



Annual report 2010-2011

Annexe 6: Evaluation of the Prostate Cancer Priority Setting Partnership

Introduction

The James Lind Alliance (JLA) Prostate Cancer Priority Setting Partnership (PSP) was established in 2009. The PSP began its process in June 2009, with an initial awareness meeting for stakeholders, and held its final priority setting workshop in October 2010, where a top 10 list of prostate cancer treatment uncertainties for research were agreed by patients and clinicians.

As with previous PSPs, on completion of exercise, each PSP member was asked to feed back their views on the process, via an anonymous online survey. This was an opportunity to identify stakeholder views of the strengths and weaknesses in the JLA process. 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 Prostate Cancer PSP. Thirteen responses were received, so the report focuses on actual numbers, rather than percentages – such a small number of responses cannot be interpreted as statistically representative of the whole PSP. If totals do not add up to 13, this means respondents had skipped the question. While participation in the survey was done anonymously, care has been taken to ensure the analysis does not reveal any individual identities.

The respondents

Of the 13 respondents, six were patients or patient representatives, three were clinicians, one was a carer and three respondents ticked 'other', describing themselves as various kinds of charity representatives.

Information provision

All respondents were satisfied with the level and detail of the information provided to them throughout the JLA process, with eight saying they were very

satisfied. Comments suggested that the information received included clear instructions, and that regular updates had been appreciated.

Meetings and communications

Five respondents said they had attended either the introductory and/or the interim meeting. Those who had not attended provided a range of reasons, including ill health, family issues, a tube strike and not being in post yet.

Everyone said they were satisfied with the way the JLA communicated with them between meetings, with eight being very satisfied.

Submitting uncertainties

Eight respondents said they had submitted uncertainties, while four said they had not, either because they were not in post at that point, or because they felt it wasn't appropriate for them to participate in that stage of the process.

Of the respondents who did submit uncertainties, four were very satisfied, two were satisfied and two were neither satisfied nor dissatisfied with the process. It was commented by one person that the process was "great but time consuming", and one other suggested that it could have been explained more clearly. Finally, one person drew attention to the barriers faced by people without internet access:

You assume everyone lives in, or near, London, and has access to the internet. I live [elsewhere] and three so-called 'providers' have failed to get the internet into my house. I have to use the local library.

Interim priority setting

Nine respondents said they participated in the interim priority setting exercise, ranking their top ten treatment uncertainties from the long list. Three people said they had not taken part at this stage, either because they were excluded from the voting process, or because they had other commitments at the time.

Of those nine, five were very satisfied with the process and three were satisfied. One person was dissatisfied, again due to feeling that the process required internet access.

Final priority setting meeting

Six respondents attended the final priority setting meeting. Six people said they did not attend, for reasons including ill health, holiday and prior commitments. Of the six, five were very satisfied and one was dissatisfied with the process.

Very well organised, good, robust, open discussion.

Good debate and interesting comments from all who had a point of view.

*Organisation and balance of the clinicians with the patients was excellent.
Well organised and excellent.*

One person had concerns about the potential for participants to dominate the discussion and suggested that should this be the case, the facilitators should speak privately to them, to ensure they are aware that everyone will need to have their say.

Overview of the JLA process

Nine respondents said they thought the priority setting process was fair and in line with the JLA's objectives of independence and freedom from bias. Two did not agree and one was not sure.

I was not involved right from the start, but it seemed to me to be a very fair process from the time I became involved.

You achieved the correct level of impartial balance between the parties involved.

Eight 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 prostate cancer.

To make any difference to the type of research which is performed, there needs to be more buy-in from researchers and funders.

Hopefully, it will provide a better research focus for what patients and clinicians feel the research needs are.

For the first time ever in the UK the needs of the patients and the clinicians have been met.

One felt that the process would not have an impact (they were critical of the efficiency of the process), and three were not sure. There were concerns expressed about a perceived lack of engagement from clinical representatives, and that patient representatives had worked harder to engage colleagues and raise awareness of the initiative.

Ten respondents said they would recommend the JLA process to their colleagues or peers.

The JLA seem very proficient at this sort of exercise, as they have also demonstrated when working with other charities regarding research priorities.

I found the whole process totally professional, non-biased and independent - quite excellent.

One person was not sure if they would recommend the process and one person said they would not.

Aspects of the JLA process which respondents felt worked particularly well were:

- the collaboration between patients and healthcare professionals
- the harvesting of uncertainties, and the amount of raw data it generated
- the opportunity for open debate
- the final workshop
- the prioritisation of the top 10

A resounding agreement seemed to be reached which suggests that the process was very rigorous in identifying the areas of research need.

Aspects which participants would like to have changed were:

- developing a clearer process for assembling the final list of uncertainties
- ensuring the final balance between patients and clinicians is completely equal

While one respondent was generally unhappy with the process, and its accessibility, the majority were happy and felt that the process had been well organised and worthwhile taking the time to participate in.

Recommendations for the JLA

- Continue to use the Guidebook to simplify the concept of the priority setting process, so partners can see and understand how the process has worked in practice for others.
- Articulate the reasons for the methods chosen for the process, particularly where it may be perceived to be longwinded or complicated.
- Offer and promote the opportunity for people to participate in ways other than email/online, including by post or telephone. Reinforce the message that the exercise is inclusive and accessible, regardless of the limitations of technology, or geography.
- Discuss ways for facilitators to address the issue of dominance in the discussion, both in terms of setting out ground rules to mitigate against it, and being ready to intervene should it arise, or be approached should it become a concern to others.

Written by Katherine Cowan, James Lind Alliance