The James Lind Alliance Guidebook

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Chapter 1 – INTRODUCTION

Welcome to the James Lind Alliance (JLA) Guidebook. The Guidebook is aimed at people interested in the JLA's priority setting process: namely, patients and their carers, clinicians and the organisations that represent them. It is a step-by-step guide 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 (or as they can sometimes be referred to 'evidence uncertainties') in specific conditions or areas of healthcare, for research, using JLA methods.

When the JLA was originally conceived, the term 'treatment uncertainties' was used to define the unanswered questions that are identified and prioritised in a PSP process. We now use the term 'evidence uncertainties' instead. This reflects the broader scope of many PSPs that include uncertainties around interventions that are beyond 'treatments', such as care, support and diagnosis. Some PSPs extend their scope further to include evidence uncertainties relating to cause or prognosis.

This change in terminology was an important development for the JLA, intended to reflect the changing health and care landscape and the evidence needed to support this landscape. The change was made following consultation with the wider community at a JLA stakeholder event in 2017.

Although the term 'evidence uncertainty' is used to describe unanswered questions in this Guidebook, each PSP may agree to use their own terminology in order to reflect the uncertainty within their setting or condition. The JLA simply requires transparency around how that terminology is defined and used.

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

> Examples from PSPs:
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> Some examples of how PSPs have approached parts of their work are highlighted throughout the Guidebook in boxes like this.

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 or evidence uncertainties that they agree are most important for research to address.

The National Institute for Health Research (NIHR – www.nihr.ac.uk) funds the infrastructure of the JLA to oversee the processes for PSPs, based within a small team at the Wessex Institute, University of Southampton. This includes the recruitment, training and supervision 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 PSPs.

The JLA team at the Wessex Institute, together with the JLA Advisers, oversees the JLA methodology as set out in this Guidebook. They also oversee the operational and day-to-day activity of the JLA. The JLA has an Advisory Group that provides ad hoc advice and

guidance to the JLA. The JLA Advisory Group is made up of people who have been involved in JLA PSPs and is a mix of patients, carers, health and care professionals, and researchers.

Acknowledgements

Chapter 2 – JAMES LIND ALLIANCE METHODS AND PRINCIPLES

Why involve patients and clinicians in setting research priorities?

People have suffered and died unnecessarily because uncertainties about the effects of treatments have not been addressed in research [1], [2], [3]. Patients and the public have a right to expect that research funders, researchers and health professionals will identify uncertainties about whether treatments or other interventions 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.

Historically, research on the effects of treatments has overlooked 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 can be a mismatch between the research being carried out and the research evidence needed by patients and clinicians every day [4],[5]. This also leads to an avoidable waste of precious research funds [6]. The JLA method was developed to address this.

Why the JLA method?

The JLA involves both patients and clinicians equally in setting priorities for research. The JLA method is designed to raise awareness of research questions that are of direct relevance and potential benefit to patients, their carers and the healthcare professionals who work with them, with the aim of leading to changes in the way research funding is granted. The method has been developed and refined since the completion of the first PSP, in Asthma, in 2007.

The optimum long-term outcome for any JLA PSP is that one or more of the uncertainties it identifies is turned into a research study, and that this goes on to have a life-changing impact on the treatments or services available to patients and the way in which these are delivered.

Focusing on specific conditions, or areas of health and social care, the JLA facilitates PSPs which:

- bring patient, carer and clinician groups together on an equal footing
- identify evidence uncertainties which are important to these groups

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[1] *Chalmers, I. 'Confronting therapeutic ignorance'. BMJ 2008;337:a841*

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

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

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

[5] *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*

[6] *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 2*

- work with these groups to jointly prioritise the uncertainties
- produce a 'Top 10' list of jointly agreed uncertainties as research questions to be presented to funders.

The JLA PSP process results in a Top 10. The aim of the Top 10 is to highlight important areas for research, but not necessarily to come up with the specific research questions. The Top 10 may include broader areas of importance where patients, carers and health professionals have agreed that there is a need for research. This informs researchers and research funders about priorities so that they can make their research as meaningful as possible to the people who need it.

At the outset of a PSP it is important to consider who the PSP wants to influence, the impact it hopes to make on the research and funding community and how this might be achieved. PSP Steering Groups need to consider the long-term ownership of the priorities and take responsibility for encouraging the research and funding community to address the priorities. Investing time at the outset to consider and agree who the priorities will be promoted to, how they will be developed into research, and how this long-term support for the priorities will be resourced is vital for the success of the PSP.

In 2019, Sally Crowe and Kristina Staley undertook a project to identify the most effective ways for JLA PSP priorities to influence the research agenda by evaluating the different approaches PSPs have taken. Their report *More than a Top 10: How James Lind Alliance Priority Setting Partnerships transform research, people and organisations* provides useful insight for anyone thinking of establishing a PSP, including examples of the practical steps that PSPs have taken to maximise their impact. You can see more about this here www.jla.nihr.ac.uk/news/sally-crowe-and-kristina-staley-reflect-on-their-recent-evaluation-of-jla-psps/22590. This published article also describes their work https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00210-9

A simple summary of the JLA PSP process is now available as an animated video at https://youtu.be/BGuTYf5iJQQ .

What is a Priority Setting Partnership?

The aim of PSPs is to bring patients, carers and clinicians together to jointly identify priorities for research. The JLA's current portfolio of PSPs is 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, carers and clinicians together to identify uncertainties or unanswered questions 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 and researchers, independently of the JLA.

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

- people with experience of the health area in question
- carers and families of those affected

- health and social care professionals working with patients and carers in the health area in question.

Who's who in the Priority Setting Partnership?

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

Partners: organisations and groups that advocate for or represent the interests of patients, carers or clinicians, which get involved in helping the PSP to promote its work to those groups.

Patients: individuals with experience of the health problem and those who represent them, including relatives and charities. Some PSPs use alternative words to describe this group such as 'service users' or 'people living with…'.

Carers: including informal and unpaid carers such as family members.

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

The scope, structure and aims of the PSP are set out in the Protocol document. There are many examples of PSP Protocols on the JLA website on the individual PSP pages at http://www.jla.nihr.ac.uk/priority-setting-partnerships/ including those for the Bleeding Disorders PSP, the Adult Social Work PSP, and the Diabetes (Type 2) PSP.

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 principles across JLA PSPs:

- equal involvement
- inclusivity
- transparency
- a commitment to using and contributing to the evidence base.

These principles are demonstrated in a set of features that help PSPs to ensure consistency and maximum learning:

- transparency of process, methods and interests
- balanced inclusion of patient, carer and clinician interests and perspectives
- exclusion of non-clinician researchers for voting purposes, although they may be involved and helpful in other aspects of the process

- exclusion of groups/organisations that have significant competing or commercial interests, for example pharmaceutical companies
- audit trail of original submitted uncertainties, to final prioritised list
- priority setting only commencing after the uncertainties have been formally verified as unanswered
- a recognition that making priority decisions does not create new knowledge but reviews existing evidence of uncertainty.

Each JLA PSP signs up to a protocol describing its process and intentions (see protocol template for each PSP to discuss and adapt 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 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.

Exclusions

Traditionally the health research agenda has been largely determined by the pharmaceutical industry and researchers themselves [7]. 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 by including those who don't already have a say in research.

The JLA does not invite representatives of the pharmaceutical industry, other commercial businesses, or those in the research community who are not also clinicians, patients or carers to take part in the priority setting process. These types of representatives might be perceived as having a vested interest in the outcomes of the process. They also have existing opportunities to influence the research agenda. It is recognised however that in some health areas, it is important to hear from commercial providers of services to patients and the NHS, e.g. high street pharmacists. In these cases, PSPs have worked with members of such organisations as part of the Steering Group but they have not taken part in priority setting. It is important that PSPs are transparent about these relationships in their PSP Protocol and Terms of Reference. The funding of JLA PSPs should not come directly from sources that may have a commercial interest in the outcomes.

Researchers may sit on the Steering Group if the group feels this is appropriate. Their experience is often useful when thinking about working with funders and other researchers to develop the final priorities into research questions. 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.

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

What are evidence uncertainties?

The JLA definition of an evidence uncertainty is that:

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

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.

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

The methods used by each PSP to check current and relevant evidence should be transparent, agreed with the PSP Steering Group and JLA Adviser, and clearly documented on the JLA's Question Verification Form. There is a template for the Question Verification Form 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 . A PSP's completed form should be published on the JLA website as soon as it is agreed, to ensure transparency about the PSP's scope and process. There is more information about evidence checking later in the Guidebook. You can see examples of what PSPs have published about their evidence checking at http://www.jla.nihr.ac.uk/documents/bleeding-disorders-psp-question-verification-form/24076 and http://www.jla.nihr.ac.uk/documents/anaesthesia-canada-question-verification-form/23647.

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

JLA Advisers

JLA Advisers are independent, self-employed facilitators who are recruited, trained, and supervised by the JLA. PSPs contract directly with them. 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. They are experienced in working with PSPs in the UK and internationally. The JLA Advisers guide PSPs through the JLA method and will also regularly update the JLA about the progress of the PSPs they are supporting.

JLA Advisers normally start working with a PSP when the first PSP Steering Group meeting is being set up. Some 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 independently chaired by a JLA Adviser throughout the 12-18-month priority setting work of the PSP.

Practical involvement of the JLA Advisers 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.

"The support of our JLA Adviser has been absolutely invaluable. We have been gently led through the process and having an experienced and, importantly, independent individual very much supports the transparent and equal way of working which is so crucial to the success of the PSP. Bringing expertise of what others have done, what worked well and what else we may want to consider in the context of our specialist area, has been particularly helpful."

From PSP feedback survey to the JLA

Chapter 3 - HOW TO ESTABLISH A PRIORITY SETTING PARTNERSHIP

Initial enquiry

The coordination of JLA Priority Setting Partnerships (PSPs) is managed by the JLA Secretariat team at the Wessex Institute, University of Southampton. The JLA Secretariat team manages enquiries about potential PSPs and then assesses their readiness to proceed. Once both parties are confident that a PSP has the right expertise and infrastructure in place, the JLA will allocate a JLA Adviser to work with that PSP. The self-employed JLA Adviser then contracts directly with the PSP. JLA Adviser time is chargeable to the PSP once they start work.

The JLA Secretariat team uses a readiness questionnaire to help people consider the areas important for setting up a PSP (for example financial and people resources, scope, patient and carer involvement, which research funders the priorities will be aimed at and how the PSP plans to engage with them). 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 following is a summary of the key competencies, tasks and responsibilities relating to roles within a JLA PSP. All PSPs are different, and therefore the resource needs may vary between PSPs, but the summary below provides an example of the typical roles required to successfully complete a PSP.

Role	Competencies	Example tasks	Average time needed over the 12-18-month priority setting work of the PSP
JLA Adviser	- Detailed knowledge of the priority setting process and the JLA Guidebook - Facilitation and chairing skills and experience - Public speaking skills - Negotiation sensitivity and ability to arbitrate in the absence of expert knowledge of the topic - Good communication and people skills, ability to recognise and manage the potential personal and political sensitivities of the topic	- Chair regular Steering Group meetings - Chair first awareness meeting - Provide ad hoc support in use of Guidebook - Provide support for data management process and interim priority setting exercise - Chair final priority setting workshop, with at least 2 other JLA Advisers to facilitate small group work - Ad hoc meetings/presentations - Liaise with other people working with the PSP	10 Days

PSP Lead	• Collaborative, in order to work effectively with all Steering Group members and the stakeholders of the PSP • Will take overall responsibility for successful delivery of the PSP, including securing the resources required to run the process, and for making sure that the Steering Group follows the JLA Adviser's recommendations regarding JLA priority setting methods • The institution where the lead of the PSP is based will have overall responsibility for all data protection laws, safeguarding and other legal requirements • Well-connected within the PSP's health area, or able to develop the right networks to encourage participation in the process and support for the PSP's outputs • An understanding of, and commitment to, partnership working between patients, carers and healthcare professionals • Able to communicate effectively with patients and carers, as well as health professionals	• Will work closely with the JLA Adviser the project administrator/ coordinator and the Steering Group to champion the PSP and ensure it is successfully promoted, completed, and disseminated to funders	Varies with time taken to set up and scope the PSP, organise funding, organise a Steering Group, and other tasks taken on by the leader throughout the project and after the priority setting work is complete
PSP Coordinator	• Good written and verbal communication skills, including the ability to communicate effectively with people from different backgrounds • Excellent organisational skills and ability to work to deadlines • Attention to detail • Collaborative and flexible • Partnership working with Steering Group members • Access to appropriate online surveying tools and skills • Social media use	• Organise Steering Group meetings, including producing agendas and related paperwork • Write and follow up on action notes • Manage communications with the Steering Group, stakeholders and the community • Prepare a website • Communicate via Twitter • Develop the questions/survey • Seek feedback from Steering Group and amend	A minimum of 1-2 days per week for the priority setting work of the PSP, depending on activities which fall into this role

		• Ability to present results clearly and succinctly	• Place survey online (potential additional software cost) • Pilot with small group of people and amend • Help to publicise the survey • Download the survey results ready for the information specialist to work on • Regularly report on results of survey to Steering Group • Coordinate interim survey stages • Organise the priority setting workshop, including participant recruitment and venue coordination	
Information Specialist	• Database management experience • Critical appraisal skills: comfortable with managing and categorising large amounts of qualitative data • Ability to carry out qualitative analysis of the categorised data to produce summary research questions • Experience of medical terminology • Attention to detail – methodical and organised • Able to work to deadlines • Ability to communicate complex data to 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		• Clean and organise the raw data from the initial PSP survey • Examine each submitted 'uncertainty' and allocate into categories with guidance from Steering Group • Format submissions into PICO format where possible • Liaise with the PSP Steering Group on work to identify relevant systematic reviews and guidelines, and any other relevant sources of evidence • Check the in-scope formatted questions against the evidence base, noting true uncertainties and questions that have already been answered • Prepare a long list of verified uncertainties for interim prioritisation • Provide regular updates of progress to the PSP project team and Steering Group and work within overall timescales agreed across the PSP	20 – 30 days. The precise amount of analysis will depend on the number of survey responses

The PSP Lead

All PSPs require good leadership and a considerable time commitment from the PSP lead who has overall responsibility for successful delivery of the PSP and for making sure that the Steering Group follows the JLA Adviser's recommendations regarding JLA priority setting methods. The PSP lead is usually the individual or representative of the group that made the initial approach to the JLA to carry out the PSP. The PSP lead needs to demonstrate commitment to the process, drive the PSP forward to completion and be able to generate stakeholder engagement and enthusiasm across the sector that the PSP will cover.

The PSP lead will work closely with the JLA Adviser, PSP Coordinator, and Information Specialist. It is important that the PSP lead can engage, motivate, 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 any voting on priorities throughout the process.

The organisation where the leader of the PSP is based has overall responsibility for the PSP and ultimate responsibility for the actions and behaviours of the PSP. It will be the responsibility of that organisation to ensure that the PSP complies with all necessary safeguarding, data protection laws and other legal requirements throughout the existence of the PSP.

The PSP Coordinator

The Coordinator is responsible for the day-to-day running of the PSP. He or she will work closely with the Steering Group and is usually the main point of contact with the JLA Adviser. Tasks include organising Steering Group meetings, writing and following up on action notes, maintaining the PSP contacts database, managing communications with stakeholders and the community, organising the priority setting 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. Typically, this involves a minimum of 1-2 days a week for the life of the project, with some periods being busier than others.

PSP coordination activities can vary and the time taken for these activities may also depend on the ability and willingness of members of the PSP Steering Group to take on tasks such as communicating with patient, carer and clinician groups, or focusing on social media.

Some larger PSPs have employed a Coordinator for this role, other smaller groups have been supported by someone already available in their own organisation.

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

The Information Specialist

A PSP needs to be able to manage data. This includes reviewing and sorting survey responses, reviewing existing research evidence, and formulating and presenting indicative (or 'summary') research questions. In some cases, one person has the skills to perform all the tasks; in other cases, more than one person is needed to share the task or to take on different aspects of it.

The importance of establishing how this will be managed cannot be over-emphasised. It is key to the success of the process and is one of the most time-consuming and technical roles in the PSP. This is the work that will turn the raw survey submissions into researchable questions and then verify that those questions are true uncertainties, thus ensuring that the work of the PSP is credible and up to date. A large amount of qualitative data needs to be managed and presented. Content knowledge in the subject area of the PSP is helpful. However, with good support from the Steering Group this may not be essential. Often, the leader of the PSP or other Steering Group members can identify the right person or people to do this work from within their existing networks. It is important that PSPs discuss the role requirements with their JLA Adviser when considering who this might be. Some PSPs have openly advertised for an Information Specialist. If a PSP has difficulty in identifying a suitable person for this role, the JLA team may be able to advise on finding people who have experience of this activity.

The tasks will involve:

- Cleaning the dataset of survey responses generated from the initial PSP survey to gather uncertainties
- Categorising the survey responses, then creating clear, formatted indicative (or summary) questions - or uncertainties which capture the meaning of the original submissions - and presenting these to the Steering Group for review and agreement
- Checking existing systematic reviews and guidelines or other evidence, to an agreed search strategy, to identify which questions have already been answered and to find any other research recommendations
- Checking for relevant ongoing studies
- Preparing a long list of indicative questions or 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 priority setting workshop
- Managing a record of all PSP survey data, traceable back to the original survey submissions
- Supplying the PSP's working spreadsheet of indicative questions or uncertainties and the prioritised list of indicative questions or uncertainties from the priority setting workshop to the JLA, for publication on the JLA website
- Providing regular updates of progress to the Steering Group, including enabling members to critique and have input to the analysis and development of the indicative questions
- Working within overall timescales agreed.

The activity will require the following:

- 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 information to patients, carers and clinicians, when working with the Steering Group and when formulating and agreeing indicative questions
- Familiarity with the JLA process would be helpful, but not essential
- Awareness of the PSP health area would be useful, but not essential.

The estimated number of days work for the Information Specialist for the life of the PSP is approximately 20-30 days. However the precise amount of analysis (and therefore cost to the PSP) will depend on the scope of the PSP, the number of survey responses, and the number of indicative questions to check against the evidence. This can be a complex piece of work and will need to be thoroughly supported by the Steering Group, which will have overall responsibility for the delivery and quality of this work.

The PSP Steering Group

PSPs need a committed and proactive Steering Group.

The Steering Group oversees the PSP, organises and completes its activities, and is ultimately accountable for key decisions made about the PSP. It will be made up of a mix of representatives of patients, carers 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, carer and clinician populations and access to networks of patients, carers and clinicians. It may be unrealistic for members of a Steering Group to be fully representative of all its stakeholders and communities. Nevertheless, members should be aware of those communities and be able to ensure the process is accessible to those groups.

It is important that Steering Group members have the time to commit to the work of the PSP both in Steering Group meetings and in between meetings. The PSP leader will need to facilitate good teamwork amongst the Steering Group so that everyone on the group is fully engaged in the PSP.

The Steering Group is responsible for several 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 often around 12 but may be larger or smaller. Too large and it becomes difficult to arrange and manage meetings, make decisions and enable meaningful input from everyone; too small and not all of the required people may be represented, and capacity will be limited. It is usual for a Steering Group to meet each month to keep momentum around the PSP and to maintain their relationship as a team.

It is important that the PSP is transparent about how Steering Group members were selected and their relevant experience that leads them to be able to represent the views of communities within the health condition or area of the PSP. It follows therefore that it may not be appropriate for a person to sit on more than one PSP Steering Group unless the PSP is certain that they have full and appropriate experience of that health condition or area. All Steering Group members will be asked to complete an Interests and Privacy form, as well as sign a Terms of Reference that includes a code of conduct.

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 and taking part in an initial awareness meeting if this happens (and if it happens after the Steering Group has been recruited)
- taking part in monthly Steering Group meetings
- publicising the PSP to potential partners
- developing the survey form, and other methods where necessary, to gather uncertainties
- disseminating and publicising the survey as widely as possible
- overseeing the analysis and interpretation of the survey data
- developing a strategy for searching existing research evidence to see whether suggested uncertainties have already been answered
- managing and helping promote interim priority setting
- agreeing the list of priorities to be discussed at the priority setting workshop
- publicising and helping to recruit to the priority setting workshop
- supplying the PSP's working spreadsheet of uncertainties and the prioritised list of all uncertainties from the priority setting workshop to the JLA for publication on the JLA website, with information about the numbers and types of people who responded to surveys and came to the priority setting workshop
- 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.

The PSP will rely on the Steering Group to advise on appropriate language, methods and inclusive engagement strategies to reach a diverse range of patients, carers and clinicians. Steering Group members should be prepared to approach and utilise their established contacts and networks to help promote the work of the PSP. They will be individuals who are able to listen to, respect and incorporate different perspectives into the process. 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 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 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.

You can see published examples at http://www.jla.nihr.ac.uk/documents/adult-social-work-psp-steering-group-terms-of-reference/23638 and http://www.jla.nihr.ac.uk/documents/bleeding-disorders-psp-steering-group-terms-of-reference/24225.

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 expertise and staffing resources that can be sourced from within the participating organisations. It is also important to consider the impact that the size and scope of the PSP will have on costs. As a guide, the JLA has a spreadsheet that shows examples of potential

costs, based on the costs experienced by previous PSPs. Please email
jla@southampton.ac.uk if you would like a copy.

All PSP costs need to be covered by the PSP budget. JLA PSPs must avoid being
influenced by parties with a commercial interest in their topic. This includes avoiding PSPs
being directly funded by a commercial organisation that could benefit commercially from the
results.

Funds may come from one main organisation or charity or smaller contributions may be
made by several partners in the PSP. If supporters of a 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 – the PSP contracts directly with the JLA Adviser for their time
- PSP Coordinator time
- PSP Leader's time
- Information Specialist time
- venue hire, refreshments and payment of travel expenses (and accommodation costs
  where necessary) for any face-to-face Steering Group meetings and the priority
  setting workshop
- payment of patients and carers for time spent on the Steering Group or at the priority
  setting workshop if this is offered
- website, communication and survey costs
- the cost of at least two further JLA Advisers at the priority setting workshop, in
  addition to the PSP's dedicated JLA Adviser, who will facilitate the breakout groups
  on that day
- publications, reports or articles about findings, and making these open access if
  possible
- other follow-up work to encourage uptake of the priorities amongst researchers and
  funders, for example follow-on workshops or conference presentations.

How long does a PSP take?

The time taken to run a PSP will vary depending on scope and resources. Typically, the
process will take 12 - 18 months to agree the priorities. One factor in this is the time it takes
to achieve meaningful engagement with patient, carer and clinician communities. It is also
unlikely that anyone will be working on the PSP full time with no other commitments to work
around. Speed and volume of response to the survey will also impact on the timetable. An
example timetable template that can be adapted by PSPs can be seen at
http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm.

A completed timetable from the **Alcohol-Related Liver Disease PSP** can be seen in the
Key Documents section of the JLA website for that PSP or at
http://www.jla.nihr.ac.uk/priority-setting-partnerships/alcohol-related-liver-
disease/downloads/Example-PSP-project-plan-from-Alcohol-related-Liver-Disesase-
PSP.pdf.

Of course, the timings above relate only to the process of identifying and agreeing the
priorities. The PSP will also need to spend time disseminating the priorities, translating them
into questions for researchers and funders to work with and undertaking broad engagement

with the research and funding community as well as tracking the impact of the priorities. This process can be ongoing and may take months and years.   PSPs should plan early for this activity. The report *More than a Top 10: How James Lind Alliance Priority Setting Partnerships transform research, people and organisations* provides some useful examples of how PSPs have done this. You can read more about that here www.jla.nihr.ac.uk/news/sally-crowe-and-kristina-staley-reflect-on-their-recent-evaluation-of-jla-psps/22590. This published article expands on that report https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-00210-9

Chapter 4 - SETTING UP A PRIORITY SETTING PARTNERSHIP

Setting up the Steering Group

The Steering Group is made up of key organisations and individuals who collectively can represent all or most issues related to the Priority Setting Partnership (PSP), either individually or through their networks. It is helpful if some 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 need to 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 against existing evidence
- resources for the day-to-day running of the PSP
- the anticipated outcomes of the process, including plans for dissemination and ongoing follow up.

The Steering Group will work closely with the PSP Coordinator and the JLA Adviser. The Steering Group will typically meet monthly. Meetings may be held remotely 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 (if feasible – see Chapter 8 for detail on the JLA's online workshop format, developed in response to the COVID-19 pandemic). The JLA Adviser will chair the Steering Group meetings to ensure neutrality, transparency and adherence to the JLA process.

The PSP Leader/Coordinator should check whether any Steering Group members wish to remain anonymous and not be publicly identifiable as being involved in the PSP. This may mean not including some names in public documentation or on the PSP website. The template Steering Group Interests and Privacy Form online at http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm will 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, the Steering Group tasks and level of involvement and describes a code of conduct.

2. The **PSP Protocol**, which sets out the aims, objectives, scope and methods of the PSP. This is an important document for the PSP and to ensure the PSP process is transparent, it should be published on the PSP website and the JLA website once agreed by the Steering Group.

3. A **Steering Group Interests and Privacy form**, 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 for PSPs to discuss and adapt 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 or health area and its unique issues. It may also be influenced by the size of the evidence base against which priorities will need to be checked. 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 **Depression PSP**) may take longer, require greater resource and incur more costs than a PSP which has a tighter remit (like the PSPs 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 gather more evidence uncertainties, which will increase the time needed to check and process these. A higher number of systematic reviews may be uncovered, so more time will be required to check the indicative questions against them and to extract the research recommendations for inclusion in the process. This extra time needed may have an impact on costs.

The JLA website at www.jla.nihr.ac.uk includes details of current and completed PSPs, showing their scope and health areas. Details of PSP scopes are shown in their protocol documents (for examples see the Key Documents sections of the PSPs in **Diabetes and Pregnancy**, **Anaesthesia (Canada)**, or **Digital Technology for Mental Health** on the JLA website). Many of the PSPs have published final reports that give an idea of how many initial uncertainties were gathered and how many people they came from. You can see PSP final reports here http://www.jla.nihr.ac.uk/psp-final-reports.htm. A table on page 44 also gives examples of the numbers of survey respondents and numbers of questions submitted to PSPs.

In the early years of the JLA, the main output of a JLA PSP was a top 10 list of uncertainties that focused on treatment. Over the years, many PSPs have extended their scope to a wider range of interventions beyond treatments. Steering Groups will need to agree how they will approach this for the condition and setting they are working in. They should be aware that decisions around scope might have implications for both volume of data generated and the method of evidence checking, as well as for the type of researchers and funders that will be interested in the final agreed priorities.

Out-of-scope, or 'answered' questions

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 are nevertheless important or topics that are shown to be already answered by research. A transparent process is needed for management and reporting of these. There may be organisations that can use or communicate the 'out-of-scope' or 'answered' questions. Some PSPs have prepared a second publication (in addition to one detailing the Top 10 and the process) which highlights the out-of-scope questions discovered. Others have listed out-of-scope questions as part of

the final PSP report. The Steering Group should also consider at the outset that a large amount of rich data and patient stories might come from the survey. Some PSPs have produced a separate report from this data after the PSP process to ensure that patient stories are not lost. It is important however that this extra work does not distract from the main purpose of the PSP, which is to gather and prioritise uncertainties that fall within remit.

When agreeing its scope, a Steering Group may want to consider the following:

- Are the patient, carer and professional groups clearly identifiable?
- Can the scope/topic be clearly communicated?
- Will it generate questions that can be prioritised against each other?
- What volume of data will it generate?
- How many systematic reviews and guidelines or other sources of evidence will need searching?
- What are the limitations and risks?
- What are the implications for personnel, resources and timetable?

Identifying and managing partners/stakeholders

Steering Group
Key organisations and individuals who collectively can represent all or the majority of issues related to the PSP

Partners
Organisations or interest groups that can reach and advocate for patients, carers and clinicians

JLA Adviser, PSP Leader, PSP Coordinator

Stakeholders
Patients, carers, health and social care professionals with experience in the area of the PSP

The diagram above shows the range of people and organisations who are involved in PSPs. The JLA Adviser, the PSP Leader and the PSP 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. While Steering Groups may not be able to be fully representative of their communities of interest, the Partnership can aim to be.

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

- people who have had experience of the health area in question
- carers and relatives of those affected
- health and social care professionals working with patients and carers in the health area in question.

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 condition
- other professional organisations and networks involved in the care of people with the health condition.

Partners will be approached to ask if they would like to support the PSP. With permission, they may 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. They may produce materials, guidance and templates to make is easy for Partners to promote the PSP to their networks.

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 information email sent to contacts of the **Alcohol-Related Liver Disease PSP** can be seen on the JLA website at http://www.jla.nihr.ac.uk/priority-setting-partnerships/ in the Key Documents section for that PSP or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/alcohol-related-liver-disease/downloads/ARLD-Partner-information-email.pdf . Steering Groups should be prepared to approach and utilise their established contacts and networks, as well as reaching out to new ones. An example press release from the **Diabetes and Pregnancy PSP** can be seen on the JLA website in the Key Documents section for that PSP or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/diabetes-and-pregnancy/downloads/Diabetes-and-Pregnancy-PSP-press-release.pdf. The **Occupational Therapy PSP** produced a wide range of resources to help people to promote the PSP which can be seen at http://www.jla.nihr.ac.uk/priority-setting-partnerships/occupational-therapy/.

Finally, a PSP can benefit greatly from the involvement of the relevant **Cochrane Review Group**, and other parts of Cochrane, both in terms of identifying relevant systematic reviews at the evidence checking stage, and for promoting the priorities that may require a systematic review.

Cochrane (www.cochrane.org) is an independent network of researchers, professionals, patients, carers, and people interested in health. Cochrane's 11,000 members and over 68,000 supporters come from more than 130 countries. They 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. Information about Cochrane Review Groups can be found at: www.cochrane.org/contact/review-groups.

Cochrane also works with a global community of patients and carers. This includes the Cochrane Consumer Network (www.consumers.cochrane.org) which is a network of patients, carers and others who may be able to contribute to the work of a PSP. You can contact the Cochrane Consumer Engagement Officer for a range of support in recruiting to PSPs and help promoting surveys to patient communities.

Cochrane has produced freely accessible learning resources called 'Cochrane Evidence Essentials'. The four co-produced learning modules are an introduction to evidence-based medicine, clinical trials, systematic reviews and how to find and understand Cochrane reviews. They may be valuable for those who are involved in research priority setting but who are new to these areas https://training.cochrane.org/essentials.

Initial awareness or scoping meeting

Some PSPs hold an initial awareness or launch meeting to raise the profile of the PSP among patient and clinician groups and to encourage their interest and participation. While this meeting is not essential and may be dependent on the resources available to the PSP, it can present the potential priority setting exercise to a wider audience. It can be helpful for topic areas that do not have established networks or communication channels. It is an opportunity to explain the idea of research priority setting, gauge interest, answer questions and secure involvement as partners. Some PSPs have also used this meeting as an opportunity to gather thoughts from stakeholders on the potential scope of the PSP, or even to identify potential Steering Group members.

This is also a useful opportunity for the PSP to consider what will happen once the Top 10 is agreed, how they will work with the priorities, which researchers and funders they are hoping to influence with the priorities and what impact they want to achieve.

Potential attendees are usually identified through the Steering Group members' networks and contacts, or through the PSP Lead's networks if the Steering Group has not yet been recruited.

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, process and outcomes
- why a PSP on this topic is relevant and important
- feedback, including anticipated challenges, opportunities and how to engage with relevant communities
- what happens next, including getting involved, commitment and 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 who the stakeholders of the PSP are and what its scope should be. These groups should be identified in advance and delegates should be asked to indicate where their interests lie, to ensure that everyone can take part in a discussion that 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 that the PSP is likely to uncover. It will also ensure delegates begin to understand their practical role as partners within the JLA process. Some PSPs make available videos and other materials from the awareness meeting for those unable to attend.

To save costs, it may be possible to run this kind of awareness or scoping meeting at an event that potential stakeholders are already attending. For example, the **International Liver Glycogen Storage Disease PSP** was initiated at the International Glycogen Storage Disease Conference in The Netherlands. There are examples of the launch meeting invitation and agenda for the **Occupational Therapy PSP** in the Key Documents section of the PSP on the JLA website at http://www.jla.nihr.ac.uk/priority-setting-partnerships/occupational-therapy/.

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 in the area full time, others may be working in a voluntary capacity, in addition to existing commitments.

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

The JLA encourages PSPs to work in a consultative and inclusive way. This ensures that everyone can contribute to decision-making. PSPs should be transparent about how decisions are made.

It is important that no one party or organisation dominates the process, regardless of size or resource. Part of the JLA Adviser's role is to ensure the process is fair and inclusive. All participants 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 that they want the priority setting exercise to address. For some this may be intensely important to them on a personal level or professionally. 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 others, 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. All members should be mindful of the implications of any existing clinical relationships between patient and clinician members.

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

- patients', carers' and clinicians' individual priorities, based on personal experience
- priorities that 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 own uncertainties using the initial survey. 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 as agreed by group consensus. 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 that will be used throughout the process and particularly at the launch of the PSP, launch of the surveys and announcement of results. This helps to make the best use of websites, social media, videos, press releases, events and presentations. It could include a list of organisations and individuals to be contacted, the names of the Steering Group members responsible for contacting them, and draft text to be used either in emails, social media, presentations or newsletters. It is worth considering whether there is an experienced communications person, either within the organisation leading the PSP or in an organisation represented on the Steering Group, who can offer some advice on how best to communicate the PSP activity, as effective communication is an important part of the success of a PSP.

> For an example of a communications or promotions plan, please see the Key Documents section of the **Detecting Cancer Early PSP**, the **Diabetes and Pregnancy PSP**, **Occupational Therapy PSP** and the **Dementia PSP** on the JLA website at http://www.jla.nihr.ac.uk/priority-setting-partnerships/. The **Epilepsy (Canada) PSP** used a Google document, shared amongst the Steering Group, to agree names and organisations that should be told about the PSP, who from the Steering Group would contact them, and then track what the response and outcome was.

Other considerations when planning and executing PSP communications may include:

- Defining the PSP image, including title, logo and hashtags
- Developing and maintaining a PSP website
- Developing promotional videos and multimedia material
- Devising and coordinating photo opportunities
- Sourcing and supporting events including conferences, open days, charity events
- Identifying opportunities to blog or contribute to newsletters
- Drafting media releases and case studies
- Developing accessible and easy-read materials.

It is likely that the Steering Group will be able to identify these opportunities and members would normally work with the PSP Lead and Coordinator to deliver them.

The JLA website contains links to individual PSP websites. Individual PSP websites range in size from a standalone site to a page or section on an existing website belonging to a

charity or group involved in the PSP. The PSP 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. Many PSPs choose to develop their own logo.

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
- news items and blog-style articles for the JLA website, see www.jla.nihr.ac.uk/news-and-publications
- social media updates using for example Twitter with appropriate hashtags or Facebook, podcasts or videos on YouTube. For example: https://twitter.com/HeartSurgeryPSP and https://twitter.com/TYAPSP 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.

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

It is important that the Steering Group retains the interest and engagement of the wider community throughout the process. This is especially important during the stages when input from the community is not actively required, for example emailing them or using social media to let them know what is happening when the survey data is being analysed and checked against the evidence base.

Partners in the PSP should 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. This is important for priority setting but also at the next stage: raising research funders' awareness of the outcomes of the PSP's work.

The Pediatric Cancer (Canada) PSP wrote about their experience of researching the best ways to use social media to boost responses to their survey. You can read this here https://www.jla.nihr.ac.uk/news/social-media-use-when-engaging-research-users-in-setting-the-priorities-for-research/26133

Working with patients and carers

Patients, carers and the networks that represent them are diverse. Some will be used to working in a professional environment and contributing to open debate. Others may be from smaller groups of volunteers that 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 that 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.

These are some examples of how PSPs have involved the voices of young people in Steering Groups:

- Holding meetings at times and in locations that fit with the young people's needs and schedules, taking school/college holidays into account
- Having a group of young people who rotate their attendance at Steering Group meetings
- Having a separate young people's advisory group who communicate about the PSP separately by their own chosen method, at a time that suits them, and then feed back into the main PSP Steering Group
- Deciding that videoconferencing is more inclusive for young people than teleconferencing
- Communicating with them outside of school/college time
- Recruiting Steering Group members whose organisations already work with young people, who can support and buddy with young people with whom they have an existing relationship, including liaising with their parents and, for example, meeting them off trains.

Key to the successful involvement of children and young people is having the time and resources to adapt how they work with the Steering Group. INVOLVE gives some guidance specifically around involving children and young people in research at https://www.invo.org.uk/wp-content/uploads/2019/10/Involving-children-and-young-people-as-advisors-in-research.pdf and has identified a series of articles about this at https://www.invo.org.uk/current-work/involving-children-and-young-people/articles-about-involving-and-engaging-children-and-young-people/

An evaluation of young people's involvement in the **Teenage and Young Adult Cancer PSP** has been published. It includes information about how the young people felt about their involvement, what worked well, and lessons learned. You can read it here http://www.twocanassociates.co.uk/wp-content/uploads/2020/05/An-evaluation-of-young-peoples-involvement-in-the-Teenage-and-Young-Adult-Cancer-JLA-PSP-May-2020.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 or social media. Even for those that do, the option of receiving paperwork through the post or talking on the phone 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 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, e.g. Easy Read
- If requested, take time to talk people through any online tools over the phone which they may be using for the first time
- Be prepared to send presentations and materials electronically in advance of meetings to people who have sight or hearing impairment, if requested
- Be prepared to support participants who are accessing meetings virtually, for example by offering to test any technology being used with them before the meeting
- 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 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 take part if they have financial limitations so payment for at least travel expenses, and possibly time (e.g. to go towards covering childcare costs or absence from work) may need to be built into the PSP budget at the planning stages. This may help a more diverse range of people to take part. Guidance from INVOLVE on payment for patient and public involvement, including travel, can be found at https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/. It is important to make patients aware that receipt of payments from a PSP (excluding refunds of expenses) 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 taking part 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. Steering Groups should think carefully about all practical requirements or sensitivities that they may need to plan for, to make sure that patients and carers can contribute fully to meetings.

Facilitators and chairs should ensure patients and carers have equal voices to those of clinicians in meetings and workshops. It is also important to recognise that the views of patients and the views of carers may differ. Neither group should feel that their voice is more or less valid than the other's is. The environment of any PSP meeting should be respectful.

Taking extra time to support patients before, during and after meetings will ensure they 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 in a suitable format and a pre-meeting telephone call if this would help
- a quiet space to take time out from the meeting if necessary and another member of the meeting prepared to offer support if needed
- 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.

The Cystic Fibrosis PSP wrote about the efforts they made to ensure people with Cystic Fibrosis were able to fully contribute to the PSP including involvement in the priority setting workshop, despite not being able to meet in person because of the risk of cross infection. You can read about it here
https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-019-0159-x
Further reading:
INVOLVE publications around good practice in public involvement. See www.invo.org.uk

Working with clinicians

The clinical world is made up of established networks. Health and social care professionals will have good contacts that 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 meeting attendance could merit **Continuing Professional Development (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 contribute to the discussion equally to patients and carers. Sometimes there are high levels of dissatisfaction with available clinical treatments. It is important that sessions do not become a forum for criticising 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.

Many different healthcare professionals may treat people with the condition in question, so it is important to ensure that clinical diversity for the condition is considered when recruiting partners and inviting representatives to participate in prioritisation. For example, the **Schizophrenia PSP** ensured that a range of viewpoints was captured in prioritisation, including psychiatrists, psychologists, social workers and advice line staff.

Clinicians who have been involved in JLA PSPs have reported finding it very rewarding to be able to listen to patients' views outside of the normal consultation environment. See http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/what-people-say.htm

Chapter 5 - GATHERING UNCERTAINTIES

Uncertainties will usually come from four sources:

- patients/service users with experience of the health or care area or setting
- carers
- clinicians
- existing guidelines and systematic reviews.

In the definition of 'patients', Priority Setting Partnerships (PSPs) may wish to include those at risk of the condition. In 'carers', PSPs usually include partners, relatives or other stakeholders who may have a viewpoint.

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

Uncertainties are typically gathered via an online survey 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 discussion groups, as well as via a survey. Reaching patients does not need to be costly or time-consuming. Most patient organisations can use existing communication mechanisms, including newsletters, meetings, email networks and online message boards to help communicate the survey.

Steering Group members should draw on their knowledge of the clinical area to work out who their target groups are, how to reach them, who might face barriers to involvement and how best to communicate. It is important to consider how to reach patients and carers where there is not a specific support group or charity through which a PSP might typically be able to engage people and promote the opportunity to participate (for example, the PSPs for Elbow Surgery, and Foot and Ankle Surgery).

The JLA Adviser can offer guidance on gathering uncertainties, but PSPs should draw on the knowledge and experience of their Steering Group members and use a method that is suited to their context, resources and infrastructure. While patients and carers are asked to share unanswered questions relating to their experience of a healthcare area (which could come from a problem or concern), clinicians are requested to identify uncertainties that are immediately relevant to treating a patient or delivering an intervention or service. They are asked to recall and share any issues or questions that 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. It is important that respondents know that uncertainties that 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 specific expertise. 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.

Groups that support people with a 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.

Here are some examples of how PSPs have promoted the survey and gathered responses:

The **Obstructive Sleep Apnea PSP** in Canada wrote an update for the JLA website about how they engaged with residents in the Saskatchewan province, which has a large number of rural and remote communities, as well as a number of Indigenous communities and two city centres to consider. Read that here https://www.jla.nihr.ac.uk/news/tailored-engagement-strategies-for-our-unique-landscape/24611

A news item from the **Digital Technology for Mental Health PSP** explains their methods of collecting responses, in addition to the online survey. Read that here http://www.jla.nihr.ac.uk/news/digital-technology-for-mental-health-reaching-out-to-people/9127.

A news item http://www.jla.nihr.ac.uk/news/utilising-your-resources-for-a-successful-priority-setting-partnership/10117 from the **Heart Surgery PSP** explains how they gathered responses.

The **Type 2 Diabetes PSP** created a video to explain the PSP and promote the survey. See the video here https://youtu.be/kkFx46eFNuU.

You can see a video from the **Occupational Therapy PSP** here https://youtu.be/Dn2ed3_AzyE. That PSP also produced guidance on how to have facilitated discussions to gather responses http://www.jla.nihr.ac.uk/priority-setting-partnerships/occupational-therapy/downloads/Occupational-Therapy-PSP-facilitated-discussion-guidance.pdf. You can read their update for the JLA website on reaching people with lived experience here https://www.jla.nihr.ac.uk/news/reaching-people-with-lived-experience-through-a-survey-lessons-from-the-occupational-therapy-psp/23510

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

The Chief Social Worker for Adults in England recorded videos about why it was important to contribute to the survey for the **Adult Social Work PSP**. You can see more here http://www.jla.nihr.ac.uk/priority-setting-partnerships/adult-social-work/. This PSP also made an easy read version of the survey http://www.jla.nihr.ac.uk/priority-setting-partnerships/adult-social-work/downloads/Adult-Social-Work-PSP-easy-read-survey.pdf.

At the planning stages, PSPs should consider how to reach out to relevant but often under-served groups who should ideally have a say in the research priorities. It is important to be clear about this at the budget planning stage as reaching out to these, particularly marginalised or vulnerable groups, may have cost implications.

Each PSP is different, but examples of groups that may be important in certain health areas could be:

- those whose first language is not English
- those who face cultural barriers to discussing certain health issues or research
- children and young people (thinking about the rules to consider when involving them in surveys, Steering Groups and workshops, and the different social media that they might use to communicate)
- anyone who might be excluded from online surveys due to lack of access or skills.

The Steering Group's knowledge of the communities it represents will be crucial in designing an effective outreach strategy.

"We adapted the process for our PSP and I do think these additions to the method helped us:

1. *For both the first survey and the interim survey we supplied paper and pencil versions to the outpatient clinics, and this resulted in a lot of response from people with lower education levels. On the online surveys the people with higher education levels were found to be overrepresented.*
2. *Young children under 15 years of age were underrepresented in the first survey as well, so in the first round we added two focus groups of young children (10-13 years old) on a meeting of the patient and parent organization in November 2018. The focus groups were organized and facilitated by someone very experienced in involving children in research. This resulted in about 90 questions that we added to the others.*
3. *For the interim survey, we added two prioritizing focus groups of young children (10-13 years old) on a meeting of the patient and parent organization in November 2019. Together, they formulated a Top 5. This was added to the Top 10s of patients, parents and clinicians. The Top 2 from the young children's focus group are part of the final Top 10. In the final discussion in the priority setting workshop, the fact that the children rated one question as highest, was an important argument for it re-entering the Top 10."*

Casper Schoemaker, Juvenile Idiopathic Arthritis (Netherlands) PSP.

For more information about the PSP see DOI: 10.21203/rs.3.rs-59431

https://www.researchgate.net/publication/346386040_Dutch_patients_caregivers_and_healthcare_professionals_generate_first_nationwide_research_agenda_for_juvenile_idiopathic_arthritis

PSPs should allow time to pilot the survey, including with seldom-heard groups. JLA Advisers rely on the PSP Steering Group to identify relevant groups and to advise on how to reach them. PSPs should however keep in mind what is reasonable, relevant and practical within their clinical area.

> *"in retrospect we probably should have planned to spend more time with some of the seldom heard groups who won't necessarily respond to an online questionnaire."*
>
> From PSP feedback survey to the JLA

The approach taken by the **Type 2 Diabetes PSP** to engage and involve people from Black, Asian and Minority Ethnic (BAME) groups is described in an article from the PSP in the news section of the JLA website at http://www.jla.nihr.ac.uk/news/making-sure-your-research-priorities-are-built-on-diversity/7641. A toolkit for increasing the participation of BAME groups in health and social care research can be found here http://arc-em.nihr.ac.uk/clahrcs-store/increasing-participation-black-asian-and-minority-ethnic-bame-groups-health-and-social. Many of the lessons in it are applicable to priority setting.

There are relevant resources on the INVOLVE website, including

http://www.invo.org.uk/posttypepublication/diversity-and-inclusion-what%E2%80%99s-it-about-and-why-is-it-important-for-public-involvement-in-research/

http://www.invo.org.uk/posttypepublication/strategies-for-diversity-and-inclusion-in-public-involvement/

http://www.invo.org.uk/wp-content/uploads/2014/11/9982-Social-Media-Guide-WEB.pdf

> *"I am conscious that people's experience differs depending on where they live – region by region and city contrasted with rural communities. It does concern me that research is often focused around cities and universities but to truly represent the priorities of the country we need to focus on strategies to reach out as far and wide as we can."*
>
> From PSP Steering Group member feedback survey to the JLA

How many responses is enough?

There is no recommended maximum or minimum number of responses. Survey responses from previous PSPs have varied from 100s to 1,000s. Steering Group members should be mindful of the volume of responses that they can manage and think about the response they would like and are likely to achieve knowing their clinical area and the numbers of patients and clinicians involved. 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. To put it into perspective, if 1,000 people take part in the survey

and submit around three questions or comments each, that will produce 3,000 lines of narrative data to assess.

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. When thinking about numbers of responses, PSPs should consider aiming for quality not quantity, whilst ensuring that there has been reasonable representation from the range of possible stakeholder groups.

It can be more effective to aim for a diverse range of respondent types by taking a targeted approach when promoting the survey, rather than simply looking for high numbers. Although of course if the numbers are too low, it may be difficult to say that they adequately represent a community's concerns. Some PSPs have created a target list of the groups of people they would ideally need to hear from. The PSP Steering Group needs to be confident that responses represent the community effectively, cover a broad range of issues, and are from a good balance of patients, carers and clinicians. If the range of topics in the submissions is too narrow, there could be important evidence gaps that are missing.

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 groups they want responses from, and that targeted communications are planned to ensure they reach those people, rather than using solely mainstream routes of communication, which may generate a large response but without hearing from some important groups
- agreeing in advance to stop the analysis once saturation point is reached (when no new themes are emerging).

It is important for Steering Groups to be realistic about what their resources will allow and to be transparent in their reporting at the end of the process about the limitations and challenges, as well as the successes of the project. There is more information about how the **Autism PSP** managed potential numbers of responses in an article from the PSP in the news section of the JLA website at http://www.jla.nihr.ac.uk/news/manageable-data-sets-and-equal-representation-from-a-diverse-community/3476

Survey design

Most PSPs develop a survey questionnaire (electronic and paper-based) to gather uncertainties. This is usually promoted widely by the PSP, including by partners distributing 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, or how it can meet the needs of both clinicians and patients.

Examples of questionnaires used can be seen in the Key Documents sections of many of the PSPs on the JLA website at http://www.jla.nihr.ac.uk/priority-setting-partnerships/ including for the **Anaesthesia and Perioperative Care PSP**, **Heart Failure PSP**, **Parkinson's PSP**, **Post Mastectomy Breast Reconstruction (Canada) PSP, Adult Social Work PSP, Broken Bones in Older People PSP**, **Physiotherapy PSP, Stroke 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
- time is allowed for members of the Steering Group to pilot the survey with a small number of patient and clinician contacts, to check whether potential respondents would understand what they need to do just by reading the instructions (without help from the people arranging to pilot the survey).

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' but that they are simply encouraged to write about what is important to them.

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 demographic information from respondents is for this purpose only and will not be part of the later analysis of the data. The number of demographic questions asked should therefore be kept to a minimum as too many can be off-putting. Surveys may also ask respondents whether they are interested in taking part in the prioritisation stages of the PSP by either completing the interim survey or potentially taking part in the priority setting workshop. **Personal information needs be stored securely, and the PSP is responsible for complying with data protection regulations.** You can see a privacy notice created by the **Heart Surgery PSP** to make it clear what would happen with data in the Key Documents section of the PSP on the JLA website or here http://www.jla.nihr.ac.uk/priority-setting-partnerships/heart-surgery/downloads/Heart-Surgery-PSP-privacy-notice.pdf.

Translation of surveys may be one way of accessing diverse communities. In practice however, few JLA PSPs have used this as a method. A more pragmatic solution may be to work with key members of communities, through existing networks, including the community and voluntary sector organisations, to understand the best way of reaching people and mechanisms available to do that. These may include a talk at an existing meeting, or place of worship, or a session on the local radio station.

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 download and forward its survey responses to its Information Specialist weekly so that the cleaning and categorisation of the data can begin early while the survey is still live.

As the Steering Group monitors the responses and targets any under-represented groups, it may decide to close the survey early or to extend the deadline, depending on the range of responses and the themes being identified. 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, social media and e-mails. Regular updates to the Steering Group on the demographic profile of the respondents will help to inform and target this ongoing publicity.

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 questionnaire must make it clear exactly what the data will be used for. This may include the publication of the uncertainties on the JLA website and, potentially, the use of the data in the PSP's final report and dissemination materials. PSPs that have a plan for processing their out-of-scope or 'answered' questions may also want to make it clear who that data will be passed on to.

A PSP must make it clear that people's uncertainties may be published anonymously and that questions which fall outside the scope of the PSP may be reported on anonymously to other organisations. The Steering Group should consider early in the process whether they might want to use the data in any other ways later. If this is likely, the group needs to consider how to make this clear to those completing the survey. The survey should either ask explicitly 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. The organisation holding the data is responsible for complying with data protection legislation.

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 that explains that participation in the survey automatically indicates consent for anonymous publication of questions, please see the **Autism PSP** survey, available in the Key Documents section of that PSP on the JLA website or here http://www.jla.nihr.ac.uk/priority-setting-partnerships/autism/downloads/Autsim-PSP-initial-survey.pdf.

Although it is important to choose and apply priority setting methods ethically, PSPs do not normally come under the remit of Health Research Authority (HRA) approvals, where

research priority setting is seen as service evaluation and development. More information is available from the HRA here https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/ along with a decision tool to help identify whether or not a study would be considered 'research' by the NHS. It may be helpful for PSPs to record evidence of having used the HRA decision tool to identify whether the work is research, in case of later queries.

Despite not normally requiring ethics approval, if PSP work is being done within certain NHS settings, local Research and Development department 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 statement was developed by the HRA 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.

For PSPs working outside of the UK, Steering Groups should check the ethical approvals required for that country.

> *"Applying for and receiving ethics approval is a key part of the PSP process in Canada (it isn't required in the UK). Approval is typically required for any initiative that involves consulting with the broader community, but it also provides oversight and facilitates the publication of study results in scientific journals. Depending on the affiliations of the lead investigator, organizations will have the option to apply either to an institutional Research Ethics Board (REB) at a hospital or university, or a community-based ethics board. Receiving approval may take several months depending on the workload of the Board and their understanding of the project so you will need to plan accordingly. A high level of detail is required for the application, so be prepared to provide information about how participants will be recruited, how participant anonymity will be preserved, how data will be stored, how inclusiveness will be ensured in your survey population, etc.*
>
> *Our main recommendation would be to budget more time than you think is necessary to receive approval, and start this process as soon as possible to avoid delaying the PSP timeline."*
>
> Amaya Singh, Epilepsy (Canada) PSP

Searching existing literature for uncertainties

As well as uncertainties submitted by patients, carers and clinicians, documented sources of information may 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 earlier section on the role of the Information Specialist.)

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). To avoid duplication of effort, PSPs have gathered this information while using the literature to check whether survey-submitted uncertainties have already been answered or not.

Chapter 6 - DATA PROCESSING AND VERIFYING UNCERTAINTIES

Unlike most surveys, which are designed to collect answers, JLA Priority Setting Partnership (PSP) surveys are designed to collect questions. Their aim is to generate questions that patients, carers and clinicians want health research to address. As we are actively consulting with a non-researcher audience, we expect the responses to be a mix of specific questions, personal stories and themes/issues. A survey submission may not immediately look like a research question, but it may still contain an unmet evidence need. The survey responses need to be reviewed, interpreted, sorted and turned into a list of indicative questions for research or 'evidence uncertainties'. For this reason, analysing the survey responses (or data) is the most complex and time-consuming part of the process.

To enable open access to the full list of uncertainties identified, PSPs need to ensure that on completion of their priority setting exercise, **all** 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/templates-and-useful-documents.htm for PSPs to use to manage their data. The completed spreadsheet will be published on the JLA website once the PSP is ready to announce its results.

	Alcohol-related Liver Disease JLA Priority Setting Partnership		Total number of verified uncertainties identified by the PSP = 45	Date of priority setting workshop 16th September 2016	
Question Rank	Uncertainty	Explanatory note / original uncertainties	Evidence	Source of Uncertainty	Health Research Classification System
1	What are the most effective ways to help people with alcohol-related liver disease stop drinking?	While it is widely accepted that stopping drinking alcohol is the most important first step in treating ARLD,"there is little certainty about which treatments are available to people affected by alcohol-related liver disease that usefully (i.e. that there is a good evidence base of efficacy for) reduces alcohol consumption - and therefore ongoing disease progress. In particular, patients hospitalised with complications of cirrhosis, who are most at risk and who benefit most from stopping drinking, are excluded from most trials. There is one trial of baclofen, but no other agents with a role in alcohol relapse prevention have any evidence base yet. Given that the STOPAH study confrmed that resuming alcohol intake was the major cause of mortality in alcoholic hepatitis there is an urgent need for such studies."	None identified.	12 Patients, 10 Carers, 53 Professionals.	Oral and Gastrointestinal
2	What are the most effective ways of delivering healthcare education and information about excessive alcohol consumption, the warning signs and the risks of alcohol-related liver disease to different demographics (including young people)?	A common concern is how best to inform people of the risks associated with alcohol consumption. "How can you educate people about the dangers of alcohol without appearing to preach?". "How are health professionals trying to make people aware of the addictive nature of regular consumption of alcohol?" The risk to young people is a particular concern "Does early education of risks associated with alcohol reduce alcohol problems developing in young people?". The use of information technology to educate people is a recurring theme "Exploring YouTube / interactive educational apps for delivering health education in different settings for the prevention of ARLD."	Systematic review: Scott-Sheldon LA; Terry DL; Carey KB; Garey L; Carey MP. Efficacy of expectancy challenge interventions to reduce college student drinking: a meta-analytic review. Psychology of Addictive Behaviors. 2012;26(3);393-405.	25 Patients, 15 Carers, 48 Professionals.	Oral and Gastrointestinal
3	What is the most effective model of community-based care for patients with alcohol-related liver disease?	The organisation and effectiveness of care and support in the home or community are important issues across all groups with an interest in this topic. "What care models work best to support people who cannot stop dinking and their carers? Currently most alcohol services will not provide input for people who continue to drink yet these are the people most at risk of serious health outcomes.". "Which services in the community are most able to prevent alcohol-related liver disease?" Care at home is another important issue "How can we offer better support including outreaching more into the house?"	None identified.	2 Patients, 2 Carers, 2 Professionals.	Oral and Gastrointestinal

Example spreadsheet of data submitted to the JLA website

Evidence uncertainties generally come from the survey responses from patients, carers and clinicians or may be identified within relevant literature in the form of research recommendations.

- Uncertainties submitted to the survey by patients, carers or clinicians may be:
    - unique questions submitted by just one respondent
    - indicative or summary uncertainties, which are formed to combine duplicate or similar responses.
- Research recommendations may be identified in relevant
    - systematic reviews
    - clinical guidelines
    - 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
Contraception	318	480
Dementia	1,563	4,116
Depression	3,000	10,000+
Diabetes (Type 1)	583	1,141
Diabetes (Type 2)	2,500+	8,000+
Digital Technology for Mental Health	644	1,529
Lichen Sclerosus	652	2,500+_
Lyme Disease	253	967
Multiple Sclerosis	507	1,084
Patient Safety in Primary Care	237	443
Scoliosis	697	1,692
Sight Loss and Vision	2,220	4,461
Life after Stroke	106	548
Teenage and Young Adult Cancer	292	855
Womb Cancer	413	786

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. Page 15 explains more about the role description for the Information Specialist who performs this task.

> *"I knew from the onset that managing the data components of the PSP would be a major task but I was surprised, once the first survey was completed, at how much data there actually was to process... All steering group members helped with refining the uncertainties/out of scope/unanswerable questions and the clinicians and some patients checked them against published research ensuring that any questions that had already been answered by research were removed."*
>
> From PSP feedback survey to the JLA

Resources required for this task will vary depending on the number and type of survey 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.

It is essential to adopt a systematic, transparent and accountable approach to managing and processing the survey submissions in order to create a list of uncertainties for prioritisation.

However PSPs choose to organise the survey responses, once the priority setting workshop is complete they need to provide the JLA with a JLA PSP data management spreadsheet, which will be published on the JLA website. We therefore recommend that PSPs use this spreadsheet from the start to help organise the survey responses. A copy of the data management template is available from http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm

The suggested approach to managing the data is divided into five stages:

1. Download the survey data
2. Remove out-of-scope survey submissions
3. Categorise eligible survey submissions
4. Form indicative questions
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
- give a reference number to each submission to maintain an audit trail
- anonymise the data by removing any personal details (i.e. name and address).

Example survey responses from Childhood Disability PSP:

PSP survey question: What question(s) about neurodisability would you like to see answered by research?	Respondent type
Do any of the alternative therapies out there actually work in supporting Autism?	Parent
Is there any evidence milk and gluten free diets influence autism?	Clinician
Does changing the lighting intensity and colour tone in classroom settings help children with neurodiverse conditions? Eg a) children with ADHD to concentrate for longer? b) children with dyslexia to read/see written images more clearly and therefore speed up their reading time or reduce visual stress headaches?	Parent
How effective are Complementary Therapies such as massage, reflexology, relaxation techniques in helping children and young people affected by neurodisability?	Parent
Assessment on the impact of language and cognitive growth with the provision of assistive and augmentative communication devices for those children unable to communicate orally.	Clinician
Does multi-level surgery improve the long-term quality of life in children with cerebral palsy?	Clinician
Are the teaching styles, social interactions and dynamics of the traditional school environment too stressful for many of these young people. My reason for asking is I know of many children with ASD/ADD (my 13 year old daughter being one) who have had breakdowns in mainstream education and have had to be removed from school and put into therapy. These are intelligent children whose grades are falling due to stress.	Parent

Stage 2. Remove out-of-scope survey 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, e.g. whether questions around GP awareness or availability of support will fall within the scope. 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.

PSPs should have decided in advance what to do with submissions that fall out of scope of the PSP. Some PSPs have arranged with relevant organisations to pass them on and will have mentioned in the consent information in the survey that this was a possibility.

The **Sight Loss and Vision PSP** agreed to send submissions better suited to social research to a partner organisation that was interested in addressing these. The **Dementia PSP** removed submissions that had already been answered by research. These submissions showed there was a need for better information sharing and awareness of the answers, so they passed them to the Alzheimer's Society communications team. The **Scoliosis PSP** decided to pass questions about cause to the British Scoliosis Research Foundation, which funds cause research, as the PSP's scope did not include cause.

With input from the Steering Group, the Information Specialist must carefully consider each response and assess whether it can be turned into a researchable question. Some responses may not need to be answered by research, for example, they may be questions seeking further information or advice on a topic, or issues around awareness. The Steering Group should decide whether these fall within scope or out of scope and what they will do with these responses, as an output of the PSP that is separate to its priority setting remit. For instance, a PSP might pass these responses on to relevant charities to create frequently asked questions, or to inform their awareness raising activities.

Stage 3. Categorise eligible survey submissions

After the survey period is over and out-of-scope submissions have been identified and removed, work will begin to categorise people's submissions, grouping the duplicates/similar questions and creating summary, or 'indicative', questions.

The aim is to retain the sense of what the respondent meant, but in the form of a clear, researchable question. These researchable questions will be checked against the evidence base, and those that are 'unanswered' will go forward for prioritisation.

Allocating submissions into categories 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, although it will not affect the later prioritisation. Developing a system of categorisation can help PSPs to make their data more manageable by reducing the data into smaller, more manageable sections.

It is important that a good version control system is used when sending question lists to Steering Group members to avoid confusion.

Categories may be developed iteratively as the data is analysed. Or, the Steering Group may have suggestions or access to an existing set of categories or taxonomy. These might include '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 for consideration.

Stage 4. Form indicative questions

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, or summary, questions based on groups of similar or duplicate submissions.

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.

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

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, where possible, be worded using the PICO format, which is described below.

This part of the process is interpretative and subjective. It is therefore vital that Steering Group members are offered opportunities to contribute to and comment on the process to ensure they are satisfied that the interpretation of the submissions is fair, neutral and accurate. Their experiences as patients, carers or clinicians will help ensure the submissions of those groups are interpreted and captured appropriately in the formatted questions.

Steering Groups will also need to make decisions about the extent to which questions are combined. Too many very specific questions will be difficult to prioritise and may risk diluting a key theme across multiple questions in the prioritisation. Conversely, questions that are too broad may be difficult for researchers to interpret or may contain too many elements with no sense of priority between them. It is recommended that the workings of the Information

Specialist are brought to the Steering Group at an early stage of the analysis, to ensure it is informed by members' input, advice and scrutiny.

Example indicative questions created from responses to the Mesothelioma PSP survey:

Sample of submitted questions and respondent type	Summary/indicative question
• He found internet support groups helpful. Our GP visited or phoned regularly and was as a concerned friend, unhurried and available [bereaved carer] • We also had support locally from a nurse from our local hospice who made home visits and was always available on the phone, as were the district nurses and community nurses [bereaved carer] • I have been given various phone numbers contacts so that if I have any questions I can ask. If I have to leave a message I do always get a return call. It is good to know that I can make contact if I need to [patient]	What is the value of weekly telephone support for mesothelioma patients during chemotherapy in reducing hospital admissions, side effects and anxiety?
• Does exercise such as pilates or yoga help with building patients' lung capacity and easing pain after treatment for mesothelioma? It seems to help some people. What is its effect? [carer] • What about the role of exercise and physical activity interventions to help prevent/minimise deconditioning that so often accompanies people's experience of living with mesothelioma. [clinician]	What is the best current treatment for breathlessness in mesothelioma patients (e.g. exercise, handheld fans, etc)?
• Anti-oxidants/vitamins in large doses have been given to 'long' survivors of meso (in USA). Why not in UK? (to boost immune system) [bereaved carer] • Can the immune system be stimulated to fight mesothelioma? [patient] • Again no one seems to be able to tell me if extra vitamin tablets will help his immune system? I now have started to give him BioCare multivitamins to help his immune system after a lot of sickness nausea and not wanting to eat. He has lost over two stones. [carer] • What research is taking place into ways to strengthen the immune system to fight this disease (i.e. acupuncture, nutrition, exercise, meditation, positive outlook)? I have been having weekly acupuncture since diagnosis and scans show tumour is shrinking slightly. I am doing all of the above to some degree and would like to know which is the most useful. [patient] • His immune system is too low to have any treatment [carer]	Does boosting the immune system improve response and survival rates for mesothelioma patients?

Example indicative question created from responses to the Scoliosis PSP survey:

Sample of submitted questions and respondent type	Summary/indicative question
• How effective is the use of hip abduction shorts at night in preventing scoliosis in children with cerebral palsy? [clinician] • Does trihexphenidyl prevent scoliosis? [clinician] • Is there anything that can be done to help prevent onset of scoliosis in children of scoliosis sufferers? [patient] • Linked to risk factors, what might be done to prevent the early development of scoliosis? What can be done to halt its progress, e.g. the influence of intensive and individually focused exercise therapies such as Schroth? [patient] • Is there evidence for the use of spinal bracing in preventing scoliosis in patients with neuromuscular conditions? [clinician] • Can any scoliosis be attributed to a bad gait in the growing period and if so can adjustments be made to a person's gait to help avoid the onset of scoliosis? [patient]	What are the best strategies for preventing scoliosis (combining physiotherapy, orthotics, alternative treatments, diet, exercise)?

Rephrasing and combining the submissions

It is important to note that the questions written for prioritisation are, generally, not written as research questions. They are researchable questions that capture the concerns and ideas of patients, carers and clinicians, but the process of turning them into refined, fundable research questions will happen after the priority setting workshop.

Nevertheless, it is important that the questions are written in a clear and consistent style. Where possible, the JLA suggests that it can be helpful to re-write submissions using the PICO format, to include:

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

PICO is a helpful framework to aim for, but the JLA recognises 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, especially if the PSP has a broad scope that includes a wide range of question types. PSPs should aim to ensure that the uncertainties are in a format that will ultimately be clear and of value to the research community.

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, on a given condition may be combined into a theme of 'diet'.

This process is more straightforward if submissions have been allocated to a category 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 uncertainty was submitted are documented. This detail can be discussed and considered 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. **To reiterate, 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 priority setting workshop.**

Finalising the long list of indicative questions

This process can be time consuming and labour intensive. The indicative questions (the evidence uncertainties) that are created at this stage are the ones that are likely to go into the interim prioritisation survey, to be discussed at the priority setting workshop, and ultimately to go on to become the published results of the PSP.

While the Steering Group should have had oversight of and input to the data management from an early stage, it is recommended that time is allocated for members to review the long list of questions, ideally in person. In doing this, they should keep in mind that the questions need to be clearly understood, unambiguous, and accessible to members of the public who will see them in the interim prioritisation survey and at the priority setting workshop.

The questions should contain wording for the topic area of the PSP, so that they can stand alone and be searchable on websites. They should also be worded neutrally and avoid personalised language, such as 'we' or 'I'.

These questions will ultimately become the outputs of the PSP and cannot be changed once they have gone into the interim prioritisation survey, so it is important that they have been considered carefully. Steering Group members representing patients and clinicians will need to be content that they faithfully reflect the original survey submissions and that they will also be valuable to the research community. It is also important to consider the research and funding community at this point. If the aim of the PSP is to influence the research agenda, it is important to consider what that research funding community might need to know and understand to fund research in this area. PSPs often create broad thematic questions at this point, but it is helpful to bear in mind how the research community will be able to respond to them and the translation activity that may be required after the priorities have been agreed.

> *"We realised we could have spent more time avoiding questions that had overlap or were different aspects of what was fundamentally the same question."*
>
> From PSP feedback survey to the JLA

The JLA's experience suggests that participants at the priority setting workshop may want to debate or even dispute the shortlisted uncertainties, for example the wording, or whether any questions could be considered duplicates of each other. It is essential that the Steering Group is confident that it can defend the shortlist that goes out to prioritisation. 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 or variation of interpretation?

- Are any of the questions too similar?

- Are there any that may be better combined into one question? Or separated into more than one question?

It is important that the Information Specialist considers how to make sure that rephrased and reformatted questions can always be traced back to previous versions of the question and to the original submitted uncertainties.

PSP Examples

In the **Asthma PSP**, over 100 survey responses 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 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?'

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 1,141 uncertainties
- 890 were true uncertainties
- 118 uncertainties came from research recommendations/literature
- After combining duplicates there were 350 verified uncertainties

Stage 5. Verify the uncertainties

Each indicative question (evidence uncertainty) needs to be verified as a true uncertainty before it can go forward for prioritisation. For example, some of these questions may have already been addressed by research without all patients or clinicians being aware of this.

To check that an indicative question is a true uncertainty, a search needs to be undertaken for relevant and reliable systematic reviews and guidelines that might address the uncertainty. Large-scale registry data may be available for the condition, which can be reviewed. Other types of evidence may be considered if the Steering Group agrees that this is relevant and appropriate to the topic area in question.

Each PSP must agree and publish a **Question Verification Form** to describe and account for their evidence checking. The PSP Steering Group must discuss and agree an appropriate strategy for checking all relevant evidence for the condition or setting to which the PSP relates.

A requirement of the JLA PSP process is that the PSP's Question Verification Form is published on the JLA website. This should be published once the Steering Group and JLA Adviser have signed it off. A template Question Verification Form is available from the Templates and useful documents section of the JLA website http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm

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

It is suggested that at the same time as verifying the indicative questions, uncertainties from research recommendations are recorded and added to the list of indicative questions for prioritisation. Where research recommendations duplicate a question that has come from the survey, this can be taken as an indication of that question being unanswered.

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 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, up-to-date, and reliable. The JLA recommends that an up-to-date systematic review is less than three years old. The sources listed above can be assumed to be reliable and meet methodological standards. If a PSP decides to look beyond these, it will need the knowledge and expertise to be able to assess the reliability of its sources. 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/ https://methods.cochrane.org/gradeing/ or http://www.gradeworkinggroup.org/ .

The JLA recommends that the evidence search is pragmatic and proportionate. A PSP should be confident that the questions it puts forward for prioritisation are broadly unanswered and should demonstrate clearly and accountably in the Question Verification Form how it came to that conclusion. If a PSP finds that the number of systematic reviews that are relevant to its area is unmanageable within 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 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 inform future awareness-raising exercises and education programmes. 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 into the PSP's Protocol.

The **Psoriasis PSP** created two videos where health professionals talked about the questions received by the PSP which had already been answered by research. You can find these here https://www.jla.nihr.ac.uk/priority-setting-partnerships/psoriasis/

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 (so can be combined with those), or they may be unique. The Steering Group will need to decide whether 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 to 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 considered. 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 be resolved 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, agree the best approach for their PSP, and ensure that decisions are consistent, documented and transparent.

Preparing uncertainties for prioritisation and publication on the JLA website

To manage the data throughout the PSP process, it is strongly recommended that the PSP uses the data management template supplied by the JLA that 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.

A requirement of the JLA PSP process is that the completed data template is published on the JLA website. This should be sent to the JLA as soon as the PSP is ready to announce its results. It forms a transparent, public 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 evidence 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) that 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 (and a link where possible) 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 workshop (this is usually a maximum of 30), PSPs should show the following in addition to the above:

- **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, providing details of what the uncertainty is and why it is a priority to research. This is an essential step in supporting researchers and funders to understand why the uncertainty is a priority and what impact any research could have on patients, carers and health and social care professionals. PSPs may wish to include examples of the original survey submissions within the note.

Following the priority setting workshop the PSP should:

- Update the data sheet to include any agreed changes made to the uncertainties during the priority setting workshop, e.g. merging or rewording submissions
- Ensure that the final ranking and explanatory note is included against all the uncertainties discussed at the workshop
- Send the completed data file to the JLA for publication on the JLA website as soon as possible, so that researchers and funders can benefit from the additional information about the priorities.

The Excel spreadsheet supplied to the JLA will enable the JLA to create individual pages for each of the questions that were discussed and prioritised at the workshop. These individual pages feed into the NICE Evidence Search website https://www.evidence.nhs.uk/Search?om=%5b%7b%22srn%22:%5b%22James%20Lind%20Alliance%22%5d%7d%5d&sp=on, making the PSP questions publicly available on an additional website. For an example of these individual pages, please see the **Foot Health PSP** Top 10 on the JLA website at http://www.jla.nihr.ac.uk/priority-setting-partnerships/foot-health/top-10-priorities.htm.

The data management steps involved in a PSP are summarised below.

Summary of data management stages

STAGE 1: DOWNLOAD THE SURVEY DATA

- May be completed by the Information Specialist or the PSP Coordinator.
- All survey responses to be in included in SurveyMonkey or similar survey software – add any paper responses into the survey software before downloading, for ease of monitoring demographics.
- Download into Excel spreadsheet.
- Add in any relevant uncertainties from other sources, such as discussion groups, published research recommendations or healthtalk.org.

- Format Excel according to suggested minimum fields in JLA data handling template.
- Remove blank rows or consider how to manage incomplete responses.
- Each respondent will have a unique identifier. 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 identifying personal details.

STAGE 2: REMOVE OUT-OF-SCOPE SURVEY SUBMISSIONS

- Responsibility of the Information Specialist and Steering Group.
- Remove submissions that fall outside the scope of the PSP, and those that are not uncertainties. Refer to the PSP Protocol for the agreed scope.
- Ensure that those removed are kept separately, with all the associated details, e.g. number of patients, carers, clinicians who submitted the question.
- Pass the list to the Steering Group for review, confirmation of exclusion, and decision about how to handle, e.g. passing to other organisations/PSPs.

STAGE 3: CATEGORISE ELIGIBLE SUBMISSIONS

- Responsibility of the Information Specialist and Steering Group.
- Decide how to categorise the submissions. This might be an existing taxonomy, e.g. UK Clinical Research Collaboration Health Research Classification System, or Cochrane. Or, it might be done iteratively as the data is processed.
- Allocate submissions into categories, as a first step to organising the data.

STAGE 4: FORM INDICATIVE QUESTIONS

- Responsibility of the Information Specialist and Steering Group.
- Submissions that fall within the scope of the PSP to be rewritten or rephrased to help clarify the precise uncertainty. Where possible, use PICO format (Patient/Population, Intervention, Comparison, Outcome). Lay language to be used. 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.
- If 'Outcome' variable is difficult, the Steering Group to consider generic outcomes, e.g. efficacy, adverse effects of complications, quality of life.
- Produce a list of those eligible submissions that cannot be standardised. The full list will be circulated to the Steering Group for confirmation and discussion of any issues. Once approved, these submissions will be combined with other eligible submissions.
- Eligible submissions (now in standard format) in duplicate are combined, with their frequency recorded. Frequency is dependent on the number of times one

uncertainty is submitted by a particular participant or group, e.g. patients, carers or health professionals, and the number of times it is submitted by different groups.
- Ensure all original information is combined with each set of combined questions, e.g. original survey submissions.

Note:
- Some Steering Groups may choose to do the formatting work after combining duplicates if the number of questions is high, although the process of formatting submissions may help with identifying duplicates.

STAGE 5: VERIFY THE UNCERTAINTIES

- Responsibility of the Information Specialist with input from Steering Group where required.
- Check the evidence base for relevant, up-to-date systematic reviews.
- Check the list of formatted questions against the evidence base to identify whether any have already been answered ('unknown knowns').
- Agree with the Steering Group how to treat any questions that may have been partially answered by research.
- If there are any 'unknown knowns', extract them and pass to Steering Group for a decision on how to handle/who to inform.
- Keep the true uncertainties, i.e. where no current evidence exists, in the Excel spreadsheet format supplied by the JLA.
- If the Steering Group has agreed this is in scope, then add to the list any further uncertainties identified from checking the existing research evidence, noting the source.
- For ease of data review, if possible, the uncertainties should be put into broad categories such as care pathway, or area of interest, e.g. sepsis, communications.
- The list of true uncertainties to be reviewed and agreed by Steering Group.

Notes:
- This stage should take place once the list has been reduced to a more manageable length, e.g. 100, prior to the interim process.
- JLA definition of uncertainty: no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty about the effects of the intervention exist; or up-to-date systematic reviews of research evidence show that uncertainty exists.
- Reviews to check should include, but not be limited to, the Cochrane Database of Systematic Reviews, NICE guidelines, SIGN clinical guidelines and relevant Royal Colleges' guidelines. Other sources of evidence to be used and recorded if appropriate.

NEXT STEPS: Preparing uncertainties for interim prioritisation

- Responsibility of the Information Specialist and the Steering Group.
- The verified uncertainties and research recommendations become the long list which will go forward to the community for interim prioritisation.
- If there are a large number of questions on the list, the Steering Group will need to do an initial prioritisation process to reduce the list to a more manageable number

for interim prioritisation, e.g. no more than 70. Steering Group to be mindful of no one perspective or single agenda dominating this process.

INTERIM PRIORITY SETTING

- Responsibility of the PSP Coordinator or the Information Specialist.
- Questions will be scored and ranked (as agreed by the Steering Group), and should be tracked accordingly, again keeping all relevant details.
- The top 25/30 will go forward to the final prioritisation workshop. Question cards may show details of interim rankings from patients, carers, clinicians on the reverse to help with discussion at the workshop and may need examples of original questions and numbers of contributors of different types if questions have been combined.

AFTER FINAL PRIORITY SETTING

- Responsibility of the Information Specialist.
- The Top 10 will emerge from the workshop. Any changes to the questions that were agreed at the workshop should be tracked accordingly on the spreadsheet with all relevant details.

PUBLICATION ON THE JLA WEBSITE

- Responsibility of the Information Specialist.
- Send the final spreadsheet of data, after any changes made at the priority setting workshop, to jla@soton.ac.uk
- Also submit completed Question Verification Form to explain the evidence checking process.
- Publication on the JLA website is an important step in making sure that researchers and research funders can find information on all the uncertainties, what the key areas of the questions discussed at the workshop were, and what people were concerned about in their original survey submissions.
- 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/templates-and-useful-documents.htm for PSPs to use to manage their data. The completed spreadsheet will be published on the JLA website once the PSP is ready to announce its results.

Chapter 7 - INTERIM PRIORITY SETTING

What is interim prioritisation?

Interim prioritisation is the stage where the long list of indicative questions (evidence uncertainties) is reduced to a shorter list that can be discussed at the final priority setting workshop.

To do this, stakeholders are asked to prioritise the questions, based on their own knowledge and experience. This then creates the shorter list of questions for the priority setting workshop.

The interim survey

The Steering Group should agree the number of uncertainties 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.

> Instructions for the survey should be clear, and ideally piloted before dissemination to test whether users would know what they need to do just by reading them. Instructions should note that respondents are not being asked to answer the questions (a common misunderstanding), but just to choose the ones they think are most important for research to address. The **Type 2 Diabetes PSP** ran a focus group to pilot its interim survey. The results of this can be seen in the Key Documents section of that PSP on the website or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/diabetes-type-2/downloads/Diabetes-Type-2-interim-survey-focus-group-findings.pdf.

Clear presentation of the list is important, and the Steering Group should consider how to structure it. Steering Groups may consider the use of categories to help respondents navigate the data, and whether 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. Different forms of survey software may allow randomisation of questions or the facility to choose questions and then drag and drop them into an order. Examples of survey software that PSPs have used for interim priority setting include SurveyMonkey, Qualtrics, Google Forms, OptimalSort, Lime Survey and Online surveys, but there may be other suitable platforms.

Many PSPs keep interim surveys open for around one to two months, depending on the responses they are receiving from appropriate groups of people.

Steering Groups are encouraged to use alternative means of consultation for interim prioritisation if a survey is not suitable for all their patient and carer groups. Capacity to process responses will be a key factor when designing a PSP's approach to interim prioritisation.

The number of indicative questions to include in interim prioritisation

From experience, a maximum of around 60-70 indicative 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.

If the long list of indicative questions is deemed too long, and there is no scope for reducing the list by merging questions, the JLA Adviser can help the Steering Group decide on how to reduce it in a fair and transparent way. It is still important that any questions removed to reduce the list are published and are not 'lost'.

Some examples of criteria considered by Steering Groups to help reduce a list of indicative 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 number of people
- Whether the question has been suggested by different kinds of professionals
- 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.

The **Stillbirth PSP** used the following criteria to help reduce the large list of uncertainties received to 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
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 <u>and</u> as research recommendations in guidelines.

The **Dementia PSP** reduced its long list by removing questions that were based on submissions by just one or two survey respondents. The removed questions were checked by a team at the Alzheimer's Society helpline with a view to retaining questions that were known to be of importance to marginalised groups and those less likely to have been able to complete the survey.

Who should complete it?

Those asked to complete the interim prioritisation survey may include the following:

- Partner organisations
- original survey participants, if details have been collected for this purpose and they have given permission to be contacted again
- the general patient, carer and clinician communities – an open call like the original survey was. Researchers may take part if they are also clinically active.

It is important that patients, carers and clinicians and the groups representing them participate. Interim priority setting can be done by email and/or post or online, depending on the communication preferences of the partner organisations and the capacity of the Steering Group to process the responses. Some PSPs have supplemented their survey work with

face-to-face work, to facilitate input from groups that are less likely to do an online survey or who need extra support to participate.

<div style="border:1px solid #000; padding:10px; background:#eee;">

This article in the news section of the JLA website at http://www.jla.nihr.ac.uk/news/adapting-psp-surveys-and-workshops-to-make-sure-everyone-can-get-involved/6635 describes how the **Dementia (Canada) PSP** used face-to-face discussions in its interim priority setting. Members of the Steering Group from the **Adult Social Work PSP** also worked with groups of people face-to-face to complete the interim priority setting survey.

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Depending on the timing of this survey, Steering Groups may consider using the survey to ask if respondents would be interested in an opportunity to attend the priority setting workshop, if this question was not already asked in the initial survey.

Approaches used

The Steering Group may design an interim priority setting approach that they feel is appropriate for the communities they are targeting.

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 needs of participants, 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 conducted the interim prioritisation 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.

Approaches used by JLA PSPs include:

- Asking people to choose the 10 most important questions in their experience
- Asking people to choose the 10 most important questions and rank them 1-10.

Examples of these are below:

Choose and rank 10
• 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
• 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.

- Asking respondents to rank their 10 questions produces a slightly clearer and more nuanced result, with a lower risk of questions being ranked in joint place, particularly if the interim survey includes a smaller number of questions.
- It also gets respondents into the frame of mind of ranking and choosing a Top 10 in the priority setting workshop.

Disadvantages
- 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
- See example of the interim survey ranking form in the Key Documents section of the **Childhood Disability PSP** and the **Type 2 Diabetes PSP** on the JLA website.

Choose 10
- 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
- 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
- When carried out via email/post, can potentially generate a lot of data that needs to be manually entered into a spreadsheet.
- When done online, can result in a very long list that may be hard to digest.
- Not asking participants to rank their choices may result in more questions being in joint place, particularly when an interim survey includes a lower number of questions.

Example
- See example of the interim survey in the Key Documents section of the **Anaesthesia and Perioperative Care PSP** and the **Adult Social Work PSP** on the JLA website.

In the past, a small number of PSPs have used a Likert scale for respondents to rate the importance for each question. The JLA does not recommend this approach for interim prioritisation as the results tend to generate very small differences in scores between the

questions. This does not provide a meaningful indication of the relative importance of the different questions for different groups, making prioritisation very challenging.

Examples of interim priority setting

Here are some examples of the numbers of survey responses received by PSPs:

PSP	Number of participants in initial survey	Number of questions in interim survey	Number of participants in interim survey	Approach used
Adult Social Work	485	61	632	Choose 10
Autism	1,213	40	1,266	Choose and rank
Blood Transfusion and Blood Donation	408	50	568	Choose 10
Childhood Disability	369	57	75	Choose and rank
Diabetes (Type 2)	2,500+	114	1,500+	Choose and rank
Palliative and end of life care	1,403	83	1,331	Choose 10
Scoliosis	697	54	750	Choose and rank
Stillbirth	574	48	1,118	Choose 10

The **Diabetes (Type 2) PSP** had a large response to their survey, which resulted in a long list of 114 indicative questions. The Steering Group queried whether this list was too long and whether they needed to find a way to reduce it. After much deliberation they decided to include all 114 questions in their priority setting survey. They felt that the response to the first survey indicated that the community were sufficiently engaged to not be put off by a long list. Over 1,500 people took part in the interim priority setting survey, in which they were asked to choose and rank 10 questions. Reviewing the results, the Steering Group decided not to generate a combined ranked list, as the difference between patient and clinician priorities was very marked. By selecting the top 10 questions identified by either (or both) people living with diabetes and their carers and healthcare professional groups, a shortlist of 23 questions was generated. The Steering Group then discussed the need to support the black, Asian and minority ethnic voice in the PSP and decided to shortlist questions that were also ranked in the top 10 priorities by black, Asian and minority ethnic respondents, leading to the inclusion of one additional question that was not already included. This left 24 questions in the final shortlist which were taken forward to the priority setting workshop. This process is described in more detail in their paper at
https://onlinelibrary.wiley.com/doi/full/10.1111/dme.13613

The **Oral and Dental Health PSP** survey resulted in the production of 38 indicative questions. These were all included in the interim priority setting survey, which asked people to choose up to 10 questions. It was agreed that a simple approach was required to encourage people to complete the survey, due to the challenge of engaging people in the first survey (perhaps due to the lack of single patient group, and the tendency for people not to necessarily see themselves as patients, unless they had experienced a dental health problem). To ensure equal influence, points for each respondent category were tallied separately, generating a total for healthcare professionals, and a separate total for patients, carers and the public, for each of the 38 questions. Within each of the groups, the total points for each question were put into order from highest to lowest and given a new score according to their position, from 38 (for the most popular question) down to 1 (for the least popular). Questions which had the same total, were ranked in joint place. These scores were added together to calculate a total combined score for each question and were then put into ranked order. The Steering Group was satisfied that both groups' top 10 choices were included in the top-ranked questions in the shared list, and a shortlist of 25 questions was taken to the priority setting workshop.

Collating and scoring interim priorities

Steering Group members will need to have agreed who will be responsible for coordinating, collating and listing the interim prioritised uncertainties (indicative questions). This process is closely monitored by the JLA Adviser to ensure transparency and minimisation of bias.

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 different constituent groups. 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

To ensure equal influence of all stakeholder groups, regardless of actual numbers of responses, totals for both patients/carers and clinicians should be recorded, ranking the questions and giving them a score based on their position in each groups' list. **It is those position scores that may then be 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, in line with the JLA's principle of equal involvement of patients and clinicians.**

However, there have been cases of such disparity between the patient/carer priorities and those of the clinicians that the combined scoring has led to questions that are important to one group being left out of the shortlist for the workshop. In this situation the Steering Group should consider whether an alternative working should be applied. For example, the **Adult Social Work PSP** created a shortlist for the workshop based on including the separate Top 10s for each of its three stakeholder groups which, taking into account the overlaps, led to 21 questions being taken to the priority setting workshop.

The JLA Adviser will work with the Steering Group to agree how many of the prioritised indicative questions to take to the workshop. Generally, this will be around 25 questions for an in-person workshop (please see Chapter 8 for adaptations made for the online format). The JLA advises a maximum of 30, otherwise the workshop process can become unmanageable, with too little time available to be able to meaningfully discuss every question. However, for some groups it will be more appropriate to have a smaller number nearer to 20. 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. The nature and needs of the participants should also be considered, as should the topic area. Narrower topics, such as single diagnostic areas, may mean participants have a shared understanding, experience and vocabulary, the impact of which could be a more easily established group dynamic and a faster-flowing discourse. Broader topics may need more time to be understood and discussed, and therefore bringing fewer questions to the workshop may be sensible. There may be an obvious place in the list of questions to draw the line, for example, where scores drop off rapidly. There may be a reason for including questions that 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 or was of clear concern to a group who might be less likely to engage with the process.

The shortlist of questions should be sorted into random order, i.e. not the ranked order, and each question assigned a letter of the alphabet as a reference.

Here are some examples of the numbers of questions that PSPs have taken to the priority setting workshop:

PSP	No. of questions at workshop
Adult Social Work	21
Frailty (Canada)	21
Multiple Conditions in Later Life	21
Dementia (Canada)	23
Autism	25
Blood Transfusion and Blood Donation	25
Idiopathic Intracranial Hypertension	26
Depression	27
Living With and Beyond Cancer	27
Palliative and end of life care	28
Teenage and Young Adult Cancer	30

Chapter 8 - FINAL PRIORITY SETTING

Final priority setting principles

The final stage is to rank all the shortlisted indicative questions in priority order, with an emphasis on the Top 10.

For JLA Priority Setting Partnerships (PSPs), final priority setting is ideally done in a face-to-face workshop, using small and whole group discussions. With the Covid-19 restrictions introduced in 2020 and the need for social distancing, the JLA has developed and tested an online workshop method that will be explained later in this chapter.

The priority setting 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' opinions and experiences. They are making decisions based on what they already know. Bringing people together in a workshop enables them 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. The JLA recognises that there is subjectivity here and that a different set of people on a different day could give a different result. However, there is immense value in bringing people together to engage in careful consideration and quality discussion to make shared decisions and reach genuine consensus.

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 ranking 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.

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 method

The JLA supports an adapted Nominal Group Technique for PSPs choosing their 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. There is no hierarchy between the different participants; no one individual or group's views or experiences are more valid than another's.

Nominal Group Technique is a well-established and well-documented 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 considered. 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 group 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
- Participants are not used to working together
- The issue is controversial or there is heated conflict.

Three JLA Advisers facilitate the final priority setting process to ensure fairness, accountability and transparency. The JLA's facilitation approach is neutral and empowering and has no influence over the outcomes of the workshop discussions. The facilitators will ensure that the process takes place and the JLA's principle of equal involvement of patients, carers and clinicians is upheld.

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

Who should take part?

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

- Patients or carers with direct experience of the health area being discussed, or representatives from patient support groups, patient charities etc

- Clinicians – a balance of appropriate clinicians for the health area being discussed, e.g. specialist nurses, consultants or senior registrars, paediatricians, GPs, surgeons, physiotherapists, dieticians, advice line nurses, speech therapists.

It is recommended that a minimum of 12 people and a maximum of 30 are recruited. The more participants, the more difficult it will be for everyone to have their say and come to a consensus. Some people can struggle to participate in larger groups. The Steering Group should consider if this will cause stress to its stakeholder group and either adjust the numbers accordingly or consider having four smaller breakout groups, rather than the usual three.

The Steering Group should agree a list of the ideal range of types and numbers of people to attend the workshop, for the workshop organiser to recruit. Generally, workshop participants are recruited in a range of ways, for example:

- through the surveys
- through the Partner organisations and the Steering Group's extended networks
- through an open call on social media and via the PSP's mailing list.

Workshop participants decide the final order of the priorities, so it is important that the PSP is confident that a range of voices and perspectives are represented and that they are transparent about how they were selected to take part.

Selection should involve a screening process to ensure an appropriate mix of participants, so that a diverse range of professionals and patients/carers are identified. It should not be done on a first-come-first-served basis. The Steering Group should also consider whether it is important to have a variety of geographical areas represented at the workshop, bearing in mind the costs of travel and perhaps accommodation that this may incur.

Clinicians with research interests as part of their role are eligible to take part in the final priority setting workshop if they also treat patients and are currently clinically active. They will need to declare their research interests.

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*" [8]. 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 and Needs document, which is summarised and given to all workshop participants on the day.

Finally, with the JLA Adviser, the Steering Group should decide whether they wish Steering Group members to be present at the workshop. Some Steering Group members may decide they can legitimately be involved as participants, or they may decide that a new set of voices should be brought in to make the final decisions. They may simply wish to observe.

Workshop observers

It is not unusual for observers to be invited to, or request to attend the priority-setting workshop. This can be a great opportunity for key influencers and stakeholders, including funders and researchers, to see the priority setting process in action and gain an insight into the development of the research priorities. Observers are often enthused and moved by witnessing the process of patients and clinicians working in partnership and can become strategically helpful champions of the resulting priorities. In addition, PSPs sometimes allow people running other PSPs to observe the workshop for learning purposes.

Members of staff from organisation(s) on the Steering Group are also likely to attend the workshop in a non-participatory capacity, to help run it. Roles might include registration, event management, photography and troubleshooting.

The JLA recognises the benefits of having observers and staff involved in priority setting workshops. It also understands that the organisation(s) running the event may want to carry out secondary activities at the workshop to enable effective dissemination, such as media work, social media, reporting and photography.

The JLA suggests that observers are briefed in advance about the nature of the workshop and their role on the day. Points to keep in mind include:

- The role of the observer is simply to observe the process. The workshop chair will introduce them at the start of the day to ensure participants know why they are there.

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

- Observers are not invited to take part in the discussion and should sit separately from the participants during group discussions (e.g. at the edge of the room, not at the table). Facilitators will allocate specific seats to them.
- In general, a maximum of two observers per small discussion group is recommended, although for very small groups or rooms this may be too many. It is important that participants do not feel uncomfortable or on display.
- Both facilitators and participants are required to exercise high levels of concentration throughout the workshop. Observers should be mindful of this and should refrain from talking among themselves, frequently entering or leaving the room, or typing loudly on their laptops during the discussions. They should not offer explanations or other commentary unless requested to by the facilitator. Discretion is paramount.
- Where topics for discussion are likely to be very sensitive, the PSP Steering Group should decide on the appropriateness of having observers.
- Observers should always be aware of their role during the day, including breaks and lunchtime and should not engage in conversations that could influence the views of a workshop participant.

Preparing for the workshop

Planning the workshop takes considerable resource and time and should be done well in advance: **early preparation is vital**. PSPs should have made decisions about the workshop and be able to invite participants **at least** eight weeks before the workshop, to allow people to make arrangements to attend.

> It is important for the Steering Group to think in advance about how best to support patients and carers, both with information before the workshop and with any support that they might need on the day. The **Autism PSP** provided detailed photo instructions to the workshop venue, which can be seen on the PSP web page on the JLA website at http://www.jla.nihr.ac.uk/priority-setting-partnerships/autism/. The Steering Group also thought carefully about what requirements and sensitivities people with autism might have during the workshop, so that arrangements could be made to help them feel comfortable and able to contribute effectively. This included having a fourth facilitator, so the small groups had fewer participants and were less overwhelming, and the provision of a quiet space for people to use if they needed time out.

PSPs will need to consider reimbursement of travel expenses, accommodation if needed, payment for the time of patients/carers and provide expenses claim forms on the day of the workshop. When inviting participants, it is important to be clear about what costs will be covered.

Once participation has been agreed, the following should be prepared before the workshop, with guidance from the JLA Adviser. It is helpful to create a detailed checklist of what will need to be done before the workshop.
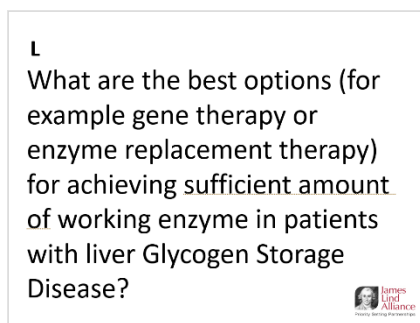
- A confirmation email, sent at least a month in advance, containing:
  o An Interests and Needs form for participants, which also requests a short biography. This can also include a request for permission to take photos or video during the workshop if needed and to ask about dietary, access and any other requirements. This could be done by setting up an online form.

- A reminder email sent a week in advance, containing:

- o the workshop agenda (see an example in the Key Documents section of the **Mesothelioma PSP** on the JLA website or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/mesothelioma/downloads/Mesothelioma-PSP-final-workshop-agenda.pdf)
  - o a plain language guide to the workshop (see the Key Documents section of the **Adult Social Work PSP** on the JLA website or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/adult-social-work/downloads/A-guide-to-the-Adult-Social-Work-final-workshop.pdf)
  - o a participant worksheet showing the shortlist of questions (not in ranked order, with an alphabetised reference for each question). This should include clear instructions asking participants to rank all of the questions before the workshop, bring the list with them, and be prepared to discuss them on the day (see the Key Documents section of the **Frailty (Canada) PSP** on the JLA website or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/frailty-canada/downloads/Pre-workshop-form-for-participants.pdf)
  - o a list of workshop participants, including their biographical details (some people may feel more comfortable participating and less intimidated if they know some simple, friendly details about the participants beforehand)
  - o clear directions to the venue
  - o a glossary for participants if this is felt appropriate, although it may not be necessary as accessible language should be used throughout.

- A briefing paper for the facilitators (prepared by the JLA Adviser). A briefing call should be carried out by the Adviser, with the facilitators, PSP lead and coordinator, at least a week before the workshop.

- Materials for the workshop:
  - o one set of A4, landscape cards per small group, showing the questions to be discussed, printed double sided. To include interim priority setting data and other background information as appropriate on the reverse to help with group discussions (see example below). These should be printed on a different colour of card for each small group. They should not be laminated (which reflects light). The font size should make the question and reference letter clear and visible
  - o name badges (with just first and last names, rather than titles, to discourage any perceptions of hierarchy between the participants)
  - o register of attendees for people to sign on arrival. This may be used as a means of collecting consent to being photographed or filmed. Non-consenting participants should be highlighted to whoever oversees photography
  - o Spare copies of the worksheet, agenda and participant list, along with spare pens should anyone need to complete their rankings on arrival
  - o allocation of participants to morning and afternoon small groups, pre-agreed with the JLA Adviser, ensuring a balance of patient, carer and clinician representation and considering any sensitivities already known about. At least one person from each of the morning groups should be in each of the afternoon groups
  - o One-page ranking forms for each of the small groups, to be completed by the small group facilitators after each ranking session
  - o travel expenses claim forms (ideally with freepost envelopes to return them)
  - o signs to use on the doors of meeting rooms (if required)
  - o a workshop feedback form, to be either included in the delegate pack or sent later (JLA Advisers can refer PSPs to an online JLA version of a feedback survey which can be used. Please ask jla@soton.ac.uk for this if you haven't seen one already)
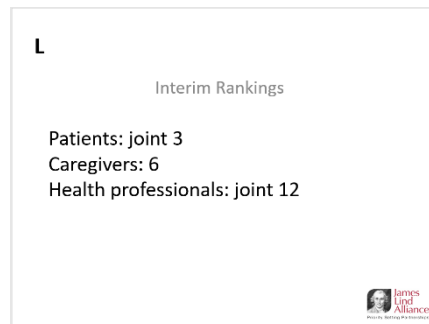
- o Some workshops have used additional materials to enhance accessibility, such as coloured tablecloths to assist with the priority setting, a list of the questions on one page of A4 for ease of access, and questions shown on slides during plenary discussions. The JLA Adviser will discuss these options with the Steering Group during the workshop planning stages.

- A draft 'thank you' email for use afterwards, including the JLA's online feedback form for workshop participants if feedback was not collected on the day.

Below is an example of an uncertainty card produced, landscape, on card not paper, for the **Liver Glycogen Storage Disease PSP** priority setting workshop. Workshop participants will split into three small groups, so three sets of these cards will be needed, each set on a different colour of card for ease of identification.
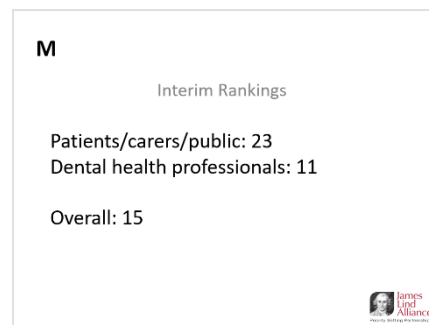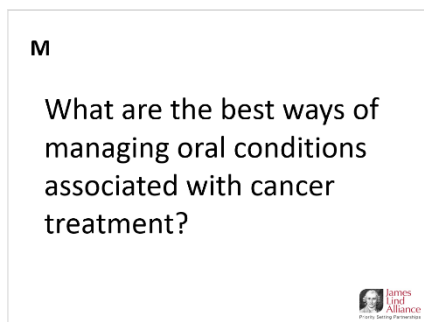
Front   Back

L

What are the best options (for example gene therapy or enzyme replacement therapy) for achieving sufficient amount of working enzyme in patients with liver Glycogen Storage Disease?

L

Interim Rankings

Patients: joint 3
Caregivers: 6
Health professionals: joint 12

This is an example of an uncertainty card for the **Oral and Dental Health PSP** priority setting workshop.

M

What are the best ways of managing oral conditions associated with cancer treatment?

M

Interim Rankings

Patients/carers/public: 23
Dental health professionals: 11

Overall: 15

It is important to make the right arrangements for an accessible meeting venue that is located somewhere convenient for people to travel to. The venue will need to include one main meeting room, set up theatre style with movable seating for all participants, and a rectangular table to one side to accommodate one of the small groups. Two additional breakout rooms set up boardroom style, with observer chairs to the side, will be needed for the other two small groups and these should be as close as possible to the main room for ease and speed of moving between rooms. A quiet space within the venue should be identified in case participants need to take a break from the workshop at any time.

Priority setting workshops typically start with registration at 9.30am and finish at 4pm, so refreshments and lunch will need to be provided throughout.

Steering Groups should decide beforehand how they would like participants to use social media on the day and state this at the beginning of the workshop, particularly whether they will be happy for results to be announced on social media immediately or whether they would like participants to keep the results confidential until a more formal announcement can be made.

There are reports of PSP workshops on the JLA website that describe how the meeting is organised. This video shows a typical JLA PSP workshop in action https://youtu.be/bXbIjDg3MAQ

Workshop process on the day

This section describes what happens in a standard JLA final priority setting workshop. The workshop is chaired by the JLA Adviser who has been supporting the PSP throughout. In addition, two other JLA Advisers will facilitate small group priority setting work on the day, so a total of three Advisers will be at the workshop. The meeting is held in person to give an opportunity for sharing of experiences and consensus building. However, adaptations may be required depending on the group of people needed at the meeting.

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.

At a PSP workshop, the JLA Adviser will set the scene, introduce the JLA and explain the ground rules for the day. This will include ways of working and behaviours on the day. Participants will be asked to work in partnership with each other, respect different opinions and maintain confidentiality.

The PSP lead, or another member of the Steering Group, will then provide background about the PSP itself. This is generally a short presentation, but should explain that the questions came from patients, carers and clinicians, how the questions were developed and why they are deemed unanswered.

Workshop phase 1: small group discussions
- In small groups (three groups of up to 10 people – equal mix of patients, carers and clinicians), each participant in turn contributes their views on the questions they feel are most important for research. These are noted down by the facilitator. Participants then talk about the questions they feel are least important in their opinion. Usually this involves focusing on each participant's top and bottom three questions.
- The discussion is reviewed by the group to further explore areas of agreement or divergence, and to clarify any aspects of the uncertainties.

Workshop phase 2: first round of small group ranking
- The same small groups begin to discuss the ranking of the 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 views.

- 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 any contextual information on the back of the uncertainty cards, such as interim voting results, to inform the discussion and acknowledge other perspectives in the prioritisation.

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 can be 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. The discussion should aim to focus on the upper half of the list. However, the full set of questions must be ranked by the end of this session.

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, usually with the cards laid out in order on a table or the floor.
- The ranking is discussed in the large group, with the aim of agreeing the Top 10 by the end of the discussion session.
- 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, and the rank order of the all the questions at the workshop, are agreed. The Steering Group should already have considered whether a public announcement of the Top 10 can be made immediately or whether an announcement will have more impact at a different time.

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 confidentiality, respect for different opinions, 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 the items for prioritisation are accessibly worded, unambiguous, and free from duplication.
- 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.
- Consider in advance how late arrivals to the workshop will be managed. It can be disruptive to the small groups if people arrive in the middle of discussions. While delays may be unavoidable, no participant should be invited who only plans to come for part of the day.

It is not unusual for participants to suggest merging questions. While some suggestions may make sense, it may also be seen as 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 submissions already. However, suggestions for merging may also be made because participants can see a genuine duplication that 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 alter the original meaning of the question and is agreed by all participants in the plenary session. It is up to the Steering Group to agree its position on this in advance, so the facilitators can maintain that throughout the meeting.

Finally, some participants may argue that questions are not unanswered, for example when there may be some evidence around specific aspects of the question. The Steering Group must ensure that the questions can all be defended as being broadly unanswered and/or contain some elements of uncertainty that research still needs to address.

The JLA priority setting workshop online

Due to the 2020 COVID-19 pandemic, the JLA has taken steps to adapt its established in-person workshop to be delivered in an online setting. This section of the Guidebook aims to support PSPs in making the decision to plan and run a workshop online. It sets out the current approach and learning to date. The JLA will continue to evaluate this approach, gathering feedback from PSP leads, Steering Group members and workshop participants, and will develop its guidance accordingly.   A *Report on JLA PSP online priority setting workshops* can be seen in the JLA Lab section of the website https://www.jla.nihr.ac.uk/development-of-online-priority-setting-workshop.htm .

Background
In establishing how best to deliver its priority setting workshop model online, the JLA is working to develop an approach that:

- maintains the JLA's principles of inclusivity of patients, carers and clinicians, equal involvement of those groups, transparency of process and a commitment to the evidence base
- retains the established and trusted steps by which the JLA workshop enables consensus development – so while adaptations have inevitably been made, the process, and the facilitation of that process, should still be recognisably "JLA"
- retains the characteristics which make the JLA workshop model successful in setting priorities: encouragement of open dialogue, participation, trust, fairness, exchange of views, teamwork, and neutral facilitation; and
- offers reassurance and consistency to the PSPs who must take this option, acknowledging its limitations and challenges, while ensuring their outputs are as robust and credible as possible.

Overview of approach taken to date

The programme for online workshops so far has very closely replicated the in-person workshop. The main difference has been the removal of the third round of prioritisation, which is usually done within a plenary setting with all participants. This is a complex discussion and can be challenging for participants. Facilitators rely on non-verbal cues and body language, as well as verbal input, to support the group to reach consensus. These factors are missing in an online setting. The JLA acknowledges the importance of a final opportunity to review and revise the top 10 priorities, and that this is a limitation online. To try and partially compensate, the JLA is currently advising PSPs to provide an opportunity for participants to share comments and reflections on the top 10 priorities, and on the questions that fell outside the top 10. This has enabled PSPs to collect more nuanced narrative data to accompany the Top 10 and the other questions, to better understand and report on the rationale for the decision-making that has taken place within the two rounds of prioritisation.

The JLA's current approach to the online workshop is therefore divided into the following sessions:

- Plenary session: introduction and background
- Breakout session 1: comparing priorities
- Breakout session 2 (same groups): first round of prioritisation (using virtual question 'cards')
- Plenary session: reviewing the shared ranked order of the questions
- Breakout session 3 (new groups): second round of prioritisation (revising the shared ranking)
- Plenary session: presenting the top 10, sharing initial reflections, next steps
- Follow up after the workshop: feedback on the priorities and evaluation of workshop.

Key considerations

When planning an online workshop, PSPs should work closely with their JLA Adviser and draw on the knowledge of their Steering Group to ascertain the following:

Number of participants

It is important to be realistic about the number of people who can take part. The limitations of an online setting (including lack of non-verbal communication and potential technical problems) mean that group discussions are likely to be less fluid than they are in person. Some groups of people may find it more difficult than others to participate online and their needs should be considered. The number of breakout groups may need to be increased to accommodate a larger total number of participants, while retaining manageable numbers

within each of those groups. Recent JLA PSP online workshops have opted for around 20 to 24 participants, divided into four breakout groups of five to six people.

Number of questions for prioritisation

Again, the online setting limits the number of questions that can be discussed and prioritised. Having too many questions is likely to result in a rushed discussion to which no one is able to contribute meaningfully or comfortably. To date, JLA has advised PSPs to aim to take the top 15 questions from the interim priority setting survey to ensure that the final prioritisation task is not overwhelming. In some cases, this has increased to 18, but each individual PSP should be mindful of the complexity of the questions and topics, and the needs of the participants, when agreeing its number. The JLA recognises that this is a limitation of the online workshop, meaning fewer questions are discussed than there would be in person (usually around 25).

One- or two-day format

Most in-person JLA workshops take place within one day. Working online can be intense and tiring. So far, PSPs that have run their workshop online have decided to either do it in one day, or to divide it across two (ideally consecutive) days. The Steering Group should consider the needs of the participants, including burden on patient/carer participants, as well as the availability and capacity of their clinicians, for whom taking time off for one day may be more feasible than two part-days. In both cases, designing an agenda which allows for enough screen breaks is key.

Support for participants

Consideration should be given to the kind of support participants may need to take part in an online workshop. This might include an induction or training in using the online platform, provision of guidance on how to take part, technical support on the day and provision of workshop papers in electronic and hard copy. Duty of care should also be considered, given that questions for prioritisation can include sensitive and upsetting topics. It is harder in an online setting for the facilitators to detect if someone is struggling. Provision of emotional support during or after the workshop should be planned for.

Planning time

The JLA's experience has been that the delivery of an online workshop is at least as time-consuming and resource intensive as the delivery of an in-person workshop. PSPs will need to carefully consider the practical implications and work closely with their JLA Adviser to map out their approach, including recruitment, briefing sessions, delivery and follow-up.

Costs

Compared with a face-to-face version, the online workshop does not require PSPs to budget for a venue, catering, accommodation and travel costs. However, there are significant cost and resource implications to delivering an online workshop and moving to an online workshop is not necessarily a lower cost option. For example, PSPs should still consider budgeting for:

- Time needed in preparation for the workshop including participant recruitment and liaison, sending hard copy workshop materials to all participants and the costs of technical support of participants both before and during the workshop
- Subscription to a suitable online platform
- Reimbursement payments in recognition of the time patients and carers spend preparing for and attending the workshop
- Up to four JLA Advisers to facilitate the workshop. A typical face-to-face priority setting workshop involves one JLA Adviser to chair the workshop plus two

additional JLA Advisers to facilitate the small group discussions. For online working, it is highly recommended that participants are split into four small facilitated breakout groups to enable a large enough number of people to take part.

Limitations

There will be limitations in any workshop, whether delivered in person or online. Some people will find it easier to participate in an online workshop, rather than travel to a meeting in person. JLA is conscious of the unique logistical limitations that an online workshop poses, where participation will require an appropriate device, enough connectivity, and access to a quiet, private space. PSPs should think carefully about this and be open about those limitations in any reporting. The JLA will continue to work closely with its PSPs to review these limitations and understand their impact.

JLA online workshops will continue to develop. We welcome any comments and feedback, so please email jla@soton.ac.uk if you would like to contribute to the discussion around this.

Feedback from the workshop participants

Getting feedback about the workshop may help PSPs understand how the process has worked for them and the participants and to address any individual concerns. A feedback form from the PSP may be included in the delegate pack for completion on the day and/or emailed afterwards. Some PSPs have produced short reports of the feedback they received and have made them publicly available.

The JLA also welcomes feedback from workshop participants and has developed a standard workshop feedback questionnaire, which PSPs can use instead of or in addition to their own. This is to help the JLA review its processes, gather a range of views from participants, and improve the guidance we provide for future PSPs. The PSP can work with their JLA Adviser and Steering Group to agree the most appropriate time and way to distribute a survey, and whether to carry out one survey in partnership with the JLA or if separate approaches are required.

In the Key Documents section on the JLA website at http://www.jla.nihr.ac.uk/priority-setting-partnerships/ for the **Diabetes (Type 1) PSP,** the **Preterm Birth PSP** and the **Bipolar PSP** you can find examples of their final workshop reports, including workshop evaluations.

Chapter 9 - DISSEMINATION AND PUBLISHING OF TOP 10

Agreeing the Top 10 research priorities is not the end of a Priority Setting Partnership's (PSP's) work. It is essential that PSPs 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 should create a dissemination plan for the results, identifying their audiences and how to reach them, and agreeing how Steering Group members can help with the dissemination process by using their own networks. This might include finding appropriate ways to disseminate the priorities to funding organisations, researchers, people who took part in the PSP, and patient and clinician groups who have an interest in the priorities. Dissemination at the end of the PSP should be a consideration throughout the PSP process to maximise its success. Before the priority setting workshop, the Steering Group should agree on the best time to announce the results to ensure the greatest impact, without delaying the announcement for too long. After the workshop, Steering Groups typically meet to discuss the results, any further action that they need to take on the questions, and what extra information they can offer to researchers and research funders to ensure that the priorities are successfully translated into questions, propositions or briefs for research.

> The **Coeliac Disease PSP** Top 10 announcement included personal stories from patients affected by each of the uncertainties. You can read the announcement on the PSP page on the JLA website or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/coeliac-disease/downloads/research-priorities-web-brochure-2.pdf.

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
- mainstream and social media.

> The **Learning Difficulties (Scotland) PSP** Top 10 launch was covered by a number of different mainstream media. Links to the coverage it received are in the articles and publications section of the JLA website http://www.jla.nihr.ac.uk/news-and-publications/psp-articles-and-publications.htm. The same website section also shows an article in *The Sun* about the **Endometriosis PSP** Top 10 launch. There is an example of how the **Multiple Sclerosis PSP** was publicised in the MS Society *Research Matters* magazine in the Key Documents section of that PSP on the JLA website or here http://www.jla.nihr.ac.uk/priority-setting-partnerships/multiple-sclerosis/downloads/Research-Matters-Newsletter-Jan_Feb-2014.pdf.

PSPs usually report on the whole process and methods, the people involved, the results, reflect on successes, 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.

The PSP needs to ensure the correct consent has been sought for any materials that will go into the public domain, for example that agreements have been sought with individuals to use photographs or any quotes that are associated with a name. Even if names are not to be included, descriptions of individuals should also be unrecognisable. Although this means individual names are not associated with particular contributions, it is important to acknowledge those who have given time and effort to the PSP.

PSPs should email their fully completed data management spreadsheet to the JLA as soon as possible after the workshop as this will be included on the JLA website. An example of a completed spreadsheet is here http://www.jla.nihr.ac.uk/priority-setting-partnerships/mesothelioma/downloads/Mesothelioma-PSP-final-data.pdf

There are a range of final reports, of varying lengths, in the PSP final reports section of the JLA website http://www.jla.nihr.ac.uk/psp-final-reports.htm

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

- 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.
- Go to https://researchinvolvement.biomedcentral.com/ for advice about submitting to Research Involvement and Engagement.

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 **Cystic Fibrosis PSP** had an article published in Research Involvement and Engagement. 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.

In 2019, a 'Reporting Guideline for priority setting of health research (REPRISE)' was published to help facilitate comprehensive reporting of priority setting activity and improve transparency. You can read about this here https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-019-0889-3

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 jla@soton.ac.uk.

JLA reporting requirements

A key principle of the JLA is transparency of process. In addition to reporting and disseminating the Top 10 priorities, and any other reporting and dissemination activity the PSP chooses to do, the PSP is required to provide the JLA with the following for the JLA website. We ask that PSPs provide these as soon as possible once the Top 10 has been agreed.

- **The full list of indicative questions** (uncertainties) that were discussed at the priority setting workshop, in the agreed order of priority
- **Data management spreadsheet**, which includes the full long list of priorities, examples of original survey submissions, explanatory notes about the priorities and references to relevant evidence
- **PSP engagement summary**. This provides details of the numbers of people who took part in each stage of the PSP. PSPs are also asked to record some statistics, including the number of survey responses, how many uncertainties were received, and the number of people at the priority setting workshop. Publishing this information makes the work of each PSP transparent. It helps everyone to understand the detail of each priority setting process and can provide helpful information to prospective PSPs. It is also helpful for PSPs to have this information summarised so that they have all the statistics needed for a final report all in one place. For a completed example, please see http://www.jla.nihr.ac.uk/documents/anaesthesia-canada-engagement-summary/24057

The following documents are also required for the JLA website:

- The PSP Protocol
- The PSP Question Verification Form
- The PSP Steering Group Terms of Reference

Templates can be found at http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm

> *"Traditional dissemination of the Top 10 through publications and presentations will occur over the next 6 months. Planning for broader dissemination and uptake by funding bodies will begin within the next 2 months and will be ongoing for the foreseeable future."*
>
> From PSP feedback survey to the JLA

Chapter 10 - TAKING PRIORITIES TO RESEARCH FUNDERS

The JLA process is designed to produce research priorities. Once these 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 Priority Setting Partnerships (PSPs).

Top 10s vary in the way they are worded and presented. They contain questions and topics that matter to patients, carers and clinicians, written in terms that a wide audience can understand. However, they are not usually precisely worded research questions that research funders can immediately work with. Further work will be required by the Steering Group after the Top 10 announcement, to identify potential research questions that meet a research funder's requirements, from the research priorities. Research funders have many competing priorities. It is important for each PSP to plan for how to bring its priorities to the attention of the right funders and to think about what information funders will need to make their decision to fund the work as easy as possible.

The JLA strongly encourages PSP leads and researchers to work collaboratively to develop research questions from the priorities and to work out what research methods are needed to address them and what any barriers might be. The PSP Lead and the Steering Group have a unique insight into the priorities. They understand the meaning of the priorities and the unmet needs of the patients and clinicians that have informed them. It is therefore important that they help funders and researchers who have not been involved in the PSP to understand the priorities and be able to translate them into propositions for research.

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 should involve going back to the original survey submissions to identify the interventions and outcomes that patients, carers and clinicians highlighted as important aspects of the questions.

It is important to consider who has the right skills and experience to do this work of influencing researchers and funders and to think about how the community can continue to be involved in this.

After the **Cystic Fibrosis PSP** agreed its Top 10, the group explored four of the Top 10 priorities in more depth, using online surveys and focus groups amongst the cystic fibrosis community. The aim was to develop practical and important clinical trial questions in those priority areas. They then undertook a follow-up survey asking the community to rank eight specific trial questions in terms of importance and asked patients how likely they would be to take part in the trials. More information about this is on that PSP page on the JLA website http://www.jla.nihr.ac.uk/priority-setting-partnerships/cystic-fibrosis/, including links to the articles and publications that they have created about their work and the priorities that they looked at in more depth.

The **Heart Surgery PSP** produced two different types of final reports. One (the 'report of the results' https://le.ac.uk/~/media/uol/docs/academic-departments/cardiovascular-sciences/uol_priorities_for_adult_cardiac_surgery_research_pr.pdf?la=en) is aimed at their whole audience and describes the process and the priorities, including all of the questions the PSP received. The other (the 'plan to help the research community address the priorities' https://le.ac.uk/~/media/uol/docs/academic-departments/cardiovascular-sciences/uol_randomised_trials_2019-pr.pdf?la=en) provides additional information relevant to researchers and funders, e.g. further details of the evidence gap and suggestions for the type of research questions that might help address these. This news item on the JLA website also explains their approach to establishing working groups to discuss each of the priority areas in detail and work with members of the Heart Surgery community to translate the priority areas into applications for clinical trials. https://www.jla.nihr.ac.uk/news/heart-surgery-psp-takes-its-next-step-to-translate-priorities-into-clinical-trials/25960

The **Teenage and Young Adult Cancer PSP** brought together researchers, funders and charities in a workshop to discuss the priorities, consider opportunities for funding, and promote collective thinking about the issues involved. More information is on the JLA website at http://www.jla.nihr.ac.uk/news/latest-steps-from-psps-to-focus-the-attention-of-researchers-funders-and-charities-on-the-agreed-priorities/22462. The PSP described this as a 'funders' workshop', other PSPs have described this step as having a 'knowledge translation workshop'.

PSPs can help to promote their priorities to key people:

- patients and carers and organisations which represent them
- research funders
- researchers
- the wider research and policy community.

Examples of research funded as a result of PSPs can be seen in the Making a Difference section of the JLA website http://www.jla.nihr.ac.uk/making-a-difference/.

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 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)
- Wellcome (www.wellcome.ac.uk)

Finding out how funders work, their criteria, and their remits is essential. It is important to consider which funders may be interested in which types of questions and then target them accordingly.

Some funding programmes set their priorities for research then advertise for research teams to conduct the research. These are **commissioning research programmes**.

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 or researcher-led research programmes**.

Other key information for research funders is:

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

In September 2019, the then Director of the NIHR Health Technology Assessment Programme, Hywel Williams, spoke in a video about the inclusion of JLA topics in NIHR applications, and the need to describe the importance of the topic in more detail. You can see the video here https://www.youtube.com/watch?v=f6nRZyx3Xdc&list=PLIa1oelW_zJ9QWfVwz6q91i9c9cZo8zUs&index=2&t=0s

For some funders, the response to a priority topic may be to commission a systematic review, or to update an existing one, rather than necessarily seeking 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.[9] Because of patient input, fatigue is now one of the core set of recommended outcomes for assessing a range of treatments for rheumatoid arthritis. [10]

The **Research Design Service** https://www.nihr.ac.uk/explore-nihr/support/research-design-service.htm 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 NIHR research programmes and explains how researchers wishing to prepare grant applications can benefit from its specialist advice and support.

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[9] 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)
[10] 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

The **NIHR Journals Library** www.journalslibrary.nihr.ac.uk provides a searchable archive of published and ongoing NIHR research. You can also find out more about NIHR Funding and Awards here https://fundingawards.nihr.ac.uk/search.

Communicating with appropriate researchers

It is important that PSPs communicate their results to researchers who may be interested in developing a proposal for one of the priority areas identified by the PSP and submitting it to a funder. 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 https://www.nihr.ac.uk/explore-nihr/support/clinical-research-network.htm . 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 is 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 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.

Thinking about communicating your PSP priorities to the NIHR?

The NIHR commissions and funds projects looking at the usefulness of new and existing tests, treatments and devices and at new and existing ways of doing things. It also looks at how to improve public health to see what really works in practice.

The NIHR funds research through a broad range of funding programmes, which cover many different types of research. It has ten different research programmes that researchers can apply to, each of which funds different types of research. There are two main routes for research funding from the NIHR: through researcher-led applications, and through research teams responding to commissioned calls advertised by NIHR. You can find information about NIHR calls for commissioned research and the responsive or researcher-led funding opportunities at https://www.nihr.ac.uk/researchers/funding-opportunities/.

NIHR considers PSP priorities in the context of the different NIHR programme remits and it is unlikely that the NIHR will respond on the basis of the list of PSP priorities alone. Additional information is usually required before the priorities can be taken forward.

For example, the NIHR's Health Technology Assessment (HTA) Programme's purpose and remit 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 when considering research questions for potential commissioning are:

- **P**opulation (what is the population of interest?)
- **I**ntervention (what are the interventions of interest?)
- **C**omparison (what are the comparisons of interest?)
- **O**utcome (what are the outcomes of interest?).

A PSP may therefore want to consider providing additional information for their priorities which might include:

- What is the question that needs to be addressed?
- If possible, details of the patient group, intervention, comparator and proposed outcomes
- Why the question is important
- What the existing evidence is
- If the question is specific to a condition, or more broadly applicable.

A good research question for the HTA Programme to consider, through its commissioning or researcher-led work stream, is:

- Important to the NHS and its patients
- Supported by current evidence
- Of high scientific quality
- Feasible
- Timely (i.e. 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.

A national pragmatic HTA trial typically costs over £1m of public funds, so the HTA programme will want to be sure that an intervention is ready for an HTA evaluation. Generally, an intervention is ready for HTA evaluation if:

1. There is a reasonable chance that it will be effective
2. It has already been tested in a typical NHS or social care setting
3. There is a reasonable chance it will be used across the NHS if shown to be effective.

HTA evaluation may also be appropriate if the intervention is already widely used in the NHS, but evidence of benefit and harms is lacking.

If this is not the case, then the research question may be more suitable for a different NIHR programme or a different research funder. Read more about interventions being ready for HTA evaluation at https://www.nihr.ac.uk/documents/is-an-intervention-ready-for-hta-evaluation/ .

The development of research topics takes time, and it can take many months or years before topics and themes are taken forward by the NIHR.

Some of the 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 at https://www.nihr.ac.uk/explore-nihr/ about NIHR research funding programmes. You can also search the NIHR Journals Library at www.journalslibrary.nihr.ac.uk for examples of research already funded in a PSP's area of interest.

Chapter 11 - FOLLOW UP

Following up with the JLA

After the priority setting workshop, the JLA would like to hear any feedback from Priority Setting Partnerships (PSPs) about their experience of the process. The JLA will send a short feedback questionnaire to PSP Leads who are encouraged to complete it and to pass it on to other relevant people involved in the PSP. The JLA has a separate feedback survey for Steering Group members which the JLA Adviser will send to the PSP Lead to email to the group. The responses from all these surveys will come directly to the JLA Secretariat team who will treat the responses in confidence. The questionnaires provide an opportunity for those involved in the PSP 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.

Long-term impact

The JLA recognises that assessing the value and impact of a PSP is challenging. It can take a long time to go from identification of a priority to starting funded research, and even longer for that research to report its outcomes. Any researcher, anywhere in the world, may start a project because of the PSP priorities and may not report this back to the PSP or the JLA. It is worth considering who will be able to keep this follow-up going on behalf of 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 and publishes reports from PSPs here www.jla.nihr.ac.uk/making-a-difference/reporting-on-results-and-impact.htm. This includes reports from the **Sight Loss and Vision PSP,** the **Autism PSP** and the **Tinnitus PSP** reviewing the impact of their PSPs after completion.

An 'After the Top 10 – bringing community priorities to life' report from the **Neurodevelopmental Disorders (Canada) PSP** explains what happened to the priorities during the year following the priority setting workshop. It can be seen on the JLA website in the Key Documents section for that PSP or at http://www.jla.nihr.ac.uk/priority-setting-partnerships/neurodevelopmental-disorders-canada/downloads/After-the-top-10.pdf. An update from the National Cancer Research Institute called 'Highlighting progress made in living with and beyond cancer research' gives examples of the progress made since the **Living with and Beyond Cancer PSP** published its priorities. https://www.ncri.org.uk/ncri-blog/progress-made-in-living-with-and-beyond-cancer-research/

The JLA's website provides details of research that has been funded as a direct result of PSPs as well as other ways in which PSPs have had an impact (see www.jla.nihr.ac.uk/making-a-difference) so please keep the JLA team updated when you find out about this. It is important feedback to the patients, carers and health and social care professionals who took the time to contribute to the PSP.

There are more examples of impact in the *More than a Top 10* report that you can read about here www.jla.nihr.ac.uk/news/sally-crowe-and-kristina-staley-reflect-on-their-recent-evaluation-of-jla-psps/22590.

Chapter 12 - TOOLBOX OF KEY PRIORITY SETTING PARTNERSHIP DOCUMENTS

The following documents provide information and templates when planning and establishing a JLA PSP. They are available from the Templates and useful documents section of the JLA website www.jla.nihr.ac.uk/about-the-james-lind-alliance/templates-and-useful-documents.htm. Please check the website for updates to these.

Advice on using the JLA logo

Setting up a PSP: Some questions answered

Flowchart of the PSP process

Timeline of PSP activities

PSP Steering Group Interests and Privacy Form

Also available from that section of the website are the following **mandatory documents for JLA PSPs**. To ensure transparency, each PSP is expected to publish these on the JLA website as soon as they have been finalised by the Steering Group

PSP Protocol – to be discussed and tailored by each PSP and published on JLA website to show what the PSP plans to do

PSP Steering Group Terms of Reference – to be discussed and tailored by each PSP and published on JLA website to show what the Steering Group agrees to do and who they are

PSP Data Management template - for completion by each PSP and publication on JLA website to give researchers and funders more information when they are considering how the questions can be addressed

PSP Engagement Summary - for completion by each PSP and publication on JLA website to show how many people got involved in the PSP and what types of people they were

PSP Question Verification Form - for completion by each PSP and publication on JLA website to show how the PSP checked that its questions were unanswered

Examples of work done by previous PSPs

The JLA website contains many examples of the work done by individual PSPs. Amongst these are:

PSP timetables

Acne, Alcohol-related Liver Disease, Bipolar, Hyperemesis Gravidarum

Initial awareness meeting/launch meeting materials

Occupational Therapy, Prostate Cancer, Mesothelioma, Diabetes (Type 1)

First Steering Group meeting agenda

[Miscarriage](#)

Communication/promotion plans

[Diabetes and Pregnancy](#), [Dementia,](#) [Detecting Cancer Early,](#) [Occupational Therapy](#)

Expression of interest form to join the Steering Group

[Occupational Therapy](#)

Initial surveys

[Diabetes and Pregnancy](#), [Advanced Heart Failure,](#) [Physiotherapy,](#) [Prostate Cancer,](#) [Urinary Incontinence,](#) [Vitiligo,](#) [Anaesthesia and Perioperative Care,](#) [Parkinson's,](#) [Cavernoma,](#) [Sight Loss and Vision,](#) [Broken Bones in Older People,](#) [Adult Social Work,](#) [Learning Difficulties (Scotland),](#) [Heart Surgery,](#) [Foot Health,](#) [Multiple Conditions in Later Life (large print),](#) [Myeloma (Canada),](#) [Palliative and end of life care,](#) [Vascular Conditions,](#) [Stroke,](#) [Foot and Ankle Surgery](#)

Facilitated survey discussion guidance

[Occupational Therapy](#)

Easy read surveys

[Adult Social Work,](#) [Advanced Heart Failure,](#) [Foot Health,](#) [Occupational Therapy,](#) [Stroke](#)

Survey information sheets/invitations to participate

[Learning Difficulties (Scotland)](#), [Multiple Conditions in Later Life](#)

Survey 'jargon buster'

[Digital Technology for Mental Health](#)

Examples of combined questions

[Cleft Lip and Palate](#)

Interim surveys

[Diabetes (Type 1),](#) [Diabetes (Type 2),](#) [Anaesthesia and Perioperative Care,](#) [Learning Difficulties (Scotland),](#) [Miscarriage,](#) [Adult Social Work,](#) [Broken Bones in Older People,](#) [Dementia,](#) [Hair Loss,](#) [Occupational Therapy,](#) [Epilepsy (Canada)](#)

Posters promoting the PSP, the surveys, or the results

[Learning Difficulties (Scotland),](#) [Neurodevelopmental Disorders (Canada),](#) [Heart Surgery,](#) [Hyperacusis,](#) [Lichen Sclerosus,](#) [Myeloma (Canada),](#) [Oral and Dental Health,](#) [Palliative and end of life care,](#) [Rare Inherited Anaemias,](#) [Revision Knee Replacement,](#) [Seniors' Health (Alberta),](#) [Vascular Conditions,](#) [Epilepsy (Canada)](#)

Postcards

Alcohol-related Liver Disease, Vascular conditions, Venous Thromboembolism (Canada)

Leaflets

Learning Difficulties (Scotland), Emergency Medicine, Bipolar, Mental Health in Children and Young People, Diabetes and Pregnancy, Hyperacusis, Hypertension (Canada), Juvenile Idiopathic Arthritis (in Dutch), Miscarriage, Occupational Therapy, Paediatric Lower Limb Surgery, Seniors' Health (Alberta)

Infographics

Neurodevelopmental Disorders (Canada), Detecting Cancer Early, Seniors' Health (Alberta), Mental Health in Children and Young People, Anaesthesia (Canada), Nutritional Screening and Malnutrition, Oral and Dental Health, Patient Safety in Primary Care

Press Releases

Diabetes and Pregnancy, Mental Health in Children and Young People, Dementia (Canada), Community Nursing

Newsletters

Hip and Knee Replacement for Osteoarthritis, Palliative and end of life care, Occupational Therapy, Skin Cancer Surgery

Example tweet sheets

Multiple Conditions in Later Life, Physiotherapy, Community Nursing

Results presentations

Hyperacusis

Poster and social media images for recruitment to workshop

Detecting Cancer Early

Pre-workshop ranking forms

Surgery for Common Shoulder Problems, Adult Social Work, Frailty (Canada)

Pre-workshop guides

Adult Social Work, Learning Difficulties (Scotland)

Priority setting workshop agendas

Surgery for Common Shoulder Problems, Emergency Medicine

Priority setting workshop question cards

Adult Social Work, Liver Glycogen Storage Disease (International), Oral and Dental Health

Example certificate of attendance at workshop

Diabetes (Type 2), Learning Difficulties (Scotland), Occupational Therapy

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Media coverage of Top 10 announcements

Endometriosis, Learning Difficulties (Scotland)

Reports of whole PSP process

All PSP final reports are listed here

PSP articles and publications

All PSP articles and publications are listed here

Examples of videos produced by PSPs

We have collected many examples of videos produced by PSPs and the JLA together in a playlist here
https://www.youtube.com/playlist?list=PLgcbSc9ywB4NL8hYfG3JArKlO7dB_dFwp

There are some example videos on the JLA website on the PSP pages for

Skin Cancer Surgery

Elbow Conditions

Living With and Beyond Cancer

Hyperhidrosis

Intensive Care

Emergency Medicine

Scoliosis PSP

Diabetes (Type 2)

Occupational Therapy

Safe Care for Adults with Complex Health Needs

Paediatric Hospital Care (Canada)

Psoriasis

Examples of PSP Twitter feeds and #

https://twitter.com/PedCancerPSP

https://twitter.com/myelomaPSP

https://twitter.com/PspStroke

https://twitter.com/EarlyPsp

https://twitter.com/TYAPSP

https://twitter.com/jlarevisionknee

https://twitter.com/MalnutritionPSP

https://twitter.com/HeartSurgeryPSP

https://twitter.com/JLAEMPSP

https://twitter.com/PeolcPSP

#DigitalMHQ

#PhysioPriorities

#MySayForStroke