



**James
Lind
Alliance**

Priority Setting Partnerships



Leading education
and social research
Institute of Education
University of London

Description of a workshop to set research priorities in Preterm Birth January 2014

April 2014

Sally Crowe, Seilin Uhm, Lelia Duley and Sandy Oliver



Royal College of
Obstetricians and
Gynaecologists

Setting standards to improve women's health



Irish
Neonatal
Health
Alliance

Bliss

for babies born too soon,
too small, too sick



Improving quality of care and
outcome at very preterm birth
NIHR Programme Grant for Applied Research

1. Introduction and context for this report

This report describes the final prioritisation workshop of the Preterm Birth Priority Setting Workshop, both in terms of process and outcomes. Additional reports are also being prepared for publication in peer review journals, an open access journal and for wider dissemination by partner organisations.

This report will be available on the James Lind Alliance Preterm Birth Priority Setting Partnership website and the JLA website.

2. Background to the Priority Setting Partnership

Partnership objectives:

- *work with service users and clinicians to identify uncertainties about prevention of preterm birth, and short and longer term effects of preterm birth care*
- *agree by consensus a prioritised list of uncertainties*
- *publicise top 10 uncertainties, including to research funding bodies and researchers*

2.1 Setting up the partnership:

An awareness meeting was held in July 2011 to talk about research in Preterm Birth, and float the idea of a Priority Setting Partnership. The partnership was convened in November 2011 with Sally Crowe, a James Lind Alliance adviser as chair of the steering group. The partnership is funded from the National Institute of Health Research (NIHR) as part of wider research programme called “Improving care and outcome at very pre term birth”.

A wide range of partner organisations joined the partnership, some of these had a more active role in the process than others and these were:

Bliss, the special care baby charity, Cochrane Neonatal Group, MCRN Neonatal Clinical Studies Advisory Group, National Childbirth Trust, Royal College of Paediatrics and Child Health, TinyLife - premature baby charity NI, Royal College of Obstetricians and Gynaecologists, and Irish Neonatal Health Alliance. Irish Premature Babies were involved in the partnership earlier on.

A Steering Group was convened with members from these organisations, in addition a member of the NIHR Research Programme, and the Social Science Research Unit, Institute of Education, London joined as the group. A PhD student Seilin Uhm, and the NIHR Programme Grant Management Team provided administration and data support to the partnership, and for the final workshop.

3. Developing the shortlist of research questions, for discussion and prioritisation at the workshop

The partnership followed an established route for gathering and prioritising treatment uncertainties (we called them 'research questions') in preterm birth as described in the James Lind Alliance Guidebook <http://www.jlaguidebook.org/> and consisted of the following key steps:

3.1 Gathering research questions:

- A survey asking for suggestions for research in Preterm Birth was done online and in paper format (including being distributed in high risk preterm birth antenatal clinics, and neonatal units) between March and December 2012.
- 386 people completed a survey (online/paper); 58% of respondents were people affected by Preterm Birth (mostly parents), 30% were health professionals and 12% were people who said they were both.
- The survey responses contained a total of 593 potential research questions (potential as they needed to be checked against existing research).
- Existing research and guidelines were searched for unanswered research questions. There were 540 potentially relevant reviews of research and clinical guidelines.

3.2 Analysing the research questions gathered:

- The Steering Group screened the research questions suggested in the survey and they were allocated to categories; similar questions were identified and merged, and 38 were removed as they were not within the scope of the process.
- An independent information specialist (with help from the Steering Group) checked and removed research questions that were fully answered by up to date and relevant reviews of research.
- This dual process resulted in **70 questions from the survey** remaining in the process.
- Because there were so many research questions from reviews of existing research and clinical guidance, the steering group did a separate exercise to assess and prioritise these in June 2013. This resulted in **28 questions from reviews and 24 from clinical guidance** remaining in the process.
- The combination of these was 122, but there were some overlapping questions (18) so the steering group did some final merging of questions.
- This process resulted in a 'long list' of 104 unanswered research questions that went out for a public vote.

3.2 Interim prioritisation:

- The 104 unanswered research questions were made available for public voting between September and December 2013.
- The numbers of people participating increased to 537 with about half people affected by preterm Birth, and half health professionals
- The Steering Group met in December to review the voting exercise and agreed the shortlist of 30 unanswered research questions to go forward to the final prioritisation workshop in January 2014. They took into account the voting

preferences, and the share of the vote between service users and health professionals, they also reviewed the overall balance of the topics on the shortlist.

4. Workshop objectives

1. To give an overview of work so far by the Preterm Birth Priority Setting Partnership
2. To discuss and vote on a shortlist of research uncertainties
3. Together, agree the 10 most important of these
4. Consider next steps, to ensure that the priorities are taken forward for research funding

4.1 Participants of the workshop

A total of 34 people participated in the priority setting at the workshop; 13 were parents and ex-preterm adults, 21 were from a range of health professions; neonatology, obstetrics and midwifery, speech therapy and psychology. Several of these health professionals also had direct experience of pre term birth.

There were four facilitators; two from the James Lind Alliance and two non voting members of the steering group. There were three observers, one from the James Lind Alliance, one from a research funding organisation in Canada and one from the Institute of Education. There were four members of the NIHR Programme Grant team in support roles at the workshop.

4.2 Methods

Prior to the workshop, all participants were asked to provide short biographical information about themselves, complete a declaration of competing interests for preterm birth research, and review and rank the shortlist of questions under consideration.

First Phase

Participants introduced themselves briefly; this process complemented the biography document, which was compiled and circulated prior to the workshop.

The background to the James Lind Alliance Preterm Birth Priority Setting Partnership was briefly described by Lelia Duley and participants invited to make comments about the process, and seek clarification. Everyone seemed happy with the process so far.

The workshop priority setting process was described by Sally Crowe and participants encouraged to interact in their allocated small groups, and discuss the 30 questions under consideration.

Second Phase

Following this clarification phase, the participants were assigned to small groups, each of which had a mixture of parents, carers and people who were born preterm and health professionals.

Within each group, time was spent discussing, exploring and comparing each participant's individual rankings of 30 uncertainties. After some time considering these individual comparisons, the groups refocused on the shortlist as a whole, and started to identify shared priorities. Each group had a set of cards with each of the 30 questions (and voting

information and examples of original questions on the flip side) and these were placed according to group agreement in a rank order of 1 - 30 (1 = the most important).

The facilitators for each group had the task of ensuring that no one person dominated the discussion or exerted undue influence on the group, and ensure that all group members participated in the discussion. Facilitators were supported by non voting members of the Steering Group, who were able to provide contextual information.

As the workshop approached the lunchtime break, groups were encouraged to agree the final ranking. Over the lunch period, data from the three groups were entered into an Excel spreadsheet designed to aggregate the scores across the groups.

Following lunch the whole group reconvened and discussed the aggregate scores after the first round of ranking. The purpose of this was not to reorder the list but to clarify where there was existing consensus between groups, and where there were differences.

The four small groups from the morning were combined into three larger groups to create new combinations of participants. This time the groups appraised and discussed the new aggregate ranking order from the first round of priority setting. Similar processes were used as in the first round, but the focus here was on having a clear agreement of the top ten, as well as a complete 1 - 30 rank of questions.

Final Phase

During the refreshment break the JLA team again collated the results from this second round of ranking, and the 30 were laid out on the floor for the whole group to see. The debate was then opened up for everyone to contribute. There was much debate, for example about the nature and balance of this list, and by consensus two questions were merged at this point. Although there was consensus about the top seven questions, there was much less consensus and some anxiety about the next 3 and the questions sitting at 10 – 15. With 10 minutes to the end of the workshop it was suggested we had consensus on a Top 15 and that straining this to achieve a top ten was counter productive. It was suggested that settling on 15 would be more appropriate in view of the broad scope of this partnership. This was voted on by the workshop participants and agreed.

4.3 The final Top 15

1. Which interventions are most effective to predict or prevent preterm birth?
2. How can infection in preterm babies be better prevented?
3. Which interventions are most effective *to prevent* necrotising enterocolitis in premature babies?
4. What is the best treatment for lung damage in premature babies?
5. What should be included in packages of care to support parents and families / carers when a premature baby is discharged from hospital?
6. What is the optimum milk feeding strategy and guidance (including quantity and speed of feeding and use of donor and formula milk) for the best long-term outcomes of premature babies?
7. What is the best way to judge whether a premature baby is feeling pain (for example, by their face, behaviours or brain activities)?
8. Which treatments are most effective to prevent early onset pre-eclampsia?

9. What emotional and practical support improves attachment and bonding, and does the provision of such support improve outcomes for premature babies and their families?
10. Which treatments are most effective for preterm premature rupture of membranes?
11. When is the best time to clamp the umbilical cord in preterm birth?
12. What type of support is most effective at improving breast feeding for premature babies?
13. Which interventions are most effective *to treat* necrotising enterocolitis in premature babies?
14. Does specialist antenatal care for women at risk of preterm birth improve outcomes for mother and baby?
15. What are the best ways to optimise the environment (such as light and noise) in order to improve outcomes for premature babies?

5. What next for the priorities?

The steering group, met after the workshop to review the results, agree the final wording of the Top 15 and develop a plan to share, and raise awareness of the research priorities. This will include presentations at conferences, short summarised articles and more detailed accounts of the process and results. These will be shared with professional publications as well as newsletters and be available on the websites of the partner organisations. Social media will also be used to spread the word.

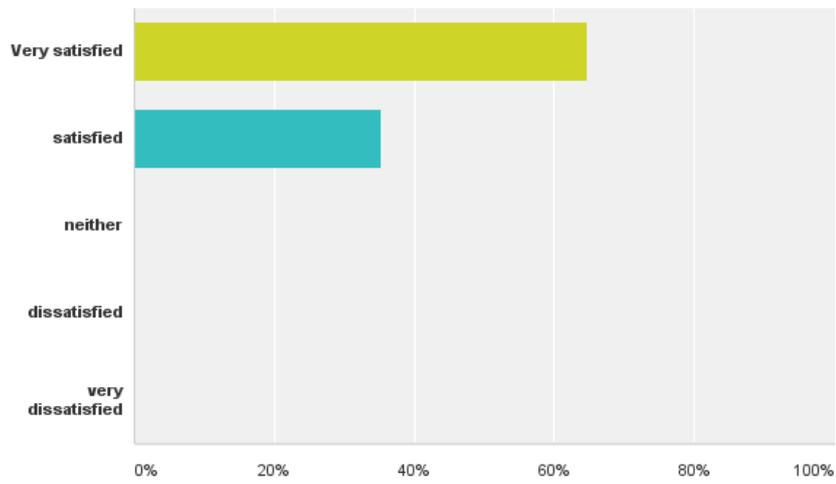
6. Acknowledgements

The Preterm Birth Programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG- 0609-10107). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health

Appendix: Feedback from the Evaluation Forms

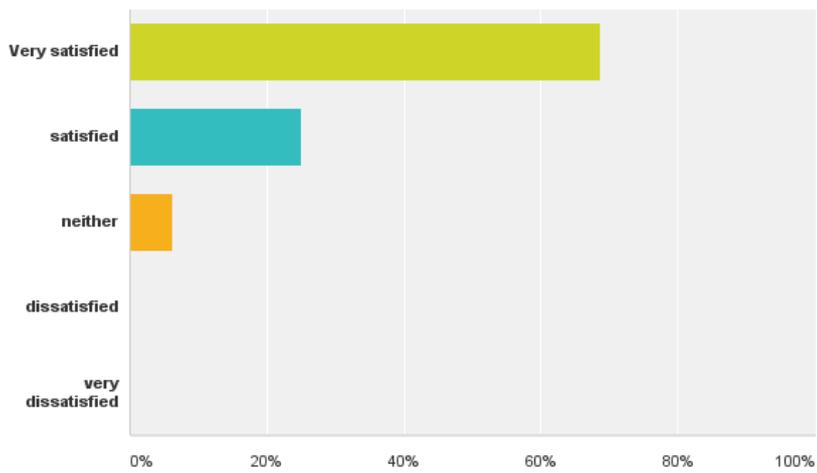
Q2 Workshop facilitation

Answered: 17 Skipped: 10



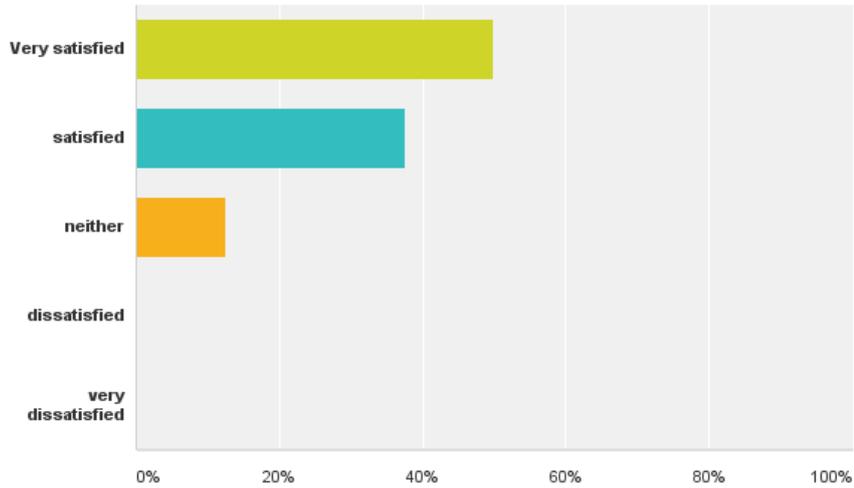
Q3 Workshop content

Answered: 16 Skipped: 11



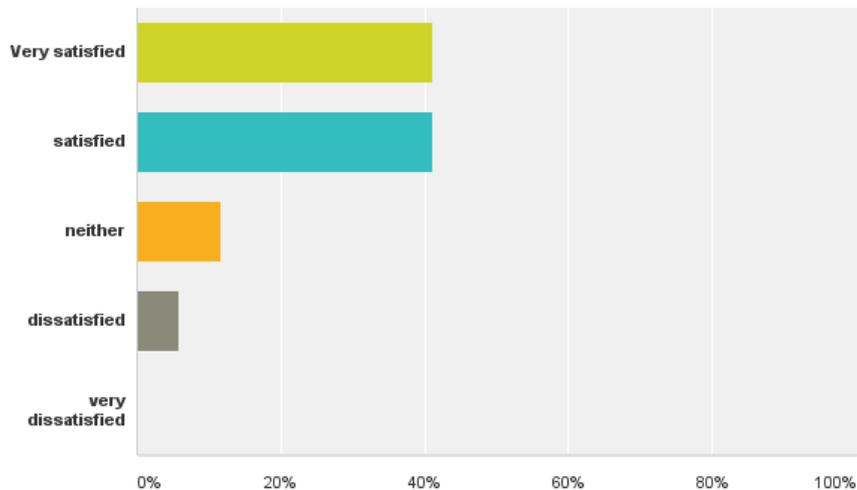
Q4 4. Priority Setting process

Answered: 16 Skipped: 11



Q5 5. Workshop outcomes

Answered: 17 Skipped: 10



Comments

- I was very impressed with the professionalism of those involved in the workshop. I felt very privileged to be involved, both as a midwife and as a mother of a preterm baby myself. [Service user)
- I thought that the participating obstetricians were allowed to dominate discussion and influence priority setting unduly. Consultant clinicians were permitted to speak at length with no limit, whereas not everyone was treated with similar deference. On a positive note, it was a very well-organised event and it was interesting and rewarding to participate. I feel that a final 15 did not adequately meet the objective of the day's purpose, it is 50% above the 'top ten' objective. Perhaps the day ran short of time and we could have done better with another hour. [Researcher, HCP in Neonatal Medicine, and grandparent]

- I was attending the workshop in an observer role so did not contribute to the prioritisation process. But I thought the process went really well and was very well organised and facilitated. [JLA Adviser]
- The format of the day was clearly explained and I felt that I had the opportunity to advocate as parent for service user priorities. This was facilitated by recently studied for a master's degree in education with premature children as a focus. I am not sure how well the parent voice can be represented in this format without this type of specialist knowledge. [Service user/parent]
- Very informative, facilitated and chaired so well, letting everyone have a say. Organised very well and a great mix of parent/client groups as well as medical and staff personal. [Service user/parent]
- The workshop was really well conducted and facilitated. The process for prioritisation was fair and transparent, and allowed all groups to contribute equally to the shortlist. That the workshop came up with tangible results is itself an enormous achievement as many such exercises results in very amorphous thoughts than conclusive results. Well done. [Neonatologist]
- Excellent facilitation and involvement of all participants, I really enjoyed this workshop. It was a day well spent. I would like to be kept informed of progress as the end was slightly rushed and I was not entirely clear of the 'next steps'. [HCP in neonatal unit]
- I thought the whole day was very good. The facilitation was excellent. I felt that everybody was given the opportunity to express their views, and the groups provided space for open and honest discussions. [Service user/parent]
- Shame that we couldn't agree a final top ten. A top ten had been defined as a result of the various workshops during the day - but it was only at the final discussion on the day that it suddenly expanded to 15. [Paediatric consultant]
- I found the first part (am) was excellently facilitated by Sally, however the second section not so much. This may have been the nature of the discussions but felt the facilitation was generally less helpful and not inclusive of everyone in the group. [Researcher and HCP]