



## **James Lind Alliance Priority Setting Partnerships**

### **Setting priorities for treatment uncertainties - a review of methods**

**Compiled by Sally Crowe – September 2009**

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## **1. Purpose of this review**

*This review is designed to support James Lind Alliance (JLA) Priority Setting Partnerships in their discussions about priority setting approaches. These Partnerships will bring to bear their own experiences and skills and, informed by this review, decide on the methods they will use to reach their shared top 10 treatment uncertainties.*

Issues that are addressed in this review include the context of priority setting and priority setting partnerships in the JLA; some underpinning principles for priority setting in the JLA; current evidence of shared priority setting; a review of methods and processes associated with priority setting; and the JLA's preferred approach to priority setting.

A full description of all the methods and processes of the JLA will be available early in 2010 in the JLA Guidebook (currently under development) online.

[www.lindalliance.org](http://www.lindalliance.org)

## **2. James Lind Alliance Priority Setting Partnerships**

The partnership between the British Thoracic Society and Asthma UK was the first formal Priority Setting Partnership to complete the JLA process (Elwyn 2009). The Urinary Incontinence PSP followed in 2008 (Buckley et al 2009), and Vitiligo and Prostate Cancer Priority Setting Partnerships will complete in 2009. Eczema will follow in 2010, and it is likely that there will be partnerships in type 1 diabetes, schizophrenia, wound management, stroke, and ear nose and throat conditions.

The varied nature and composition of partnerships has implications for how each approaches priority setting. Different Priority Setting Partnerships have different drivers for undertaking what is challenging and, at times intensive work. They have differing resources and capacity to undertake key tasks, and different styles of leadership and communication.

Partnerships must choose methods for priority setting that best suit their needs and levels of partner participation. It is also important that priority setting activity fits with partners' organisational aims and aspirations for clinical research.

### **3. Context for priority setting in JLA Priority Setting Partnerships**

Each Priority Setting Partnership will have contributed to a NHS Evidence UK DUETs (Database of Uncertainties about the Effects of Treatments) collection of treatment uncertainties [www.library.nhs.uk/duets](http://www.library.nhs.uk/duets). To achieve this, partner organisations will have canvassed their membership for uncertainties, or unanswered questions, about the effects of treatments. Methods to gather questions may have included questionnaires, focus groups and internet message boards.

They will also have appraised documents/policies/guidelines that identify unanswered questions about treatments, such as BMJ Clinical Evidence, Clinical Practice Guidance, Cochrane Reviews, NICE Guidance Recommendations and registers of ongoing research, such as the UK Clinical Trials Gateway. Partner organisations may also have existing research strategies/priorities that could be considered. Some partners may have extended this consultation exercise to patients/health professionals who are not necessarily members of the partnership organisations, but have potentially valuable perspectives.

In the JLA's experience, this process can yield between 200 and over 1,100 potential treatment uncertainties. Further refinement and checking ensures that uncertainties that are entered into UK DUETs meet its eligibility criteria are genuine and accurate. The refinement process records the provenance of each uncertainty, where there are duplications, where there are shared uncertainties (i.e. the same uncertainty has been submitted by different groups), and where themes of uncertainties exist.

Only when partners are happy that there has been an attempt to systematically collect treatment uncertainties from a variety of perspectives will work on priority setting start.

## 4. Overview of JLA priority setting

### 4.1 Underpinning principles and understandings

Priority Setting Partnerships need to consider and choose priority setting methods that take account of the available resources and skills of partner organisations. The JLA provides templates and worked examples for priority setting, but does not impose strict rules, as each Priority Setting Partnership is different. To ensure consistency and maximum learning, the JLA asks each partnership to ensure that their methods address a set of underpinning principles.

These are:

- Transparency of process
- Balanced inclusion of patient and clinician interests and perspectives
- Exclusion of non-clinician researchers for voting purposes, but who may be involved in all other aspects of the process
- Exclusion of groups/organisations that have significant competing interests, for example pharmaceutical companies
- Audit trail of original submitted uncertainties, to final prioritised list
- Recognition that making priority decisions does not create new knowledge, but reviews existing evidence of uncertainty.

As well as promoting the underpinning principles to be observed by partners, the JLA has tried to achieve clarity about the nature of the work undertaken by each member. Capturing this in a protocol has helped ensure that all partners 'own' and understand their chosen process. A protocol is likely to address the following:

- Only uncertainties contained in the relevant UK DUETs specialist collection will be used for priority setting
- Consensus is to be sought on the adjudged *importance* of the priority areas of uncertainty about treatment effects and nothing else.
- As well as numerical data relating to the uncertainties to be prioritised the existing knowledge base/experience of participants is a core feature of the process.
- A broad range of perspectives is necessary, from gathering uncertainties to final priority setting. This means ensuring that different types of clinicians/health professionals, and different types of patients and carers are involved

- Strong disagreement, as well strong agreement, will be acknowledged and recorded
- The JLA can act as an 'honest broker' in parts of the priority setting process, should this be required. This could mean chairing a meeting or teleconference, or listening in to teleconferences.
- Time and resources are likely to be limited, so both must be used efficiently.

#### **4.2 Priority setting large datasets of uncertainties**

From the experience of the first two partnerships, it became apparent that a large dataset of treatment uncertainties requires a staged approach to priority setting.

Initial gathering of uncertainties and entering them into UK DUETs yields a 'long list' that can include anything from 200 to over 1,100 separate data items. Caron-Flinterman (2005) suggest no more than 30 data items for final stage priority setting, and JLA experience to date suggests that prioritising 30 treatment uncertainties at final stage is still too many. Future partnerships will be guided towards a short list of no more than 20 uncertainties. To reduce the long list to a short list requires interim priority setting methods.

The JLA has always considered that mixed methods for priority setting were advantageous. Methods that incorporate numerical handling of the treatment uncertainty data, as well as opportunities for a wide range of people to discuss them, and achieve consensus were worth exploring.

The first two Priority Setting Partnerships used mixed methods to achieve their short list of priorities. In the Asthma experience partners undertook discussion and voting to achieve a short list of 17 uncertainties. In the Urinary Incontinence PSP the long list was sent to all partner organisations. They were asked to choose ten uncertainties that they wanted to see on the short list, and were then invited to rank them. These results were aggregated and a short list of 29 agreed.

It is possible that subsequent partnerships will want to pursue methods that concentrate on either numerical/voting approaches with little interaction between people, or just concentrate on achieving consensus through dialogue.

### **4.3 Priority setting and partnership working**

JLA priorities are achieved by partnerships of organisations that have shared interests in particular health problems. Successful methods for priority setting will owe some success to the *quality* of partnership working, and decision making that underpin them.

Regular reviews by the JLA of ongoing day-to-day decisions made in Priority Setting Partnerships has revealed a number of helpful approaches developed by past and current Steering Groups of priority setting activity. These include:

- Agreeing 'who does what', including allocation of time and resources, within the Steering Group
- Being clear about the role of JLA and UK DUETs representatives in the process
- A commitment from Steering Group members to contribute fully to email and phone dialogue
- Being prompt in responding to requests for information, perspectives, etc
- Being fair and broad thinking in decision making – allowing all views to be heard, then taking a vote
- Allowing discussions to flow between partners so that they evolve and reach consensus gradually
- Allowing peer group pressure to 'reign in' more dominant personalities
- Forming sub groups for particular activities
- Having regular formal 'check in' contact that has an agenda and is chaired

The JLA and partner organisations capture and document actions agreed, key changes in direction of decisions and any 'illuminating moments'. This is an important audit trail, and provides useful material for reporting and writing articles for publication. The other advantage of 'growing' strong partnerships through a priority setting process is that ownership of the final priorities is stronger, with a consequent will to see those priorities translated into research proposals and bids.

### **4.4 Priority setting as a group experience**

Day to day partnership working to achieve a priority setting process is a group experience, with partners interacting on the telephone, face-to-face or via internet. As well as observations made by the JLA on successful group working, Murphy et al

(1998) discussed the benefits and challenges inherent in interactive group work of this kind.

### **Benefits**

- A wider range of views and direct knowledge and experience is brought to bear on the process
- The interaction, if facilitated well, will stimulate consideration of a wide range of factors about each area of uncertainty, e.g. burden of disease, new technologies and patient experience
- The debate will encourage the challenging of received ideas and historical perspectives

### **Challenges**

- Ensuring the choice of participants is balanced and appropriate for the process
- Avoiding dominance of any one person
- Cost
- Tendency to treat the group's decisions as unanimous, even when dissent may have played a part in the decision making process
- Agreeing voting rules, for example, a threshold of % vote for decisions to be put through, etc

The size of the partnership is also an important feature of undertaking priority setting. Murphy suggests a minimum of 12 is required but groups over 25 start to yield diminishing returns in the quality of decision-making. The JLA has found that there is a balance to be struck between having a number of partners that is small enough to make decisions and see through actions, but big enough to being to bear the multiple perspectives that are required to ensure that the process takes account of patient and clinician viewpoints.

### **4.5 Who participates in priority setting?**

The JLA wants to explicitly work with patient and clinician groups only. Very few previous studies address the particular considerations needed when working with clinicians and patients in developing consensus and priority setting. Generally clinicians and patients are more likely to work separately than collaboratively in identifying research topics, Stewart and Oliver (2008) so this is a special feature of

the JLA. Current partnerships in 2009 are showing the value of using existing clinical and patient networks (formal and informal) to recruit partners to the process. Well established networks add value to JLA partnerships, with shared understandings of a health problem already established and respected.

Recruiting clinicians may include approaches to Cochrane Groups, National Institute for Health Research (or other) Clinical Trial Networks, membership organisations, including specialist associations/societies and Royal Colleges. It is likely that professional groups will be comfortable working online.



*Members of the type 1 diabetes PSP meeting in 2009*

From a patient perspective, the networks are often more informal. Coalitions, alliances and other umbrella organisations can provide useful starting points, as can the National Institute for Clinical and Health Excellence, which has a large database of patient organisations. Exploring how best to communicate with patient group members is an essential step as some may not have access to, or be familiar with the Internet.

It is essential to be clear about the distinction between patients' individual treatment uncertainties, perhaps based on intense personal experiences, and treatment uncertainties experienced as 'difficult consultations' from clinician viewpoints. Everyone has an opportunity to submit their particular uncertainties to the process leading up to a UK DUETs specialist collection. However, when it comes to priority setting, participants may have to relinquish personal agendas and work with priorities that will deliver greater benefit overall, by reducing the burden of a health problem. It is important to ensure people are treated fairly and with sensitivity and support during this process.

Being transparent about how and why decisions are made, will help to address concerns about fairness. In addition, the Priority Setting Partnership Steering Group, should encourage people to raise their concerns at the earliest possible opportunity. An effective steering group will have created a culture of feedback and openness within the partnership, so that issues can be dealt with and overall progress to goals maintained. More guidance on these aspects of priority setting will be found in the JLA Guidebook (available March 2010).

## **5. Evidence of shared priority setting**

As well drawing from the pragmatic experience of the JLA programme of partnerships for this review, other studies provide useful examples of shared priority setting approaches.

A sizable research literature addressing patients' and clinicians' priorities for research and outcomes for assessment was revealed with a JLA commissioned project in 2008. *"A systematic map of studies of patients' and clinicians' research priorities"* included 258 studies of clinicians' and patients' views gathered by traditional searching methods.

An initial exploration of these accounts has improved the JLA's understanding of how clinicians and patients might contribute to research priorities, namely:

- Directly, through consideration of research, through active collaboration in setting research priorities, and through consultations asking about research priorities
- Indirectly, through consideration of health problems and services, through active collaboration or consultations, following which researchers interpret the implications for research priorities.

10 accounts, which reported prioritised research questions and used a range of methods to achieve these, are described in the final report:

[http://www.lindalliance.org/Map\\_studies\\_patients\\_clinicians\\_research\\_priorities.asp](http://www.lindalliance.org/Map_studies_patients_clinicians_research_priorities.asp)

O'Donnell's and Entwistle's survey of UK Funders of Health Related Research in 2002 showed how funders use various decision making structures and processes to determine what research is funded. Patients and the public were involved in these processes in different ways (the survey didn't report on clinician involvement).

These included 'identifying topics on which they would like to see research conducted; commenting on the relevance of several possible topics and ranking topics according to their importance'.

The issues of concern expressed by research funders in Entwistle's review were similar to those reported in more recent work undertaken for the JLA in 2008; *"Scoping research priority setting (and the presence of PPI in priority setting) with UK clinical research organisations and funders"*. The aim of this project was to find out whether and how clinical research organisations set research priorities, and whether and how patients and the public are involved in this work. Results showed that most organisations (31 of 52) operate in 'responsive mode'; and 21 of the 52 organisations reported that they had identified priorities for research.

Methods used to identify priorities sourced from this project are similar to those reported elsewhere, and included consulting patients and researchers and/or other stakeholders through surveys, focus groups or meetings; relying on informal communication with patients/members, or asking a group of experts (e.g. a Board or Scientific Committee) to make recommendations. Few organisations identify the research priorities of clinicians and patients in a way that is consistent with the JLA's mission. The dominant tendency is to consult the research community as part of developing research strategies, rather than aiming to deliver the research that will meet the expressed needs of clinicians and patients.

When considering priority setting methods, the JLA has taken into account the unusual nature of partnerships of clinicians and patients, and the likely issues that will need to be addressed.

## **6. Priority setting methods**

Different models are available for structuring thinking towards consensus and prioritisation, and any method chosen by a JLA Priority Setting Partnership needs to be well structured, inclusive and transparent.

### **6.1 Delphi Technique**

Consensus development and prioritisation using the Delphi technique are well described Phill (1971). The process is undertaken predominantly by questionnaire. Selected participants answer questionnaires in two or more rounds. After each round, an anonymous summary of the results from the previous round is circulated, with the reasons for judgments. This encourages participants to revise their earlier answers in light of the replies of other participants in the process. During the process, the range of the answers decreases and the group will converge towards a consensus. This

approach could be adapted for use in JLA interim priority setting, simply by ranking uncertainties in the order of their perceived importance.

Owens et al (2008) found that the Delphi approach helped to establish common research priorities in mental health across mental health service users, informal carers, mental health practitioners and service managers.

## **6.2 Expert Panels**

Expert panels in the Health Technology Assessment Programme are described by Oliver et al (2001), and concern the collective prioritisation of topics that is conducted simultaneously with the refinement of research questions for commissioning health technology assessments. Expert panels are assisted by briefing papers, and background information about the proposed research topic under scrutiny (called 'vignettes'). These review the extent of the health problem, outline existing or planned research, and clarify the research question. These vignettes are prepared by consulting key sources of research and topic and lay experts. Expert panels follow normal committee rules.

Discussion has been considered more inclusive when chairs have invited panel members who are not experts to introduce each topic for discussion. Decisions are made at two stages: first, by deciding which topics are sufficiently important to deserve a vignette to inform discussions; second, to decide which vignettes and their integral research questions should lead to commissioned research. Decisions are made through private voting/ranking.

Expert panels include two public advocate members (soon to be three) who are well placed to influence individual decisions and the culture of the panel meetings. There has been no evaluation of lay members' influence of individual decisions. However, lay members and other members perceive a change in attitudes and sensitivity towards public perspectives in health technology assessment decision making.

## **6.3 Nominal Group Technique**

Nominal group technique is a well established and described decision making approach Jones (2000). It can be used by groups that want to make decisions quickly, for example, by voting, but want everyone's opinions to be taken into account. Each participant reviews the items for discussion, and gives their view. A shared voting or ranking exercise is undertaken with further structured small group discussions followed by ranking or voting. The ranking orders for each item from

each contributor are totaled, and the priority with the lowest (i.e. most favored) total ranking is selected as the final priority/decision.

It has been suggested that Nominal Group Technique can be useful when:

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

#### **6.4 Consensus Development Conference**

A consensus development conference is a meeting that debates summary statements of health care and treatment then seeks consensus on the most important of these.

Johanson and colleagues describe a research meeting of the ASQUAM group (Achieving Sustainable Quality in Maternity) (2002). The objectives were to choose a new set of research priorities for the year 2000, and to ascertain the voting pattern of service users compared with health professionals. There were 10 discussion groups, each with approximately 10 participants from a mixture of backgrounds, including obstetricians, senior midwifery staff, general practitioners, paediatricians and service users. In all there were 90 health professionals and 11 consumers. The leader of each group introduced key research issues and welcomed novel ideas from participants.

From the many topics discussed during the one-hour session, each of the 10 groups agreed on two topics they wished to propose (framed within the terms of health technology assessment). Following short presentations on all 20 topics, all delegates voted on paper for up to 10 topics, without ranking, in order to identify the ten most popular.

#### **6.5 Electronic Nominal Group and Online Voting**

The advent of the Internet has provided an online platform for priority setting. In the BRISK trial Edwards et al (2004) describe how prioritisation was achieved with an electronic nominal group and online voting.

Key steps included:

1. Create a website that provides the list of topics in random order (changes every X minutes) and so takes out any availability bias
2. Invite people to join a prioritisation panel
3. Give each participant a unique login access via password (one login allowed) - if incomplete vote - new login issued and try again.
4. Post hoc analysis of groups by age, sex and any other variables that are important to consider (collect as part of request to vote).
5. If the panel is large enough and diverse enough, there will be a good possibility for subgroup assessment of various influences.

### **6.6 Interactive Research Agenda Setting**

Colleagues from the Athena Institute in Holland have collaborated with the JLA in sharing their research agenda-setting work in asthma and chronic obstructive pulmonary disease (COPD). This work included patients, researchers and health professionals. Their work is summarised in a paper by Caron-Flinterman and colleagues (2006).

Below is a summary of their approach undertaken between 2003 and 2004.

- *Preparation and initiation*; reviewing the literature and semi-structured interviews with “relevant actors” in the field of asthma and COPD, identifying barriers to involving patients and ways of overcoming them. Identified three key groups to work together patients (through a national asthma organisation), scientists/researchers and health professionals.
- *Consultation*; process of taped discussion meetings resulting in the three groups developing their research priorities for research on COPD and asthma. Also five semi-structured interviews with socio-cultural scientists, resulting in four priority lists.
- *Collaboration*; integration of the priority lists, through a meeting of 32 people from the aforementioned groups. Summaries of consultation phase were sent out by post beforehand and lay summaries provided. After a plenary session of the results of the consultation three, mixed, parallel groups prioritised using different coloured posts on flip charts. This was followed by further prioritisation (to avoid pseudo-consensus) using a personal prioritisation matrix.

- *Outcome*; the resulting societal research agenda is being used for the formulation of research policies and programmes and “will eventually result in the actual funding of research projects as well as possible lobbying activities towards the pharmaceutical industry, government and other actors”.

### **6.7 Focus Groups**

Corner et al (200?) used 17 focus groups and nominal group techniques across the UK to involve people affected by cancer in cancer research prioritisation. This has been a previously underdeveloped area of work. The National Cancer Research Institute supported the consultation exercise.

The research generated 15 broad research themes, with three identified as high priority based on the number of ‘votes’ cast by the 105 participants.

Special consultation groups were run with people under-represented in research; patients from ethnic minorities; those receiving palliative care; and those aged over 75 years. There is no current information available about the pros and cons of prioritising in this way, and this study concerned patients only.

The Wales Epilepsy Research Network and Mental Health Research Network Wales organised 5 focus groups (two for professionals and three for patients and carers) to gather epilepsy treatment uncertainties. They were then asked to rank the most important of these. The research team conducted a thematic analysis of the questions and standardised the ranking, by using a statistical package that analyses the variance between rankings. This gave them a table of uncertainties in rank order, and is reported by Lloyd and Cella (2009).

### **7. The JLA-preferred approach to interim priority setting**

Interim priority setting is different to final priority setting – the dataset of submitted treatment uncertainties is likely to be large (+200 data items) and complex. The purpose of interim priority setting is to reduce the initial long list to a short list of no more than 20 treatment uncertainties to go forward for final prioritisation.

Analysis of all the treatment uncertainties will reveal features about the dataset that are useful, for example, the frequency a particular uncertainty is submitted, and whether it is a shared uncertainty. The partnership may want to share these features with partners ahead of interim priority setting, or keep them concealed.

The two main options that the JLA currently asks PSP's to consider are:

1. A consultation exercise with partners on the 'long list' of treatment uncertainties, asking them to submit the 10 that they would like to see funded, in a rank order. All the returned 10's are aggregated to assemble a 'short list' of priorities. JLA does not prescribe how the partnerships achieve this, but does wish to know how they went about it. The JLA has learnt that this approach needs clear instructions, a definite deadline, and a format for the long list of uncertainties that is as accessible as possible. This includes grouping uncertainties in identified (and validated) themes, or by the kind of research required, e.g. a systematic review or new primary research.
2. Involve partners in agreeing a set of factors to apply to a long list of uncertainties to achieve a short list. Factors could include frequency of uncertainties submitted; whether similar/same uncertainties are submitted by different partners (a shared uncertainty); the relative importance of the symptoms/outcome with which the treatment uncertainty is associated; the health and economic deficit associated with the treatment uncertainty; or taking a balanced portfolio approach to selection, allowing several from each long list sub-category.

At an agreed time the results of whatever process has been adopted need to be reviewed and 20 uncertainties need to be signed off for final priority setting. This is achieved by discussion within Steering Group and with the JLA.

The current Vitiligo Priority Setting Partnership (2009) is using a web based voting tool for its' interim priority setting exercise. This will be piloted and used in late 2009. The JLA will ensure that learning from this exercise is shared widely.

#### **8. The JLA-preferred approach for final priority setting**

After considering the various methods available, the JLA has decided to support a *Nominal Group Technique* for final priority setting. This has now been trialled by the Asthma and Urinary Incontinence partnerships. Observation reports and evaluations are available on the JLA website [www.lindalliance.org.uk](http://www.lindalliance.org.uk)

Features of the nominal group technique (and similar priority setting methods) have been summarised by Rowe et al (1991). It is attractive as a priority setting and

consensus development approach because it takes account of the different perspectives of patients and clinicians.

<i>Anonymity</i>	To avoid dominance, can be achieved by use of a questionnaire and each participant not knowing how others are voting and responding before they meet to discuss priorities.
<i>Iteration</i>	Processes occur in “rounds”, allowing individuals to respond to other views and perspectives and change their opinions
<i>Controlled feedback</i>	Showing the distribution of the partners response at each stage of the process
<i>Statistical group Response</i>	Expressing judgement using summary measures of the full group response, giving more information than a simple consensus statement.

### **8.1 Nominal Group Technique**

The literature suggests that a nominal group meeting be facilitated either by an expert on the topic or a credible non-expert, and that the meeting should be structured as sequential steps of consensus building. For the purposes of JLA Priority Setting Partnerships we recommend:

#### **Phase 1**

- The short list of treatment uncertainties is provided for participants before the meeting.
- Participants are asked to rank these and consider their views about each treatment uncertainty - before the group meeting.

#### **Phase 2**

- In small groups (3 – 4), each participant, in turn, contributes their views on the treatment uncertainties. These are recorded by the facilitator. This continues until all ideas/views have been expressed.
- There the discussion is reviewed by the group to clarify any aspects of the uncertainties.



### Phase 3

- The same small groups move the discussion to ranking the short list of uncertainties.
- The ranking is entered into an Excel database, all three groups' results are tabulated and presented to the whole group. An overall ranking of the short list is derived at this point.
- The overall ranking is discussed and re-ranked in similar size but different small groups.
- These scores are again entered into the Excel database, tabulated and presented to the whole group. An aggregate ranking is presented.
- This final ranking is discussed in the large group, with the aim of agreeing the top ten by the end of the discussion session.



Alongside the consensus process, there may be a non-participant observer collecting qualitative data on the process. Whilst the Nominal Group Technique focuses on a single goal (for this purpose the selection of the ten most important treatment uncertainties) and is less concerned with eliciting a range of ideas or the qualitative analysis of the group process *per se*, the JLA has found an observer account of the process helpful in review and analysis.

## **8.2 Who should take part and how many?**

Each participant must be justifiable in some way as an “expert”. They will be affiliated in some way to one of the partner organisations. We suggest a minimum of 12 people and a maximum of 30.

They may be:

- Clinician e.g. consultant or Senior Registrar, paediatrician, GP, specialist nurses, physiotherapists, dieticians, advice line nurses
- A patient or carer/parent with direct experience of the health problem(s), patient group staff.

The JLA has always considered achieving a balance of clinical and patient viewpoints more important than the representativeness of each participant. This is important, because, as Stewart and Oliver noted in 2008 most examples of priority setting show “clinicians are more involved than patients in the whole process”. Participants are encouraged to share biographical information about themselves and their perspectives of the treatment uncertainties that are to be prioritised. Helpful discussions have occurred in partnerships about the participation of young people, parents, disabled people, people from ethnic minority groups, and older people. These discussions have focussed on how to involve people to ensure a wide range of perspectives are considered.

## **8.3 Actions that enhance the Nominal Group Technique Approach**

- Establish a clear structure for the priority setting meeting and the ‘taking turns’ aspect of the feedback – this should help restrict any dominance of particular individuals.
- Agree “ways of working” (ground rules) at the outset of the meeting (to include aspects of communication and use of jargon)
- Provide a glossary of research terms prior to the workshop
- Provide biographical information about participants ahead of the meeting
- Ensure that all participants are familiar with the items to be discussed – offer them an opportunity to discuss these beforehand with JLA team members or relevant partners

*The final priority setting should achieve the following:*

- An informed, structured and purposeful debate amongst people who have previous experience and/or direct experience of treatment uncertainties in question
- A list of the most important shared priorities for future clinical and health research – we suggest that Priority Setting Partnerships aim for 10.
- A description of where there is disagreement, and why.
- Further developments sharing the priorities with a wider constituency and plans to refine and submit the uncertainties for further research
- JLA partners may choose to continue to work together on related issues.

## **9. What are the expected outcomes of a JLA Priority Setting Partnership?**

- The full set of uncertainties in UK DUETs is an important outcome in its own right and represents an invaluable dataset of multiple perspectives of treatment uncertainties
- The short list developed from interim priority setting is another important outcome, and represents the views of important stakeholders in clinical and health research
- The partnership process will have enabled a group of people with a shared interest working collaboratively to a common goal.

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