James Lind Alliance
Priority Setting Partnerships

INPRES
INternational Perinatal RESearch partnership

Priority Setting Partnership for the Most Premature Babies

Frequently Asked Questions (FAQ)

What is a James Lind Alliance Priority Setting Partnership (PSP)?

Established in 2004, the James Lind Alliance (JLA) is a non-profit initiative that provides a platform for the research priorities of patients, carers, and healthcare professionals. They facilitate Priority Setting Partnerships (PSPs) which strive to:

- **Unite** patients, families, friends, carers, clinicians, and healthcare professionals, by encouraging them to work together to identify unanswered research priorities – whether they are questions, interests or concerns about the causes, symptoms, treatments, diagnosis, or impact of the condition – that, if answered, would reduce risk, and improve their lives, and the lives of others affected by a healthcare concern in question, driving positive change
- **Collate** research priorities from all patients, carers and clinicians affected by the healthcare area in question
- **Publicise** the methods and results of the PSP to ensure complete transparency of the process
- **Communicate** the results of the PSP with researchers, research funders, pharmaceutical companies, and other organisations to drive change

Through the JLA's reliable and rigorous process, the PSP results in a list of Top 10 unanswered research priorities. These are the most important uncertainties for the condition in question, as identified by those affected – either personally or professionally.

While the JLA facilitates these partnerships, the funding and organising are done by the PSP itself – which, in the case of the Most Premature Babies PSP, is coordinated and funded by the INPRES Partnership.

To find out more about the James Lind Alliance watch "An introduction to James Lind Alliance Priority Setting Partnerships"

You can read about a wide range of JLA's undertaken here.

What is INPRES (International Perinatal Research Partnership)?

INPRES is a unique partnership between the Murdoch Children's Research Institute's (MCRI) Melbourne Children's Trials Centre (MCTC) and the University of Oxford's National Perinatal Epidemiology Unit (NPEU) Clinical Trials Unit, whereby its vision is to form a collaboration which improves the health of newborn infants and their families, through high-quality research, whereby the productivity of the collaboration is greater than the sum of the individual centres.

The INPRES Partnership's mission is to develop and facilitate clinical and observational research in a cross-border collaborative approach, which in turn will lead to novel, scientific and practice-changing discoveries in the perinatal, neonatal, and paediatric population. The Partnership's ultimate goal is to improve health outcomes for infants and their families.

What is the INPRES Priority Setting Partnership (PSP)?

The INPRES Most Premature Babies PSP is an Australia and UK wide survey collating the views of the entire premature babies community. We are seeking the input of all those who work with the most premature babies and all those affected by premature births, including those with lived experiences and those family, friends and carers who look after them.

This is a unique opportunity for you to have your say in driving and shaping the future of research.

Have you ever had a question relating to the most premature babies born before 25 weeks of gestation (i.e. around 4 months early) during their hospital admission, with a focus on the following:

- Care and treatment of the most premature babies
- Mental health and wellbeing of parents and carers of the most premature babies
- Other relevant areas/aspects that could benefit from research

Have you ever wondered how your opinion could make a difference? If so, we would like to hear from you.

This Australian and UK-wide survey will collate the views of the entire premature infants' community – healthcare professionals, partner organisations, people affected by prematurity, their parents, families, friends and carers. By completing this survey, you will help guide research into the most premature babies and their families, and make sure that researchers focus on the most urgent needs.

Whether you are an expert or not, you can take part. We want ideas and thoughts from people with different experiences and backgrounds.

The rigorous JLA PSP process will reveal the Top 10 research uncertainties for a particular condition, in this case: the Most Premature Babies born before 25 weeks gestation (about 4 months early). The responses to the survey will highlight areas that are important to those affected by the condition in question but does not require individuals to come up with specific research questions.

INPRES has committed funds and resources to undertake this programme of work and has convened a Steering Group, which comprises of stakeholders from leading Australian and UK prematurity charities, healthcare professionals from both countries, and people living with, and affected by premature births.

Who is this aimed at and what are we asking you to do?

We want to hear from:

- People born extremely prematurely themselves
- Parent of premature babies born before 25 weeks of gestation (around 4 months early)
- Carers, family members and friends who care for premature babies born before 25 weeks of gestation
- Healthcare professionals consulting, treating, and caring for the most premature babies
- Organisations representing people affected by prematurity

We want you to use your own experiences and complete the survey telling us your unanswered questions. By telling us your questions, we can work out what research is needed to improve outcomes for these babies and their families.

Why we need your help

We’re asking you to submit the most pressing questions that you feel need to be answered about:

- the treatment and care of the most premature of babies born before 25 weeks of gestation (i.e., around 4 months early), during their hospital admission and/or
- the mental health and wellbeing of parents/carers/families of the most premature of babies.

Your questions will help us find important areas to research in order to improve the healthcare, outcomes and wellbeing of these babies and their families.

This survey is the first step in collecting your questions, and it will be open until 13 March 2023.

It will be followed by a second survey to prioritize the questions that are received. We will share the final “Top 10” list of unanswered questions directly with researchers and research funders to encourage them to focus on the most urgent needs in this area of healthcare. Those who have taken part in the survey will also receive the results.

What do we mean by unanswered questions?

An unanswered question is any uncertainty you think is related to the most premature babies born before 25 weeks of gestation (i.e., around 4 months early), that could benefit from research. You do not need to know whether or not the question has actually been answered. Our team will collect your questions and check them against published research to check whether or not they have been answered. Some examples of questions include:

- What is the best treatment for life-threatening lung damage in the most premature babies?
- How can infection in the most premature babies be better prevented?
- Why do I have problems with my hearing, but my brothers and sisters don’t?
- How does having a premature baby born before than 25 weeks of gestation impact the mental and physical wellbeing of their parents?
- How can healthcare professionals in the neonatal unit best support the development of the most premature babies?

Do I have to write a research question and check that it is unanswered?

No. The most important thing is to draw on your own personal experience of premature birth. It is enough to write a short sentence about something that is important to you.

Will my answers be kept confidential?

Absolutely!

However, by participating in this survey, you are agreeing to have your priorities included in the INPRES Most Premature Babies Priority Setting Partnership. Your unanswered questions will be analysed and published but not linked to you or your organisation. Survey submissions can be anonymous; however, you also have the option of providing your contact details at the end of the survey should you wish to be informed of the final outcome.

Any personal data submitted will remain confidential.

What will you do with the results?

We will use the results of this survey to guide future research.

This survey is the first step to collect your questions about premature babies born before than 25 weeks' gestation (i.e., around 4 months early), and it will be followed by a second survey to prioritise the questions that are received. By sharing what we find with the international research community, we hope to shape research into the most premature births, not just in the UK and Australia, but all over the world. This will help us decide what research should be funded and we'll make sure other organisations that fund research know how important the priorities are. This way, we can make sure that research is relevant to the most premature babies and the people that care for them every day.

Who is involved in the INPRES Most Premature Babies PSP?

1. **PSP Project Team**
The PSP Project Team comprises of:

    - JLA Advisor – Katherine Cowan (Senior Advisor, James Lind Alliance)
    - PSP Lead – Stacey Peart (Neonatologist, Royal Women's Hospital, Melbourne Australia)
    - PSP Coordinator – Laura Galletta (Clinical Trial Manager, Murdoch Children's Research Institute, Melbourne Australia)
    - PSP Project Team Member – Charles Roehr (Neonatologist and NPEU Clinical Trials Unit Clinical Director, University of Oxford, Oxford UK)
    - PSP Project Team Member – Brett Manley (Neonatologist, Royal Women's Hospital, Melbourne Australia)
    - PSP Project Team Member – Pollyanna Hardy (Biostatistician and NPEU Clinical Trials Unit Director, University of Oxford, Oxford UK)

2. **Steering Group**
We have brought together a Steering Group of 18 individuals, including healthcare professionals across Australia and the UK and people with a personal connection to premature birth i.e. parents of premature babies and those born premature themselves.

    The Committee supervisors the PSP, convening at monthly intervals to guide the partnership using their unique knowledge and backgrounds.

3. **Partner Organisations**
Once the survey is live, we will be contacting all the major patient advocacy groups in both Australia and the UK, which cover premature babies. We want to reach as many people as possible, from every walk of life, and every corner of both countries, to ensure we receive representative views and responses from the entire premature baby community.

    We intend on partnering with several key organisations to help promote the survey initially, and ultimately, advertise the priorities identified by this survey, to the individuals they represent, researchers they fund, industry they know and the wider public.

4. **People affected by Prematurity**
The involvement of people affected by prematurity is essential for the success of the INPRES Most Premature Babies PSP. To identify the Top 10 research priorities, we are relying on

responses from across Australia and the UK and from all members of the community – including healthcare professionals, those born prematurely themselves, parents, carers, families/friends, and organisations and patient advocacy groups representing the interests of people affected by premature births.

We need your help to drive change and make a positive impact on the lives of people affected by prematurity.