

Reflective report on the
James Lind Alliance
Asthma Priority Setting Meeting

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Royal Society of Medicine

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Aims of this report

I observed the Priority Setting Meeting for the James Lind Alliance (JLA) Asthma Working Partnership in order to:

1. Contribute to an accurate record of proceedings of the day
2. Provide an 'external' description of the activities and outcomes of the workshop
3. Provide a balanced opinion and view of the strengths and weaknesses of the approaches adopted for the day, and the methods used
4. Provide qualitative information about the interactions and behaviour in the small group and plenary groups
5. Compare and contrast my observations, with the observations made by Jude Frankau of the Incontinence Working Partnership.

Towards these aims this report:

- Describes the workshop's aims and methods
- Reflects on the different methods used, their strengths and weaknesses
- Reflects on the extent to which the workshop objectives were met
- Makes recommendations for future priority setting meetings

Methods of this evaluation

In advance of the meeting, I read the background papers, including the detailed programme prepared for the group facilitators. I also had two meetings with Sally Crowe (by telephone) in order to discuss the format for the day, and my role at the meeting.

During the workshop itself, I joined in the initial introductions exercise, but otherwise was a non-participative observer. When the participants split into small groups, I circulated between the groups.

I noted who attended the workshop and the make-up of the small groups. I recorded my observations using a semi-structured form, which enabled me to take general notes, whilst also seeking to identify:

- Encouraging contributions to discussions, such as praise, acknowledging others, and inviting others to contribute.
- Discouraging contributions to discussions, such as interrupting, dominating discussions, and disagreeing with or correcting others.

Participants in the workshop were asked to complete an evaluation form at the end of the day (see Appendix 1). I had access to their responses and considered them when completing my analysis / reflections.

I read and reread my notes, reflecting on how the different methods used at the workshop, shaped the decisions that were made and drew out strengths and weaknesses of these methods. I used these strengths and weaknesses to draft initial recommendations for future workshops.

The James Lind Alliance's aims

As laid out in their website, the James Lind Alliance aims to identify the most important gaps in knowledge about the effects of treatments. In doing so, their work is based on two principles:

1. That addressing uncertainties about the effects of treatments should become accepted as a much more routine part of clinical practice
2. That patients and clinicians should work together to agree which, among those uncertainties, matter most and thus deserve priority attention.

They aim specifically to facilitate the identification of research priorities shared by patients and clinicians

To these ends, they set out to:

- Establish a network of affiliate organisations and individuals
- Help to develop a Database of Uncertainties about the Effects of Treatments (DUETs) containing questions about the effects of treatments being asked by patients and clinicians, which cannot currently be answered confidently.
- Foster the evolution of working partnerships of patients and clinicians, to identify and prioritise their shared uncertainties about the effects of treatments, and then to press for systematic reviews of existing evidence in areas where these are needed, or to influence priorities for additional research.
- Provide a setting as free as possible from major biases (distorting factors) and competing interests, in which patients and clinicians can meet to identify and promote shared priorities for addressing uncertainties about the effects of treatments.

In order to achieve their aims, as laid out above, the James Lind Alliance has brought patients and clinicians together in 'Working Partnerships' to identify and prioritise the unanswered questions that they agree are most important. One such partnership, the Asthma Working Partnership, consists of Asthma UK and the British Thoracic Society (BTS), who seek to improve the health care of people with respiratory disease.

The workshop on 26th March 2007 represented a key stage in the Asthma Working Partnership. The objectives for the day were:

- To brief the group on the process for developing Asthma DUETs, and the short list of Asthma uncertainties to be prioritised

- To reflect on, and discuss participants' individual views of the short list (all participants will have had an opportunity to see these before the workshop)
- In small groups, to rank the short list of Asthma uncertainties and look for areas of agreement and disagreement across groups.
- In the large group, to discuss, rank and if need be, vote to achieve a final 10 uncertainties in Asthma for priority funding.

An overview of the methods employed in this workshop is presented below.

An overview of James Lind Alliance workshop methods

The James Lind Alliance's approach to the day included decisions about the participants, preparation for the day, the venue, the content of the day, the priority setting process and its facilitation.

Participants

The workshop included:

- Individuals from the two partnership organisations: Asthma UK and BTS
- Facilitators from the JLA
- Independent observers

Preparation

Participants were sent (by email) a pre-workshop pack which included:

- A cover letter
- The programme for the day
- A brief overview of the Asthma partnership between Asthma UK and BTS
- A glossary of research terms
- A leaflet about the JLA
- Participant information (venue, directions etc)
- A list of 21 treatment uncertainties which individuals were invited to rank before the meeting

Venue

The workshop was hosted by the Royal Society of Medicine and held within 3 rooms

Content of the day

The day focussed on asthma treatment uncertainties

The structure of the day included:

- Introductions and ground rules
- Presentations giving background information and explaining the aims of the day
- Small group work to discuss and prioritise the treatment uncertainties
- Plenary sessions

Priority setting process

The initial 21 treatment uncertainties were narrowed to 10 during the course of the day, a process which took into account:

- The views of individuals prior to the meeting
- Discussions and decisions in 3 small groups, which fed into an initial 'top 10'
- Plenary discussions of this initial 'top 10'
- Discussions and decisions in 2 larger groups, which fed into a refined 'top 10'
- Plenary discussions of this refined 'top 10'
- Discussion and agreement of the final 'top 10'

Facilitation

Three JLA facilitators and the editor of DUETS used:

- A range of facilitation methods: nominal group technique, Delphi, Diamond 9
- A number of facilitation tools: handouts, flip charts, power-point.

Reflecting on the methods used during the meeting

In this section, I reflect on each aspect of the methods used at the workshop as outlined above, and identify strengths and weaknesses in each approach.

1. Participants at the workshop and the Asthma Working Partnership

Who attended

In theory the workshop included individuals from the two partnership organisations (Asthma UK and BTS) as well as facilitators from the JLA and some observers. In fact, the list of participants included a wider range of people.

The expected attendees included individuals from the two partnership organisations, with four people representing Asthma UK and a further eight 'Asthma Spokespersons'. One person from BTS was expected, as well as a further three clinicians: a clinical professor, a consultant physician and a clinical nurse specialist. Five members of the JLA were due to attend (an administrator, three facilitators, and the editor of DUETS), as well as three observers (a member of the Urinary Incontinence Working Partnership, the UK Clinical Research Network, and myself).

On the day there were some variations to this list of expected attendees. In all, 22 out of 24 people attended, with two of the 'Asthma Spokespersons' unable to attend due to ill health. In addition, two people were late arriving: one of the asthma sufferers and one of the observers (who was only at the meeting for a short period). Those who attended fulfilled a range of roles, from facilitator, observer and administrator, to representatives of organisations and professional bodies and individuals who came to share their personal experiences. The majority of people were women (17/22), and of the five men, two were facilitators.

Reflecting on who attended

Reflecting on the gender balance at the workshops, it is perhaps not surprising that more women attended than men, given the gender balance in health care professions. It also fits with my experience of recruiting patients to contribute to research and policy workshops,

where women are more likely to be able to attend meetings in working hours.^a Considering the level of contributions to discussions, the men at the meeting were very vocal (possibly linked to the power of their position as clinicians). The gender imbalance at the meeting is therefore less of a concern, although with only one male asthma sufferer attending, it could be argued that this group was under represented in the decision-making process.

There were also proportionally very few clinicians attending the meeting. During discussions, this did not appear to be of great concern, as these individuals were confident contributors and at times even tended to dominate discussions. However, the small proportion of clinicians at the meeting may have a negative impact on the credibility of the outcomes of the meeting amongst clinicians and funding decision-makers.

The small number of clinicians at the meeting is linked to the small BTS presence, with officially only one BTS member attending, albeit their chief executive. The imbalance between Asthma UK and BTS involvement on the day may further reduce the credibility of the meeting's outcomes, and raises some concerns about the future of the Asthma Working Partnership. This was also reflected in reluctance at the end of the meeting for individuals to take forward the outcomes of the meeting, although volunteers were eventually identified.

The contrasting significant representation at the workshop of Asthma UK staff and asthma sufferers, reflected their significant investment in the priority setting process. The implications of this are discussed in more detail in the context of the priority setting process (see Section 6).

The balance (or imbalance) in the attendees at the workshop raises the question of the extent to which it is JLA's responsibility to make the partnerships, and meetings such as this, run smoothly. From my briefings before the workshop, I understand that, despite advanced warning, the partners had left it very late before inviting their members to attend; so much so that JLA had considered whether or not to postpone the event. It is possible that reluctance

^a Stewart R, Oliver S. User involvement in systematic reviews: a structured report. An example from newborn screening. 2007. Social Care Institute for Excellence.

to take part in the meeting reflected a lack of shared goals and / or a lack of support for the process of achieving those goals.

Whilst these reflections highlight some of the difficult aspects of the attendance at the workshop and the Asthma Working Partnership itself, it is important to acknowledge that the task of 'partnership building' requires significant investment, above and beyond the task of prioritising treatment uncertainties.

2. Preparation

What was the preparation?

In advance of the meeting, all participants were sent a pre-workshop pack by email. This included:

- A cover letter
- The programme for the day
- A brief overview of the Asthma partnership between Asthma UK and BTS
- A glossary of research terms
- A leaflet about the JLA
- Meeting information (venue, directions etc)
- A list of 21 treatment uncertainties which individuals were invited to rank before the meeting – of these, 16 were worded as questions, and 5 as topics.

It wasn't clear whether everyone received these emails, or whether hard copies were also sent out to individuals. I didn't receive a hard copy. One of the 12 participants, who completed the evaluation form, indicated that they hadn't received the preparation pack. Of the 11 people who completed the evaluation forms: nine indicated that they had found the preparation pack helpful and two people indicated that they neither found it very helpful or not at all helpful. One of these two erred towards 'not very helpful'.

Reflecting on the preparation

Although it isn't clear whether everyone received their preparation packs in advance of the meeting (at least one person did not), this wasn't raised as a concern by the participants in the course of the meeting, and the majority described the pack as helpful.

Sending out resources in advance of a meeting in this way is a recognised approach to 'levelling the playing field' and as such is particularly important when attendees with different backgrounds are attending. It provides people with time to read and digest the information, and an opportunity for them to seek clarity before they attend. It also saves time in briefing sessions during the meeting itself.

Three aspects of these preparation resources are worth noting. Firstly, the glossary covered research terminology, but not asthma terms, nor DUETS or treatment uncertainties. Whilst the majority of attendees had a background in asthma, and therefore almost certainly didn't require explanation of asthma terms, including definitions of key asthma terms might have enabled those without asthma backgrounds to understand more of the discussion (even though this may only have been the JLA attendees and the observers. Furthermore, including asthma terms in the glossary would be one way of acknowledging the expertise of those who attended.

Secondly, in the list of 21 pre-selected treatment uncertainties, 16 were presented as questions, and five as topics, as the following examples illustrate:

- Are there any new treatments for severe asthma other than steroids?

- Tailored interventions based on sputum eosinophils versus clinical symptoms for asthma in children and adults

This distinction does not appear to have caused any difficulties during the meeting itself. Never-the-less, it is possible that this inconsistency in style may have caused easily-avoided confusion.

Thirdly, there was some confusion on the day about DUETS and treatment uncertainties. This is discussed in more detail in Section 6, but it is worth noting here that these problems may have been resolved through greater clarity in the preparation pack. Similarly, whilst materials circulated in advance can prepare participants, there is still a need to cover this information during the meeting to ensure a shared understanding. JLA met this need through briefing sessions at the start of the meeting.

3. Venue

What was the venue like?

The workshop was hosted by the Royal Society of Medicine, and held in three different rooms on three different floors at their offices on Wimpole Street. These three rooms included one basement room without windows, which was laid out as a small lecture room and was used for introductory and plenary sessions, and two committee rooms with tables set out in a square as for a formal committee meeting. One of these committee rooms was used for refreshments including morning and afternoon tea and coffee and a buffet lunch. All three rooms were used for small group sessions. In their evaluation forms 11 of the 12 participants indicated it was good or very good, and only one person suggesting it was 'not good at all'.

Reflecting on the venue

The evaluation forms suggest people liked the venue, which was both grand and comfortable, whilst also giving some gravitas and importance to the meeting, with a feeling that the work that took place was in some way endorsed by the Royal Society of Medicine. Although there were no explicit comments about the 'medical' nature of the venue, it is possible that it provided an environment in which the health professionals were more 'at home' than the asthma sufferers who attended the meeting.

Having three separate rooms for the meeting had advantages and disadvantages. It helped with small group work, enabling people to divide into groups. Had the small groups needed to remain in one room, it would almost certainly have been noisy and distracting. Furthermore the basement room did not have any natural light, which would have made it inappropriate for an all day meeting. There did appear to be some difficulties in the distribution of the rooms on three different floors and on different sides of the building. This made it difficult for the facilitators to liaise with one another, even with an extra person 'floating' between groups. The physical separation of the small groups may have contributed to the different approaches adopted in the small groups and their outcomes. I noted that when confusion about the task arose, it was not dealt with until late in the day, possibly an issue which would not have arisen had the small group facilitators been in closer contact. Although less important, the layout of rooms also made it harder to observe the activities of the different small groups.

The use of one of the meeting rooms for refreshments also gave rise to some difficulties. Before and at the start of the coffee and lunch breaks, the small group meeting in the refreshment room was disrupted as members of the other small groups arrived. After the breaks there was further disruption when staff from the Royal College of Medicine arrived to clear away the refreshments. In both cases people seemed to take care not to interrupt the small group, never-the-less, the small group were clearly aware that they were being overheard and discussions in the group were more stilted.

The different layouts of the three rooms appeared to influence the format and facilitation of the small group sessions. When small group discussions took place seated round tables, participation differed from when the furniture was pushed to one side and the group worked on papers on the floor. In one room moving the furniture completely away was not possible, and the facilitator had to find a compromise by laying out the treatment uncertainties on the tables. My suggestion would be that the committee structure of seating was too structured for the informal style adopted in the small groups and that small group work flowed more smoothly with more people participating, when the formal seating and tables were moved aside.

4. Content of the day

What was the content of the day?

The topic of the day was asthma, specifically asthma treatments, with a focus on 21 different treatment uncertainties. The programme was designed by JLA and circulated in advance of the meeting (see Appendix 2). The actual programme differed slightly on the day as the facilitators made decisions to give more time to the small groups to enable them to complete their prioritisation tasks.

The day started with an introductions game, which was fun and light-hearted. The initial plenary session included presentations with background information from JLA, Asthma UK, BTS and DUETS. These included the use of PowerPoint and handouts. JLA explained the background to the meeting and outlined ground rules and the programme for the day. The presentation from Asthma UK explained how they had reached the 15 questions they had submitted for discussion on the day. The presentation BTS was brief and didn't include using PowerPoint, although slides had been prepared and deemed inappropriate by JLA (as I understand it). A demonstration of DUETS was given with an explanation that systematic

reviews were considered the gold standard when determining whether or not a question had been addressed or was a 'treatment uncertainty'.

The attendees were then split into small groups, which had been pre-chosen by JLA. The membership of these small groups was tweaked slightly by JLA based on who turned up on the day. Each small group then went to different rooms, each with a facilitator, who led the task of identifying the top ten priority treatment uncertainties from the list of 21 provided. Small group work in the morning and afternoon was balanced with plenary sessions to review and discuss the decisions of the small groups.

The day finished with a plenary to decide on the final top ten treatment uncertainties and a discussion of the next steps. The meeting closed with a game (a 5 minute treasure hunt) and a request for participants to complete evaluation forms.

Reflecting on the content of the day

The topic focus of the day meant that attendees had something in common, with shared experiences of asthma and common goals of prevention and treatment. This collective interest in the subject of the day was noticeable in its absence for those of us who did not have a background in asthma. For example, one of the facilitators commented at the end of the day that she didn't know anything about asthma, and I felt very ignorant of the detail of much of the discussion about treatments for asthma.

The structure of the day was key in achieving the goal of identifying the top ten treatment uncertainties. Having said this, the flexibility within the programme proved just as important in ensuring that the small groups could complete their tasks and that everyone was able to input to the final decisions. The balance of the day, between plenary, small group work, and games, kept people's interest in working together and completing the tasks.

The use of small groups meant questions could be explored in more detail than large group discussions might have allowed. However, the process of making 'preliminary' decisions about the top ten treatment uncertainties in small groups did mean that each small group developed ownership of their list of priorities and there was some reluctance to move on from these. For example in one of the morning's small group discussions, a member of the group asked whether the group would be able to keep their prioritisation of questions. The facilitator responded that it might be possible, but 'we would have to fight our corner'.

It was my feeling that the balanced membership of the small groups was important in ensuring understanding across the whole group when the small groups did have to move away from their preliminary decisions and the final decisions were made about the top ten treatment uncertainties.

5. Facilitation

What facilitation took place?

There were three JLA facilitators at the meeting, as well as a member of DUETS. They used a range of facilitation methods, including nominal group technique^b, Delphi^c and Diamond 9^d, and a number of facilitation tools, such as PowerPoint, handouts, flip charts, and visual cards. Facilitation included enabling discussion of the process of determining the top ten treatment uncertainties, and the enabling discussion of the treatment uncertainties themselves.

Discussion of the process

To differing degrees the participants in their small groups discussed the process of prioritising the treatment uncertainties. This discussion was sometimes initiated by the facilitator and sometimes initiated by a member of the group. At times the facilitators appeared uncertain about whether the approach their group was taking in order to prioritise the treatment uncertainties might be shared by the other small groups.

Discussion of the treatment uncertainties

The extent to which the participants discussed the actual treatment uncertainties varied. In some cases there was uncertainty and even disbelief that some of the questions were really treatment uncertainties and had not already been answered. Discussion of the questions was facilitated by the use of visual cards, with each treatment uncertainty written out on a card in large letters. In two small groups these cards were used as part of the Diamond 9 technique, essentially laid out in a diamond and shuffled as decisions were made to prioritise

^b Nominal Group Technique is when you go around the room asking for one contribution from each person in turn. It allows everyone a chance to say something.

^c Delphi technique includes one or more rounds of voting.

^d Diamond 9 is a method for using visual cards in a diamond shape to reflect emerging priorities in ranking exercises.

them. In one case the cards were spread out on tables and 'shuffled', and in others they were spread out on floor and similarly moved around. One small group session did not use the cards at all. The use of flip charts to record discussions and decisions also varied.

In their evaluation forms 10 out of 12 people clearly felt that JLA had done a good job; one person felt they had done less than a 'very good' job, but was still positive about the facilitation; and one person was negative, suggesting that the facilitation was 'not very good'.

Reflecting on the facilitation that took place

The completed evaluation forms suggest that participants felt the JLA team did a good job of facilitating the workshops. Reflecting on the facilitation that took place, I identified the following facilitation techniques which I felt encouraged participation from attendees:

- Checking that everyone in the room could hear each other (including the facilitator)
- Ensuring that everyone understood, before moving the discussion forward
- Seeking clarity in setting ground rules
- Revisiting the aims of the meeting at the start and end of day
- Maintaining good eye contact with the whole group
- Probing individuals for the reasoning or thinking behind their suggested prioritisations
- Acknowledging input from people, by recording on flip charts what they said, or just verbally paraphrasing what people said, and also by commenting on individuals' contributions, saying 'that's interesting' or 'fascinating'.
- Remaining flexible, particularly when seeking consensus amongst the group.

The following facilitation skills were particularly important in the small groups:

- Dealing with dominant people and ensuring that others had a chance to talk
- Drawing out quiet people, by asking them directly for their views and protecting their time from interruptions by others
- Managing disagreement amongst the group by asking open questions, drawing everyone into the discussions and knowing when to move on from the point in question

- Finding consensus in what was being said
- Making the most of the venue by arranging seating and furniture so that everyone could see one another and the list of treatment uncertainties (see the discussion about the venue in Section 3 above for more on this).

In contrast, the use of votes and weighting to rate the treatment uncertainties in small groups did not appear conducive to discussion. Indeed when one small group focussed on each individuals rating for the list of treatment uncertainties there was virtually no discussion of the questions themselves, but instead a lot of numbers and adding up votes. More open discussion using the cards of treatment uncertainties appeared more productive, than reference to the individual rating sheets which had been sent out in the preparation packs.

The number of facilitators at the meeting (4 in all), compared to the number of participants (15 if you exclude facilitators and observers), initially seems very high. However, observing the meeting, it appeared important to have all four people there. It enabled there to be one person leading each small group, and also a 'floating' facilitator who could move between the three meeting rooms. When in the afternoon, everyone was split into just two small groups, there were two 'floating' facilitators which provided a greater opportunity for communication between the groups, as well as support for the main facilitators. This additional support was particularly important when there was a clash of personalities within the group. It meant there was someone else on hand to listen to discussions and suggest solutions. Lastly, the differing styles of the facilitators added variety to the day.

6. *Priority setting process*

What was the process of priority setting?

As touched on earlier, the meeting started with 21 treatment uncertainties, with the aim of reducing these to a top ten, listed in order of priority. Over the course of the day, no additional questions were added, and the list of 21 was successfully reduced to ten. This included 'lumping' the questions about the adverse effects of treatments together into one treatment uncertainty.

This prioritisation began in three small groups with individuals sharing their own views, some of whom had pre-prepared these as requested in the meeting pack. The small groups then discussed the treatment uncertainties to prioritise their top ten. In a plenary session, the views of the three small groups were reported and their rankings pooled. This pooling

identified a 'shared' top ten. The attendees were then split into small groups for a second time (this time into two groups), and were asked to discuss the treatment uncertainties and again prioritise their top ten. A final plenary discussed the pooled votes from these two groups, resulting in a revised shared top ten.

This final plenary included consideration of how this revised shared top ten took into account the views of the initial three small groups, as well as the views of the afternoon's two small groups' decisions. There was some further discussion and agreement of the final top ten, which included a decision to lump some of the original 21 treatment uncertainties together.

Although initially, during the priority setting process, there was some disbelief amongst participants that questions hadn't already been answered and were true 'treatment the group nonetheless appeared content that the objective of the workshop was achieved by the end of the day. The evaluation forms indicate that the attendees agreed that the workshop had achieved the objective of establishing the top ten asthma uncertainties for research. Two of the 12 respondents were less confident about this, although they were still positive that this had been achieved.

Contributions to discussions

Focussing more specifically on what happened in the discussions at the workshops, everyone appeared to be engaged with the task. On the whole people listened to one another's contributions, with only very occasional independent conversations taking place during the small group sessions (when two people started to talk to each other rather than contributing to the main discussion). No one was side lined from discussions, and even those who said little, still engaged with the discussion by nodding, and adding their agreement or disagreement to general comments. Some people did only share their views when asked directly.

Some people did dominate discussions, and this tended to be the clinicians. Sometimes this domination was just by talking the most, and sometimes through the choice of technical language, which simply excluded others from the discussion. Examples of this include asserting expertise by mentioning the period of time they had worked in the field, mentioning a qualification (a PhD), and referring to journals, research papers and international conferences.

Although speaking with a very different form of authority based on experience, when patients talked about their personal experience of asthma, the group all listened carefully. Patients explained how their priorities were very much shaped by their experiences, for example parents prioritised questions relating to children, whilst those who weren't parents of asthma sufferers put these questions to the bottom of their list.

In the discussions some people talked about their own treatment uncertainty priorities in terms of the topic and then referred to the ID no. whilst in one group individuals just listed the ID numbers. This was also reflected in the limited discussion within this small group of the actual treatment uncertainties; instead they pooled their individual votes with little debate about the uncertainties themselves.

When asked in the evaluation form whether they felt they had been able to communicate their views, all the respondents responded positively. One of the 11^e was slightly less positive, but still suggested that he/she felt they had been able to communicate their views.

Contributions to decisions

As far as the decision-making process was concerned, some people appeared to be more forceful in arguing their case than others, particularly when it came to the plenary discussion when the final decision was made. In particular one of the health professionals, who perhaps had more experience of asserting his views in such settings, was particularly vocal.

The facilitators also made an important contribution in the final decision-making process. Whilst taking into account the level of consensus expressed in the group, they largely dismissed some remaining disagreements from the minority. When some participants remained sceptical of the benefits of lumping together some of the questions, rather than opening up the debate for more discussion, the facilitators brought the discussion to a close by highlighting the consensus that had been reached.

In the evaluation forms, attendees were asked whether how well they felt their views and preferences had shaped the final list of Asthma uncertainties: 11 of the 12 respondents to the evaluation completed this question, of whom ten responded positively and one

^e This question was only completed in 11 of the 12 evaluation forms.

negatively. In general responses were less confident than answers to other questions in the evaluation (as indicated on a spectrum between 'very well' and 'not very well').

Reflecting on the process of priority setting

Reflecting on what happened during the day, whilst the priority setting process was in many ways a success, there were some specific aspects which perhaps caused difficulties.

One of the difficulties in the process was the tension between a quantitative process of voting, and a more qualitative process of discussion. Whilst in the plenary sessions the system for bringing together the views of the small groups quantitatively appeared to be a successful way of providing an overview of the priorities emerging from the small groups. However, in the small groups, emphasis on votes and ranking sometimes distracted people away from the treatment uncertainties themselves.

Another difficulty, which has already been touched up in this report, was the disbelief that some of the questions were actually unanswered treatment uncertainties. The confusion about why a question might be included (ie because there is no systematic review, not necessarily because there is no primary research), almost certainly shaped the decisions that were made. This reflects a general lack of understanding about systematic reviews, what they are and why they are important, and suggests that people value primary research more highly than systematic reviews. For example, at least one of the small groups dismissed a question from the list because they knew of a trial which had been funded, but there was no question of whether or not this was sufficient to address the treatment uncertainty. Greater clarity about what was meant by treatment uncertainties, and what a systematic review is, may have improved the priority setting process.

Despite the aims of the meeting to prioritise research, the discussions sometimes got sidetracked into considering research methodology and whether or not a question could be addressed in a research study. This particularly arose in relation to whether or not to lump some of the uncertainties together. One approach to avoid this diversion might be to encourage participants to focus on the treatment uncertainties and leave the research design issues to others. However, this tendency in research agenda setting to move onto discussing research methodology has been noted in other contexts (RS to ADD REF) and suggests that it is not possible to completely separate out the task of prioritising research questions and the task of conducting research. One solution might be to include an experienced researcher in the meeting, so that any queries can be answered quickly, rather

than the group spending time debating whether or not a question can be addressed by research.

The uncertainty about whether or not to lump questions together clearly caused some anxiety during discussions, particularly in the small groups, when facilitators were unsure whether the other groups were lumping questions together or not. It may be that the calls to lump questions were partly driven by the objective of identifying a 'top ten' list of uncertainties. Had the group been asked to prioritise the whole list from one to 21, they may not have felt the need to lump some questions together. In the final plenary, when the decision was taken to lump together the five questions about the adverse effects of different treatments, the group were pleased that this allowed a more diverse range of questions to be included in the top ten.

Lastly, whilst Asthma UK had clearly invested in identifying treatment uncertainties and contributed considerably to the identification of the top 21 questions discussed at this meeting, moving on to prioritising a new top ten in this multi-disciplinary setting appeared to cause some difficulties for them. In the end, any problems were avoided, as the final top ten were similar enough to the top ten identified by Asthma UK's prior to the meeting.

On a positive note, the concerns discussed above, were not considerable by any means and did not appear to significantly affect the success of the workshop. The priority setting process used during the day clearly worked: the objective of prioritising the treatment uncertainties and identifying a top ten was achieved. From my observations everyone had an opportunity to contribute their own views to the decision, and the evaluation forms suggest that individuals felt they had been given a chance to share their opinions and shape the decisions.

Participant views on the day

Thus far, I have reported my own observations and reflections on the day. Within the evaluation forms, the participants also included their views on the day. They recorded the following comments:

- *'A most enjoyable and stimulating experience'*
- *'Very good. Managed to have a full day of discussions, agreements/disagreements, but finally achieved a very satisfactory result'*
- *'It was interesting to see how dynamics of groups changed the priorities and how priorities were influenced by open discussions with lay and professionals'*
- *'Fantastic effort with pulling it all together and keeping the energy going by the JLA team. It really made it a worthwhile experience and it all came together in the end. Shame there weren't more clinicians but those who attended really gave good and balanced input'*
- *'Well done, great day, focussed, knew what was happening – have a great sense of achievement'*
- *'Very well organised and facilitated by JLA – successful outcome'*
- *'Good mixture of views and all able to participate'.*

These comments support my own reflections that the day was very well managed and reached a successful outcome. Such positive feedback is an acknowledgement of JLA's work in making the day a success.

A short reflection on whether the JLA's objectives were achieved

The James Lind Alliance set out to identify the most important gaps in knowledge about the effects of treatments, and in doing so to:

- Establish a network of affiliate organisations and individuals
- Help to develop a [Database of Uncertainties about the Effects of Treatments \(DUETs\)](#) containing questions about the effects of treatments being asked by patients and clinicians which cannot currently be answered confidently.
- Foster the evolution of working partnerships of patients and clinicians, to identify and prioritise their shared uncertainties about the effects of treatments, and then to press for systematic reviews of existing evidence in areas where these are needed, or to influence priorities for additional research.
- Provide a setting as free as possible from major biases (distorting factors) and competing interests, in which patients and clinicians can meet to identify and promote shared priorities for addressing uncertainties about the effects of treatments.

As described in this report the meeting on the 26th March achieved the JLA's main aim of identifying the top ten uncertainties about the effects of asthma treatments according to a mixed group of health professionals and asthma sufferers and carers.

In addition the day contributed to JLA's specified objectives as described below:

Establishing a network of affiliate organisations and individuals

The participants at the workshop engaged with one another. The day presented a number of opportunities to get to know one another better and build relationships. These included playing games, having coffee and lunch together, and working together towards a shared goal. Having said this, it isn't completely clear whether the networks, which were being built, were actually the ones that the JLA intended, as there was only one person from the BTS attending. Instead the main links developed were between the JLA and Asthma UK.

Helping to develop a Database of Uncertainties about the Effects of Treatments (DUETS) containing questions about the effects of treatments being asked by patients and clinicians which cannot currently be answered confidently.

The March workshop did not actually identify any additional treatment uncertainties to include in DUETS, although it was a practical priority setting exercise using DUETS and as such it brought DUETS ‘alive’ for those at the meeting. The meeting also contributed to a process of enabling DUETS to feed into funders’ priorities with the Health Technology Assessment programme committed to taking on board the top ten treatment uncertainties determined on the day.

Fostering the evolution of working partnerships of patients and clinicians, to identify and prioritise their shared uncertainties about the effects of treatments, and then to press for systematic reviews of existing evidence in areas where these are needed, or to influence priorities for additional research.

The workshop provided an opportunity for patients and clinicians to work together to prioritise their shared uncertainties about the effects of asthma treatments, and resulted in ten questions which will now be fed into the Health Technology Assessment commissioning process. However, with this success behind them, it is not clear where the working partnership between Asthma UK and BTS will continue from here. The JLA has clearly played a key role in maintaining this partnership, and it isn’t clear whether the working partnership would exist without considerable JLA facilitation.

Providing a setting as free as possible from major biases (distorting factors) and competing interests, in which patients and clinicians can meet to identify and promote shared priorities for addressing uncertainties about the effects of treatments.

In many ways this objective was achieved at the meeting in March. This was made possible by having the JLA there to facilitate the meeting. They played a key role in encouraging patients and clinicians to talk to one another, to develop a shared understanding of the treatment uncertainties and to discuss these using neutral language.

Possible barriers to achieving a bias-free setting on the day include the focus on research questions, even when they were presented more broadly as treatment uncertainties. The venue of the Royal Society of Medicine is also arguably not a neutral setting: perhaps most evident if you consider that the opposite of this ‘medical’ venue might be to have held the meeting in an asthma sufferer’s home.

In general, therefore, the meeting met many of the JLA's objectives on the day, although it is not clear what the future is for the working partnership between BTS and Asthma UK.

Recommendations

On the basis of my observations of the day and reflections on what worked well and where difficulties arose, I have drafted the following recommendations for future priority setting meetings:

Participants and working partnerships

- Consider the gender balance of the attendees at the meeting, bearing in mind that women are more likely to be available to attend, so greater effort may have to go into recruiting men
- Consider the balance between patients and carers and health professionals, both in terms of the dynamics at the meeting and in terms of the future of the working partnership
- Do not be surprised if considerable effort is needed to facilitate the working partnership and build relationships amongst the partners. This is, in and of itself, a major challenge. Clarity over the next steps and longer term future of the working partnership may be helpful.

Preparation

- Ensure that preparation packs are posted out well in advance of meetings, and if possible, telephone attendees to check whether they have received them.
- If partner organisations are giving presentations, ask them to send through their slides in advance so any problems can be ironed out in advance.
- Consider the relevance of the glossary to the meeting, potentially including terms pertinent to the priority setting exercise and the topic focus as well as research terminology.
- Consider the format of the treatment uncertainties, whether they are in a consistent format and whether everyone will understand the technical language included within them.

- Ensure that there is clarity over DUETS and what a treatment uncertainty is, particularly in relation to why research might be needed to address it. Venue
- Consider whether the choice of venue may introduce biases into the day, particularly for patients and carers attending. Whilst 'medical' venues may be most appropriate, an awareness of how comfortable different participants may feel in such a setting is important.
- Breakout rooms for small group sessions are recommended, where possible located close to one another.
- Plan how the facilitators might communicate with one another during the small group sessions, either with a slot where they can leave the group and liaise with one another, or with a 'floating' messenger.
- Bear in mind that if one room is used for refreshments it will mean some disruption for any group working in that room.
- Aim to have as much flexibility as possible in the seating and table arrangements within the rooms. In general, 'committee' format is not conducive to participative small group work.

Content of the day

- Focusing the day on a mutual topic of interest in the way that JLA have designed the working partnerships helps to build working relationships based on common experiences and shared goals.
- Include in the structure for the day small group discussions and plenary sessions.
- A pre-prepared programme for the day ensures transparency and helps participants to know what to expect.
- Be flexible within the programme and prepared to rearrange sessions based on progress during the day.

- Consider the membership of small groups in advance and be prepared to alter them based on who turns up on the day.

Facilitation

- Although care is needed to ensure facilitators do not dominate a group, a high ratio of facilitators to participants (1:4) is recommended, particularly during small group work.
- Consider having a 'back-up' facilitator or observer who does not take a lead, but is there to listen and support the main facilitators as necessary.
- Facilitators need to be aware that their actions can encourage participation and just as easily discourage it. Bear in mind the encouraging actions as laid out in this report (see p16).
- Flexibility is important.

Priority setting

- Ensure that all the questions included as treatment uncertainties are genuinely 'uncertain' by circulating them in advance, and inviting people to challenge any which they believe are not uncertainties by providing the relevant evidence [up to date systematic review] and ensure everyone understands that research is needed on all of them (whether primary research or systematic review). This should avoid the prioritisation task being influenced by people's disbelief [see above] about whether or not a treatment uncertainty has already been addressed.
- Consider the investment of the different participants in the decisions about treatment uncertainties, which have taken place before the meeting. If anyone had already heavily invested in identifying treatment uncertainties, it may be important to talk to them in advance of the meeting about this next stage of prioritisation and how it builds on and differs from the work, which has gone before.
- Bear in mind that quantitative consensus methods can distract participants from discussing the actual treatment uncertainties. It may be worth avoiding any mention of 'votes' or 'ranks' until after initial discussion of the treatment uncertainties has taken place.

- Be aware that the discussions may get side tracked with debate about research methodology and how the treatment uncertainties might be addressed by researchers. Consider whether having an experienced researcher at the meeting might help to allay people's questions.
- Bear in mind that asking people to identify a 'top ten' list of treatment uncertainties may lead people to want to 'lump' questions together in order to include more topics in the top ten. Consider whether prioritising the whole list of questions might be more constructive than focussing on a top ten.

General points

- If time allows, consider how the meeting objectives contribute to the JLA objectives to ensure that as well as ensuring the success of the meeting, you are also contributing the success of the JLA.
- Remember that these meetings are exhausting and make sure you take time to recover and to celebrate your success before moving on to the next one.

Appendices



1. Asthma Working Partnership Workshop Evaluation Form

Please can you take a few minutes to complete this evaluation form to help us plan future workshops with Working Partnerships?

Please put a cross on a point on the line that most represents your views on each part of the workshop.

1. Pre-Workshop Pack

How helpful was the pre-workshop pack in preparing you for the workshop?

Very Helpful-----*Not at all Helpful*

2. Workshop Facilitation

How well did the James Lind Alliance Team facilitate the workshop?

Very Well-----*Not Very Well*

3. Workshop Content

How well did you feel able to communicate your views in the workshop?

Very well-----*Not Very Well*

4. Priority Setting Process

How well did you feel that your views and preferences shaped the final list of Asthma Uncertainties?

Very well-----Not Very Well

4. Workshop outcome

How well did we achieve the objective of establishing the top ten asthma uncertainties for research?

Very well-----*Not Very Well*

5. Venue

Was this a good venue to host a workshop?

Very Good-----*Not Very Good*

6. Any Other Comments about the Workshop?

7. Contact Details

We will contact you with the report of the workshop, please put your contact details here:

Name:

Address:

Telephone/Mobile:

Email:

In order to understand the types of people who participated in the workshop please circle the following statements that relate to you – *this information will be treated with the strictest confidence and is only used for our evaluation purposes.*

Are you a:

Person with Asthma Carer Parent of Child with Asthma

Health Care Professional Researcher Other (*please specify*)

(please circle all that apply).

Are you Male or Female?

Male

Female

Are you aged between?

18-30

31-45

46-55

56-65

65+

Thank You for Taking Part in the Workshop and Completing this Evaluation

2. Programme for the day



THE JAMES LIND ALLIANCE Tackling treatment uncertainties together

Research priorities in Asthma A workshop to set priorities for treatment research in Asthma

Monday 26th March, Royal Society of Medicine, Central London
09.30 – 4.30 pm

Workshop objectives:

- To brief the group on the process for developing Asthma DUETs, and the short list of Asthma uncertainties to be prioritised
- To reflect on, and discuss participants' individual views of the short list (all participants will have had an opportunity to see these before the workshop)
- In small groups rank the short list of Asthma uncertainties and look for areas of agreement and disagreement across groups.
- In the large group discuss, rank and if need be, vote to achieve a final 10 uncertainties in Asthma for priority funding

09.30	Registration and mingling with refreshments	
10.00	Introductions exercise Background to the JLA, clarify the objectives of the workshop.	Sally Crowe Lester Firkins
10.30	Developing the Asthma DUETs – process and outcomes i. Overview of uncertainty and DUETs – Mark Fenton DUETS Editor ii. Asthma UK iii. British Thoracic Society iv. DUETs Asthma module – Colin Gelder Question and Answer	
11.00	Facilitated Small Group work	
11.30	Refreshment break	
11.45	Return to small groups; proceed to small group voting on the short list of Asthma uncertainties; aim to agree a rank order for the questions	
12.45	Lunch break	
13.30	Plenary session – results of small group discussions and ranking of Asthma uncertainties	

	Small groups have an opportunity to clarify, with each other, their ranking and background discussions	
14.00	Return to small groups and discuss and review overall ranking of uncertainties in light of other groups results, proceed to identifying the 'top ten' uncertainties	
14.30	Plenary session - Small groups 'top ten' uncertainties; compare and discuss as a whole. What uncertainties do we all agree should be in the top ten? What uncertainties are left?	
15.00	Refreshment break	
15.30	Continue plenary session as before with the aim of agreeing a rank order for ten top asthma uncertainties, that need to be the focus of clinical research	
16.10	Summary of the day Ideas for funding opportunities Next steps	
16.30	Evaluation form and depart	