

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>Sharna Mathieu Lung Foundation Australia Email: sharnam@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. Despite this, there has been a recent re-emergence of silicosis in Australia. 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 silicosis. 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 silicosis
- At risk of silicosis through your job (e.g., construction, mining, quarrying, tunnelling, manufacturing, stonemasonry)
- 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 silicosis and/or preventing silica dust exposure

Do I have to participate?

Participation in this study is voluntary.

If you are interested in being part 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 will take 1.5 hours for virtual discussions and 2 hours for in person discussions and will be recorded for analysis. Additional time will be set aside for providing you with background information and breaks and is outlined in the associated agenda. In addition to small group discussions, 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.

Where will the Research Forums take place?

Depending on which Research Forum you register for and attend, the forum may take place in person or virtually. The in-person forum will be held in Melbourne on Monday 9th of October at The Savoy Hotel on Little Collins (630 Little Collins Street Melbourne VIC 3000 Australia). The virtual forum will be held via the Zoom or Microsoft Teams platform. A meeting link with instructions on how to access the virtual forum platform will be provided to all registrants. Attendance at the virtual forum will require a stable internet connection.

Additional research

Following the Research Forum you will receive a link to an online survey via the email address you provided. This survey will ask you to rank the final priorities based on your opinion. This survey is anonymous and not tied to your participation in the Research Forum or any other aspect of the project. As always, completion of this survey is optional.

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 silica exposure.

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.

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 small group discussions will be recorded for analysis in the finalisation of research themes and priority areas. These recordings will be used to generate anonymous notes (versus verbatim transcripts). 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

Attending the Research Forum and voluntarily engaging in the small group discussions will be considered as your consent for this aspect of the research. You do not have to participate in these discussions although this will form a substantial part of each Research Forum. If you do not wish to participate you can let the facilitator or member of the research team know privately. An agenda will be provided so you are aware of when small group discussions are planned, and you can leave and return. Prior to each small group discussion, the small-group facilitator will ask for each group's permission to record the discussions. The facilitator will also ensure that everyone understands the purpose of the recordings and that they are anonymous and will be deleted at the completion of the study.

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
Tel: +61 3 9905 2052 Email: muhrec@monash.edu