



**Identifying Priorities for Future
Preterm Lung Health Research**

STAKEHOLDER REPORT

Acknowledgements

The Preterm Lung Health Priority Setting Partnership Project Team would like to express their warm gratitude to the community, including parents, carers, young people, and healthcare professionals in Western Australia, for their invaluable contributions to this project. Their lived experiences and thoughtful responses to the surveys and consensus workshop outlined in this report have truly made a difference in shaping the development and implementation of this project. The team would also like to extend special thanks to the Preterm Community Reference Group members for their perspectives and insights. Without your support, this project would not have been possible.

We would further like to extend our thanks to all Aboriginal and Torres Strait Islander people, the traditional custodians of the lands on which we work, live and play. Much of this project was completed on Whadjuk Noongar Boodjar, and we acknowledge and thank their elders, past and present. We would especially like to acknowledge the Aboriginal participants of the Priority Setting Partnership for their guidance and wisdom.

A sincere thank you to everyone involved for your valuable contributions toward advancing research on preterm lung health. We sincerely hope that this report will help the littlest members of our society to live their biggest lives.

The journal article associated with this stakeholder report can be read in full at BMJ Paediatrics Open: <https://bmjpaedsopen.bmj.com/content/9/1/e003050>

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Ethics

This project was approved by the Curtin University Human Research Ethics Office (HRE2021-0718).

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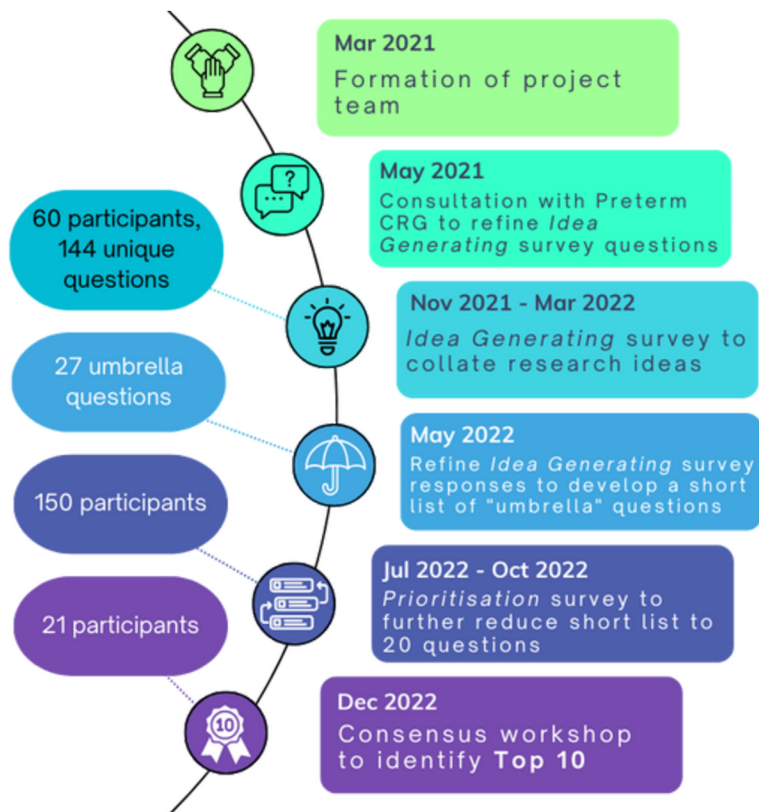
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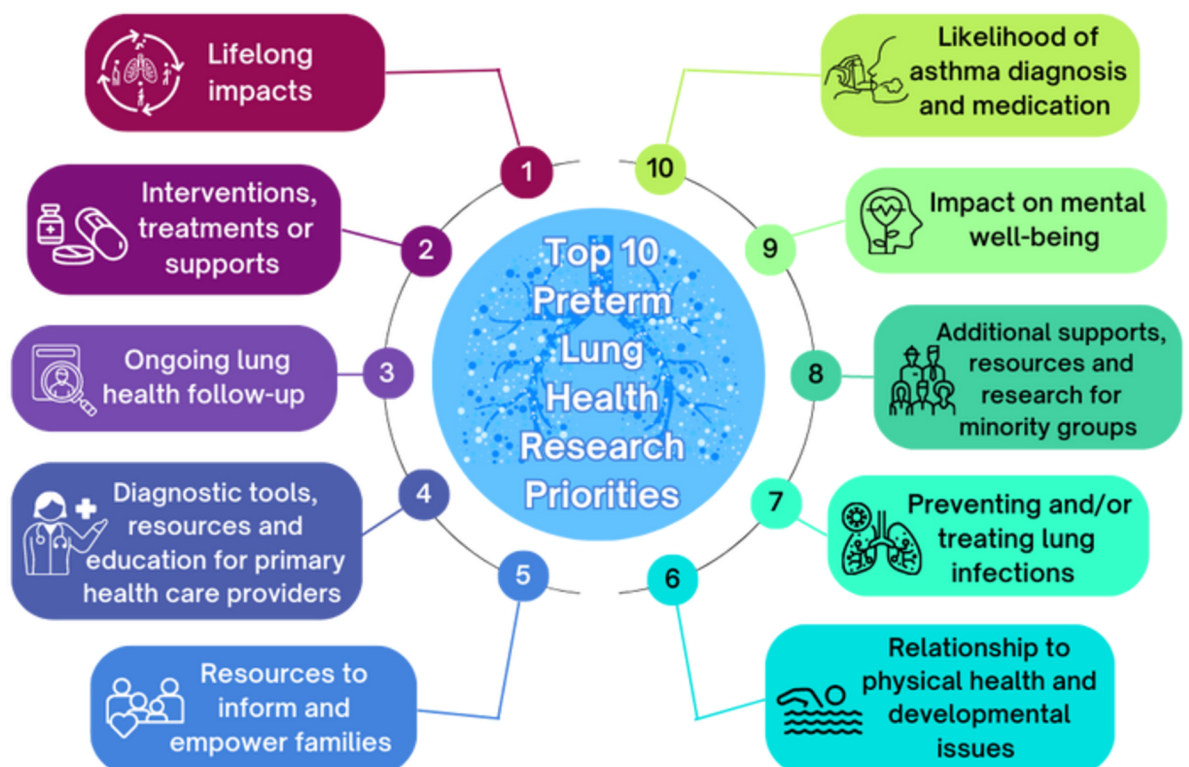
Priority Setting Partnership Summary

The Priority Setting Partnership (PSP) aimed to bring together those with lived experience and health care professionals to establish the Top 10 Priorities for future research for the lung health of people born preterm.

Process



Outcomes



Why is this important?

Project Overview

Priority Setting Partnerships involve bringing together community members and health professionals to establish the top 10 research priorities for future research in the area of interest. The priorities can then be used to focus programs of work for maximum benefit to both community members and researchers. With millions of babies born too soon globally and emerging evidence of lung health deterioration for these children across their lifetime, researchers and community members are equally concerned for the future. Coming together for the Priority Setting Partnership to identify the Top 10 Priorities for future research for the lung health of people born prematurely is just the first step in working together to ensure those born early breathe easier.

Who was involved?



Amber Bates
Chairperson
Preterm Community
Reference Group



Naomi Hemy
Senior Project
Coordinator



Belinda Frank
Community
Engagement Manager



Anne McKenzie AM
Priority Setting
Partnership Advisor



**Assoc Prof
Shannon Simpson**
Co-Head Foundations
of Lung Disease

Significant contributions were made by members of the Preterm Community Reference Group, survey respondents and workshop participants.

Process for Setting Priorities

Idea Generating Survey

The Project Team asked three open-ended questions to stimulate ideas from the community around future research into the lung health of people born prematurely. The questions were further refined by the Preterm Community Reference Group. The final questions were:

1

What questions do you think future research into breathing issues or lung health should answer for people born prematurely?

2

If you have ever looked up information online or asked anyone for advice about breathing issues, please tell us what information you were seeking. How do you think future research could fill any information gaps you experienced?

3

Is there anything else you would like us to consider for future research into the lung health of people born prematurely?

The survey was then made available to the community via a secure online platform. Links and QR codes were promoted to the community to access the survey via social media channels, email newsletters and website/blog posts. Preterm Community Reference Group members assisted in sharing and promoting the survey via their own networks.

The survey had two sections. The first section captured some basic demographic information about the person completing the survey. This was important as we wanted to try and reach a broad cross-section of the community. The second section was for capturing the responses to the Idea Generating questions.

The Idea Generating survey saw 60 people complete and submit the survey leading to 144 unique responses.

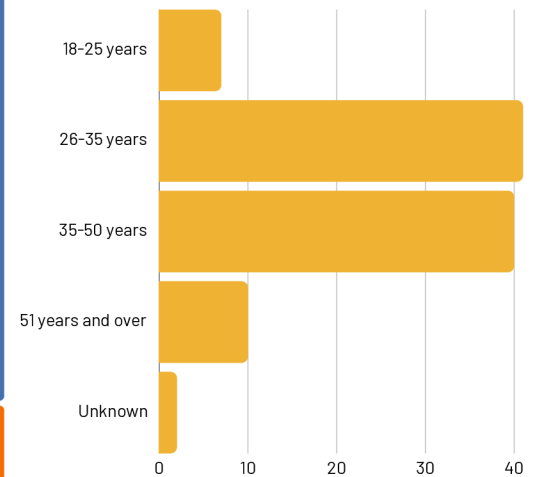
Idea Generating Survey Demographics

People who completed the Idea Generation survey identified as belonging to the following groups:

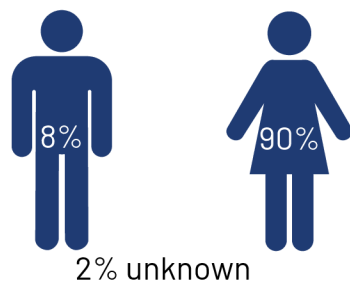
Connection to Preterm Community



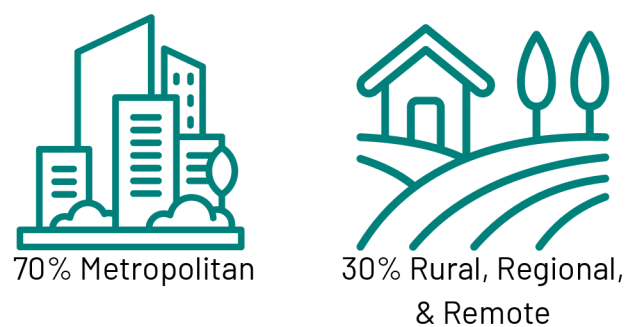
Age Group



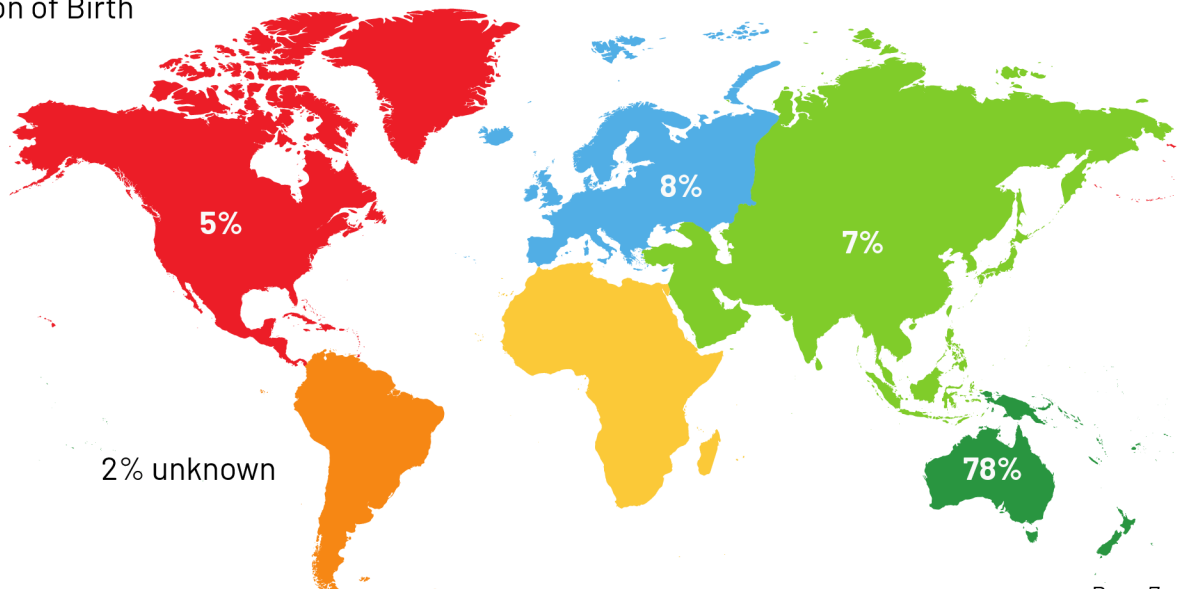
Gender



Area of Residence

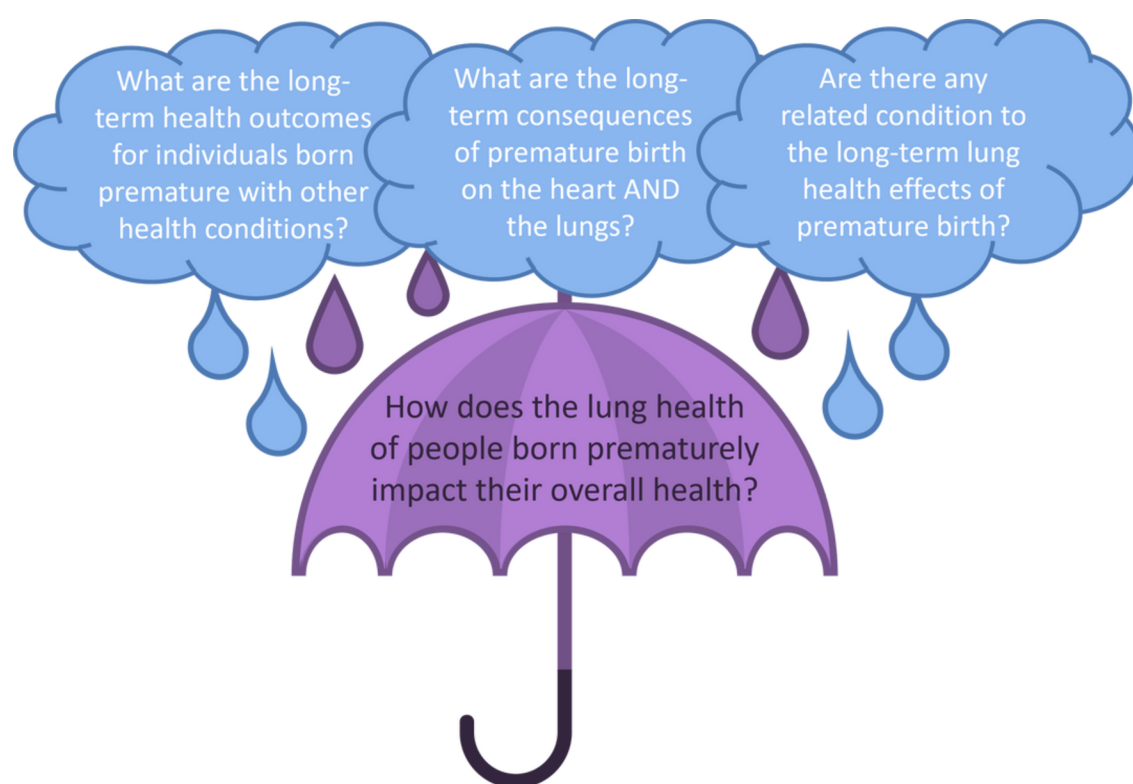


Region of Birth



Response Themes or 'Umbrella Questions'

The responses to the Idea Generating survey were converted into lay language research questions. Once duplicate and out-of-scope questions were removed, there were around 70 remaining questions that we needed to reduce to ~30 to take into the next phase, the Prioritisation survey. The Project Team then reviewed each submitted question and grouped them together where similar themes arose. Following this grouping, new questions that encompassed the ideas submitted were formed. We called these 'umbrella questions'. Here is an example:



These umbrella questions, together with the original questions were then reviewed by the Preterm Community Reference Group to ensure they were an accurate reflection of the original submitted questions. During this process some questions were ungrouped, to form stand-alone questions and some additional questions were grouped together with new umbrella question wording agreed upon. After this process we had 27 unique 'umbrella' questions.

Out of Scope Responses

Less than 10 responses were classified as completely out of scope. These predominantly related to two main themes: Quality of life/mental health impacts and vaccinations e.g. Is it better for a baby born prematurely to have their scheduled vaccinations at corrected or actual age?

Prioritisation Survey

The same networks and channels were used to promote the Idea Generating survey and the Prioritisation Survey. An important part of the Prioritisation Survey design was making sure that the questions were presented in a random order for each person responding. This was done to ensure that all questions received equal evaluation by those responding. We wanted to reduce any possible survey fatigue in our design so we used a simple tick box system. As the responder read through the list they could check the corresponding box to indicate they felt that question was important. They could also change their mind as they read on. They were asked to choose 10 questions they felt were most important to them. The survey could only be submitted when exactly 10 boxes were selected. The order of selection was not important.

Checking the box was just like casting a vote. Once the survey closed, the votes were tallied for each question and the 20 with the most votes were then taken forward to the Consensus Workshop for further exploration. The Prioritisation Survey was a useful tool in reducing the total number of questions from 27 to 20.

On conclusion of the Prioritisation Survey we received 150 completed responses.



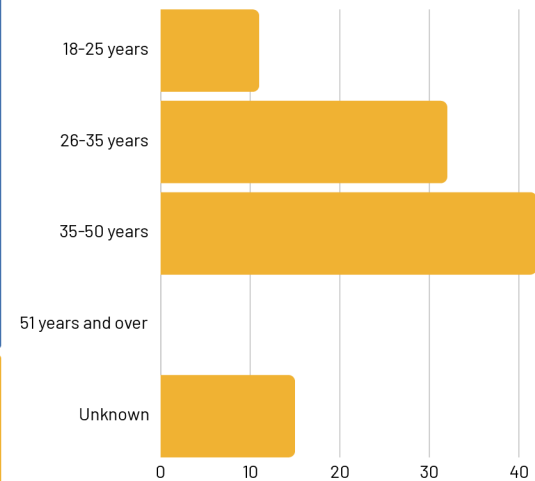
Prioritisation Survey Demographics

People who completed the Prioritisation Survey identified as belonging to the following groups:

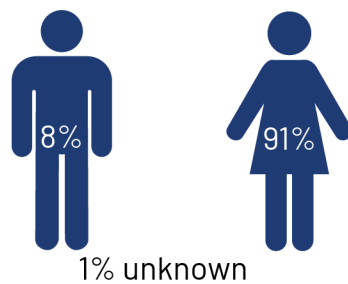
Connection to Preterm Community



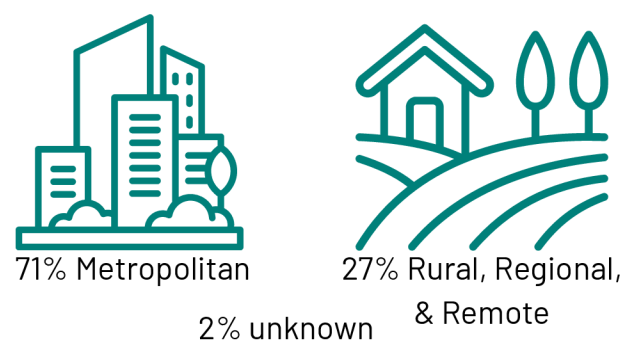
Age Group



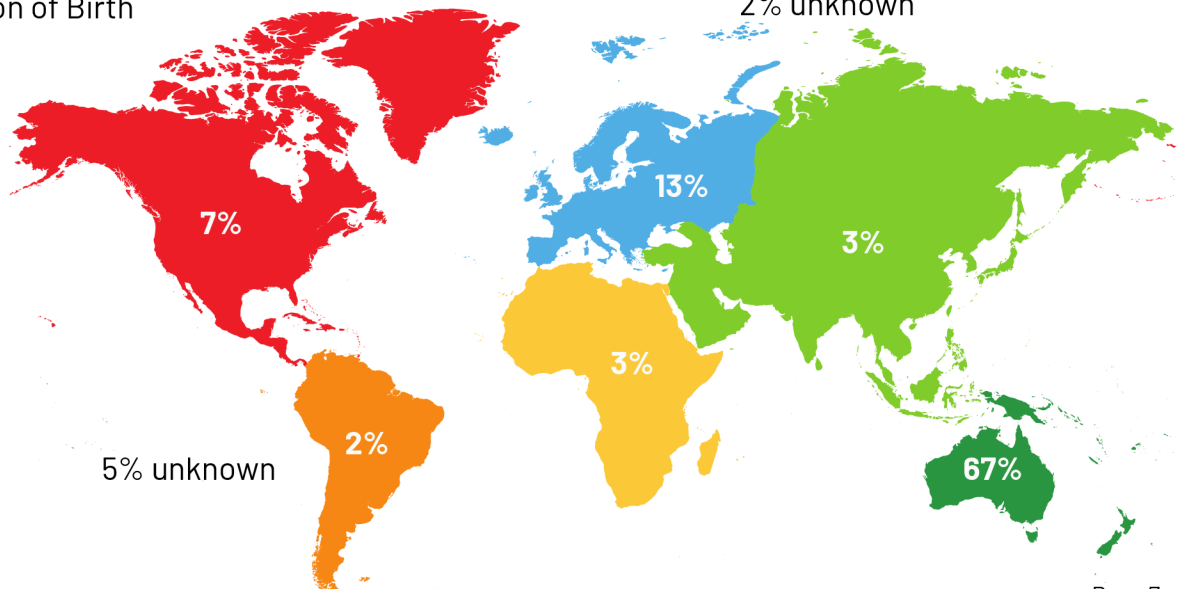
Gender



Area of Residence



Region of Birth



20 Highest Ranked Questions

Will being born prematurely have long term effects on the lungs throughout life?

What are the long-term effects of being diagnosed with chronic lung disease of prematurity as a baby?

Are there any treatments to help the lungs of people born prematurely heal/repair/get stronger as they grow and develop throughout childhood?

Are people born prematurely more likely to have sleep issues e.g. snoring, mouth breathing, sleep apnoea?

Do the lungs of people born prematurely heal/repair/get stronger as they grow and develop throughout childhood?

Will specific sports or other physical activities improve the lung health of people born prematurely?

Should there be ongoing lung health follow-up for people born prematurely?

What are the long-term lung health outcomes from the mother receiving steroids before the baby is born?

What treatment/interventions in the NICU lead to the best ongoing lung health of people born prematurely?

What are the short- and long-term impacts of COVID infection on people born prematurely?

Are people born prematurely at risk of developing a chronic lung disease later in life? What can be done to prevent this?

Are there any supplements/medications that can be taken in pregnancy to improve the lung health outcomes of babies born prematurely?

How do breathing issues relate to other health and developmental issues?

What diagnostic tools are available to primary health care providers to ensure that people born prematurely with ongoing breathing issues are directed to specialist lung health doctors?

How does the lung health of people born prematurely impact their overall health?

Are there better methods for diagnosing chronic lung disease so that we are better able to identify those babies born prematurely that will need ongoing follow-up?

Are people born prematurely likely to develop asthma and will they respond to asthma medications?

How do breathing issues impact on the physical and mental well-being of people born prematurely and what can be done about this?

What are the most effective ways of preventing and/or treating lung infections for people born prematurely?

What breathing symptoms are "normal" in babies and children born prematurely?

Questions NOT taken to Consensus Workshop

Do the medications given to high-risk mothers in pregnancy increase the risk of breathing issues/lung complications for a baby born prematurely?

Are there high-risk settings that people born prematurely should avoid to prevent respiratory illness and for how long?

What is the best way to ensure that families have access to trustworthy, evidence-based information about premature lung health?

What are the lung health impacts for people who were born at a moderate-late stage (33-37 weeks) of prematurity?

If a high-risk setting is unavoidable, what precautions should be taken by people born prematurely to avoid respiratory illness?

What impact does air pollution (e.g. car fumes, bushfire smoke, pollen) have on breathing issues for people born prematurely?

What are the risks to lung health of exposure to tobacco smoke/vaping (active or passive) to people born prematurely?



Consensus Workshop

21 people attended the Consensus Workshop which was held at Perth Children's Hospital. Some travelled from regional areas to attend, showing just how important consumers felt about this topic and the opportunity to have their say. The workshop was four hours long with a lunch break. Belinda Frank facilitated the workshop. Workshop participants were allocated to small groups who sat together around a table. Each group had an independent facilitator who had been briefed on the project, the objectives of the workshop, and their role.

The workshop commenced with an Acknowledgement of Country and an introduction to the project. It was important to set the scene and remind everyone why we were there. The small groups then spent time considering the 'umbrella' questions. Specifically, they were asked to:

- Consider if there were any important questions missing?
- Consider if any of the questions were similar and if so, could they be combined into one question?
- Consider if the language used was easy to understand and to make any necessary changes.

Following the small group discussion feedback was shared with the room in the whole group discussion. This included:

- general feedback on the questions
- ideas for questions that could be combined
- agreement on combining questions
- agreement on new wordings

Workshop Structure

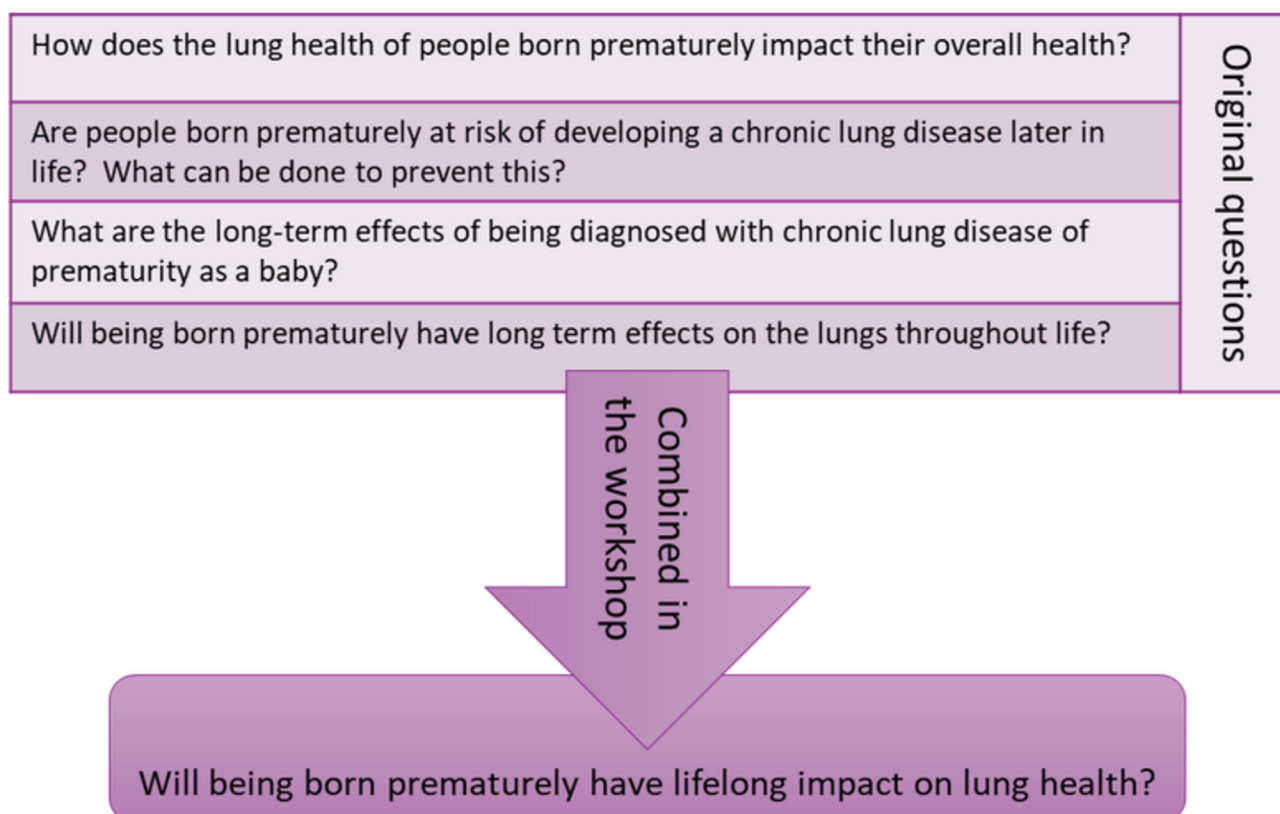


Some emerging topics of conversation at this point included: the difference in care for rural/regional and metropolitan families; how challenging it was to access health care professionals who specialise in this area; the differences between male and female babies within the NICU setting and the role sex plays in the lung health outcomes for people born prematurely. Whilst no specific questions were developed around this, the group felt it was essential to include in the reporting, and that researchers should ensure they are considering demographic data when undertaking research.

Much had been achieved in a short space of time and it was now time for a well-earned lunch break.

After lunch, the small groups were then presented with the final questions for ranking. The 20 questions we started the day with had now been combined and reworded into 15 questions.

An example of four original questions being re-worded and combined into one:



The small groups engaged in discussion and agreement on ranking. Each group developed their own method for ranking the questions from most important to least important. The table facilitators moved cards containing the questions up or down the table as a visual representation of where each question was ranked for the group. At the conclusion of this step the ranking results from each group were collated, and an overall ranking was presented to the room for discussion.

All attendees sat in a large circle with the final questions printed on cards and placed on the floor in their ranked order. There was much discussion from the room and several questions changed places at this stage, until the room reached a consensus decision for each question's final ranking.



Final Ranking

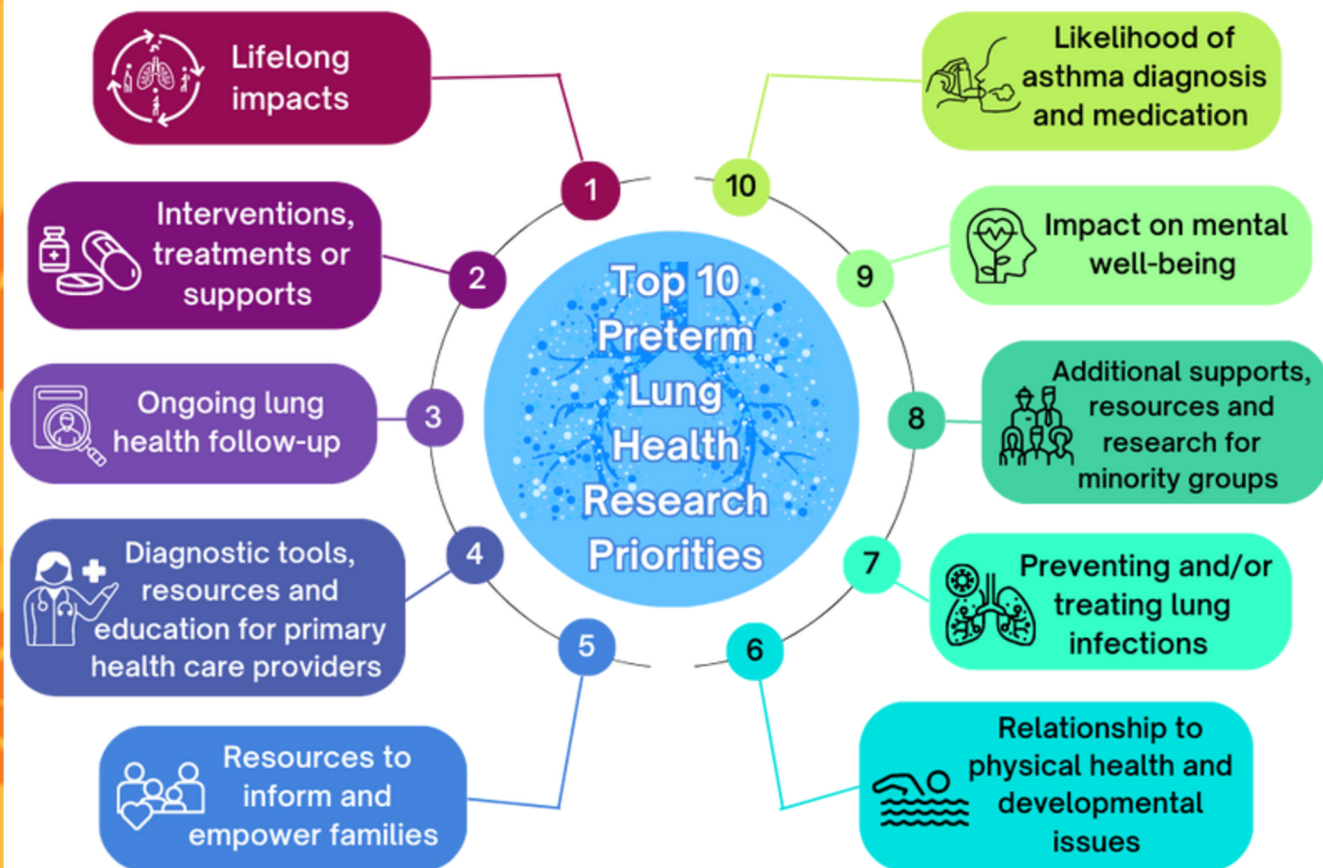
Top 10 Priorities as selected by Consensus Workshop Participants.

- 1 Will being born prematurely have **lifelong impacts** on lung health?
- 2 Are there any **interventions, treatments, or supports** to help the lungs of people born prematurely as they develop?
- 3 Should there be **ongoing lung health follow-up** for people born prematurely?
- 4 What **diagnostic tools, resources and education** are available to **primary health care providers** to ensure that people born prematurely with ongoing breathing issues are cared for and directed to specialist lung health doctors?
- 5 What resources are needed to **inform and empower families** about their premature born child's lung health, and when to seek help?
- 6 How do breathing issues relate to other **physical health and developmental issues** for people born prematurely?
- 7 What are the most effective ways of **preventing and/or treating lung infections** (including COVID) for people born prematurely?
- 8 What **additional supports, resources and research** are needed for the lung health of people born prematurely from **minority groups** such as rural/remote, Aboriginal & Torres Strait Islanders, CaLD communities, people with disabilities, LGBTQI+ etc?
- 9 How do breathing issues impact on the **mental well-being** of people born prematurely and their families and what can be done about this?
- 10 Are people born prematurely likely to **develop asthma** and will they respond to asthma medications?

Final 5 Priorities as selected by Consensus Workshop participants

- 11 Are there **better methods for diagnosing chronic lung disease** so that we are better able to identify those babies born prematurely that will need ongoing follow-up?
- 12 What **treatments/interventions in the NICU** lead to the best ongoing lung health of people born prematurely?
- 13 Are there any **supplements/medications** that can be taken in **pregnancy** to improve the lung health outcomes of babies born prematurely?
- 14 Are people born prematurely more likely to have **sleep issues**, eg: snoring, mouth breathing, sleep apnoea?
- 15 What are the **long-term lung health outcomes** from the **mother receiving steroids** before the baby is born?

Top 10 - Infographic



On conclusion of the workshop there was great energy in the room. Workshop attendees were asked to complete a brief feedback form on the workshop. They shared that they really valued the experience and opportunity to contribute. More specific feedback included:

- More time for group discussion in the final Whole Group session
- Icebreaker at the start of the workshop
- Difficult only being able to choose a Top 10

In addition to providing lunch at the workshop each attendee received an honorarium to cover their time and parking expenses.

Project Challenges

Several challenges were faced by the team during the project timeline, these include:

- The Idea Generation Survey ran over the Christmas period which is an understandably busy time for people. This may have impacted the overall response rate.
- People without internet access were not able to participate.
- Whilst all care was taken to make sure the information presented was as clear as possible, those with low literacy skills, or those who have English as a Second Language may have experienced some challenges in responding.
- Difficult to get participation from health professionals. May be reflective of the fact that preterm lung health is a niche medical speciality.
- COVID-19 was and continues to be circulating in the community, this may have impacted on Workshop attendance.
- In spite of the fact that many potential funders and grant schemes require strong consumer engagement and priority setting there is no specific funding available for prioritisation partnerships.

Conclusion

The Priority Setting Partnership was a robust way of determining the top 10 future research priorities for the lung health of people born prematurely in an Australian context. It is hoped that researchers can use these priorities to leverage funding and support for new projects to answer some of these pressing issues for the community, thus changing the lives of thousands of Australians born prematurely each year, and millions of people globally.

Further Information

Should you wish to obtain copies of the materials used or have any questions about this project please do not hesitate to contact us via email Preterm@thekids.org.au