

EXPLANATORY STATEMENT

Research Forums

Title	Research Priority Setting in Occupational Lung Disease
Project ID number	39219
Project Sponsor	Lung Foundation Australia and Monash University
Chief Investigator/s	<p>Hayley Barnes Department of Planetary Health Email: Hayley.Barnes@monash.edu</p> <p>Lauren Williams Lung Foundation Australia Email: Laurenw@lungfoundation.com.au</p>

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the email addresses listed above.

Why are we conducting this study?

Occupational lung diseases are entirely preventable. It is clear there is a need for a more coordinated and strategic approach to occupational lung disease research in Australia to improve the prevention of these conditions and how best to care for people that are impacted.

Who is funding the study?

Lung Foundation Australia was funded to complete the study by the Department of Health and Aged Care. The funding body has no role in the design or completion of the study activities, including data analysis / interpretation of findings. This will be acknowledged in all output. The Department of Health and Aged Care will receive the top priorities for future research in occupational lung disease each year in an annual report.

What are the aims of this study?

This study aims to collect and synthesise research priorities from a range of people impacted by or interested in occupational lung cancer. The findings will help guide research by ensuring that research funds and efforts are directed to the areas identified as being most important to people impacted by occupational lung diseases.

Who is being asked to participate?

You are invited to participate in this study if you are:

- Living with, or caring for, someone impacted by occupational lung cancer
- Anyone diagnosed with or suspected of having occupational lung cancer
- Anyone at significant risk of occupational lung cancer (i.e., current or former exposure to occupational lung carcinogens in the workplace)
- A multidisciplinary health professional working with people impacted by occupational lung disease

- A professional working in occupational safety or hygiene, epidemiology, public health, organisational behaviour change (particularly in high-risk industries), regulation, or other relevant fields
- A researcher working to understand occupational lung disease, including their prevention
- Another stakeholder with a professional interest in occupational lung cancer or preventing occupational lung cancer carcinogens.

Do I have to participate?

Participation in this study is voluntary.

If you are interested in being involved we ask that you read the information provided and ask us any questions before proceeding.

If you decide that you do not wish to participate this will not affect any treatment or care you currently receive or may do so in the future.

What will I be asked to do?

By registering to attend a free Research Forum hosted by Lung Foundation Australia you will be asked to voluntarily participate in small group discussions to discuss your opinion on the top priorities for future research into occupational lung disease. These small group discussions may be recorded for analysis. In addition, the Research Forums will include presentations and updates on state-of-the-art research from some of Australia's leading researchers in occupational lung health, as well as networking opportunities with policymakers and other key stakeholders.

Possible benefits and risks

There are no immediate personal benefits to you from participating in the study. Instead, your participation and the outcomes from this study will be used to ensure the valuable perspective of those impacted by or interested in occupational lung disease is included in identifying the top priorities for future research in occupational lung disease.

The research team is sensitive to how sharing your opinions in small groups may make you feel and will be on hand to ensure you feel empowered to share your experiences and valuable expertise as someone impacted by an occupational lung disease, at-risk of developing an occupational lung disease, or working with those impacted by occupational lung cancer exposures.

Confidentiality

All information you provide will be kept confidential. Personal identifying information will be stored securely on a password protected database accessible only by relevant project staff. Any study data will be stored separately to personal identifying information. Supplying personal identifying information is optional and you may use a pseudonym if preferred.

The research team is sensitive to how this may make you feel and will work with you to ensure you feel empowered to share your experiences and valuable expertise as someone impacted by an occupational lung disease, at-risk of developing an occupational lung disease, or working with those impacted by occupational lung cancer exposures. Study data may also be used for conference presentations and publication findings may be discussed in the media or used for advocacy efforts.

Storage of data

Research Forum discussions will be recorded for analysis in the finalisation of research themes and priority areas. These recordings will be used to generate anonymous notes. Recordings will then be deleted and all research notes will be retained for a period of five years upon which it will be deleted. Any personal information provided during

registration will be stored separately from research data in password protected electronic files accessible to the research team.

Use of data for other purposes

In accordance with data sharing guidelines, de-identified data may be made available for use by other authorised researchers. This data will be held on secure public repositories and may be a requirement of some journals prior to publication. Any shared data will not include your identifying details.

Results

A summary of the results will be available on the Lung Foundation Australia website after conclusion of the Research Forums.

Consenting to participate in the project and withdrawing from the study

Clicking the link at the end of this document indicates that you have read this explanatory statement and consent to participating in the study via an online survey. However, it is important to note that if you are completing the online survey anonymously (i.e., you choose not to leave your contact details) it will not be possible to identify your responses to remove these once you have submitted your responses.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Office of Research Ethics and Integrity
Room 116, Administration Building B (3D)
26 Sports Walk, Clayton Campus
Monash University VIC 3800
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Clicking 'Next' indicates that you wish to register for the Research Forum and consent to participate in this study.