

Top Research Priorities for Preterm Birth: Results of a prioritization Partnership Between People Affected by Preterm Birth and Healthcare Professionals

<https://doi.org/10.1186/s12884-019-2654-3>

For which topic were research priorities identified?

preterm birth

In which location was the research priority setting conducted?

Europe - Ireland; Europe - United Kingdom

Why was it conducted at all?

Preterm birth has major impacts on survival, quality of life, psychosocial and emotional stress on the family, and costs for health services. Improving outcome for these vulnerable babies and their families is a priority, and prioritising research questions is advocated as a pathway to achieve this. Traditionally the research agenda has been determined primarily by researchers, either in academia or industry, who have used processes for priority setting that lack transparency. This has contributed to a mismatch between the available research evidence and the research preferences of patients and members of the public, and of clinicians. Often, research does not address the questions about treatments that are of greatest importance to patients, their carers and practising clinicians.

What was the objective?

to identify and prioritize research questions in preterm birth that are most important to people affected by preterm birth and healthcare practitioners

What was the outcome?

a ranking list of 15 research questions

How long did the research prioritization take?

July 2011 - January 2014

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: stakeholders invited, scope defined. Step 2: collecting research questions: survey asking for suggestions about preterm birth experiences, services or treatments which needed to be researched and why the research would be important, additionally research questions identified from systematic reviews and from national UK clinical guidelines, 593 research questions submitted via survey, 540 potentially relevant questions identified from reviews and clinical guidelines. Step 3: data processing: survey submissions formatted into research questions, check against evidence, merging similar questions and removing those that were fully answered, 70 unanswered questions left from the survey, questions collected via systematic reviews and guidelines: steering group asked to select the 60 questions they considered to be most relevant and important, lists discussed at meeting, questions that were supported by three or more members moved forward, resulting in 28 questions from systematic reviews and 24 from clinical guidelines remaining, 18 overlapped with other questions, resulting in final longlist of 104 unanswered research questions. Step 4: interim ranking: via survey, participants were asked to select the 10 questions they considered most important from the longlist of 104 questions, overall results and results by stakeholder groups reviewed by steering group, resulting in final shortlist of 30 unanswered research questions that moved forward. Step 5: final prioritization: workshop: series of small group discussions with nominal group technique and small group rankings, followed by aggregate ranking and plenary discussion

Which stakeholders took part?

People affected by preterm birth, clinicians and researchers. Survey: 386 participants: 204 (53%) affected by preterm birth, 107 (28%) health professionals, 43 (11%) both affected by preterm birth and healthcare professional. Interim ranking: 507 participants: 231 (45%) affected by preterm birth, 216 (43%) health professional, 55 (11%) affected by preterm birth and health professional. Workshop: 34 participants: 13 parents or adults who had been born preterm and 21 health professions (neonatology, obstetrics, midwifery, speech therapy and psychology).

How were stakeholders recruited?

Partner organizations distributed the survey link. To try and access a more high risk group, paper copies of the survey were distributed at high risk specialist prematurity antenatal clinics at two tertiary level hospitals (University College London Hospital and Queen's Medical Centre Nottingham) and to patients visiting their babies in three level 3 neonatal intensive care units. For the workshop, participants were invited from across the partnership, and included representatives from organizations representing both people affected by preterm birth and clinicians, parents of babies born preterm, and adults who were born preterm.