

The James Lind Alliance Guidebook

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www.jla.nihr.ac.uk

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Chapter 1 - INTRODUCTION

Welcome to the James Lind Alliance (JLA) Guidebook. The Guidebook is aimed at people that are interested in the JLA's priority setting process: namely, patients and their carers, clinicians and the organisations that represent them. It gives step-by-step guidance to establishing and managing a Priority Setting Partnership (PSP) and the principles behind it. PSPs bring patients, their carers and clinicians together to identify and prioritise unanswered questions about the effects of treatments ('treatment uncertainties') in specific conditions or areas of healthcare for research, using JLA methods.

It is recognised that many PSPs now interpret this definition more broadly and extend their scope beyond identifying and prioritising 'treatment uncertainties'. This has been an important development and one which helps the JLA to adapt to the changing health and care landscape and to the changing needs of its users.

The Guidebook is intended to help PSPs work effectively using tested methods to ensure credible and useful outcomes.

Research priority setting: why involve patients and clinicians?

Research on the effects of treatments often overlooks the shared priorities of patients, carers and clinicians. The pharmaceutical and medical technology industries and academia play essential roles in developing and testing new treatments, but their priorities are not necessarily the same as those of patients and clinicians. Many areas of potentially important research are therefore neglected, and there is often a mismatch between the research being carried out and the research evidence needed by patients and clinicians every day^{1,2}. This also leads to an avoidable waste of precious research funds³. The JLA method was developed to address this.

Focusing on specific conditions, or areas of healthcare, the JLA facilitates PSPs which:

- bring patient, carer and clinician groups together on an equal footing
- identify treatment uncertainties which are important to both groups
- work with both groups to jointly prioritise the uncertainties
- produce a 'Top 10' list of jointly agreed uncertainties as research questions to be presented to funders.

Why the JLA Method?

The JLA is pioneering in involving both patients and clinicians equally in setting priorities for research. The JLA method is designed to raise awareness of research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them, with the aim of leading to changes in the way research funding is granted. It is a tried-and-tested method which has been used in PSPs since the first one in Asthma which was completed in 2007.

The most positive long-term outcome for any JLA PSP will be that research into one or more

¹ [*Tallon, D et al. \(2000\) 'Relation between agendas of the research community and the research consumer'. The Lancet, volume 355:2037–40*](#)

² [*Crowe, S et al. \(2015\) 'Patients, clinicians' and the research communities' priorities for treatment research: there is an important mismatch'. Research Involvement and Engagement 2015, 1:2*](#)

³ [*Chalmers I, Glasziou P, 'Avoidable waste in the production and reporting of research evidence', The Lancet, Volume 374, Issue 9683, Pages 86 - 89, 4 July 2009, doi:10.1016/S0140-6736\(09\)60329-9*](#)

of the uncertainties it identifies is commissioned, and that this goes on to have a life-changing impact on the treatment available to patients and the way in which clinicians can deliver this.

What are the principles of the JLA?

The JLA priority setting method is flexible and responsive to the needs and contexts of different groups, while maintaining the following integral features across JLA PSPs:

- the principle of inclusivity, with patients, carers and clinicians working together as equal partners
- methodological transparency
- the declaration of interests
- a commitment to using and contributing to the evidence base.

Each JLA PSP signs up to a protocol describing its process and intentions (see protocol template 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>).

This provides clarity about the nature of the work undertaken by each member of the PSP and describes the underpinning principles to be observed by partners.

The JLA method is continuously evolving. As evidence of new approaches and good practice emerge, the Guidebook will be updated.

The James Lind Alliance

The James Lind Alliance (JLA) is a non-profit making initiative which was established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the unanswered questions about the effects of treatments that they agree are most important.

The National Institute for Health Research (NIHR – www.nihr.ac.uk) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton. This includes the recruitment and training of JLA Advisers, management of enquiries, communication activity, and working with JLA Advisers to support and uphold the principles and methodology of the JLA. The NIHR does not normally fund JLA Priority Setting Partnerships.

The JLA Guidebook, the team of JLA Advisers and the JLA team at NETSCC all govern the way the JLA operates and develops. Other input to the JLA comes from a mix of lay people, healthcare and clinical research professionals and experts in patient and public involvement.

Contact us

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Or follow the JLA on Twitter at www.twitter.com/lindalliance

JLA on Wikipedia: http://en.wikipedia.org/wiki/James_Lind_Alliance

Acknowledgements

The original Guidebook was written by Katherine Cowan, Senior Adviser to the JLA, and Sandy Oliver, Professor of Public Policy at the Social Science Research Unit and EPPI-Centre, Institute of Education, University of London. Katherine oversaw versions 1 – 5. This current version (version 6), has been updated by the JLA team at NETSCC and Katherine Cowan, with input from the JLA Advisers.

Chapter 2 - TREATMENT UNCERTAINTIES

What are treatment uncertainties?

People have suffered and died unnecessarily because uncertainties about the effects of treatments have not been addressed in research ^{4, 5, 6}). Patients and the public have a right to expect that research funders, researchers and health professionals will identify uncertainties about whether treatments are doing more harm than good or whether one treatment is better than another, and should expect them to organise the research needed to reduce the most important of these uncertainties.

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.

Systematic reviews are based on worldwide searches for reliable, relevant evidence. They are comprehensive summaries and analyses of comparable published and unpublished studies of effectiveness, prepared by a team of authors. Systematic reviews are used to inform health and social care service development, policy development, and research.

It is recognised that many PSPs now extend their scope beyond identifying and prioritising 'treatment uncertainties' and include other health care interventions like prevention, diagnosis, rehabilitation, care, and service organisation and delivery. Many of these areas will require a different protocol for evidence checking, extending beyond searching for systematic reviews. The different evidence checking methods for these PSPs need to be transparent and agreed with the PSP Steering Group and JLA Adviser.

More detailed information about systematic reviews and fair tests of the effects of treatments is available in the James Lind Library (www.jameslindlibrary.org). Further information is also available at www.testingtreatments.org

To help ensure that treatments do more good than harm, gaps in knowledge about their effects – i.e. uncertainties - must be identified, and those deemed sufficiently important must be addressed in research.

⁴ [*Chalmers, I. 'Confronting therapeutic ignorance'. BMJ 2008;337:a841*](#)

⁵ [*Chalmers, I. 'Well informed uncertainties about the effects of treatments'. BMJ 2004;328:475-6*](#)

⁶ [*Evans, I., Thornton, H., Chalmers, I., Glasziou P, 'Testing Treatments: better research for better healthcare' \(2011\)*](#)

Chapter 3 - PRIORITY SETTING PARTNERSHIPS

What is a Priority Setting Partnership?

The aim of Priority Setting Partnerships (PSPs) is to bring patients, carers and clinicians together to jointly identify priorities for research. The JLA's current portfolio of PSPs can be seen online at www.jla.nihr.ac.uk/priority-setting-partnerships. JLA PSPs are characterised by following the method set out in this Guidebook and are facilitated by one of a small team of approved JLA Advisers.

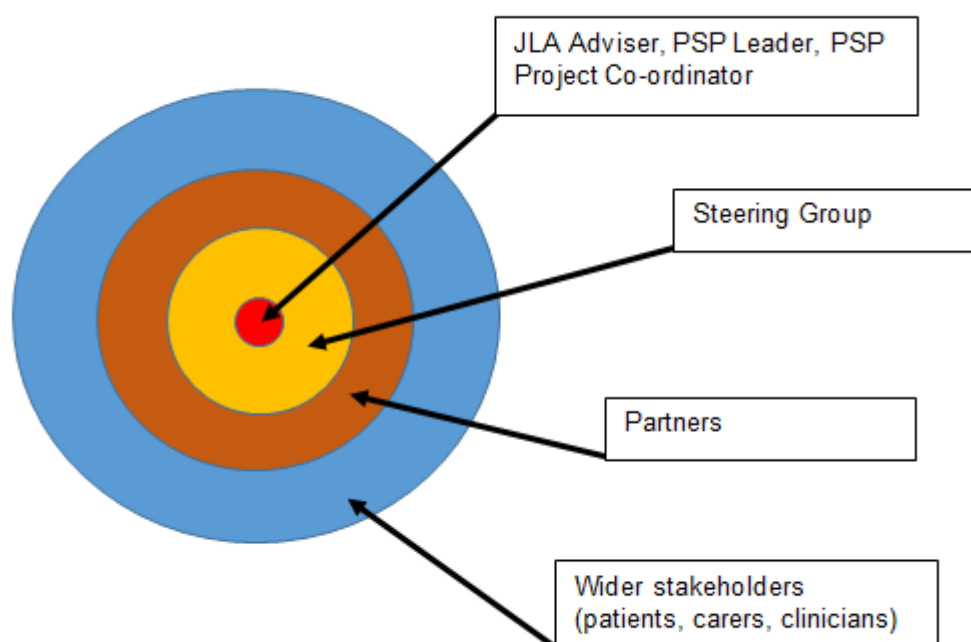
PSPs' objectives are to:

- bring patients and clinicians together to identify uncertainties about the effects of treatments for specific health issues
- agree by consensus a prioritised 'Top 10' list of those uncertainties, for research
- publicise the methods and results of the PSP
- draw the results to the attention of research funders, independently of the JLA.

Advocates of and individuals from the following groups are eligible to take part in a PSP:

- people who have or have had the health problem in question
- carers and families of those affected
- medical doctors, nurses and allied health professionals with experience of caring for people with the health problem.

Who's who in the Priority Setting Partnership?



Steering Group: a small group that coordinates and implements the activity of the PSP. It includes representatives of patients and clinicians, as well as a JLA Adviser.

Partner: a member of the PSP participating in the prioritisation of treatment uncertainties for research. A partner represents and can advocate for patients, carers or clinicians. They can be an individual or from an organisation.

Patients: individuals with experience of the health problem and those who represent them, including carers, relatives and charities.

Clinicians: all types of health professionals with experience of caring for people with the health problem, including organisations or groups who represent them.

The overall structure and role of the PSP is set out in the Protocol document. An overview of the key roles and competencies can be found online at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm> , which shows examples of key tasks undertaken by each role.

The features of JLA priority setting

To ensure consistency and maximum learning, the JLA asks each PSP 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, but who may be involved in all other aspects of the process
- exclusion of groups/organisations that have significant competing interests, for example pharmaceutical companies
- audit trail of original submitted uncertainties, to final prioritised list
- recognition that making priority decisions does not create new knowledge, but reviews existing evidence of uncertainty.

Priority setting can only occur if the identified treatment uncertainties have been checked to ensure that they have not been answered by an up-to-date systematic review.

Exclusions

The JLA does not invite representatives of the pharmaceutical industry or those in the research community who are not also clinicians, patients or carers to participate in the priority setting process. 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.

Traditionally the health research agenda has been largely determined by the pharmaceutical industry and researchers themselves. This has usually been with minimal input from patients and their carers, or patients, carers and clinicians combined.

The JLA exists to address this imbalance.

JLA Advisers

JLA Advisers are independent facilitators who have been recruited and trained by the JLA. The JLA website shows details of the advisers at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/jla-advisers.htm> .

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.

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. Other PSPs may choose to run an initial awareness meeting, to raise the profile of the exercise amongst key stakeholders before establishing a Steering Group, 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.

Practical involvement in the process (including chairing and facilitating meetings) usually reduces once the top 10 priorities have been agreed, although the Adviser may remain on hand to offer advice where needed. The PSP and JLA Adviser may wish to agree in advance at which point the Adviser's involvement is likely to end.

Chapter 4 - HOW TO ESTABLISH A PRIORITY SETTING PARTNERSHIP

Initial enquiry

The coordination of JLA Priority Setting Partnerships (PSPs) is managed by the JLA team at the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC), based at the University of Southampton. The JLA team manages enquiries about potential PSPs and then assesses their readiness to proceed. Once both parties feel confident that a PSP has the right expertise and infrastructure in place, the team will allocate a JLA Adviser to work with that PSP. The JLA Adviser then contracts directly with the PSP and JLA Adviser time is chargeable to the PSP once they start work.

The JLA team uses a readiness questionnaire in order to help people consider the areas important for setting up a PSP (for example financial and people resources, scope, patient and carer involvement, and which research funders the priorities will be aimed at). If you have plans in place to start a PSP and would like to see a copy of the readiness questionnaire, please email JLA@southampton.ac.uk.

Roles & responsibilities

The PSP lead

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 person has overall responsibility for successful delivery of the PSP and for making sure that the Steering Group follows the JLA Adviser's recommendations with regard to JLA priority setting methods. The PSP lead will work closely with the JLA Adviser and the PSP Project Coordinator. It is important that the PSP lead can engage and collaborate effectively with the Steering Group and all stakeholders involved. If the PSP lead is solely a researcher, they are not eligible to take part in the priority setting.

The PSP Steering Group

A PSP is led by a Steering Group.

The Steering Group coordinates the PSP and organises its activities. It must include representatives of patients and clinicians. 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 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 Steering Group is responsible for a number of tasks, including publicising the initiative, overseeing the checking and collating of uncertainties, and taking the final priorities to research funders. There are no set rules about how many people need to be on a PSP Steering Group. It is usually around 12 but may be larger or smaller. 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. It is usual for a Steering Group to meet either by teleconference or face to face on a monthly basis in order to keep momentum around the PSP and to maintain their relationship as a team.

What does the Steering Group commit to?

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. These stages include:

- publicising the initiative to potential partners
- publicising and participating in an initial awareness meeting
- participating in monthly Steering Group meetings/teleconferences
- developing and distributing information and forms to gather uncertainties
- collecting and collating uncertainties
- checking uncertainties against existing systematic reviews
- managing interim priority setting
- collating and aggregating interim prioritised uncertainties
- publicising and participating in the final priority setting exercise
- supplying the PSP's working spreadsheet of uncertainties and the prioritised list of uncertainties from the final workshop to the JLA, for publication on the JLA website
- publicising the final top 10 uncertainties to the research community
- developing research questions from the agreed priorities and working with research funders where necessary to provide any extra information they need.

Steering Group members should be prepared to approach and utilise their established contacts and networks. They will be individuals who are able to listen to, respect and incorporate into the process different perspectives. They will be committed to the principle of shared priority setting as well as the values of fairness and transparency. These values underpin the culture of the JLA priority setting process and are equally embedded in the JLA Adviser's approach. You can see more information about what is expected of a Steering Group in the Steering Group Terms of Reference document [here](#).

The Information Specialist

A PSP needs an Information Specialist, or someone with a relevant skill set, who can review and analyse the data collected, review existing evidence, and formulate potential research questions.

The importance of establishing how this will be managed cannot be over-emphasised. It is key to the success of the process. This is the work which will verify that the questions are true uncertainties, and will ensure the work of the PSP is credible and up-to-date. 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 may not be essential. If a PSP has difficulty in identifying the correct person for this role, the JLA team may be able to advise on finding a general Information Specialist. 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 where this is possible (questions which include the Patient/population, the Intervention, the Comparison and the Outcome – the advised minimum is the Patient/population and Intervention)
- Checking existing systematic reviews and guidelines or other evidence 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 the final prioritisation workshop
- Supplying the PSP's working spreadsheet of uncertainties and the prioritised list of uncertainties from the final workshop to the JLA, for publication on the JLA website
- 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
- Ability 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 health 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. The Steering Group will have overall responsibility for the delivery of this work and will need to agree how they will contract with the Information Specialist.

The PSP Project Coordinator

The Project Coordinator is responsible for the day-to-day running of the PSP. They will work closely with the Steering Group and are usually the main point of contact with the JLA Adviser. Tasks include organising Steering Group teleconferences and meetings, writing and following up on action notes, maintaining the PSP contacts database, managing communications with stakeholders and the wider community, organising the final workshop and being the first port of call for enquiries. The Coordinator may also get involved with preparing a website, using social media to publicise the PSP, producing and publicising the survey and downloading the survey results ready for the Information Specialist.

The amount of time this coordination takes should not be underestimated. Our experience tells us that this role could take a minimum of 1-2 days a week for the life of the project, with some periods being busier than others. PSP coordination roles can all be quite different and the time taken for the role also depends on things like the ability and willingness of the Steering Group to take on tasks, and how easy it is to find patient and clinician groups to communicate with. 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.

Ideally the administration and coordination of a PSP should be undertaken by one person or organisation on the Steering Group. The value of this vital role being held centrally and consistently throughout the process cannot be overstated.

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 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 the costs involved in running previous PSPs. Please email jla@southampton.ac.uk if you would like a copy. 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 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. Key costs are likely to be:

- JLA Adviser time
- PSP Project Coordinator time
- PSP Lead time
- Information Specialist time
- venue hire, refreshments and reimbursement of travel expenses for Steering Group meetings and final workshop
- website, communication and survey costs
- publications, reports or articles about findings and making these open access if possible.

How long does it take to run a PSP?

The time taken to run a PSP will vary depending on scope and resources. Normally the process will take between 12 and 18 months to complete. An example timetable from the **Alcohol-Related Liver Disease PSP** can be seen on the JLA website (www.jla.nihr.ac.uk) in the Key Documents on the page for that PSP.

Of course, following up on the research areas prioritised by a PSP with research funders and tracking what happens to research in the PSP area will be ongoing.

Chapter 5 - SETTING UP A PRIORITY SETTING PARTNERSHIP

Setting up the Steering Group

As set out on page 11, the Steering Group is made up of key organisations and individuals who collectively can represent all or the majority of issues related to the Priority Setting Partnership (PSP), either individually or through their networks. It is helpful if members of the Steering Group are from organisations with resources to offer to the process, such as funding, staff, time and expertise. The person who made the initial approach to the JLA will have thought about and started to prepare the following:

- a strategy for ensuring collaboration between patient, carer and clinician groups
- sources of funding to run the PSP
- resources to undertake the process of checking the uncertainties
- resources for the day-to-day running of the PSP
- the anticipated outcomes of the process, including plans for dissemination.

The Steering Group will work closely with the PSP Project Coordinator and the JLA Adviser. The Steering Group will typically meet on a monthly basis. This can be by teleconference although at certain points in the project a face to face meeting will be useful and it is always advisable to hold the initial meeting face to face to enable the group to build an effective working relationship. The JLA Adviser will chair the Steering Group meetings to ensure neutrality and transparency and adherence to the JLA process.

The Steering Group should check whether or not any members wish to remain anonymous and not be publicly identifiable as being involved in the PSP. This may mean ensuring some names are not included in public documentation or on the PSP website. There is a template form online at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm> to help with collecting consent to use personal details in publicity.

Steering Group Documentation

There are three important documents to tailor and complete when setting up a Steering Group:

1. The Steering Group **Terms of Reference**, which documents the background to the PSP and the Steering Group tasks and level of involvement
2. The **PSP Protocol**, which sets out the aims, objectives and methods of the PSP
3. A **Declaration of Interests** document, to be completed by each member of the Steering Group, to create a culture of transparency in the group and help the JLA Adviser manage potential bias.

Templates for all three of these documents can be found 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> .

Agreeing scope and protocol

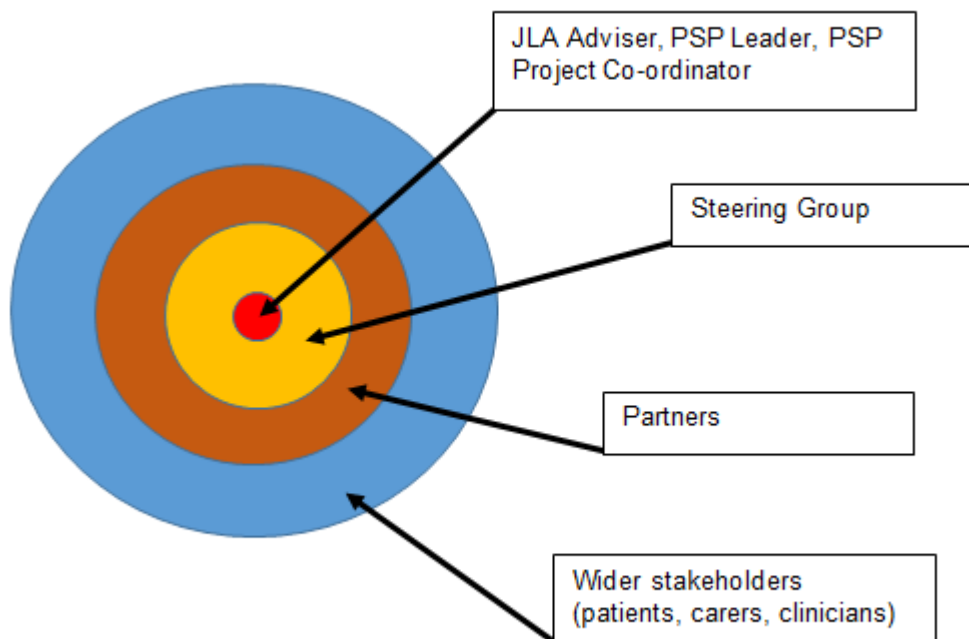
The Steering Group needs to define the PSP's scope. Scope may be defined by the patient population of interest (e.g. adults and or/children) or the breadth of the condition and the unique issues which sit within it. It may also be influenced by the size of the evidence base against which it will need to check its priorities. It is important to consider the resource implications of scope, before agreeing it. A PSP with a broad remit (such as the **Sight Loss and Vision PSP** or the **Palliative and end of life care PSP**) 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**). You can find more information about these PSPs online at www.jla.nihr.ac.uk.

A PSP with a broad remit is likely to 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. This extra time needed may have an impact on the costs of running the PSP.

The JLA website (www.jla.nihr.ac.uk) includes details of the current and completed PSPs, showing their scope and clinical areas. Details of PSP scopes are shown in their protocol documents (for examples see the Key Documents sections of the PSPs in Miscarriage, Mild to Moderate Hearing Loss, or Hair Loss on the JLA website). Many of the PSPs have published final reports which give an idea of how many initial uncertainties were gathered and how many people they came from. The main output of a JLA PSP has traditionally been a top 10 list of uncertainties that focus on treatment. It is recognised that many PSPs now extend their scope beyond identifying and prioritising treatment uncertainties and Steering Groups will need to agree how they will approach this. They should be aware that decisions around scope may have implications for both volume of data generated and adaptations to the method of evidence checking.

In addition, the Steering Group should consider what it will do if its survey generates topics that are outside the agreed scope of the PSP but that are nevertheless important. A transparent process will be needed for management and potential reporting of these. There may be organisations on the Steering Group which can use or communicate the 'out-of-scope' questions. Some PSPs have planned a second publication (in addition to one detailing the Top 10 and the process) which highlights the out-of-scope questions discovered. The Steering Group should also consider at the outset that a large amount of rich data and patient stories will come from the survey. Some PSPs have decided to produce a separate report from this data after the PSP process to ensure that important patient stories are not lost. It is important however that this extra work does not distract from the main purpose of the PSP.

Identifying and managing partners/stakeholders



The diagram above shows the range of people and organisations who are involved in PSPs. The JLA Adviser, the PSP Lead and the PSP Project Coordinator are central to the process. It is essential to reach out to partners and the patients, carers and clinicians affected by the health topic being considered.

Partners

It is important that all the organisations that can reach and advocate for patients, carers and clinicians should be invited to become involved in the PSP as partners. This helps PSPs to demonstrate that the process was inclusive and aimed to reach as wide a range of constituents as possible.

Partners should be organisations or interest groups which represent the following:

- people who have, have had, or are at risk of the health problem
- carers of those affected
- doctors, nurses and allied health professionals with experience of helping people with the health problem.

They may therefore include:

- charities or support groups focusing on patients or carers
- Royal College-related groups whose members' work involves helping people with the health problem
- other professional organisations involved in the care of people with the health problem.

The JLA process aims to enable people to participate whether they are interested in taking part in a workshop or would prefer to contribute anonymously or through a partner organisation.

Partners will be asked to confirm that they agree to support and uphold the principles of the PSP. They will be listed on the PSP website and will be asked to help spread the message about the PSP to their contacts. PSPs can maintain the interest and engagement of their partners by keeping in regular contact with them via newsletters or other communications.

An organisation's participation is likely to be encouraged if it is contacted by a known colleague, rather than approached 'cold'. An example of the partner information email sent to contacts of the **Alcohol-Related Liver Disease PSP** can be seen on the JLA website (www.jla.nihr.ac.uk) in the Key Documents section for that PSP.

Steering Group members should be prepared to approach and utilise their established contacts and networks, as well as reaching out to new ones. Example press releases from the **Pressure Ulcer PSP** publicising the project can be seen on the JLA website in the Key Documents section for that PSP.

Finally, a PSP can greatly benefit from the involvement of the relevant **Cochrane Review Group**.

Cochrane (www.cochrane.org) is a global independent network of researchers, professionals, patients, carers, and people interested in health. Cochrane contributors (37,000 from more than 130 countries) work together to produce credible, accessible health information that is free from commercial sponsorship and other conflicts of interest. Many of its contributors are world leaders in their fields - medicine, health policy, research methodology, or consumer advocacy - and its groups are situated in some of the world's most respected academic and medical institutions.

Cochrane's contributors are affiliated to the organisation through Cochrane groups: healthcare subject-related review groups, thematic networks, groups concerned with the methodology of systematic reviews, and regional centres.

Some of the uncertainties prioritised by a JLA PSP may result in new or updated Systematic Reviews of the evidence. Working with a Cochrane Review Group can be very helpful. Some financial support can be available for high priority reviews. Information about Cochrane Review Groups can be found at: www.cochrane.org/contact/review-groups.

The Cochrane Consumer Network (www.consumers.cochrane.org) is a network of patients, carers and others who may be able to contribute to the work of a PSP.

Initial awareness meeting

Some PSPs hold an initial awareness or launch meeting to raise the profile of the PSP among patient and clinician groups and to foster their interest and participation. While this meeting is not compulsory, and may be dependent on the resources available to the PSP, it can present the potential priority setting exercise to a wider audience. It is an opportunity to explain the notion of research priority setting, gauge interest, answer questions and secure involvement as partners.

Potential attendees are usually identified through the Steering Group members' networks and contacts.

While the format of the meeting may vary depending on the nature and number of attendees, the key elements to include on the agenda are:

- information about the JLA and its aims and achievements
 - context - how research is traditionally commissioned
 - what treatment uncertainties are
 - why the JLA process is significant
- how the Steering Group became involved
- prioritising treatment uncertainties
 - how priority setting works - the practical steps
 - potential outcomes of a priority setting process
- feedback, including how to access the relevant communities
- what happens next
 - how to join the PSP
 - commitment required of partners
 - timescales.

The format should also include time for questions and discussion.

Numbers permitting, it may also be helpful to break into small groups to discuss uncertainties in particular areas. These will have been identified in advance, and delegates will have indicated where their interests lie, to ensure everyone can participate in a discussion which is relevant to them. This will give people the opportunity to put their points across and serve as a rough indicator of the areas and focus of uncertainties which the PSP is likely to uncover. It will also ensure delegates begin to understand their practical role as partners within the JLA process.

Where constituent groups are spread out geographically, or where patients and carers may face challenges in attending a meeting, PSPs have found innovative solutions. For example, the **Stroke in Scotland PSP** ran a series of awareness-raising roadshows. They made their presentation available on the internet, in an accessible audio-visual format and they also provided an aphasia-friendly leaflet for those recovering from stroke. The **Sight Loss and Vision PSP** held an initial awareness meeting and made videos of the presentations available online for people who were unable to attend. These can be seen at www.sightlosspsp.org.uk/index.php/presentations

The **Mesothelioma PSP** held an initial awareness/launch meeting and videos from that meeting can be seen online at <http://www.nihr.ac.uk/research-and-impact/research/the-james-lind-alliance/mesothelioma-priority-setting-partnership/>. The agenda from the meeting and a copy of the form which asked participants how they would like to be involved in the PSP can both be seen on the JLA website in the Key Documents section for that PSP.

Managing the PSP

It is important to be sensitive to the varied capacity and individual support needs of those involved in the PSP. Some may be working on the issues full time, others may be working in a voluntary capacity, in addition to existing commitments.

Effective communication is key to ensuring people are both kept informed and able to participate fully. This can be guided by early discussions about partners' capacity and preferences for communication.

The JLA encourages everyone to work in a consultative and inclusive way. This ensures

that everyone is able to contribute to decision-making. PSPs should be transparent about how decisions are made.

It is also important that no one party or organisation is allowed to dominate the process, regardless of size or resource. Part of the JLA Adviser's role is to ensure the process is fair and inclusive. Partners should be made aware of this from the outset.

Appreciating values and perspectives

It is likely that groups and individuals in a PSP may have particular issues which they want the priority setting exercise to address. For some this may be intensely important to them on a personal level. A key role for the JLA Adviser is to encourage understanding of the differing perspectives of patients, carers and clinicians. No one group should feel marginalised or perceive that their views are less valid than any other, whether they speak as someone with the condition, as someone caring for another person with the condition or as a healthcare professional working with people with that condition. It is the JLA Adviser's role to ensure that this principle is maintained, and the responsibility of the Steering Group to model it.

Acknowledging this, it is essential to be clear about the distinction between:

- patients', carers' and clinicians' individual priorities, based on personal experience
- priorities which potentially have an impact on a larger group of people, and may reduce the collective burden of a health problem.

Everyone will have equal opportunities to submit their particular uncertainties. When it comes to priority-setting, however, participants are likely to have to relinquish personal agendas and work with priorities that will deliver benefit overall. It is important to ensure people are treated fairly and with sensitivity and support during this process.

Being open about how and why decisions are made will help to head off any concerns about fairness.

Steering Group members should encourage a culture of openness and feedback. In doing this, they should encourage people involved to raise any concerns at the earliest possible opportunity, so that they can be addressed. This can be done directly with the Steering Group, by talking to a JLA representative or by using meeting evaluation forms.

Communications

It is helpful for PSPs to create a communications plan which will apply throughout the process and particularly at the launch of the PSP, launch of the survey and announcement of results. This helps to make the best use of websites, social media, announcements, press releases, events and presentations.

For an example of a communications plan, please see the Key Documents section of the **Dementia PSP** on the JLA website at www.jla.nihr.ac.uk.

The JLA website contains links to individual PSP websites. These will range in size from a standalone site to a page or section on an existing website belonging to the charity or group initiating the PSP. The website will usually host a description of the project, a description of the Steering Group and supporters, a link to the survey, relevant updates and documents, and contacts. It is a place where results can be announced and stored and future updates of what has happened to the priorities can be published.

As well as a website, examples of other communications that PSPs have undertaken to keep people involved and informed at every stage of the process are:

- regular updates via email from the PSP Coordinator or Lead, or email/postal newsletters from organisations that are represented on the Steering Group. An example of a newsletter from the **Preterm Birth PSP** can be seen in the Key Documents section for that PSP on the JLA website
- articles for the JLA newsletter, see the archive of JLA newsletters at www.jla.nihr.ac.uk/news-and-publications
- social media updates using Twitter, Facebook or YouTube. For example: <https://twitter.com/PretermBirth> and <https://twitter.com/JLAPUP> and <https://twitter.com/JLAEMPSP> and a video from the **Emergency Medicine PSP** which can be seen on the JLA website at www.jla.nihr.ac.uk/priority-setting-partnerships/emergency-medicine

We encourage the use of the JLA brand in PSP communications and advice on using the JLA logo can be found at online at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/using-the-jla-logo.htm> .

It is important to ensure that information is relevant and accessible, written in plain English and suitable for anyone without medical or technical knowledge. Materials should be produced and distributed in formats which are accessible and appropriate to the audiences that a PSP wishes to engage with.

It is important that the Steering Group takes steps to retain the interest and engagement of the partner organisations throughout the process, especially during the stages when Partner input is not actively required, for example emailing them to let them know what is happening when the survey data is being analysed and checked against the evidence base.

Partners should be aware of how the work of a PSP will affect them, and be reminded that they are playing key roles in ensuring patients', carers' and clinicians' concerns become integrated into the research agenda. This will encourage them to continue to be actively engaged in the process and is important for priority setting but also at the next stage: raising research funders' awareness of the outcomes of the PSPs work.

Working with patients and carers

Patients, carers and the networks which represent them are diverse. Some will be accustomed to working in a professional environment and contributing to open debate. Others may be from smaller groups which are entirely dependent on volunteers and have very little funding. Individual involvement may be dependent on the nature of the patients' condition, as well as their age group.

Some PSPs work with patients who are vulnerable or at risk, such as adults with learning disabilities and children. The Steering Group should identify if there are potential safeguarding issues which might present themselves via the survey or during the prioritisation process, such as a survey respondent indicating that they are at risk of harm. The Steering Group should decide if they need a safeguarding policy. It may be possible to use an existing policy from an organisation within the Steering Group. This should be communicated to the Partners and to anyone handling the survey data.

INVOLVE has published some guidance specifically around involving children and young people in research at www.invo.org.uk/wp-content/uploads/2016/01/involvingcyp-tips-keyissues-January2016.pdf

It is important to identify the preferred methods of communication and involvement of patient and carer groups. While some will operate fully online, others may not use email. Even for those that do, the option of receiving paperwork through the post should always be offered.

Tips for inclusive communication and involvement include:

- Correspondence should be clear, concise and easy to understand
- Always include a named person and phone number, not just an email address, when providing contact details
- Offer to post copies of documents/attachments. Ensure these are formatted to allow space for forms to be filled out by hand if necessary. Allow freepost return if possible
- When providing paper copies of documents, give people the option of requesting them in large print or other accessible formats
- If requested, take time to talk people through any online tools over the phone which they may be using for the first time
- PSPs should always be willing to accept responses to anything (including formal consultations) in paper copy or in electronic formats or over the telephone. This will encourage response and ensure the process does not discriminate against people unable to use or unfamiliar with certain formats
- For meetings or workshops where places are allocated on a first-come-first-served basis, keep separate reservation lists for people responding online and by post
- Patients or patient organisations without financial resources may not be able to participate if they have financial limitations so payment for at least travel expenses may need to be built into the project at the planning stages. Guidance from INVOLVE on payment for patient and public involvement, including travel, can be found at www.invo.org.uk. It is important to make patients aware that receipt of payments from a PSP may affect any benefits they are in receipt of, and they should check how any payments will affect them
- Meetings and workshops should be organised with appropriate start/finish times to make participation as practical as possible for participants. There may be points that should be checked with participants such as a requirement for hearing loops or level access to meeting rooms, timings of their caring responsibilities, travel difficulties, telephone/virtual involvement in meetings where necessary or shorter meetings where participants with particular conditions would find that more comfortable.

Facilitators and chairs should ensure patients and carers have equal voices to those of clinicians in meetings and workshops. However, it is also important to recognise that the views of patients and carers may vary. Neither group should feel that their voice is more or less valid than the other's. The environment of any PSP meeting should be respectful. Taking extra time to support patients before, during and after meetings will ensure people are able to contribute equally and comfortably present their views, particularly because they may be talking about very personal issues.

Examples of support include:

- early provision of information and a pre-meeting telephone call if this would help
- opportunities to meet the chair and talk through the format of meetings beforehand
- evaluation forms on which patients and carers can comment on their experience, anonymously if preferred.

Many patient organisations will have a great deal of expertise and good practice experience of involving patients and carers. This should be shared across the PSP.

Further reading:

INVOLVE publications around good practice in public involvement, and guidance on the use of social media. See www.invo.org.uk

Working with clinicians

The clinical world is made up of established networks. Clinicians – health and social care professionals - will have good contacts which can be used to recruit partners.

Steering Group members should consider who they can influence to participate, and the best way to do this. Arranging brief one-to-one meetings with clinicians whose input is particularly wanted for the PSP is an effective way of securing their support. It is an opportunity to raise their awareness of the importance of the priority setting process and to explain the value of their contributions for influencing the research agenda.

It is important to give clinicians as much notice as possible about meetings and other arrangements. This will enable them to arrange for colleagues to cover their work commitments such as clinics. Clinicians working with the JLA have suggested that at least six to eight weeks' notice is required.

Consider whether or not meeting attendance could merit **CPD points**. Deaneries and medical schools can authorise a request for this. The JLA can support an application if required. PSP members may also be aware of similar points systems for other medical professionals at different grades.

Facilitators of meetings should ensure that clinicians are able to make contributions to the discussion equal to those of patients/carers. Sometimes there are high levels of dissatisfaction with available clinical treatments. It is important that sessions do not become a forum for criticising or berating those clinicians present. Equally, it is important that clinicians, who may be more used to speaking in an open forum, do not dominate the discussion at the expense of less confident members of the group.

It is also important to ensure that clinical diversity for the condition in question is taken into account when recruiting partners and inviting representatives to participate in prioritisation. For example, the **Schizophrenia PSP** ensured that a range of viewpoints were captured in prioritisation, including psychiatrists, psychologists, social workers and advice line staff.

Clinicians who have been involved in JLA PSPs to date have reported finding it very rewarding to be able to listen to patients' views outside of the normal consultation environment.

A clinician's account of being involved in the **Schizophrenia PSP** was published in *Nature* in June 2011. A copy is available in the PSP articles and publications section of the JLA website at www.jla.nihr.ac.uk/news-and-publications.

Chapter 6 - GATHERING UNCERTAINTIES

Uncertainties will usually come from four sources:

- patients
- carers
- clinicians
- existing guidelines and systematic reviews.

In the definition of 'patients', PSPs may wish to include those at risk. In 'carers', PSPs usually include wider family members/stakeholders (e.g. teachers) who may have a viewpoint.

PSPs should try to gather their uncertainties from as wide a range of potential contributors as possible. They must ensure patients are as confident and empowered as clinicians to submit their uncertainties about treatments.

This is usually done using surveys hosted on or linked to the PSP website, with paper formats available for those who are not able to contribute electronically. In some cases, people may be consulted face-to-face, for example through interviews or focus groups, if a survey is not an appropriate approach. Reaching patients does not need to be costly or time-consuming. Most patient organisations can use existing communication mechanisms, including newsletters, email networks and online message boards to help communicate the survey.

The **Intensive Care PSP** created a video to explain the PSP and promote the survey. You can see the video here <https://vimeo.com/72648172>

The **Emergency Medicine PSP** launched its survey at the Royal College of Emergency's annual conference in 2015. You can see the video at www.jla.nihr.ac.uk/priority-setting-partnerships/emergency-medicine.

While the JLA Adviser can offer guidance on gathering uncertainties, PSPs should use a method which is suited to their membership, resources and infrastructure.

Clinicians are requested to identify uncertainties which are immediately relevant to treating a patient with the particular health problem. They are asked to recall and share any issues which they have encountered during discussions or consultations between patients and those caring for them.

It is worth noting that this is not the same as recalling an area where research is lacking. What the JLA process is looking for is the uncertainty during a consultation where the doctor thinks "How am I going to treat this? I'm not sure. I wish I knew the answer."

A challenge for some clinicians may be admitting to clinical doubt. This is why it is important that respondents know that uncertainties which they raise will not be attributed to them as individuals, or their admission of uncertainty seen to reflect unfavourably on them.

Approaching the relevant Royal College for contact details of an individual or small group of people who can coordinate the dissemination of information is one way to gain access to a group of clinicians. Many Colleges have smaller committees or associated societies made up of clinicians with expertise in caring for people with a specific health problem. For example, for the **Urinary Incontinence PSP**, these included the British Society of

Urogynaecology within the Royal College of Obstetricians and Gynaecologists and the British Association of Urological Surgeons within the Royal College of Surgeons.

Also, groups which support people with a particular health problem will often have good relationships with interested clinicians and can provide contact details if required. As clinicians are often asked to participate in consultation exercises, it can be helpful if Steering Group members are willing to make personal contact with their networks of clinicians, to encourage participation by endorsing the process.

How many responses is enough?

Steering Group members should be mindful of the volume of responses that they can manage. Attracting a high number of respondents may seem desirable, but this can create problems if a PSP does not have the resources to process a high number of submitted uncertainties. In addition, it should be noted that this is a qualitative survey aimed at generating questions and themes: a high number of respondents may not necessarily result in more or better uncertainties and the range of themes needed may come from smaller numbers of responses. Some Steering Groups have taken active measures to ensure they receive a manageable number of responses while still consulting with a wide range of constituent groups. These measures include:

- placing a limit on the number of uncertainties each respondent can submit (for example limiting it to three or fewer)
- agreeing the maximum number of responses that can be processed and closing the survey on achieving that - it is advised that Steering Groups identify the range of constituent groups they want responses from, and that targeted communications are planned to ensure they are secured, rather than using solely mainstream routes of communication, which may generate a large but homogenous response
- agreeing in advance to stop the analysis once saturation point is reached and no new themes are emerging.

It is important for Steering Groups to be realistic about what their resources will allow. There is more information about how the **Autism PSP** managed potential numbers of responses in an article from the PSP dated 13 November 2015 in the news section of the JLA website at www.jla.nihr.ac.uk/news-and-publications .

Survey design

Most PSPs develop a survey questionnaire (electronic and paper-based) which partners distribute to their members and other interested parties. The Steering Group needs to consider how the survey can meet the needs of specific participants. This might include: those at a different stage of illness, such as acute or long term; or participants of a particular age, for example children or adults.

Examples of questionnaires used can be seen in the Key Documents sections of many of the PSPs on the JLA website including:

Anaesthesia and Perioperative Care PSP
Mesothelioma PSP
Parkinson's PSP
Eczema PSP

It is important to ensure that:

- information and surveys are clearly written, in language accessible to all, regardless of how familiar they are with medical terminology
- participation can take place electronically or by post (freepost if possible)
- responses are confidential.

The questionnaire will reflect the scope of a PSP and the answers that are required. Questions are usually deliberately open-ended to encourage full responses about the experience of patients, carers and clinicians. It is important that people who do not know about research feel comfortable contributing their ideas, hence the JLA does not suggest asking people for 'research questions'.

Surveys usually also ask for additional information about the respondents, such as age group, location and type of health professional. While the survey is open, this information helps the Steering Group to monitor the range of respondent types, and target their publicity towards any under-represented groups. Steering Groups should note that the collection of demographics is for this purpose only, and will not be part of the later analyses of the data. The number of demographic questions asked should therefore be kept to a minimum as too many can be off-putting. **Personal information needs be stored securely and the PSP is responsible for complying with the Data Protection Act.**

Survey duration

A survey deadline helps maintain the momentum of the project. Many PSPs have found that having a survey open for between two and three months has been sufficient time to generate enough responses to achieve saturation point, where no new themes are emerging.

A PSP may wish to forward survey responses to its Information Specialist weekly so that analysis can begin quickly.

As the Steering Group monitors the responses, it may decide to close the survey early or to extend the deadline, depending on the range of responses and the themes being secured. Where resources are scarce, a Steering Group may decide that it will close the survey once it reaches a maximum number of responses, rather than risk producing an overwhelming dataset.

During the survey period, it is important that the Steering Group continues its communications to promote the survey, using the methods it has decided on, for example, newsletters, Twitter and e-mails.

Consent and ethics

Participation in a JLA survey is anonymous and no personal data will be published. However some people, when responding to questionnaires, describe their uncertainties by telling a personal story. The survey must make it clear exactly what the data will be used for. Typically, a PSP must make it clear that people's uncertainties may be published anonymously. The Steering Group should consider early in the process whether they may want to use the data in any other ways later on. If this is likely, the group needs to consider how to make this clear to those completing the survey. The survey should either explicitly ask for consent, or make it clear that participation in the survey assumes consent.

When collecting and storing identifiable data about individuals there are legal requirements under the Data Protection Act. The organisation holding the data is responsible for complying with the Act.

The valuable contributions of the many un-named individuals deserve acknowledgement in reports. Naming partner organisations indicates the wide range of people contributing their ideas.

To see an example of wording which explains that participation in the survey automatically indicates consent for anonymous publication of questions, please see the **Cleft Lip and Palate PSP** survey, available in the Key Documents section of that PSP on the JLA website.

Although it is important to choose and apply priority setting methods ethically, **PSPs do not normally come under the remit of the NHS Research Ethics Service (NRES), where research priority setting has been seen as service evaluation and development.** The leaflet, *Defining Research* (<http://www.hra.nhs.uk/documents/2016/06/defining-research.pdf>), helps distinguish between how the NRES sees research, audit or service evaluation and public health surveillance.

Despite not requiring ethics approval, if PSP work is being undertaken within certain NHS settings, local R&D approvals may be required. Please check with the relevant NHS care organisation(s) what review arrangements or sources of advice apply to projects of this type.

If necessary, applications for permissions and approvals can be submitted through the Integrated Research Application System (IRAS): www.myresearchproject.org.uk

A decision tool is available on the HRA's website at www.hra-decisiontools.org.uk/research/ to help identify whether or not a study would be considered 'research' by the NHS.

A statement was developed by the National Research Ethics Service (NRES) and INVOLVE, to provide clarity and guidance on patient and public involvement in research and the requirements of research ethics review. <http://www.invo.org.uk/posttypepublication/public-involvement-in-research-and-research-ethics-committee-review/>

Ethics advice and approval may also be sought from within institutions hosting a PSP.

Searching existing literature

As well as uncertainties submitted by patients, carers and clinicians, documented sources of information need to be searched for evidence of uncertainty, as these may then be included in the prioritisation exercise. Steering Group members should decide who is best placed to carry out this task, in terms of time and expertise, for example, a member of the Steering Group or an Information Specialist contracted to carry out the work. (See the section on the role of the Information Specialist on page 12.)

Documented sources of uncertainties include question-answering services; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared; and registers of ongoing research. Other helpful sources may include patient helplines, online collections and resources like www.healthtalk.org and social media (for example Twitter hashtags). PSPs have gathered this information while using the literature to check whether survey-submitted uncertainties have already been answered or not.

Chapter 7 - DATA PROCESSING AND VERIFYING UNCERTAINTIES

The detailed steps involved in the data management for a Priority Setting Partnership (PSP) are summarised in a Data Management Guide contained in the Templates and useful documents section of the JLA website at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm> . The following paragraphs contain more detail.

Processing submitted uncertainties

To enable open access to the full list of uncertainties identified, PSPs need to ensure that, on completion of their priority setting exercise, uncertainties are published on the JLA website.

An Excel spreadsheet template is available from the Templates and useful documents section of the JLA website at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm> for PSPs to use to manage their data and the completed spreadsheet will be published on the JLA website once the PSP is ready to announce its results.

Uncertainties generally fall into four categories:

- individual uncertainties from patients, carers or clinicians
- indicative uncertainties formed by the PSP, reflecting those submitted by the above groups separately but which are similar to or duplicated
- uncertainties from treatment guidelines, research recommendations and systematic reviews – these may be gathered at the same time as the literature is consulted to verify the uncertainties submitted via the survey
- uncertainties being addressed by ongoing research as confirmed by relevant and reliable systematic reviews, in study protocols, or protocols for systematic reviews.

Uncertainties from patients, carers and clinicians collected via the survey can be numerous. The table below shows examples of the number of submissions received from some previous JLA survey respondents:

JLA PSP	Number of Survey respondents	Number of questions submitted
Autism	1,213	3,331
Bipolar	3,285	14,398
Dementia	1,563	4,116
Depression	3,000	10,000+
Diabetes (Type 1)	583	1,141
Lyme Disease	253	967
Multiple Sclerosis	507	1,084
Sight loss and vision	2,220	4,461
Stroke in Scotland	106	548
Vitiligo	461	1,427

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. There is a basic role description for the Information Specialist who performs this task in the Templates and useful documents section of the JLA website at <http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/about-psps.htm> .

Resources required for this task will vary depending on the number and type of submissions returned. Uncertainties can sometimes be more detailed than simple research recommendations. This phase of data management and checking can be complex and requires data management skills, critical appraisal skills, clinical knowledge and information retrieval skills.

As part of this process of verifying genuine uncertainties, two criteria must be met: (1) a measure of an uncertainty must be met, which is when a reported confidence interval in a systematic review crosses the line of no effect or line of unity, and (2) a clinician or person with relevant clinical knowledge must confirm that the outcome being reported as statistically significant in (1) is also clinically relevant.

It is essential to adopt a systematic approach to managing and processing the survey submissions in order to create a list of uncertainties for prioritisation, and for publication on the JLA website on the data spreadsheet provided by the JLA.

The suggested approach is divided into five stages.

1. Download the survey data
2. Remove out-of-scope submissions
3. Categorise eligible submissions
4. Format the submissions
5. Verify the uncertainties

We acknowledge that the JLA's data management process has evolved significantly, and while we have aimed to simplify it, we are conscious of the complex nature of the task. We welcome feedback on this section from those who are using, or have previously used, the Guidebook to inform their data management process.

Stage 1. Download the survey data

The data collected from the survey needs to be organised into an Excel file using the template provided by the JLA in the Templates and Useful documents section of the JLA website. This will include the suggested uncertainty and the type of submitter, including any background details collected. This will require data to be downloaded if collected online or entered manually if paper and telephone submissions have been gathered.

The dataset then needs to be cleaned and organised as detailed in the following steps:

- remove incomplete or blank rows
- where one respondent has submitted more than one uncertainty, ensure these are separated so there is one submission per row, always ensuring demographic data is copied across so the origins of each submission are retained
- anonymise the data by removing any personal details (ie name and address).

The Excel template will be supplied by the JLA and it is this completed template which will be shown on the JLA website at the end of the PSP. For an example of how PSP data will appear, please see the Mesothelioma Top 10 on the JLA website.

Stage 2. Remove out-of-scope submissions

The PSP's scope will have been defined in its Protocol. Scope may relate to the area of the disease, a particular type of patient (e.g. adults or children) or the type of uncertainties being addressed. PSPs should keep a separate record of submissions which are out of scope and ensure members of the Steering Group including patients, carers and clinicians and their representatives, are happy with the decisions taken about which questions are in or out of scope prior to any interim prioritisation.

Where submissions are out of scope, PSPs need to have decided what to do with them. Some PSPs have made arrangements with relevant organisations to pass them on. For example, the **Sight Loss and Vision PSP** agreed to send submissions better suited to social research to a partner organisation which was interested in addressing these. The **Dementia PSP** removed submissions which were not uncertainties, but were indicative of a need for better information sharing, and passed them to the Alzheimer's Society communications team.

Stage 3. Categorise eligible submissions

Once out-of-scope submissions have been identified and removed, PSPs may want to allocate the remaining submissions into categories, also known as a taxonomy. This is a helpful way to organise data in part to reveal instances of duplication. Essentially it is a qualitative, thematic analysis of the survey data. Developing a taxonomy (or using an existing one) can help PSPs to make their data more manageable by reducing the data into smaller, more manageable sections.

It is recommended that taxonomies from existing literature are used where possible, such as 'topics' used by Cochrane Systematic Review Groups or the UK Clinical Research Collaboration Health Research Classification System (www.ukcrc.org/research-coordination/health-research-classification-system/)

Some categories of treatment which may not be found in existing taxonomies, including diet, vitamins, complementary therapies and lifestyle, may need to be adapted and added to as the data is entered. It may be useful to consider stage of illness or age at diagnosis as additional methods of data organisation.

This categorisation process may identify further ineligible submissions, for example, topics better suited to social research, which can also be removed. As above, the person/people managing this stage of the process should keep a record of these and refer them back to the Steering Group.

Stage 4. Format the submissions

Submissions from patients, carers and clinicians may need to be rewritten or rephrased. This is to clarify the precise uncertainty, which may have been submitted with a lot of narrative text, to ensure consistency in the language used and to make it easier to check the question against the evidence base. Some PSPs have formatted each individual submission and then combined the duplicates. Others have created formatted indicative questions based on groups of similar or duplicate submissions.

PSPs may have to interpret what an intervention might be in a question, where the original submission did not indicate one. PSPs and the JLA Adviser should make best efforts to ensure that decisions made about interventions are transparent and fair. Any rewording should ensure that the language is accessible to a lay or non-medical audience but also accurate enough to engage clinicians and specialists. It is suggested that questions may be worded using the PICO format, which is described below. This process can be time consuming and labour intensive.

It is advised that this work is carried out by one or more individuals skilled in identifying systematic reviews and who have clinical knowledge, or by an Information Specialist. However, it is vital that Steering Group members are also offered opportunities to contribute to and comment on the process to ensure they are satisfied that the interpretation of the submissions is fair and neutral.

Rephrasing the submissions

Where possible, it is helpful to re-write submissions using the PICO format, to include:

- the Patient or Population
- the Intervention
- a Comparator or Control
- an Outcome.

It is important to note that not all the PICO variables will necessarily be available. The two most difficult variables to identify are the comparator and outcome.

The JLA also recognises that not all submissions are suitable for PICO structure, but PSPs should aim to ensure that the uncertainties are in a format that will ultimately be of value to the research community.

Combining duplicates

Duplicates and very similar submissions can be combined within one indicative uncertainty. Combining submissions can greatly reduce the volume of data that need to be checked for systematic reviews:

JLA PSPs	Number of submitted uncertainties	Number of verified uncertainties	Total after combining: indicatives
Ear Nose and Throat, Aspects of Balance	669	348	146
Eczema	1,070	718	65
Stroke in Scotland	548	386	226
Diabetes (Type 1)	1,141	890	650

This process is also likely to be repeated after the verification of uncertainties, and the removal of non-uncertainties, thus reducing the data further.

For example, in the **Asthma PSP** over 100 survey submissions asked about the side effects of both medication to 'relieve symptoms' and 'prevent symptoms developing' used in asthma treatment. These 100+ questions were made into two indicative questions:

- What are the adverse effects associated with long term use of short and long acting bronchodilators (medication to relieve symptoms); inhaled and oral steroids (medication to prevent symptoms developing); and combination and additive therapies (combinations of the two types of medication) in adults? (N.B this includes children aged 12 years old and over)
- What are the adverse effects associated with long term use of short and long acting bronchodilators; inhaled and oral steroids; and combination and additive therapies in children?

In the **Childhood Disability PSP**, the indicative question 'What is the safety and effectiveness of drugs compared to talking therapies (e.g. Cognitive Behavioural Therapy) to treat anxiety in children and young people with Autistic Spectrum Disorders?' came from the following originally submitted questions:

'Do medications aimed at reducing anxiety (and thereby aggression) work long term in children with severe autism? / Is the management of anxiety with medication in children beneficial and what are the side effects? / Long term impact and side effect of risperidone vs sertraline vs fluoxetine for associated anxiety, comparative effectiveness and long term side effects, is mono or multiple therapy best? / Which medication helps best for anxiety in autism / CBT is recognised as an effective treatment for ASD especially if it has been specifically modified for them. Why then can I not access this for my ASD children? / Use of CBT for repetitive behaviours in autism / What CBTs work in children with intellectual disabilities? / What is the evidence for CBT to treat anxiety in adolescents with autism?'

Combining survey submissions is an interpretative and sensitive process. It is important that the Steering Group can explain why a single submission may be better presented within an indicative question, but that it also communicates that the detail of the original questions will be retained. Combining is a pragmatic way of managing large datasets. For example, multiple submissions about the effects of specific foods or drinks (e.g. fruit, coffee, tea etc) on a given condition may be combined into a theme of 'diet'.

This process is more straightforward if submissions have been allocated to a taxonomy as outlined above. It is important to keep a record of the original submissions, so that their source (patient/carer, clinician, or both) and the frequency with which that particular uncertainty was submitted are documented. This detail can be discussed and taken into account at a later stage, when discussing the nature of the priorities with potential research funders.

It should be noted that patients, carers and clinicians, who are not researchers, do not usually formulate precise research questions. The JLA does not expect them to. Indicative questions capturing the themes and issues raised in the survey are more accessible to a non-research audience that needs to understand them in order to make priority setting decisions. The process of turning those themes into precise research questions is something the Steering Group is encouraged to work with funders and researchers on after the final workshop.

PSP Examples

The **Urinary Incontinence PSP** gathered a total of 519 submissions, of which 102 came from existing sources and 417 were submitted by partner organisations which had gathered them internally and from their members.

These were refined to remove duplicates and non-uncertainties, leaving a total of 226. Of these:

- 79 came solely from patients and carers
- 37 came solely from clinicians
- six were submitted by patients and clinicians simultaneously
- two were from patients and research recommendations
- 102 were derived solely from research recommendations

For the **Diabetes (Type 1) PSP**:

- 583 people submitted 1141 uncertainties
- 890 were true uncertainties
- 118 uncertainties came from research recommendations/literature
- Combining duplicates, there were 350 verified uncertainties.

Stage 5. Verify the uncertainties

Each uncertainty submitted, including indicative uncertainties of combined submissions as described above, needs to be verified as a true uncertainty. For example, some uncertainties may have already been addressed by research without all patients or clinicians being aware of this.

To check that an uncertainty is a true uncertainty, a search needs to be undertaken for relevant and reliable systematic reviews and guidelines, alongside any ongoing studies which might address the uncertainty. Large scale registry data may be available for the condition, which can be reviewed. PSPs which extend their scope beyond 'treatment uncertainties' may need to identify a different strategy for evidence checking, and this should be transparent and agreed with the Steering Group and JLA Adviser.

PSPs will already have agreed and noted in their Protocol who will be responsible for verifying uncertainties.

It is suggested that at the same time as verifying the submissions, uncertainties from research recommendations are recorded and added to the list of uncertainties for prioritisation.

Treatment uncertainties submitted by patients and clinicians are identified as true uncertainties by checking them against existing systematic reviews and guidelines. For each verified uncertainty, the source of verification should be cited (e.g. the systematic review identified as being relevant).

As a minimum, it is recommended that PSPs check the resources listed below to confirm whether or not a submission is an uncertainty:

- The Cochrane Database of Systematic Reviews
- NICE guidelines

- SIGN clinical guidelines
- Relevant Royal Colleges' guidance.

When checking an uncertainty against a systematic review, the review needs to be relevant and reliable. This can be measured by seeing if the authors follow a published methodology for undertaking the review, and if the methodology has made provision for managing bias. When looking at guidelines, the author needs to have made efforts to identify all relevant and reliable trials or systematic reviews. Reliability can be further ascertained from the confidence intervals around the main outcomes, enabling an informed reader to make an informed decision about the result. Narrative reviews, which do not give details or numerical results, may fail the requirements of relevance and reliability.

The Steering Group may wish to discuss how it wishes to approach grading of reliability of evidence. There are guidelines and ideas about this online, including at www.casp-uk.net/http://gradeing.cochrane.org/ or www.gradeworkinggroup.org/.

An uncertainty is deemed genuine when a reported confidence interval in a systematic review crosses the line of no effect (the line of unity). In addition to ascertaining statistical significance of an uncertainty, clinical significance needs to be checked by a clinician or person with relevant clinical knowledge who can confirm that the result obtained from investigating the uncertainty would be clinically relevant.

If a PSP finds that the number of systematic reviews which are relevant to its area is unmanageable within the constraints of its budget and timeframe, it may decide to create limitations. It should be transparent about these. The size of the evidence base is something to be aware of when setting out the scope for the PSP.

Finally, some apparent uncertainties can in fact be resolved with reference to existing research evidence – i.e. they are 'answered questions' and not uncertainties. If a question about treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. These findings may usefully inform future awareness-raising exercises and education programmes. Accordingly, the JLA recommends strongly that PSPs keep a record of these 'answerable questions' and deals with them separately from the 'true uncertainties' considered during the research priority setting process. The JLA suggests incorporating this commitment in the PSP's Protocol.

Identifying research recommendations

The searched systematic reviews and guidelines may contain research recommendations, indicating uncertainty. These may be reflected in the dataset already generated by the survey, or they may be unique. The Steering Group will need to decide whether or not the latter are appropriate to include in the dataset. Many PSPs have included them, so the questions can be considered at prioritisation. Some have chosen not include questions that are methodological or too technical and inaccessible to a non-research audience.

When deciding what goes forward for prioritisation, and the associated workload, the PSP's available resources will need to be taken into account. It may be that a Steering Group decides not to include all the identified research recommendations, if the number is going to overwhelm the questions generated by patients, carers and clinicians. Steering Groups should be transparent about their decision-making in their reporting.

Ongoing trials and studies

Some PSPs have considered the presence of ongoing trials and studies when searching the literature. An ongoing study may not mean that an uncertainty will definitely be addressed, and is therefore not worth prioritising. Indeed, the JLA uses systematic reviews to identify certainty or uncertainty, rather than single trials. However, identifying ongoing studies may help to avoid waste in research at a later stage by demonstrating that a priority may not need immediate action until a trial is complete and has reported its results. It is suggested that Steering Group members and the JLA Adviser discuss this and document any decisions made as a result of information found.

Preparing uncertainties for prioritisation and publication on the JLA website

To manage the data throughout the PSP process, please use the data management template supplied by the JLA which includes the **minimum** data fields to be collected. PSPs may choose to adapt the spreadsheet and add more fields, depending on how they wish to manage their data. For example, if a PSP has identified uncertainties from published research recommendations, then it may be helpful to list them and link to the research recommendation in an extra field.

Publication of the completed data template on the JLA website forms a publicly available record of the work of the PSP and allows researchers and funders to see the original data to help them understand what informed the indicative questions. It is an important part of the dissemination work of the PSP.

The following fields will need to be completed for every uncertainty:

- **Uncertainty**
This is the indicative uncertainty, formatted using the PICO question structure where possible. The advised minimum requirements are 'Population' and 'Intervention'
- **Original uncertainty**
This column will contain the original survey submission(s) which informed the indicative uncertainty. If a number of survey submissions have been combined to form the indicative uncertainty, they can all be listed here, separated by ~. This allows for transparency of interpretation, so the reader can see both what was originally submitted and the indicative uncertainty that was formed as a result
- **Evidence**
This column will contain the evidence checked to ensure that the uncertainty is unanswered. It should include reference to the most recent relevant systematic review identified by the PSP, plus a maximum of 2 other systematic reviews, including protocols for future systematic reviews, that the PSP considers relevant
- **Source of uncertainty**
This column will show what type of people submitted the question. If there are multiple sources, a PSP may wish to show them e.g. '1 x patient, 19 x clinician, 4 x research recommendations'.

For the uncertainties discussed at the final workshop (this is usually a maximum of 30), PSPs should show the following:

- **Final ranking** decided on at the workshop for each question

- **An explanatory note** for each uncertainty. This should be a plain language summary of up to 150 words, explaining the key points about what the uncertainty is and why it is important. PSPs may wish to include examples of the original survey submissions within the note.

Following the final workshop the PSP should:

- Update the data sheet to include any agreed changes made to the uncertainties during the final workshop (e.g. merging or rewording submissions)
- Ensure that the final ranking and explanatory note is included against all of the uncertainties discussed at the final workshop
- Send the completed data file to the JLA for publication on the JLA website.

Chapter 8 - INTERIM PRIORITY SETTING

An exercise to gather treatment uncertainties for prioritisation can yield a large amount of information. The most practical approach is to initially shortlist the uncertainties, in an interim priority setting exercise, and then to proceed to a final priority setting workshop.

The Steering Group should agree the number of questions that they think is appropriate to send to people in a survey for this interim priority setting exercise. The JLA Adviser can help with this decision. Generally, from experience, a maximum of around 80 questions is suggested, but depending on the nature of the stakeholder group being consulted, a Steering Group may decide that fewer, or even slightly more, will work.

Instructions for the survey should be very clear, and ideally piloted before dissemination. Instructions should note that respondents are not being asked to answer the questions (a common misunderstanding), but just to rank how important they think they are.

Clear presentation is important. It is advised that questions are arranged in categories, to give a sense of structure, and to make particularly large lists feel less overwhelming. Steering Groups may consider whether or not plain language explanations are added to each question, where it is difficult to make the question itself lay-friendly (e.g. due to unavoidable use of medical terms).

Capacity to process responses will be a key determinant of a PSP's approach to interim prioritisation.

Steering Groups are encouraged to use alternative means of consultation for interim prioritisation if a survey is not suitable for their particular patient and carer groups.

If the long list of questions is deemed too long, the JLA Adviser can help the Steering Group decide on a means of reducing it in a fair and transparent way. Some examples of criteria considered by Steering Groups in order to reduce a list of questions to a more manageable size for interim prioritisation include:

- Whether the question has been suggested by both patients and clinicians
- Whether the question has been suggested by a minimum of 'x' people
- Whether the question has been suggested by different kinds of professionals
- How many people overall have suggested the question
- Whether the question has been commonly expressed in other fora, such as patient helpline services
- Whether the question overlaps with one suggested by research recommendations.

Those asked to complete the interim prioritisation may include one or more of the following:

- Partner organisations
- original survey participants, if details have been collected for this purpose
- the general patient, carer and clinician communities – an open call akin to the original survey.

It is important that patients, carers and clinicians and the groups representing them participate. Interim priority setting can be conducted by email and/or post or online, depending on the communication preferences of the partner organisations and the capacity of the Steering Group.

The Steering Group may design an interim priority setting approach which they feel is appropriate for the communities they are targeting. Approaches already used by JLA PSPs include:

Choose and rank 10
<ul style="list-style-type: none"> • Participants are asked to consider the long list of questions, and then to choose and rank 10 of them. • This can be done via email and post, using a pro forma produced in Word, or online. • Each ranked question is given a score (rank 1 = 10 points, rank 10 = 1 point) and totals are tallied for each question, keeping patient, carer and clinician responses separate. • A rank order for each respondent group is calculated, and each question re-scored according to its position in the list (top ranking gains maximum points). The totals for each respondent group are added together to generate a combined ranking of all the questions.
Advantages <ul style="list-style-type: none"> • Participants have to make choices about the questions and enter into a process of priority setting, producing a genuine set of priorities. • The ranking materials can be produced easily and cost-effectively. • It also gets respondents into the frame of mind of ranking and choosing a top 10 in the final workshop.
Disadvantages <ul style="list-style-type: none"> • When carried out via email/post, can potentially generate a lot of data that needs to be manually entered into a spreadsheet. • Not all survey software allows for questions to be chosen then ranked. Alternative or upgraded software may be needed to do the exercise online, taking care not to create a page of questions that is overly-long or difficult to navigate.
Example <ul style="list-style-type: none"> • See example of the interim survey ranking form in the Key Documents section of the Childhood Disability PSP on the JLA website.

Choose 10
<ul style="list-style-type: none"> • Participants are given the long list of questions. They are then asked to choose 10, but not rank them. • This can be done using email/post, or online. • Each time a question is chosen, it is given one point. Separate tallies should be maintained for the different stakeholder groups, so the totals for each one are equally weighted when added together.
Advantages <ul style="list-style-type: none"> • Participants have an opportunity to consider the whole list, but must still make choices that involve them in genuine shortlisting. • May be suited to groups that find it hard to rank topics individually, for whom simply choosing 10 would be sufficiently challenging. • May also be useful for those PSPs where the number of questions sent for interim prioritisation is towards the upper end.
Disadvantages <ul style="list-style-type: none"> • When carried out via email/post, can potentially generate a lot of data that needs to be manually entered into a spreadsheet. • When done on SurveyMonkey, can result in a very long list that may be hard to digest online.
Example <ul style="list-style-type: none"> • See example of the interim survey in the Key Documents section of the Anaesthesia and Perioperative Care PSP on the JLA website.

<p>Likert scale</p> <ul style="list-style-type: none"> • Participants are asked to rate on a Likert scale how important they think each question in the long list is for research. • This is most easily done online. Questions' categories should be set up to be randomised, so as not to disadvantage questions at the end of the list. • Taking each respondent group separately, the score for each question can be calculated as an average score from the Likert scale, or as a total for all the scores for each question, within each respondent group. Once ranked in order, each groups' scores for each question can be added together, creating an overall ranked list of questions.
<p>Advantages</p> <ul style="list-style-type: none"> • When conducted predominantly online, this approach creates very little administrative burden. • Particularly suitable for participants who struggle with large amounts of data, or who have limited attention spans, as each question can be considered separately.
<p>Disadvantages</p> <ul style="list-style-type: none"> • There is a risk that people rate everything as important and do not think about relative importance or prioritisation. • This can result in very closely scored questions, with very marginal differences between them. • While this is a means of shortlisting, it is not a genuine prioritisation exercise.
<p>Examples</p> <ul style="list-style-type: none"> • See the example interim survey form in the Key Documents section of the Mesothelioma PSP and the MS PSP on the JLA website.

It is important to consider the respondents (and their possible health condition) in choosing the method, and to think about what it is reasonable to ask them to do.

Given the varied structures of different organisations, the JLA does not impose a strict method for this stage. It does however ask PSPs to note a detailed, transparent explanation of how they consulted on this and how rankings were agreed. It may be necessary to offer an alternative to returns by email, such as phoning in ranked uncertainties or postal returns.

Examples of interim priority setting

The **Mesothelioma PSP** listed 52 questions in the interim survey using SurveyMonkey, asking for respondents to indicate whether each one was:

'Not a priority' (scored 1)
 'Low priority' (scored 2),
 'Medium priority' (scored 3),
 'High priority' (scored 4),
 'Very high priority' (scored 5) or
 'Don't know' (scored 0).

Questions were grouped into sections (e.g. Chemotherapy, Surgery, Side effects) and the sections were randomised online so that groups of questions did not always appear in the same order. Scores were allocated to each of the answers, and the scores totalled for each type of respondent (patient, carers/families, healthcare professionals, or organisations). This allows questions to be ranked in order for all of the groups, weighting them equally, and then

finally to be given an overall ranking. Paper copies of the survey were supplied to those who preferred not to complete it online.

The **Stillbirth PSP** used the following criteria to help narrow down the large list of uncertainties received into a shorter more manageable list for interim prioritisation. It meant that questions proposed by one individual, or from only one group, would be prioritised lower than questions from several respondents from different disciplines.

1. Questions suggested by more than one group (e.g. parents, midwives, obstetricians etc)
2. Questions suggested by more than one group (ranked by number of individuals)
3. Question is within a topic area suggested by more than one individual (e.g. fetal movements)
4. Questions suggested in survey and guidelines.

The **Diabetes (Type 1) PSP** sent out a long list of 47 uncertainties, which the Steering Group had shortlisted from a much longer list, based on the original number of submissions. The interim prioritisation form which describes these, and asks partners to rank their interim top 10, is in the Key Documents section of the Diabetes (Type 1) PSP page on the JLA website.

The **Schizophrenia PSP** conducted its interim prioritisation exercise by email. Partners were asked to choose and rank their top 10 schizophrenia treatment uncertainties from a long list of 237, which was organised into a taxonomy agreed by the Steering Group.

Eleven partners responded either as individuals, on behalf of an organisation or having consulted with colleagues and/or members. The submitted rankings were collated. Separate running totals were recorded for patient, carer and clinician submissions. This enabled the Steering Group to examine each groups' rankings, as well as their combined ranking, which ultimately determined the make-up of the shortlist. This was provided as background information and was a useful discussion point at the final priority setting workshop.

A shortlist of 26 treatment uncertainties was developed as this was the logical cut-off point. This was sent out to partners to rank once again in advance of the final priority setting workshop.

Collating and scoring interim priorities

Completed interim prioritisation results should be grouped into patients and/or carers, and clinicians, and separate scores kept to ensure a fair weighting of the constituent groups. Some PSPs also score responses from organisations separately. Where people have been asked to choose and rank 10 questions, the most straightforward approach is to apply a reverse scoring system to each submission:

Rank	Score
1	10
2	9
3	8
4	7
5	6
6	5
7	4
8	3
9	2
10	1

The Steering Group should look at the totals for both patients/carers and clinicians, record these for future reference, and then rank them again and reverse score them as above. It is those ranked scores which are then combined, to work out the final interim prioritised list. This means that where a low number of patients, for example, has responded compared with clinicians, their scores will still be given equal weighting.

Submissions are only considered to have been submitted more than once if they have been received from different sources. In other words, if a single-issue organisation submits the same uncertainty multiple times, this can be noted but not counted towards prioritisation as it will bias the overall ranking.

Steering Group members will need to have agreed who will be responsible for coordinating, collating and listing the interim prioritised uncertainties.

This process is closely monitored by the JLA Adviser to ensure transparency and minimisation of bias.

The JLA Adviser will work with the Steering Group to agree how many of the interim prioritised questions to take to the final workshop. Generally this will be between 25 and 30 questions. It is important to consider the number of people who will be at the workshop and the ease with which they are likely to be able to review large numbers of questions on the day. There may be an obvious place in the list of questions to draw the line, for example, scores may drop off rapidly after priority number 26. There may be a particular reason for including questions which are on the margins, for example, a question may be about an important aspect of the condition or may have been particularly important to one group of respondents.

Chapter 9 - FINAL PRIORITY SETTING

Final priority setting principles

The final stage is to agree 10 prioritised uncertainties.

Generally final priority setting is conducted in a face-to-face workshop, using small and full group discussions.

The final workshop is an opportunity for different parties to express their views, hear different perspectives and to think more widely about treating or helping people with the health problem. While interim prioritisation involves more people, the responses gathered are based on individuals' or groups' particular opinions and experiences. Bringing people together in a workshop enables people to exchange knowledge and information, and make decisions based on a wider set of experiences. The workshop enables a group of people to agree on the Top 10 as they see it, on that day. A different set of people on a different day could give a different result. However, there is immense value in getting people together face to face to agree priorities.

The format is rigorous, but flexible enough to allow people to revise their opinions, raise concerns and correct through consensus any perceived imbalance emerging from the interim stage. This is the stage at which any concerns about fairness or representation can be openly discussed and addressed. The JLA actively encourages participants to take ownership of this debate.

There are challenges, such as:

- ensuring the choice of participants is balanced
- avoiding domination by any one person
- cost
- reaching consensus when there may have been disagreement.

The JLA's experience suggests that participants may want to debate or even dispute the shortlisted uncertainties, for example the wording, or whether or not any questions could be considered duplicates of each other. It is essential that the Steering Group is confident that it can defend the shortlist which goes to the final workshop. It is worth the Steering Group reflecting on the following questions:

- How confident are we that the questions will be understood?
- Is there scope for confusion?
- Are any of the questions too similar?
- Are there any which may be better combined into one question?

Reaching decisions with large groups of people can be challenging, but also exciting. The JLA is pragmatic about these challenges, which are not insurmountable, and encourages open debate and transparency when resolving them. Preparation and a well organised meeting are key to ensuring good outcomes.

Final priority setting approaches

The JLA supports an adapted Nominal Group Technique for PSPs choosing their top 10 priorities. One benefit of this technique is that it prevents the domination of discussion by a single person and encourages the participation of less assertive members.

Nominal Group Technique is a well-established and well-described approach to decision making. It can be used by groups that want to make decisions quickly, for example, by voting, but want everyone's opinions to be taken into account. Each participant reviews the items for discussion and gives their view. A shared voting or ranking exercise is undertaken with further structured small group discussions followed by ranking or voting. The ranked orders for each item from each contributor are totalled, and the priority with the lowest (i.e. most favoured) total ranking is selected as the top priority.

It has been suggested that this technique can be useful when:

- Some group members are much more vocal than others
- Some group members think better in silence
- There is concern about some members not participating
- The group does not easily generate many ideas
- All or some group members are new to the team
- The issue is controversial or there is heated conflict.

Overall, the JLA has developed a neutral style of facilitation, adopting a non-prescriptive approach to small group discussion about prioritisation, but maintaining the ranking approach across small groups. This helps to ensure that groups develop their own ways of working and make their decisions without being influenced by the JLA.

The JLA method for final workshops aims to prevent the domination of discussion by a single person and encourages the participation of less assertive group members.

The JLA Adviser facilitates the final priority setting process to ensure transparency, accountability and fairness. It is recommended that a JLA Adviser is used to facilitate each of the small groups.

It is important that patients, carers and clinicians can contribute equally. As such, membership of the small discussion groups should be determined in advance, to ensure an even mix of both groups.

Facilitators need to be aware that some patient and carer representatives may be less experienced than professional clinicians at contributing to open debate, and should therefore be careful to actively include patients and carers and ensure they have opportunities to share their views and experiences.

Information such as participant biographies and a clear structure for discussion and decision making must be sent to participants ahead of the workshop to help with this process. There is no hierarchy between the different participants; no one group's views or experiences are more valid than another's.

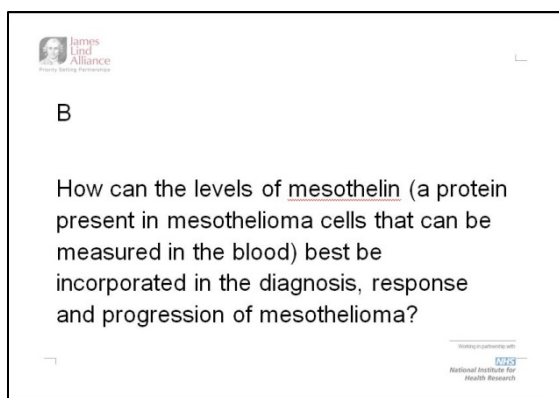
Preparing for the workshop

There are reports of PSP final workshops on the JLA website that describe how the meeting is organised. PSPs should aim to invite participants approximately eight weeks before the workshop, to allow people to make arrangements to be able to attend. Once participation has been agreed, the following should be prepared before the workshop, with guidance from the JLA Adviser:

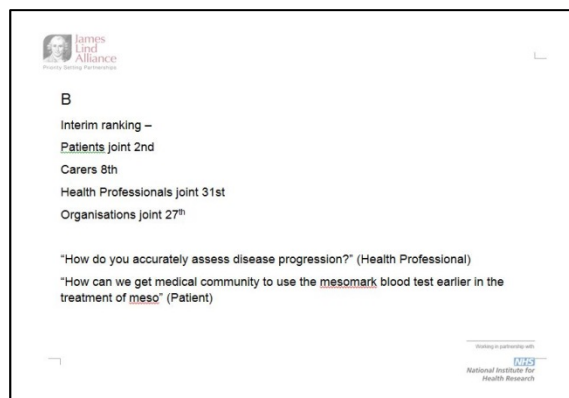
- A confirmation email, sent a month in advance, containing:
 - a Declaration of Interests form for participants, also requesting a short biography. This can also be done via an online form, perhaps using SurveyMonkey.
- A reminder email sent a week in advance, containing:
 - the workshop agenda (see the Key Documents section of the **Mesothelioma PSP** on the JLA website)
 - a plain language guide to the final workshop (see the Key Documents section of the **Anaesthesia and Perioperative Care PSP** on the JLA website)
 - a participant worksheet showing the short list of questions, with clear instructions for participants to rank the questions before the workshop and be prepared to discuss them on the day (see the Key Documents section of the **Mild to Moderate Hearing Loss PSP** on the JLA website). It is important to remind participants that these are the questions which have been chosen as important by 'real people'
 - a summary of workshop participants, informed by their biographical details (some people may feel more comfortable participating and less intimidated if they know some simple, friendly details about the participants beforehand)
 - clear directions to the venue
 - a glossary for participants if this is felt appropriate, although accessible language should be used throughout.
- A briefing paper for the facilitators (prepared by the JLA Adviser).
- Materials for the workshop
 - one set of cards per facilitator showing the questions to be discussed, printed double sided to include background information and data on the reverse to help with group discussions (see example below)
 - name badges (usually with just first and last names, rather than titles, to discourage any perceptions of hierarchy between the professionals and the patients)
 - allocation of participants to morning and afternoon small groups, pre-agreed with the JLA Adviser, ensuring a balance of patient, carer and clinician representation
 - ranking forms for each of the small groups, to be completed by the small group facilitators
 - travel expenses claim forms (ideally with freepost envelopes to return them in)
 - signs to use on the doors of meeting rooms
 - a workshop feedback form, to be either included in the delegate pack or sent later
 - spare participant worksheets and agendas.
- A draft 'thank you' email for use afterwards.

This is an example of an uncertainty card produced for the **Mesothelioma PSP** final workshop:

Front



Back



As with any meeting, it is important to make the right arrangements for an accessible meeting room that is located somewhere convenient for people to travel to, with breakout rooms for smaller group discussions. PSPs will need to consider payment of travel expenses and provide expenses claim forms on the day.

Final priority setting workshops typically start at 10am and finish at 4pm, so refreshments and lunch will need to be provided throughout.

Who should take part?

Those eligible to take part in a JLA priority setting workshop must have personal or professional experience of the condition in question:

- Patients or carers with direct experience of the health condition being discussed, or representatives from patient support groups, patient charities etc
- Clinicians – a balance of appropriate clinicians for the health condition being discussed e.g. specialist nurses, consultants or senior registrars, paediatricians, GPs, surgeons, physiotherapists, dieticians, advice line nurses, speech therapists etc.

It is recommended that a minimum of 12 people and a maximum of 30 are recruited.

When planning the workshop, the Steering Group should identify the types of professional and patient participants that should be present and aim to recruit a diverse range. However, the JLA considers achieving a balance of clinical and patient viewpoints more important than the representativeness of each participant. This is important, because most examples of priority setting show “*clinicians are more involved than patients in the whole process*”⁷. Participants are encouraged to share biographical information about themselves and their perspectives of the condition under discussion before the workshop in a Declaration of Interests document which is summarised and given to all workshop participants on the day.

Clinicians with research interests as part of their role may take part in the final priority setting workshop, as long as they also treat patients and are currently clinically active.

⁷ [Stewart R and Oliver S \(2008\) 'A systematic map of studies of patients' and clinicians' research priorities.'](#)
London: James Lind Alliance

Workshop process on the day

This section describes what happens in a standard JLA final priority setting meeting. The literature suggests that a nominal group meeting be facilitated either by an expert on the topic or a credible non-expert, and that the meeting should be structured as sequential steps of consensus building. The meeting is held in person, although the JLA has experience of including participants who have only been able to take part via Skype – this needs to be considered on a case by case basis.

The JLA offers transparency and fairness as guiding principles for PSPs. JLA Advisers have an important role in managing differences in values and perspectives at the workshop.

It is common practice for group discussions to follow 'ground rules' that participants have chosen together. These often include listening to and respecting other people's ideas, and sharing news of the event with other people but not ascribing individual names to specific statements. This last principle is known as the 'Chatham House Rule' (www.chathamhouse.org/about/chatham-house-rule).

Workshop phase 1: small group discussions

- In small groups (3 groups of up to 10 people – equal mix of patients, carers and clinicians), each participant, in turn, contributes their views on the treatment uncertainties they feel most and least strongly about. These are noted down by the facilitator. This continues until all ideas/views have been expressed.
- There the discussion is reviewed by the group to clarify any aspects of the uncertainties.

Workshop phase 2: first round of small group ranking

- The same small groups move the discussion to ranking the list of uncertainties.
- The facilitator will lay out the cards in rough groups: those which were thought to be most important, those thought to be least important and those not mentioned or where there was divergence of view.
- Participants are then invited to start discussing the ordering of the cards, with a view to ranking all of them in order. It is important that all small groups achieve a ranked order of all the uncertainties.
- Participants are also encouraged to take account of the contextual information on the back of the uncertainty cards – such as examples of original survey submissions and interim voting results.

Workshop phase 3: whole group review

- Each group's ranking is entered into an Excel spreadsheet, and a first combined (aggregate) ranked list is achieved at this point.
- The JLA Adviser chairing the meeting will present an overview of the results, usually after a lunch break. Questions, comments and concerns are discussed with the whole group present.
- Participants will then break into three new groups – with an equal balance of patients, carers and clinicians – to discuss and revise the combined ranked list.

Workshop phase 4: second round of small group ranking

- In the new groups, the facilitator should lay all the cards out in the aggregate order, although the discussion should focus more on the top 15 and any 'outliers' that participants feel strongly about. A full ranking must be done and recorded.



Workshop phase 5: final whole group review

- The small group scores are again entered into the Excel spreadsheet, and an aggregate ranking is presented to the whole group.
- The ranking is discussed in the large group, with the aim of agreeing the top 10 by the end of the discussion session. Some PSPs have also decided on more than 10 for the final list.
- This discussion is chaired by the JLA Adviser to ensure no one group or individual dominates the decision making. If consensus cannot be reached by discussion, decisions may be put to a vote.
- The top 10 questions are agreed.



Example Top 10

Below is an example of a top 10, which was published by the **Spinal Cord Injury PSP**. You can see all of the top 10s on the JLA website.

1. Does activity based rehabilitation, including functional electrical stimulation coupled with physical activity and hydrotherapy, improve outcomes such as muscle function and neuroplasticity after spinal cord injury?

2. Does stem cell therapy result in better outcomes after spinal cord injury and does this depend on the type of injury (e.g. acute or chronic; complete or incomplete)?
3. Does the provision of care packages in the community, including physiotherapy, after discharge from hospital improve the health and wellbeing of people living with spinal cord injury?
4. Which bladder management strategy is most effective in reducing the number of urinary tract infections and secondary complications that may result from these after spinal cord injury?
5. Does early mobilisation or a period of 4-6 weeks of physically active bed rest result in improved patient outcomes after surgical spinal column stabilisation?
6. Does discharge from a hospital to a physically enabling environment, including people and facilities which enable a person to become physically active, improve the quality of life of spinal cord injury patients?
7. Does the provision of specialist rehabilitation services, which includes multidisciplinary team planning, improve the health and wellbeing of spinal cord injury patients?
8. Do interventions including controlled fibre and fluid intake after spinal cord injury improve individuals' bowel function and quality of life?
9. What are the effects of ageing after spinal cord injury on the development of complications, including spasticity and bladder and bowel incontinence, and need for home-based support?
10. Does early diagnosis and treatment lead to improved outcomes for people with (a) cauda equina syndrome and (b) transverse myelitis (including relapses)?

Workshop best practice

- Establish a clear structure for the priority setting meeting and the 'taking turns' aspect of the feedback – this should help restrict any dominance of particular individuals.
- Agree 'ways of working' (ground rules) at the outset of the meeting (to include aspects of communication and use of jargon).
- Ensure everyone is aware of the nature of consensus decision making: it requires pragmatism and compromise.
- Provide biographical information about participants ahead of the meeting.
- Ensure that all participants are familiar with the items to be discussed – offer them an opportunity to discuss these beforehand with JLA team members or relevant partners.

It is not unusual for participants to suggest merging questions. While some suggestions may make sense, it may also be a means of creating more space in the top 10 for more topics. This risks creating questions which are overly broad and non-specific. It should be noted that most questions in the list will have been a result of merging survey responses already. However, suggestions for merging may also be made because participants can see a genuine duplication which the Steering Group has not previously noticed. The Steering

Group should agree its position on merging and enable the facilitators to manage that discussion consistently.

Similarly, participants may want to suggest ways to reword the questions. The JLA does not object to this if the rewording does not radically alter the question and all participants agree. It is up to the Steering Group to agree its position on this in advance of the meeting, so the facilitators can maintain that throughout the meeting.

Evaluation of the final workshop

Evaluating the workshop helps PSPs understand how the process has worked for them and to address any individual concerns. It can also create learning and good practice for future JLA PSPs. A feedback form may be included in the delegate pack for completion on the day. Alternatively, a short online feedback survey may be sent to participants when emailing them to thank them for attending. Some PSPs have produced short reports of their evaluations and have made them publicly available.

In the Key Documents section on the JLA website for the **Diabetes (Type 1) PSP** and the **Preterm Birth PSP** you can find examples of their final workshop reports.

Chapter 10 - DISSEMINATION AND PUBLISHING OF TOP 10

Agreeing a top 10 of research priorities is not the end of a Priority Setting Partnership's (PSP's) work. It is important for PSPs to publicise and disseminate the results of their priority setting exercise. This will increase the exposure of the priorities to potential funders and researchers. It is also an opportunity to promote the priority setting process itself.

Steering Groups may wish to create a dissemination plan for the results, considering how Steering Group members can contribute to the dissemination process. Dissemination at the end of the PSP should be a consideration throughout the PSP process in order to maximise its success.

Members of PSP Steering Groups will often have access to existing ways of communicating the results of the PSP. These could include:

- newsletters
- websites
- relationships with sector publications/journals
- relationships with funding charities
- presentations at conferences and workshops.

The Key Documents section of the **Multiple Sclerosis PSP** on the JLA website gives an example of how the PSP was publicised in the MS Society *Research Matters* magazine.

PSPs usually report on the whole process and methods, the people involved, the results, reflect on any lessons learned or limitations, and the next steps. It is important that these reports are written in language accessible to everyone with an interest in the condition, not just those who are medically trained.

Agreements about anonymity are important if there are to be formal evaluations and written reports. Any information kept about individuals needs to be held securely and with their permission. When reports are written, even if names are not to be included, descriptions of individuals also need to be unrecognisable. Although this means individual names are not associated with particular contributions, reports should acknowledge those who have given time and effort to the PSP.

There are a range of PSP final reports, of varying lengths, on the individual PSP pages of the JLA website. A plain English final report can be seen in the Key Documents section of the **Mesothelioma PSP** online. Two examples of larger final reports can be seen at www.sightlosspsp.org.uk/ and www.palliativecarepsp.org.uk/finalreport/

PSPs may also consider submitting an article about their work to an academic medical journal, such as the *British Medical Journal* or *The Lancet*.

- Go to <http://resources.bmj.com/bmj/authors> for advice on submitting an article to the British Medical Journal.
- Go to <http://www.thelancet.com/writing-for-the-lancet> for advice on submitting an article to The Lancet.

The **Mild to Moderate Hearing Loss PSP** had an article published in The Lancet. The **Parkinson's PSP** had an article published in the BMJ Open. The many articles which have

been published about PSPs can be seen on the JLA website at <http://www.jla.nihr.ac.uk/news-and-publications/psp-articles-and-publications.htm> .

The JLA actively encourages PSPs to keep us informed of any publicity generated by their priority setting activities. Please contact us to share this information on ila@soton.ac.uk.

Chapter 11 - TAKING PRIORITIES TO RESEARCH FUNDERS

The JLA process is designed to produce research priorities. Once the priorities have been agreed, the Steering Group should take responsibility for finding ways to disseminate them and identify potential opportunities for funded research. At this stage, the JLA Adviser's role is usually reduced, although they may be able to provide examples of dissemination activities from previous PSPs.

Top 10s vary in the way they are worded and presented. They contain questions and topics which matter to patients, carers and clinicians, articulated in terms which a wide audience can understand. However they are not usually finely-worded research questions that research funders can immediately work with. Further work is likely to be required by the Steering Group to turn the prioritised uncertainties into questions that fulfil a research funder's requirements. Some PSPs have created a sub-group of the Steering Group to take the lead on this work and to work in collaboration with funders and researchers to create researchable questions which address the topics raised by the PSP. This may involve going back to the original survey submissions to identify the interventions and outcomes which patients, carers and clinicians highlighted as important aspects of the questions.

PSPs can help to make research happen by promoting their priorities to key people:

- patients and carers
- research funders
- researchers and
- the wider research and policy community.

Finding appropriate research funders

PSPs seeking funders for their research priorities need to find those funders with an interest in: **particular health problems** or in the **effects of treatment**; and who have **funds** for a systematic review, a pilot study or a controlled trial or other relevant forms of research.

Funders of research addressing treatment uncertainties can be found in the public sector and the charitable sector, for example:

- The National Institute for Health Research (www.nihr.ac.uk)
- The Association for Medical Research Charities (www.amrc.org.uk)
- The Medical Research Council (www.mrc.ac.uk)

Finding out how funders work and targeting them with the research priorities which are within their remit is essential.

Some funding programmes set their priorities for research then advertise for research teams to conduct the research. These are **commissioning research programmes**. As an example, you can find information about NIHR calls for commissioned research at <http://www.nihr.ac.uk/funding-and-support/current-funding-opportunities/>

Whether or not research funders set priorities of their own, they may invite researchers to submit their own ideas for conducting research, and may then fund these ideas within their **responsive research programmes**. You can find information about NIHR responsive or 'researcher-led' funding opportunities at <http://www.nihr.ac.uk/funding-and-support/current->

[funding-opportunities/](#) The **Research Design Service** (www.rds.nihr.ac.uk) provides support to health and social care researchers across England to develop grant applications to the NIHR and other national peer-reviewed funding programmes. Its website gives information about the types of research funded by the NIHR research programmes and explains how researchers wishing to prepare grant applications can benefit from its specialist advice and support.

The NIHR Journals Library (<https://www.journalslibrary.nihr.ac.uk>) website provides a searchable archive of published research funded by the NIHR.

Other key information for research funders is:

- the health care setting in which treatments are used, and
- why this research or evidence is important to patients and clinicians.

The response required to a priority topic may be to commission a systematic review, or to update an existing one, rather than necessarily designing and doing primary research.

As well as identifying important questions, priority setting discussions may have identified important outcomes or measures for health research. For example, patients and clinicians have been involved in standardising outcomes for assessment in clinical trials on arthritis and fatigue is a recommended patient-centred outcome measure.⁸ As a result of patient input, fatigue is now one of the core set of recommended outcomes for assessing a range of treatments for rheumatoid arthritis.⁹

Finding appropriate researchers

If funding is to come from responsive research funders, a research team must be found to develop a proposal for one of the priority areas identified by the PSP. They might be found individually by searching the internet for research centres, university departments or medical schools.

Alternatively researchers may be found through their networks. Particularly appropriate for research addressing treatment uncertainties are:

- **The NIHR Clinical Research Networks** which coordinate and support research in a wide range of diseases and clinical need. More information can be found at <http://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/crn/> Clinical research networks provide researchers with a forum to discuss research. Each network has a clinical studies group to ensure it develops a balanced portfolio of high quality clinical research studies and has a route through which new studies can be developed. Each network also has a strategy for involving patients and the public.
- **The Cochrane Collaboration**, which aims to improve healthcare decision-making globally, through systematic reviews of the effects of healthcare interventions. More information can be found at www.cochrane.org. Where the need is not for a primary study, but for a systematic review, top 10 priorities may be of interest to the Cochrane

⁸ Tugwell P, Boers M, Brooks P, Simon L, Strand V, Idzerda L. OMERACT: An international initiative to improve outcome measurement in rheumatology. *Trials* 2007; 8(38)

⁹ Kirwan JR, Minnock P, Adebajo A, Bresnihan B, Choy E, de Wit M, Hazes M, Richards P, Saag K, Suarez-Almazor M, Wells G, Hewlett S. Patient perspective: fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. *J Rheumatol.* 2007 34 (5): 1174-7

Collaboration review groups. Patients and clinicians can work with experienced reviewers in preparing systematic reviews of the effects of treatment. They can also offer to help by commenting on reviews being prepared by other people. Contact details for all Cochrane review groups are available at www.cochrane.org/contact/review-groups

An example of working with the NIHR Health Technology Assessment (HTA) Programme (<http://www.nihr.ac.uk/funding-and-support/funding-for-research-studies/funding-programmes/health-technology-assessment/>)

PSPs have benefitted from contacting the NIHR's HTA Programme, via the JLA, to discuss which of their research priorities are in remit for funding from that programme and working together with the HTA team to create potentially fundable research questions. When working with PSPs, the HTA team has also identified areas of specific interest where it would be keen to fund more research, so that the PSP can focus on the questions from its priority list in these areas.

The purpose and remit of the HTA Programme is to deliver information about the effectiveness, costs and broader impact of healthcare treatments and tests for those who plan, provide or receive care in the NHS. Health technologies include all interventions used to promote health, prevent or treat disease, improve rehabilitation or long-term care including drugs, devices, procedures, settings of care and screening.

The core elements that the HTA Programme needs to identify (with help from the PSP if necessary) when creating research questions for potential commissioning are:

- **Population** (what is the population of interest?)
- **Intervention** (what are the interventions of interest?)
- **Comparison** (what are the comparisons of interest?)
- **Outcome** (what are the outcomes of interest?).

A good research question for the HTA Programme to consider is:

- Important to the NHS and its patients
- Supported by current evidence
- Of high scientific quality
- Feasible
- Timely (ie, research will continue to be relevant following completion of a study which may take many years to publish. It may be felt that changes in practice will overtake the results of any study which would therefore not be relevant by the time it is finished and published)
- Clear and well-defined (able to be worked into PICO format by researchers in collaboration with the PSP)
- Represents value for public money.

Stumbling blocks that the HTA Programme reports when working with suggested research questions from any source, including JLA PSPs, are:

- The challenge of questions that are either too broad, and therefore need more work to define what the most important component of the question is, or are already too specific
- The feasibility of answering the suggested research question
- Defining what current standard practice or care is

- Existing ongoing research, either in the NIHR portfolio or from other funders, which overlaps with the question, meaning that more research is unlikely to be funded at this moment in time
- The relative importance of the question compared to other disease areas.

There is [more information online](#) about the HTA Programme and other NIHR research funding programmes. Some other programmes work with and advertise much broader questions for commissioning than the HTA, focussing less on creating a PICO. You can also search the [NIHR Journals Library](#) for examples of research already funded in a PSP's area of interest.

Chapter 12 - FOLLOW UP

Following up with the JLA

After the final workshop, the JLA is keen to receive feedback from PSPs about their view of the process, methods, results and costs. PSP Leads are encouraged to complete a short feedback survey which they will receive from the JLA, and to pass it on to other members of the Steering Group where appropriate so that they can feed their comments back directly to the JLA. The survey provides an opportunity for PSPs to comment on the JLA process which will help to inform future development work for the JLA. The JLA team is keen to hear all views – good or bad.

PSP Leads are also asked to record basic statistics for the JLA. These include the number of survey responses, number of uncertainties received, and the number shortlisted for interim prioritisation. Having this information enables the JLA to better understand the detail of each priority setting process, and provide helpful information to prospective PSPs.

Long-term evaluation

The JLA recognises that assessing the value and impact of a PSP is challenging. It can take a significant amount of time to go from identification of a priority to starting funded research, and even longer for that research to report its outcomes. Tracking the outcomes of the priorities is also challenging as they may be taken up by any researcher across the world, who may not report back to the PSP.

The JLA is nevertheless interested in reflecting on what difference the PSP has made in the long term. It is interested in how PSPs can track the impact of their process in innovative ways. For example, the **Sight Loss and Vision PSP** reviewed the impact of their PSP one year after its completion and reported on funded research on the PSP website at www.sightlosspsp.org.uk/. Members of the **Childhood Disability PSP** team wrote a news item for the JLA website (see www.jla.nihr.ac.uk/news-and-publications dated 24 September 2015), just over a year after the PSP was completed, reviewing what had happened to some of the priorities identified. The Palliative and end of life care PSP also wrote an update one year after completion of the PSP, which can be seen in a news item on the JLA website dated 15 January 2016.

To help with tracking and reporting on what impact PSPs are having overall, it is useful for the JLA to know about funded research resulting from the work of a PSP. The JLA team will note NIHR research that they can identify as relating to a priority identified by a PSP. It will also be helpful to hear when research is recognised by the PSP as answering uncertainties it discovered and occasionally during the years following a PSP, the JLA may contact PSP Leads to ask for their feedback about impact

Chapter 13 - TOOLBOX OF KEY PRIORITY SETTING PARTNERSHIP DOCUMENTS

The following documents provide more useful information when planning a PSP. They are available from 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> . Please check the website for new templates and useful documents which have been added.

[Advice on using the JLA logo](#)

[Summary of Setting up a PSP](#)

[Flowchart of the PSP process](#)

[PSP Key Roles and Competencies](#)

Also available from the Templates and useful documents section of the website are the following templates which can be adapted for use by individual PSPs.

[PSP Protocol](#)

[PSP Steering Group Terms of Reference](#)

[Declaration of Interests Form](#)

[Agreement for use of personal details in publicity](#)

[Summary of involvement for patients in a PSP Steering Group](#)

[Timeline of PSP activities](#)

The following templates in the Templates and useful documents section of the website are particularly important when planning the data management of a PSP:

[PSP Data Management Guide](#)

[PSP Data Management template](#)

Examples of work done by previous PSPs

The Key Documents sections of many of the [individual PSPs](#) on the JLA website contain examples of the work they did. Amongst these are:

PSP Timetables – [Acne](#), [Alcohol-related Liver Disease](#), [Bipolar](#)

Initial awareness meeting agendas/invitations – [Cleft Lip and Palate](#), [Prostate Cancer](#), [Mesothelioma](#), [Diabetes \(Type 1\)](#)

First Steering Group meeting agenda – [Miscarriage](#)

Surveys – [Cleft Lip and Palate](#), [Eczema](#), [Ear, Nose and Throat – Aspects of Balance](#), [Prostate Cancer](#), [Diabetes \(Type 1\)](#), [Urinary Incontinence](#), [Vitiligo](#), [Mesothelioma](#), [Anaesthesia and Perioperative Care](#), [Parkinson's](#), [Cavernoma](#), [Sight Loss and Vision](#)

Survey information sheets/invitations to participate – [Diabetes \(Type 1\)](#), [Ear, Nose and Throat – Aspects of Balance](#)

Communications plans – [Dementia](#)

Promotional activities – [Dementia](#), [Eczema](#), [Pressure Ulcers](#), [Alcohol-related Liver Disease](#), [Sight Loss and Vision](#), [Bipolar](#), [Childhood Disability](#), [Emergency Medicine](#), [Inflammatory Bowel Disease](#), [Stillbirth](#)

Examples of combined questions – [Cleft Lip and Palate](#)

Interim surveys - [Cleft Lip and Palate](#), [Mesothelioma](#), [Diabetes \(Type 1\)](#), [Anaesthesia and Perioperative Care](#), [Multiple Sclerosis](#)

Final workshop agendas - [Schizophrenia](#), [Mesothelioma](#), [Vitiligo](#), [Stroke in Scotland](#), [Surgery for Common Shoulder Problems](#)

Final workshop question cards - [Cleft Lip and Palate](#), [Schizophrenia](#), [Vitiligo](#)

Final workshop reports – [Hip and Knee Replacement for Osteoarthritis](#), [Preterm Birth](#)

Reports of whole PSP process – [Lyme Disease](#), [Palliative and end of life care](#), [Sight Loss and Vision](#), [Stillbirth](#), [Tinnitus](#), [Mesothelioma](#)

Pre-workshop ranking forms - [Mild to Moderate Hearing Loss](#), [Surgery for Common Shoulder Problems](#)

Final workshop facilitators brief – [Vitiligo](#)

Final workshop group ranking form – [Vitiligo](#)

Final workshop individual ranking form - [Vitiligo](#)

These are examples of videos produced by PSPs

[Intensive Care PSP](#)

[Emergency Medicine PSP](#)

[Palliative and end of life care PSP](#)

These are examples of PSP Twitter feeds

<https://twitter.com/JLAEMPSP>

<https://twitter.com/PeolcPSP>

<https://twitter.com/JLAPUP>