



Setting up a Priority Setting Partnership Some questions answered

This is a summary of the steps involved in establishing a James Lind Alliance (JLA) Priority Setting Partnership (PSP). If you are interested in setting up a PSP, it is essential that you read the JLA Guidebook at www.jla.nihr.ac.uk to familiarise yourself with the detailed JLA process.

What is the JLA?

The JLA is a non-profit making initiative, established in 2004. It brings patients, carers and clinicians together in [PSPs](#). These PSPs identify and prioritise evidence uncertainties, or unanswered questions, that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to the people who need to use the research in their everyday lives. The coordination of the JLA is funded by the [National Institute for Health and Care Research](#) (NIHR) and the JLA team is based at the NIHR Coordinating Centre (NIHRCC) at the University of Southampton.

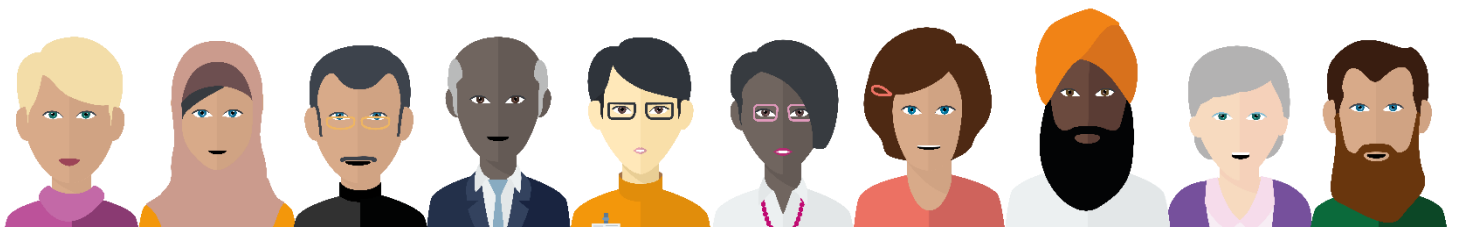
Groups wishing to initiate a PSP will submit a Readiness Questionnaire to the JLA. The JLA coordinating team reviews the questionnaire to ensure that appropriate preparations and resources are in place to complete the PSP successfully. A JLA Adviser is then allocated to chair and advise the PSP. The PSP contracts directly with the JLA Adviser and pays for the JLA Adviser's time.

You can ask for a copy of the readiness questionnaire by emailing jla@soton.ac.uk

What are the principles of JLA priority setting?

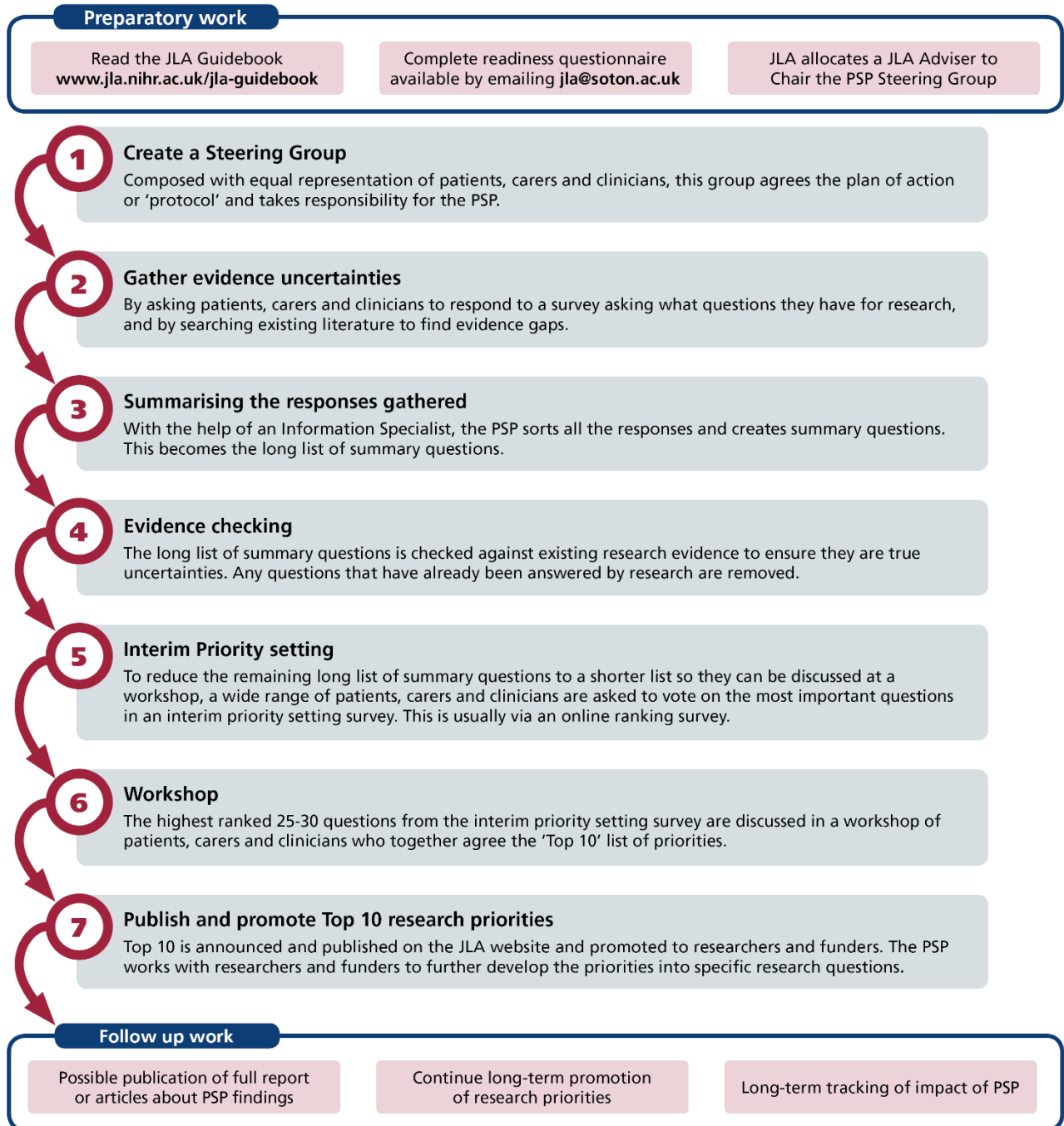
PSPs enable clinicians, patients and carers to work together to identify and prioritise important evidence uncertainties that could be answered by research. To ensure consistency and maximum learning, the JLA asks PSPs to demonstrate the following features:

- transparency of process
- balanced inclusion of patient, carer and clinician interests and perspectives
- exclusion of non-clinician researchers for voting purposes (they may be involved and helpful in all other aspects of the process)
- exclusion of groups/organisations that have significant competing or commercial interests, for example pharmaceutical companies
- audit trail of original submitted uncertainties, to final prioritised list
- priority setting only commencing after the uncertainties have been formally verified as unanswered.



What is the PSP process?

Below is a diagram representing the stages of a PSP. A detailed explanation is in the [JLA Guidebook](#).



What is in the online JLA Guidebook?

It is essential to read the [Guidebook](#) early in the planning stages of the PSP. The Guidebook is a practical guide to all of the steps involved in running a PSP. It includes helpful templates and ideas, including:

- Templates for use when setting up a Steering Group
- Examples of methods and questionnaires used by previous PSPs for gathering uncertainties
- Methods and questionnaires that PSPs have used for interim priority setting
- Templates for reporting methods and results on the JLA website
- Examples of how PSPs have promoted their final list of research priorities.

Shaping the scope of the PSP

The Steering Group needs to define the PSP's scope. Scope may be defined by the patient population of interest (e.g. adults and or/children) or the breadth of the condition or health area and its unique issues. It is important to consider the scope of the PSP in terms of the resources available. A PSP with a broad remit, such as [Sight Loss and Vision](#) or [Palliative and end of life care](#), may be likely to gather more uncertainties, which will increase the time and resources required to process the responses, compared with a PSP with a more focussed remit. The scope of the PSP might also have implications for type and amount of evidence to be checked.

The [JLA website](#) gives details of the current and completed PSPs, showing their scope and health areas. In the Guidebook, you will find examples of the numbers of people who responded to the initial survey and the number of uncertainties submitted to different PSPs.

What are evidence uncertainties?

Evidence uncertainties are questions about healthcare that cannot be answered by existing research. These might be questions about particular treatment options, methods of care, or diagnostic tests. The JLA definition of an evidence uncertainty is that:

- No up-to-date, reliable systematic reviews of research evidence addressing the uncertainty exist.
- Up-to-date systematic reviews of research evidence show that uncertainty exists.

Many PSPs now extend their scope beyond identifying and prioritising simply 'treatment uncertainties' and include other healthcare interventions like prevention, diagnosis, rehabilitation, care, and service organisation and delivery. The JLA recognises that a systematic review may not always be the best source of evidence for every topic area or type of uncertainty. Many of these other areas will require different evidence checking, extending beyond searching for systematic reviews.

How are evidence uncertainties gathered?

Uncertainties usually come from four main sources – patients/service users, carers, clinicians and existing guidelines and systematic reviews. Typically, patients, carers and clinicians are asked to submit their unanswered questions via an online survey, with paper questionnaires provided where requested. Other methods should be considered if a survey is not appropriate for all audiences. One of the key roles of the Steering Group is to identify how to communicate the survey to as wide a range of patients, relatives, carers and health and care professionals as possible. Social media, press releases, contacts of the Steering Group, the PSP website, and contacts with professional and patient organisations are all good ways of communicating the survey.

How are survey responses turned into uncertainties?

The questionnaire used to gather unanswered questions is open-ended, to encourage responses from a wide range of people. Responses are therefore qualitative and can be complex and personal. The Information Specialist (who processes the information on behalf of the PSP) will pick out the unanswered questions from the survey responses and review whether they are within the scope of the PSP, referring to the Steering Group for agreement. The Steering Group should consider how to deal with questions received that are outside the scope of the PSP (and those which are already answered) as these may still be important. The Information Specialist, working closely with the Steering Group, will form summary questions from all the responses, ensuring the summary questions remain true to the original responses received.

The summary questions must be checked against existing research evidence to ensure they are unanswered before prioritisation can begin. This is one of the most labour-intensive stages of the JLA process and the Steering Group needs to identify how it will be resourced and actioned. How the evidence will be checked will be agreed by the Steering Group and set out in the Evidence Checking Form, which will be published by the Steering Group to ensure transparency of process.

Any questions that are shown to be answered during the evidence checking process can be deemed as not requiring further research and can be removed from the process. Questions that cannot be answered by existing evidence can go forward into the prioritisation process. At the end of this process, the PSP will have a long list of summary questions that are ready to go into the next phase of the PSP.

How are the uncertainties shortlisted for discussion at the prioritisation workshop?

In order to reduce the long list of summary questions into a shorter list to be discussed at a final prioritisation workshop, the questions go into an interim priority setting exercise. This usually takes the form of an online survey of patients, carers and clinicians who are asked to rank, from their point of view, the most important questions. The highest-ranking 20-30 questions from this exercise are then taken to the prioritisation workshop for discussion. Examples of how PSPs have done interim priority setting are available in the [JLA Guidebook](#).

What happens at the prioritisation workshop?

At the final prioritisation workshop, a group of patients, carers and clinicians come together and share their knowledge and experience to discuss the 20-30 highest-ranked questions and agree together the Top 10 list of priorities for research. The day follows a standard JLA format consisting of a mix of plenary and small group discussion sessions. The PSP's JLA Adviser chairs the workshop, and two further JLA Advisers facilitate the small group discussions. By the end of the day, the final Top 10 priorities for research are agreed.

What happens after the workshop?

Using a range of communication tools, the Steering Group should take responsibility for finding ways to disseminate the Top 10 and identifying potential opportunities for funded research, targeting in particular research funders, charities and the research community. The JLA will support this process by passing the list of priorities for consideration to the NIHR research programmes.

Top 10s vary in the way they are worded and presented. They contain questions and topics that matter to patients, carers and clinicians, written in terms that a wide audience can understand. However, they are not usually precisely worded research questions that research

funders can immediately work with. The Steering Group may need to work with funders to discuss the full background to the questions.

Steering Groups are also encouraged to monitor what happens to the research priorities in the long term and, where possible, to keep interested parties updated with details of research that results from the work of the PSP. The JLA website includes examples of research funded as a result of PSPs.

Roles and responsibilities within a PSP

What does the PSP lead do?

The PSP lead is usually the individual or representative of the group who made the initial approach to the JLA to carry out the PSP. This person will work closely with the JLA Adviser and the coordinator or administrator and take overall responsibility for successful completion of the PSP. The PSP lead needs to demonstrate commitment to the process, drive the PSP forward to completion and be able to generate wider stakeholder engagement and enthusiasm across the sector that the PSP will cover.

What does the JLA Adviser do?

The JLA Adviser supports and guides the PSP as a neutral facilitator, ensuring that the process is fair and transparent, with equal input from the perspectives of patients, carers and clinicians. For some PSPs, the first time they need the help of an Adviser will be when they are setting up the first Steering Group meeting. Some PSPs may choose to run an initial awareness meeting to raise the profile of the exercise amongst key stakeholders, and will involve the JLA Adviser at this stage. The JLA Adviser throughout the 12-18 month life of the PSP chairs the PSP Steering Group. JLA Advisers are independent consultants and are paid directly by the PSP.

What does the PSP Steering Group do?

PSPs need a committed and proactive Steering Group. The Steering Group oversees the PSP, organises its activities, and is ultimately accountable for key decisions made about the PSP.

The group must include representatives of patients, carers and clinicians, and these are often members of a charity or professional organisation within the area of the PSP. Members will bring with them knowledge of the condition or health setting, an understanding of the patient population 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.

Amongst the tasks that the Steering Group is responsible for are publicising the PSP, overseeing the checking and collating of uncertainties, and taking the final priorities to research funders. There are no rules about how many people should be on a PSP Steering Group, but typically, it is around 12. Too large and it becomes difficult to arrange meetings and make decisions, too small and not all of the required people may be represented.

What does an Information Specialist do?

A PSP needs to be able to manage data. This includes reviewing and sorting survey responses, reviewing existing research evidence, and formulating and presenting summary research questions. In some cases, one Information Specialist has the skills to perform all of the tasks; in other cases, more than one person is needed. The tasks will involve:

- Reviewing and sorting the responses from the initial PSP survey to gather uncertainties

- Categorising the survey responses, then creating clear, formatted summary questions which capture the meaning of the original submissions, and presenting these to the Steering Group for review and agreement
- Checking existing systematic reviews and guidelines or other evidence, to an agreed search strategy, to identify which questions have already been answered and to find any other research recommendations
- Checking for relevant ongoing studies
- Preparing a long list of summary questions for interim prioritisation, ensuring that they are understandable for the patients, carers and clinicians who will be involved in this step and in the final workshop
- Managing a record of all PSP survey data, traceable back to the original survey submissions
- Supplying the PSP's working spreadsheet of summary questions or uncertainties and the prioritised list from the final workshop to the JLA, for publication on the JLA website

The precise amount of time will depend on the number of survey responses and the scope of the PSP but the estimated number of days work for these activities is approximately 25-30 days.

What does the PSP Coordinator do?

Tasks for a PSP Coordinator may include organising teleconferences, Steering Group meetings and the final workshop, which will include recruitment of the individuals attending, writing and following up on action notes and managing communications with stakeholders and the wider community. Depending on skills, this person could also get involved with communication activity such as preparing a website, communicating via Twitter, and producing and publicising the survey and downloading the survey results ready for the Information Specialist.

The amount of time this takes should not be underestimated and could be 1 - 2 days a week across the life of the project, with some periods being busier than others. Some larger PSPs have employed a project coordinator for this role, other smaller groups have been supported by someone already available in their own organisation.

What are the costs involved in running a PSP?

PSPs need to find their own resources for undertaking a PSP. The costs involved in running a PSP can vary considerably. Many of the costs depend on the in-house knowledge and resources of the PSP, the help that can be provided in kind by Steering Group members and other supporters and the scope of the PSP. As a guide, the JLA has a spreadsheet of indicative costs, based on examples from previous PSPs. Funds may come from one main organisation or charity or a number of partners in the PSP may make smaller contributions. If supporters of your PSP can provide, for example, administration support, meeting rooms and catering, or the time of an Information Specialist, at no cost, then overall PSP costs will be kept to a minimum.

If you have any questions, please email us at jla@soton.ac.uk