The process and outcomes of setting research priorities about preterm birth – a collaborative partnership

Traditionally researchers, funders or policy makers have decided the future research agenda, rather than the service users or clinicians who deal with the consequences of the health condition every day. This article presents the process and outcomes of a collaborative partnership between patients, parents, families and healthcare professionals to prioritise the uncertainties about preterm birth. The Top 15 preterm birth research priorities are described.

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Key points

Uhm S., Crowe S., Dowling I., Oliver S. The process and outcomes of setting research priorities about preterm birth – a collaborative partnership. *Infant* 2014; 10(6): 178-81.
1. The Preterm Birth Priority Setting Partnership (PSP) represents the first large service user consultation concerning preterm birth.
2. The PSP used Nominal Group Technique and the James Lind Alliance's five stages of prioritisation to guide the process.
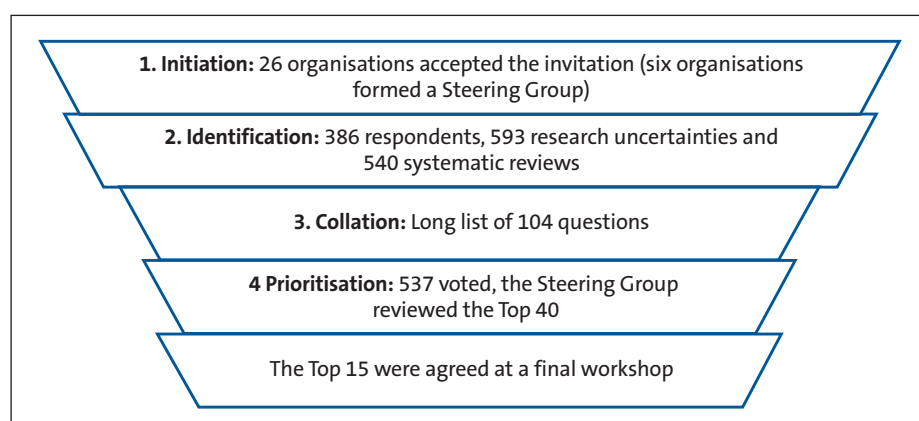
Background

Being born premature is one of the most important factors that can impact directly on an infant's survival, quality of life and the baby's family life, not forgetting the healthcare costs associated with preterm birth. In the UK one in every 100 babies are born before 32 weeks' gestation;[1] they have multiple underdeveloped organs and often require both life and feeding support from the moment they are born. Those who survive the initial stages may spend months in hospital and often suffer ill health or disability in childhood as a result.[2] Many uncertainties still exist about the treatment of preterm infants and research into this area is much needed.

Historically, the research agenda in this area has been determined primarily by researchers and the processes for priority setting in research have often lacked transparency. Therefore clinical research may not have fully addressed the questions that were important to service users and clinicians.

Aims and objectives of the Preterm Birth PSP

The Preterm Birth Priority Setting Partnership (PSP) was set up to discover the research questions for preterm birth and to grade them according to their importance for infants and families. The study also included family members with experience of preterm births, charity groups representing parents and healthcare professionals from both maternity and neonatal care.[3] A platform was provided for the exchange of views and information between service users and clinicians without the influence of pharmaceutical or medical industries. This priority setting partnership was established in November 2011 and was part of a wider research programme.[4]

First, the priority setting partnership was established, which meant that people born preterm, parents and families of preterm babies, charities supporting parents, midwives, obstetricians, antenatal nurses,

FIGURE 1 The collaborative working process of Preterm Birth PSP.

Figure content:
1. **Initiation:** 26 organisations accepted the invitation (six organisations formed a Steering Group)
2. **Identification:** 386 respondents, 593 research uncertainties and 540 systematic reviews
3. **Collation:** Long list of 104 questions
4. **Prioritisation:** 537 voted, the Steering Group reviewed the Top 40
The Top 15 were agreed at a final workshop

neonatal nurses and neonatologists were invited to take part and a Steering Group was identified.

Methods/design

FIGURE 1 shows the collaborative working process of the Preterm Birth PSP.

1. Initiation of the partnership

Potential partners were identified through a process of peer knowledge and consultation, Steering Group members' networks and the James Lind Alliance's (JLA) existing register of affiliates. Potential partners were contacted and informed about the Preterm Birth PSP and invited to participate in an initial meeting. 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
- Medicines for Children Research Network (MCRN) Neonatal Clinical Studies Advisory Group
- National Childbirth Trust (NCT)
- Royal College of Paediatrics and Child Health (RCPCH)
- TinyLife, the premature baby charity in Northern Ireland
- Royal College of Obstetricians and Gynaecologists (RCOG)
- Irish Neonatal Health Alliance (Irish Premature Babies was involved early on in the partnership).

The initial stakeholder meeting took place in July 2011. Different levels of involvement were explained and participants were invited to join either as a member of the Steering Group or as partners of the PSP. The Steering Group managed the scope of the PSP and the day-to-day decisions. Following this meeting, the organisations that had decided to participate in the PSP were asked to complete a declaration of interests, including disclosure of relationships with the pharmaceutical or medical devices industry.

2. Identifying treatment uncertainties

Both service users and healthcare workers were asked for their views on issues which they felt needed to be answered and had not been researched to date, this was carried out through online and paper surveys. Social media networks were used to reach as many people interested in the topic as possible and ethics approval was obtained to approach women attending preterm birth clinics. The Steering Group committee, using an agreed format, then put these questions into categories.

Existing sources of information about treatment uncertainties in preterm birth were also searched. These included research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews in preparation and registers of ongoing research.[2,5]

3. Collation: refining questions and uncertainties

The Steering Group decided who would be responsible for this stage of priority setting. The consultation process produced 'raw' unanswered questions about many aspects of preterm birth including the effects of treatments. These raw questions were assembled and categorised, and then refined by information specialists into 'collated indicative questions' that were clear, addressable by research and understandable to all. Similar or duplicate questions were combined where appropriate. The existing literature about preterm birth was screened to assess the extent to which these refined questions had, or had not, been answered by previous research.
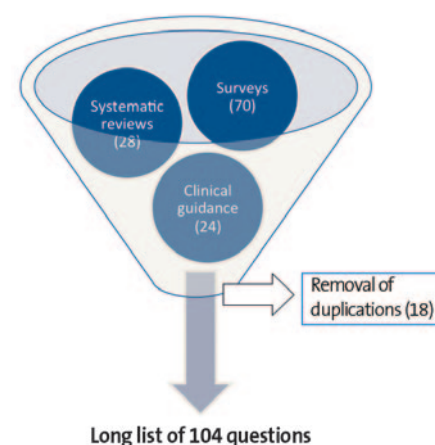
4. Prioritisation – interim and final stages

The aim of the final stage of the priority setting process was to prioritise through consensus the identified uncertainties relating to the cause, treatment or management of preterm birth. This was carried out by service users and clinicians, including members of the Steering Group and the partner organisations.

The interim stage helped to reduce a long list to a shorter list. Organisations and their membership were asked to consider the long list and then ranked their Top 10 most important uncertainties via an online survey over three months. The final stage, to prioritise the shortlisted uncertainties and agree a Top 10, was conducted in a face-to-face meeting, using group discussions and plenary sessions guided by the Nominal Group Technique.[6-8] The JLA facilitated this process to ensure transparency, accountability and fairness, and financial support was offered to cover travel and overnight stay costs for the parents and grandparents contributing.

Results

The whole process took over three years, from March 2011 to March 2014.

FIGURE 2 The process of generating a 'long list'.

Throughout the process the partnership had a total of 14 meetings including:
- two major events (Awareness and Final workshops)
- nine face-to-face meetings
- three teleconferences

The meetings took place in two different geographical locations (London and Nottingham) and three different organisations (academic, clinical and charity).

1. Gathering research questions

A survey (online/paper) asking for suggestions was completed by 386 people; 58% of respondents were people affected personally by preterm birth (mostly parents), 30% were health professionals and 12% were people who said they were both.

To identify research uncertainties about preterm birth from the survey, 593 research questions were raised. Many were similar so they were merged or grouped into larger questions; 38 were removed for being unclear or out of scope. A further 52 questions were added from a review of published work on preterm birth. Existing research and guidelines were searched for unanswered research questions: there were 540 potentially relevant reviews of research and clinical guidelines.

2. Analysing the research questions gathered

This process resulted in 70 questions from the survey remaining in the process. Since there were so many research questions from the reviews of existing research and clinical guidance, the Steering Group performed 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 survey, systematic

reviews and clinical guidance was 122, but there were 18 overlapping questions and so the Steering Group merged some final questions. This process resulted in a 'long list' of 104 unanswered research questions that went out for a public vote. **FIGURE 2** shows the process of generating the long list.

3. Interim prioritisation process

Between September and December 2013 a list of 104 research questions was distributed. In approximately equal numbers, 537 service users and professionals voted for their preterm birth research priorities. 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. The Steering Group 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. Final prioritisation workshop

A total of 34 people participated in the priority setting at the workshop:
- 13 parents of preterm births and adults who were born preterm
- 21 health professionals ranging from neonatology, obstetrics, midwifery, speech therapy and psychology (several of these health professionals also had direct experience of preterm birth).

In addition there were:
- four facilitators: two from the JLA and two non-voting members of the Steering Group
- three observers, one from the JLA, one from a research funding organisation in Canada and one from the Institute of Education
- four members of the National Institute for Health Research (NIHR) Programme Grant team who undertook workshop support roles.

The aim of the workshop was to rank the shortlisted Top 30 questions and produce a list of the Top 10 research priorities for preterm birth. Prior to the day of the workshop, all participants submitted a short biography, completed a declaration of competing interests for preterm birth research and also reviewed and ranked the shortlist of questions under consideration. The allocated groups on the day were facilitated thereby ensuring an equal discussion by all present.

- Which interventions are most effective to predict or prevent preterm birth?
- How can infection in preterm infants be better prevented?
- Which interventions are most effective to prevent necrotising enterocolitis in premature infants?
- What is the best treatment for lung damage in premature infants?
- What should be included in packages of care to support parents and families or carers when a premature infant is discharged from hospital?
- 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 infants?
- What is the best way to judge whether a premature infant is feeling pain, eg by their face, behaviours or brain activities?
- Which treatments are most effective to prevent early onset pre-eclampsia?
- What emotional and practical support improves attachment and bonding, and does the provision of such support improve outcomes for premature infants and their families?
- Which treatments are most effective for preterm premature rupture of membranes?
- When is the best time to clamp the umbilical cord in preterm birth?
- What type of support is most effective at improving breastfeeding for premature infants?
- Which interventions are most effective to treat necrotising entercolitis in premature infants?
- Does specialist antenatal care for women at risk of preterm birth improve outcomes for mother and baby?
- What are the best ways to optimise the environment (eg light and noise) in order to improve outcomes for premature infants?

TABLE 1 The final outcomes of the Preterm Birth PSP: the Top 15 research priority questions. [9]

First phase

Participants introduced themselves briefly; this process complemented their biographies, which were circulated prior to the workshop. The background to the JLA Preterm Birth PSP was briefly described and participants were invited to make comments about the process and seek clarification. Participants were encouraged to interact in their allocated small groups and discuss the 30 questions that were under consideration.

Second 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). These were placed according to group agreement in a rank order of one to 30, one being the most important.

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.

Final phase

During the break, the JLA team again collated the results from this second round of ranking and all 30 were laid out on the floor for the whole group to see. The debate was then opened up for everyone to contribute. Although there was consensus about the Top 7 questions, there was much less consensus, and some anxiety, about the next three and the questions sitting at 10-15. With only 10 minutes left at the end of

the workshop, it was suggested that there was consensus on a Top 15 and that straining to achieve a Top 10 was counterproductive – settling on 15 would be more appropriate in view of the broad scope of this partnership.[9] This was voted on by the workshop participants and agreed. The Top 15 preterm birth research priorities can be seen in **TABLE 1**.

5. Publicity and publishing results

As well as alerting funders, the Steering Group members and partners were encouraged to publish the findings of the Preterm Birth PSP using both internal and external communication mechanisms, including raising awareness of the results among the public and scientific audiences. The JLA and charity organisations also captured and publicised the results, through descriptive reports of the process. This exercise would be distinct from the production of an academic paper, which the partners are also encouraged to prepare.

Conclusions

Preterm birth has a major impact on infants, parents and their families and presents a significant clinical problem in obstetrics and neonatology. As such, it is frequently cited as a research priority in these fields. This PSP represents the first large service user consultation concerning preterm birth and provides a unique opportunity to define a research agenda tailored to the needs of service users and those clinicians who do not usually take place in research. It was recognised that preterm birth is a problem that disproportionately affects families from ethnic minority groups and less advantaged socioeconomic backgrounds and particular efforts were made to ensure that these groups were represented at all stages of the process.

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