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## Background

- The most immature and highest risk subset of extremely preterm infants, born before 25 weeks of gestation, has not been well studied.
- To improve outcomes for these infants and their families, it is critical to establish the research priorities of healthcare professionals and people with lived experience, including parents of children born extremely preterm, and adults themselves born extremely preterm.
- The James Lind Alliance<sup>1</sup> is a non-profit making initiative that brings together patients, carers and clinicians in Priority Setting Partnerships (PSPs). PSPs aim to identify and prioritise the most important unanswered research questions in a particular topic area.

## Aim

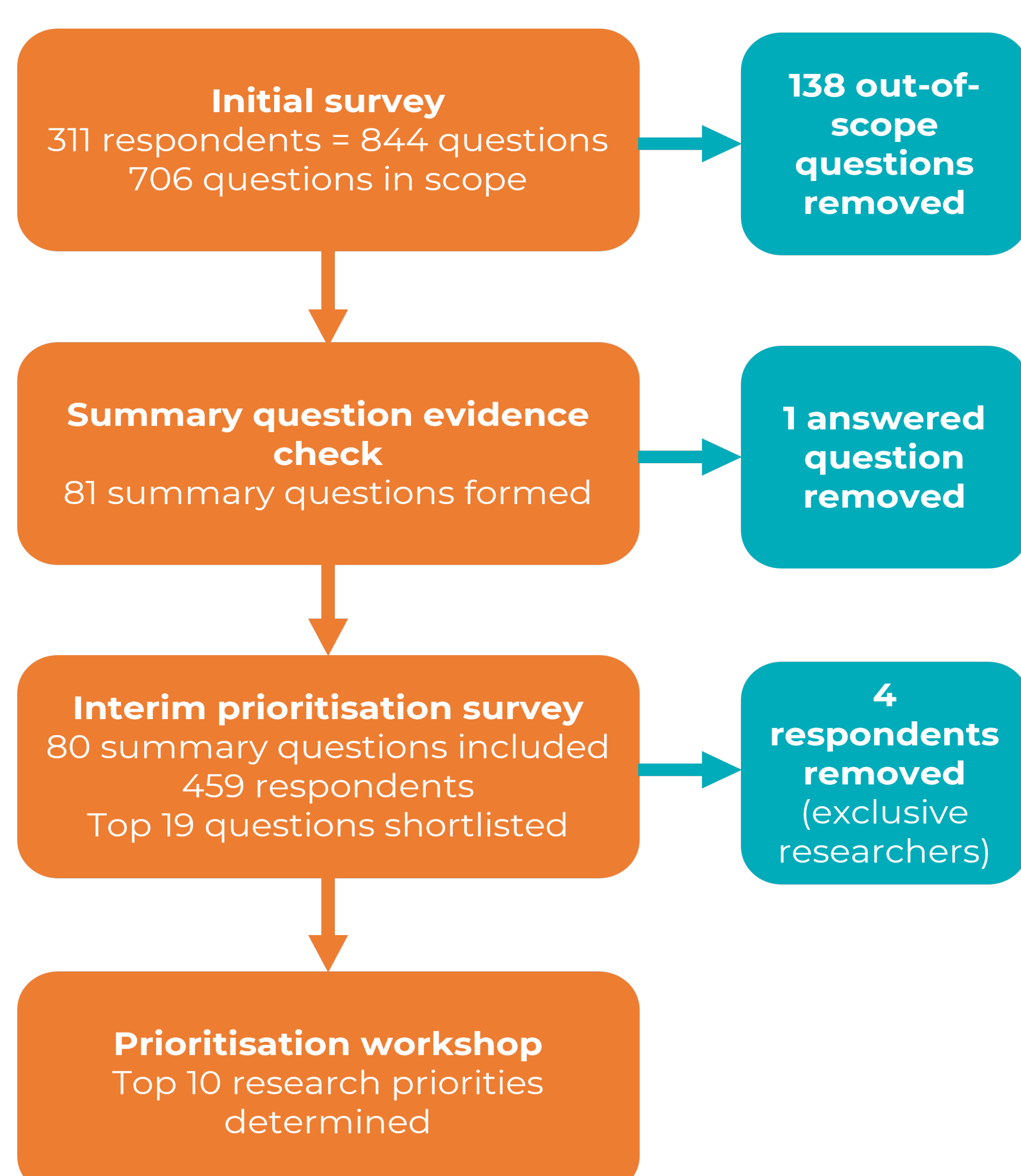
In association with the James Lind Alliance, the "Most Premature Babies" Priority Setting Partnership (PSP)<sup>2</sup> aimed to identify the most important research questions for babies born before 25 weeks' gestation.

## Methods

- An international Steering Group was formed with representation from healthcare professionals and people with lived experience, including parents of children born extremely preterm and adults themselves born extremely preterm.
- An online survey was disseminated to people with lived experience and healthcare professionals across Australia, New Zealand and the UK to ascertain their questions for research relating to infants born before 25 weeks of gestation.
- Summary questions were formed and checked against existing evidence to determine whether they were answered.
- Unanswered questions were included in a second interim prioritisation survey, from which respondents selected their ten most important questions.
- The 19 highest-ranked questions were taken to a final prioritisation workshop where health professionals and people with lived experience determined the Top 10 research priorities.

## Priority Setting Partnership (PSP) Process

Figure 1. Priority Setting Partnership Flowchart



## Results

- From the initial survey there were 311 respondents, of which 308 provided information about their role in answering the survey:
  - 210 (67.5%) were healthcare professionals,
  - 71 (22.8%) were parents or carers of preterm-born children,
  - 13 (4.2%) were adults born extremely preterm,
  - 14 (4.5%) members or employees of third sector organisations.
- 844 questions were received from the initial survey, of which 706 (84%) were in scope. From these, 81 summary questions were formed, of which 80 were unanswered and included in the prioritisation survey.
- The prioritisation survey had 455 eligible respondents, of which:
  - 304 (66.8%) were healthcare professionals,
  - 104 (22.9%) were parents or carers of preterm-born children,
  - 37 (8.1%) were adults born extremely preterm,
  - 10 (2.2%) members of employees of third sector organisations.
- The 19 top ranked questions from the prioritisation survey were taken to the prioritisation workshop, in which the Top 10 research questions were determined (see Table).
- There was significant overlap of priorities between people with lived experience and healthcare professionals – all groups had a similar number of their top 19 questions included in the prioritization workshop & the top 7 ranked questions were the same for healthcare professionals and people with lived experience, albeit in a different order.

Table: Top 10 research questions for infants born < 25 weeks of gestation

Rank	Research Question
1	What can be done in the neonatal intensive care unit to improve long-term health and developmental outcomes?
2	How can we improve the care of babies at delivery and in the hours after birth to improve outcomes?
3	What is the best way to prevent brain injury, including intraventricular haemorrhages (bleeding in the brain)?
4	What interventions or treatments during pregnancy and labour can improve outcomes?
5	What are the long-term outcomes and how are they best predicted?
6	What is the best way to manage pain and distress in babies?
7	What is the most effective postnatal steroid treatment regimen to improve outcomes?
8	What is the best way for families to be more involved in the care of their baby during their hospital admission?
9	How can antenatal counselling be improved for families facing the possible delivery of a baby before 25 weeks' gestation?
10	How can families be best supported during their baby's neonatal intensive care admission?

## Discussion

- This PSP identified the most important research questions for improving outcomes for infants born before 25 weeks of gestation.
- The Top 10 questions in this PSP were varied and likely reflect the complex needs and challenges faced by this population in the neonatal unit and beyond.
- The Top 10 priorities identified should be used to develop focussed research questions amenable to study.
- The findings are limited in their generalisability - this PSP was limited to high-income settings and English-speaking respondents from Australia, New Zealand and the UK. Males and people of Indigenous and non-Caucasian ethnicity were under-represented.

## References

<sup>1</sup>James Lind Alliance: [www.jla.nihr.ac.uk/about-us](http://www.jla.nihr.ac.uk/about-us).

<sup>2</sup>Most Premature Babies PSP: [www.npeu.ox.ac.uk/most-premature-babies](http://www.npeu.ox.ac.uk/most-premature-babies).