



## **Evaluation of the Urinary Incontinence Priority Setting Partnership**

### **Introduction**

The James Lind Alliance (JLA) Urinary Incontinence Priority Setting Partnership (PSP) was formed in 2006 to identify uncertainties about the effects of treatment for urinary incontinence, and to agree ten top priorities for medical research. Twenty one organisations representing both patients/carers and clinicians actively contributed to the process of identifying and prioritising the uncertainties, and were each involved to varying extents.

On completion of the JLA process, each PSP member was asked to feed back their views on how the process itself worked for them, via an anonymous online survey. This was an opportunity to identify strengths and weaknesses in the process, from a stakeholder perspective. Data captured by the survey will be used by the JLA to inform, develop and improve future PSPs.

This report summarises the responses from members of the Urinary Incontinence PSP. As only 13 responses were received, the report focuses on actual numbers, rather than percentages. Where totals do not add up to 13, it should be assumed that some respondents skipped the question. While the survey was anonymous, care has been taken to ensure the analysis does not reveal any individual identities.

### **The respondents**

Of the 13 respondents, seven were clinicians, three were patients, two were researchers and one indicated 'other'. Due to the small numbers it has not been possible to isolate significant differences or trends between the different types of respondent, although some clear divides do emerge from people's comments.

### **Information provision**

Twelve out of 13 respondents were satisfied with the level and detail of the information provided to them throughout the JLA process – five of these said they were very satisfied. It was suggested that communication was very clear and

information was always received in good time. However, more information on the 'behind the scenes' processes would have been welcomed. One person said they were very dissatisfied with the level and detail of the information provided, but offered no further explanation.

### **Meetings and communications**

Seven respondents said they had attended either the introductory and/or the interim meeting. Eleven people were happy with the way the JLA communicated with them between meetings, of which seven said they were very satisfied. One person was very dissatisfied.

*The information communicated provided was very clear and concise and kept me up-to-date with what was happening.*

*Very clear and informative email communication.*

### **Submitting uncertainties**

Eight of the 13 respondents said they had submitted uncertainties. One explanation from someone who had not submitted any was that they had sent the request for uncertainties to members who would have responded on behalf of their different organisations. Another respondent suggested that the issue of uncertainties in treatment was not quite relevant to their membership.

Of the eight respondents who did submit uncertainties, five were satisfied and one was very satisfied.

*From what I could understand a great deal of effort was put into the process of both gathering and harvesting.*

*The screening stage, collation and final meeting were all transparent and seemed very robust.*

One person was neither satisfied nor dissatisfied, and one person was dissatisfied.

*[One particular] perspective was discounted at an early stage in favour of "surgical" options. I fully agree with the utilitarian approach, but feel that non-"surgical" priorities were overwhelmed.*

*I did not think the questions were clearly posed and the method of harvesting was not controlled.*

Two respondents suggested that the language used to request uncertainties was unclear.

*The only thing I would mention is that the phrasing of the uncertainty question was found by some in my organisation to be obscure and we eventually had to reword it a little to get much response.*

### **Interim priority setting**

Eleven respondents said they participated in the interim priority setting exercise. One person indicated why they had not taken part at this stage:

*I sent this out to a few of our members, but a couple found it too complicated and others said there was nothing relevant to them.*

Of those eleven, seven were satisfied with the process, while two were very satisfied.

*It was very straightforward.*

*Very difficult to do as a group but we got there.*

One person was neither satisfied nor dissatisfied, while one person was dissatisfied. The perceived challenges of the interim priority setting exercise included having missed an earlier meeting and finding it hard to catch up, finding the requirements of the process overwhelming and finding it hard to engage colleagues with one particular specialism.

*[It was] quite difficult to rank the whole list. I eventually asked my colleagues to rank their own top 50 if they could bear it, or top 30 if they couldn't!*

### **Final priority setting meeting**

Eight of the respondents attended the final priority setting meeting. There were a number of reasons for non-attendance (mainly other commitments), but two people noted that another representative of their respective organisations attended in their place. Of the eight, two were satisfied and three were very satisfied with the process.

*I believe it was done very fairly with everyone able to put their point of view.*

*[It was a] very inclusive and helpful process.*

*This meeting was excellent. Robust but civilised debate was had and I think everyone was happy.*

One person was neither satisfied nor dissatisfied, while two were dissatisfied. Perceived flaws in the process which were identified included the composition of the final group, namely the under-representation of patient groups, which had occurred as a result of last-minute apologies from certain partners. It was suggested that as a result, clinicians may have had undue influence. Indeed, one respondent felt that their contribution to the small group discussion was overwhelmed by the clinical perspective and suggested there was a lack of openness to their viewpoint. It was also suggested that the final discussion was dominated by those with a particular agenda.

*I also felt very much in the minority as a single [patient representative] in the group trying to have some input on behalf of patients. In some cases I felt that it wasn't even worth trying as the clinician was clearly determined that their opinion stood.*

Interestingly, one respondent said they sensed that the JLA would have welcomed more actual patients to the table, as opposed to representatives of patients, but that they thought patient groups may have been reluctant to encourage this.

It should be recognised however that of the final top 10 priorities, five were submitted by clinicians, four by patients and one came from recommendations in a Cochrane Review.

The method for arriving at a top 10 was thought by some respondents to be unclear. It was noted that the different groups had taken different approaches, which was thought by some to be unhelpful and confusing.

Seven respondents felt that the priority setting process was fair and in line with the JLA's objectives of independence and freedom from bias, while four were not sure.

*I think every effort was made to achieve this, but not sure that it did due to the process.*

Subsequent concerns had arisen for one respondent who had noted a number of emails being circulated by medical professionals, which suggested to them that a medical bias may be present. It was also felt that there should be a way to ensure the views of those who were not at the final meeting, but who had been involved in the process up until then, were taken account of when setting final priorities. Some people thought that more proportionality between patients and clinicians may have seen different final results.

## Overview of the JLA process

Seven respondents felt that working with the JLA to prioritise treatment uncertainties for research will make a positive difference to patients, clinicians and researchers in the field of urinary incontinence.

*Certainly I as a researcher will use this information to inform what projects we take forward in future.*

*It has helped to clarify research uncertainties, and hopefully it will give incontinence research some credence and standing. Too often, funding is hard to come by because incontinence is considered not to be very sexy.*

No one suggested that it would not make a positive difference, but four were not sure about this. Reasons included the fact that prioritisation of a wide range treatment uncertainties was not relevant to the membership of the organisation they represented. It was also suggested that although it was a useful and interesting exercise, it was still too early to measure any positive impact:

*The extent of difference will be critically dependent on the response of research funders - and peer reviewers. If they don't agree that the processes are appropriate, the whole exercise will come to nothing! [It was] still a good exercise though.*

Nine respondents said they would recommend the JLA process to their colleagues or peers. The opportunity to bring patients and clinicians into the same debate was viewed as particularly valuable, and something to be developed and replicated.

*I think it is a very valuable way of encouraging an interchange of views which does not usually happen between clinicians, researchers and patients. It has reaffirmed my views of the need to involve patients much more in such work.*

*It is a good and manageable process to involve consumers in determining research priorities.*

*[I would recommend it] because it is so straightforward and achieves results.*

Two people were not sure.

*There were some very positive aspects of the process which I would be keen to see replicated but remain uncertain on others.*

The key aspects of the JLA process which respondents felt worked particularly well were:

- the opportunity to bring different groups together
- the widespread engagement of different stakeholders
- the independent facilitation and communication
- the final priority setting meeting
- the harvesting process
- the consistency of the group throughout the process and shared understanding of its objectives
- the fact that face to face meetings were held

Aspects which it was felt could have been improved were:

- the lack of age diversity among represented patient groups
- the low level of patient representation
- the methodology, which was perceived by one respondent not to be robust

Overall, it was suggested that the JLA Urinary Incontinence priority setting process had been “helpful”, “a very enjoyable and worthwhile project” and “an enjoyable and useful experience”. Even for those who had found the experience less positive, the collegiate aspect and the opportunity to work with a different people was still a positive one:

*Despite the negative comments I enjoyed the meetings and am very pleased to have taken part. It was good to work with colleagues and learn from them.*

## **Recommendations**

### *Communication and information*

- The JLA should continue to communicate clearly with PSP members and ensure information is shared in a timely manner.
- PSP members would welcome more background detail and information on the process. This could include references to steering group activity and the nature of the work carried out between meetings.

### *Submitting uncertainties*

- The rationale for allowing or disallowing uncertainties should be clear and made openly.
- The JLA should continue to ensure the language used to request uncertainties is simple and in plain English.

### *Interim priority setting*

- Instructions for interim priority setting should be very simple and clear even to those who may have missed earlier meetings or instruction.
- The JLA should consider limiting the number of interim priorities PSPs are asked to identify to ensure the task is completed and not considered to be too overwhelming.

### *Final priority setting*

- The JLA should continue to emphasize the importance of attendance at the final priority setting meeting, and should ask PSP members to nominate a deputy to attend in their absence.
- The JLA should consider how PSP members who are unable to attend the final meeting, or send a deputy, can still make a contribution to the final process.
- The process for arriving at a top 10 needs to be clarified, including the issue of rewording and combining uncertainties. There should be a consistent approach across all the small groups to avoid confusion and facilitators should be fully briefed to manage this.
- Facilitators of the small discussion groups should be equipped to give extra support where needed to the input of non-professional participants, and to ensure that no one group dominates the discussion.
- In this exercise, the final 10 were well balanced between uncertainties submitted by patients and clinicians. The JLA should emphasize this in its reports to reassure interested parties about the fair and pragmatic nature of the exercise.

### *Representation of patients and clinicians*

- Where there is an imbalance in the numbers of patient representatives and clinicians, the JLA should consider how under-represented parties' input may be weighted.
- Where steps have been taken to recruit a diverse range of members, but there is still under-representation of certain groups, the JLA should be open with this information and make it clear that efforts were made.
- If there is an under-representation of patients involved, the JLA should encourage organisations representing patients to actively involve their members in the meetings if feasible, as well as in the harvesting and prioritising processes.

### *The future*

- The JLA should consider options for the longterm monitoring of its process, to measure the impact of the priority setting exercise on research funders' decisions and outcomes for patients.