

Pernicious Anaemia Priority Setting Partnership Steering Group - Terms of Reference

12th October 2020

This document sets out the Terms of Reference for the Steering Group of the James Lind Alliance (JLA) Pernicious Anaemia Priority Setting Partnership (PSP).

In line with JLA principles, this Steering Group will include representatives of patients, carers and clinicians. These may be people with lived experience, members of a charity or professional organisation or individual health professionals 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 Pernicious Anaemia PSP are set out in its Protocol.

Introduction to the James Lind Alliance and priority setting

The JLA is a non-profit making initiative which enables patients, carers and clinicians to work together to identify and agree priorities for research.

Each PSP consists of patients, carers and their representatives, and clinicians, and is led by a Steering Group. The Steering Group oversees the activities of the PSP and has responsibility for the activity and the outcomes of the PSP. Collaboration between patients, carers and clinicians to set the research agenda is 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 agree which of these are the most important. The first stage is to ask patients, carers and clinicians, often via an online survey, for unanswered questions about the Diagnosis and Treatment of Pernicious Anaemia. These questions are then assessed to check they are in scope for the PSP and are checked to make sure they have not already been answered by research. An interim prioritisation exercise then takes place, where people with an interest in the Diagnosis and Treatment of Pernicious Anaemia choose which questions are most important to them. Finally, there is a priority setting workshop where participants discuss the most important questions and agree a list of the Top 10.

The aim of the PSP is to highlight the important areas of research to the research and funding community and to work with them to develop the priorities into researchable questions.

In addition to the PSP's own reporting activity, the JLA will publish all priorities on the JLA website. Further details about the JLA and PSPs are at <https://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 <https://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm>

The Pernicious Anaemia Priority Setting Partnership

Membership of the Steering Group

The Steering Group membership must include patients, carers and professionals.

It is agreed that for the Pernicious Anaemia PSP, two patient/carer representatives and two healthcare professionals will need to be present for Steering Group meetings to be quorate.

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 supportively, respectfully and constructively and aiming to ensure the full range of patient, carer and clinical stakeholders 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. 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 Pernicious Anaemia 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 will:

- 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
- 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
- Sign off the final shortlist of questions to be taken to the priority setting workshop
- Oversee the planning for the 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. Participants are patients, carers and the healthcare professionals or support workers who actively work with them. Typically, not all members of the Steering Group take part, 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.

Specific Roles

Chair: The PSP will be chaired by Katherine Cowan, a JLA Adviser. The JLA Adviser also Chairs and runs 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: Martyn Hooper 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: Karyl Carter 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: Petra Visser is the Information Specialist for the PSP. Her role is to advise the Steering Group on data management and analysis strategies and agree these with the group. She also reviews and analyses the data collected, review existing evidence, and help develop the long list of questions, under the guidance and assurance of the Steering Group. It is helpful if the Information Specialist has content knowledge in the subject area of the PSP. However, if the Information Specialist is well supported by the Steering Group this is not essential. The outputs delivered by the Information Specialist will be approved by the Steering Group.

Code of Conduct

It is important that members of the Steering Group work to high personal and professional standards. Steering 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 Steering Group members, partners and 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 Steering 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

Steering Group members are asked to declare any interests relevant to the Pernicious Anaemia PSP. The JLA provides an example 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. 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 Pernicious Anaemia PSP first Steering Group meeting will be on 17th November, 2020. We propose that the priority setting workshop takes place in September 2021 (TBC).

Name	Affiliation	Role in Steering Group
Katherine Cowan	James Lind Alliance	PSP Chair
Martyn Hooper	Patient	PSP Lead
Karyl Carter	Patient	PSP Coordinator
Petra Visser	Patient	PSP Information Specialist
Sophie Barry	Patient	Steering Group member
Jaqui Gold	Patient	Steering Group member
Stephen Ganter	Patient	Steering Group member
Dr Rakesh Koria	General Practitioner	Steering Group member
Dr Nicola Ward	Pharmacist	Steering Group member
Dr Heidi Seage	Chartered Psychologist	Steering Group member
Dr Asim Naqvi	General Practitioner	Steering Group member
Dr John Warren	Retired Consultant Physician	Steering Group member