



Setting up a Priority Setting Partnership Some questions answered

This is an introduction to some of the practical details involved in setting up a PSP. Much more information is available in the online JLA Guidebook, within the JLA website at www.jla.nihr.ac.uk. If you are interested in setting up your own PSP, you will need to read through the Guidebook to understand the exact steps involved.

What is the James Lind Alliance?

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004. It brings patients, carers and clinicians together in [Priority Setting Partnerships](#). These partnerships identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments 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 both patients and clinicians. The infrastructure of the JLA is funded by the [NIHR](#) and the JLA is based within the University of Southampton.

During preparation for a PSP, the potential partnership will submit a 'readiness questionnaire' to the JLA. Once the JLA co-ordinating team has reviewed this and can see that everything is in place to successfully start the PSP process, a JLA Adviser will be allocated. The JLA Adviser's support to the PSP from then on will be funded by the partnership.

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

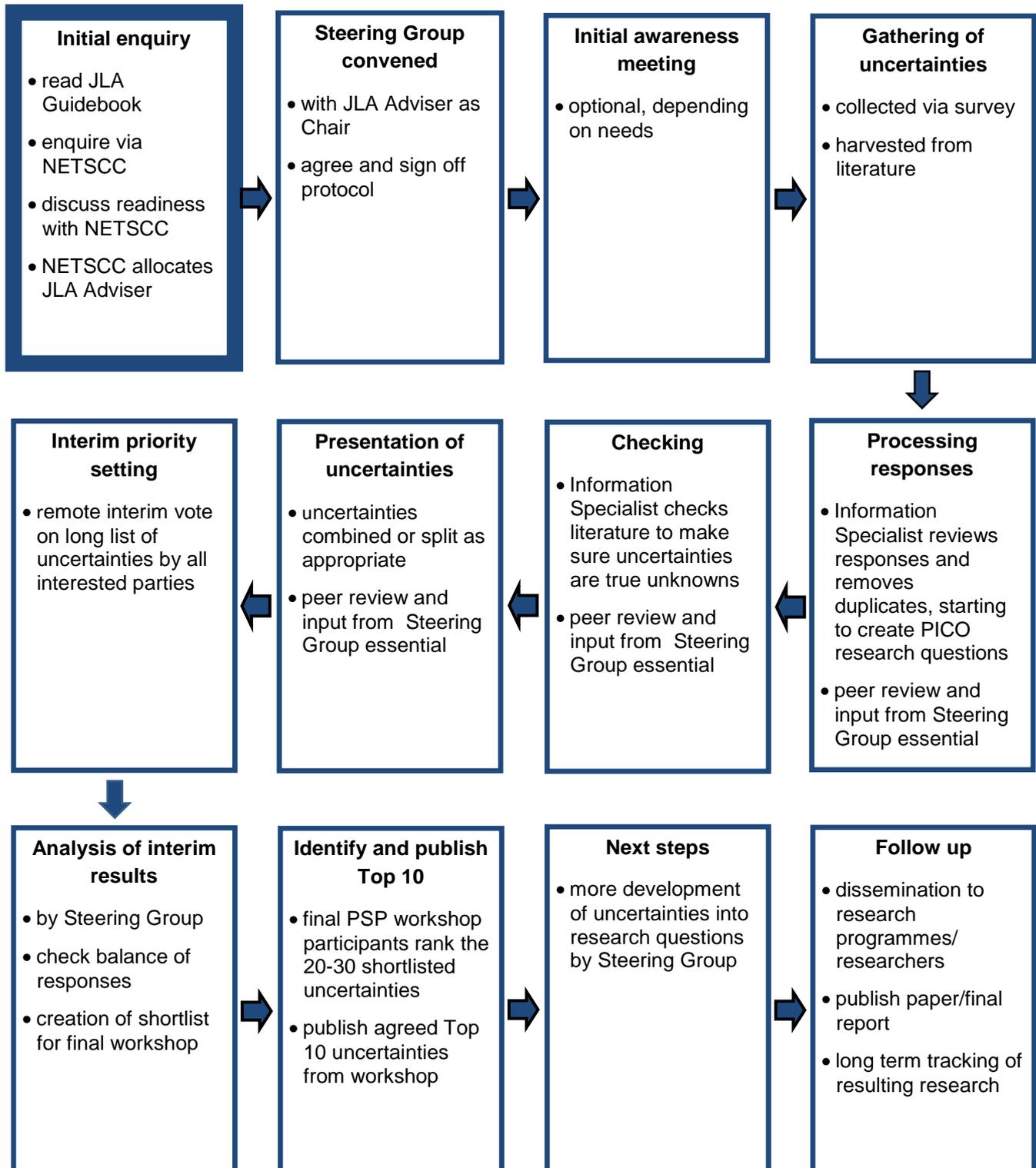
What are the principles of JLA priority setting?

The JLA is about 'tackling treatment uncertainties together'. PSPs enable clinicians, patients and carers to work together to identify and prioritise important uncertainties about the effect of treatments, that could be answered by research. To ensure consistency and maximum learning, the JLA asks each partnership to ensure that their methods address a set of underpinning principles. These are:

- 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 in all other aspects of the process)
- exclusion of groups/organisations that have significant competing interests, for example pharmaceutical companies
- maintained audit trail of original submitted uncertainties, to final prioritised list.

What is the PSP process?

Below is a diagram representing the usual stages of a PSP. More details of all of these recommended steps are provided in the [JLA Guidebook](#).



What is in the online JLA Guidebook?

Reading the [Guidebook](#) early in the planning stages is essential. The Guidebook is a practical guide to all of the steps involved in running a PSP. Alongside all of the written support, you will find plenty of helpful templates and ideas, including:

- An overview of the key roles in a PSP and the skills required
- Examples of methods and materials used by previous PSPs for gathering uncertainties
- Methods and materials that PSPs have used for interim priority setting
- Templates for materials used in final priority setting workshops
- Examples of how PSPs have promoted their final prioritised list of uncertainties

How broad should the scope of a PSP be?

The steering group needs to define the PSP's scope. Scope may be defined by the patient population of interest (eg, adults and or/children) or the breadth of the condition and the unique issues which sit within it. It is important to consider the implications of scope, before agreeing it. A PSP with a broad remit (such as Sight Loss and Vision or Palliative and end of life care) will generally take longer, require greater resource and incur more costs than a PSP which has a tighter remit (like the PSPs undertaken in Tinnitus or Mesothelioma).

For example, a PSP with a broad remit will receive more uncertainties which will increase the time needed to check and prioritise these. A higher number of systematic reviews may be uncovered, meaning more time will be required to check the uncertainties against them and to extract the research recommendations for inclusion in the process.

The [JLA website](#) shows details of the current and completed PSPs, to give you some idea of the scope and clinical areas of those undertaken so far. In the online Guidebook, you will also find examples of how many initial uncertainties were gathered by PSPs, how many were true uncertainties, and how many people they came from. The main output of a JLA PSP should be a Top 10 list of uncertainties that focus on treatment. It is acceptable to include prevention, care and diagnosis within this definition if an intervention can be specified. PSPs may choose to examine areas other than treatment but in a related area – this can be done alongside the central focus on treatment.

What do we mean by a treatment uncertainty?

Treatment uncertainties are questions about treatments and healthcare interventions which cannot be answered by existing research. These might be questions about particular treatment options, methods of care, or diagnostic tests. The JLA definition of a treatment uncertainty is that:

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

How are treatment uncertainties gathered?

Uncertainties will come from four main sources - patients, carers, clinicians and existing literature. Patients, carers and clinicians will be asked to submit their questions via an online survey, with paper questionnaires provided where requested. One of the key roles of the steering group is to identify how to communicate this survey to as wide a range of patients, relatives, carers and health 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 main survey question is open-ended, to encourage responses from people who might not normally think about research. Responses are therefore qualitative and can be complex and personal. The Information Specialist will pick out the potential unanswered questions from the survey responses and review whether they are within the scope of the PSP, referring to the steering group. The steering group should consider how to deal with questions received which are outside the scope of the PSP as these may still be important questions.

Uncertainties must be checked and verified as true uncertainties 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.

Any questions that are answered by a systematic review can be deemed as not requiring research and can be removed from the process. Questions that cannot be answered by evidence presented in systematic reviews can go forward into the prioritisation process.

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

The exercise to gather treatment uncertainties can yield a large amount of information. The most practical approach is to shortlist the uncertainties in an interim priority setting exercise, and then proceed to a final priority setting workshop. In interim priority setting, patients, carers and clinicians are asked to examine the long list of treatment uncertainties and choose those which in their experience are the most important for research to answer. The exact approach to ranking is dependent on the number of valid uncertainties gathered and the number of uncertainties the steering group has agreed to shortlist. The steering group will help to design a process which is accessible and appropriate to the target audiences. Examples of how PSPs have undertaken this process are available in the [JLA Guidebook](#).

What happens at the final prioritisation workshop?

The final workshop enables a top 10 list of prioritised uncertainties to be agreed upon by a balanced group of patients, relatives, carers, members of organisations and healthcare professionals. It will be facilitated by the JLA Adviser who has been chairing the PSP and usually two other JLA Advisers to help with the small group work throughout the day.

What happens after the final workshop?

Steering group members are encouraged to disseminate the top 10 priorities using a range of communications to target in particular research funding bodies, charities and researchers. The prioritised list of uncertainties will also be reviewed by the NIHR research programmes managed by NETSCC, for consideration for their commissioned work-streams. The steering group is expected to develop the prioritised uncertainties into research questions and to work to establish the research needs of those unanswered questions to use when approaching potential funders or when allocating funding for research themselves, if applicable.

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 which results from the work of the PSP.

Roles and responsibilities within a PSP

What does the PSP lead do?

The PSP lead is usually the individual or representative of the group which made the initial approach to the JLA to carry out the PSP. This is the person who will work closely with the JLA Adviser and the project co-ordinator or administrator to make sure the PSP is successfully completed. The PSP lead may be a researcher. However, in accordance with the JLA's aims, only those representing patients and clinicians are able to participate in priority setting, so in this case the PSP lead would not take part in prioritising the questions raised.

What does the JLA Adviser do?

The role of the JLA Adviser 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 the perspectives of patients, carers and clinicians. For some partnerships, the first time they need the help of an adviser will be when they are setting up the first steering group meeting. Other partnerships 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 PSP steering group will be chaired independently by a JLA Adviser throughout the 12-18 month life of the PSP. JLA Advisers are independent consultants.

“The guidebook is fairly helpful, but the Adviser's knowledge and experience from other PSPs, on top of the guidebook, is hugely beneficial. She is able to provide insight on deviations and alternatives that would be way too confusing to a solo reader of the guidebook alone.” (Ongoing PSP)

What does the PSP steering group do?

Each PSP needs a steering group to coordinate the partnership and organise its activities. The group must include representatives of patients 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, 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 initiative, overseeing the checking and collating of uncertainties, and taking the final priorities to research funders. Much more information about the steering group, including an example Terms of Reference, can be found in the online JLA Guidebook. There are no set rules about how many people need to be on a PSP steering group. It is often around 12 but it can be larger or smaller than that. Too large and it becomes difficult to arrange and manage 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 an Information Specialist who can review and analyse the data collected, review existing research, and formulate potential research questions.

The role will involve:

- Creating, listing and categorising questions from the initial PSP survey responses
- Preparation of taxonomy
- Allocation of uncertainties into taxonomy with guidance from the steering group
- Putting submissions into PICO format (questions which include the Patient/population, the Intervention, the Comparison and the Outcome)
- Checking existing systematic reviews 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 uncertainties 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
- Preparing the questions for final prioritisation
- Providing regular updates of progress to the steering group and working within overall timescales agreed.

The individual will be someone with:

- Database management experience
- Critical appraisal skills: comfortable with managing and categorising large amounts of qualitative data, for example responses to open-ended survey questions
- Experience of medical terminology
- Attention to detail - methodical and organised
- Able to work to deadlines
- Ability to communicate complex data to both patients, carers and clinicians
- Familiarity with JLA process would be helpful, but not mandatory
- Awareness of the PSP disease area would be useful, but not mandatory.

The precise amount of analysis will depend on the number of survey responses but the estimated number of days work for the information specialist for the life of the PSP is approximately 25-30 days.

What does the PSP Project Co-ordinator/Administrator do?

Tasks for a Project Co-ordinator or Administrator can include organising teleconferences, steering group meetings and the final workshop, 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 preparing a website, communicating via Twitter, producing and publicising the survey and downloading the survey results ready for the information specialist to work on.

The amount of time this co-ordination takes should not be underestimated and could be 40 – 60 days across the life of the project. Some larger PSPs have employed a project co-ordinator 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?

The costs involved in running a PSP can vary considerably. Many of the costs depend on the in-house knowledge and resources of the partnership, 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, developed after looking at the money spent during recent PSPs. Costs need to be covered by the PSP budget. Funds may come from one main organisation or charity or smaller contributions may be made by a number of partners in the PSP. If supporters of your partnership 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 about PSPs, please email us at ila@soton.ac.uk

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