and matters of importance, 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.

Specific Roles

Chair: The PSP will be chaired by Toto Anne Gronlund, a JLA Adviser. The JLA Adviser also observe and facilitate the 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: Gunilla Åhrén is the lead for the PSP. 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.

Coordinator: Emelie Axwalter 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 Coordinator: Johanna Wangdell is responsible for the coordination of different stages of the data assessment and the different information specialist. The Information Coordinator works closely with Information Specialist and will provide support on methodology and analysis.

Information Specialist: Jeanette Melin is the PSP’s Information Specialist. The Information Specialist’s role is to advise the Expert Group on data management and analysis strategies. They 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 Expert Group. The outputs delivered by the Information Specialist will be approved by the Expert Group.

Code of Conduct

It is important that members of the Expert Group work to high personal and professional standards. Expert Group members are expected to:

- behave in a manner which does not bring the PSP or the JLA into disrepute or damage the relationship with partners or any other stakeholders in the PSP
- maintain confidentiality when sensitive information is shared
- actively support diversity and inclusion and not discriminate against any person.

Everyone involved in the PSP should feel safe, respected and able to contribute fully.

Anyone found to be in breach of this code may be removed from the Expert Group at the discretion of the PSP leader. Any concerns related to conduct should be raised with the PSP leader and/or the JLA Adviser.

Declaring interests

Expert Group members are asked to declare any interests relevant to the SCI in Sweden PSP in the “JLA Interests and Privacy form”, and the interests of each member will be shared among the group. This is to encourage a culture of openness and transparency. The same form asks Expert Group members to consider their agreement to being named in publicity about the PSP.

Researchers may sit on the Expert 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 SCI in Sweden PSP first Expert Group meeting will be on 25-26 November 2020. We propose that the priority setting workshop takes place in March 2022.

Expert Group members:

The names of the Expert Group members can be found in the protocol.