MONASH
University

EXPLANATORY STATEMENT

Respiratory and thoracic physicians managing people with an interstitial lung disease

TOWARDS INDIVIDUALISED AND EQUITABLE CARE FOR INTERSTITIAL LUNG DISEASE (ILD)

Project ID: 41236

Chief Investigator: Professor Anne Holland

Co-Investigator: Dr Gabriella Tikellis

Organisation: Monash University & Alfred Health

This research is being funded by the National Health and Medical Research Council (NHMRC) Centre of Research Excellence in Pulmonary Fibrosis (ID #2015613)

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed below.

1. What is the study about?

People with interstitial lung disease (ILD) require ongoing monitoring and treatment from their health professionals. Specialist ILD services are available across Australia however, important gaps in the equity of care were identified particularly in rural/regional Australia. Regional patients were found to have poor access to clinical trials, non-pharmacological therapies and psychological support. **Participation in this study will help address the inequity of care outside tertiary ILD centres by identifying barriers to optimal care for those working in these environments**. This in turn will help guide the establishment of a network of ILD care so that more people with ILD will be able to access optimal care.

2. Why were you invited to participate in this research?

The study is being promoted through the TSANZ monthly Research Round Up e-bulletin that is emailed to all TSANZ members, Lung Foundation Australia and through ILD clinics throughout Australia.
As a respiratory and/or thoracic physician who manages people with ILD but is not currently working as part of an ILD service, we are looking to understand your perspective on the access you have to ILD care services in your working environment. We are particularly interested in identifying any barriers that you may be encountering and your thoughts on what could be done to address these challenges.

3. 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 below and ask us any questions before proceeding.

If you decide that you do not wish to participate this will not affect your association or dealings with TSANZ or any of the any of the affiliated organisations and institutes involved in this research.

4. What do I need to do to participate?

Participation involves completing the online questionnaire. The questionnaire will ask you to contribute your perspectives on your access to ILD-related services associated with the diagnosis and management of patients with ILD. The questionnaire can be completed by either clicking on the link or scanning the QR code and should take about 10-15 minutes to complete.

5. Consenting to participate in the project and withdrawing from the research

Completion of the online questionnaire implies that you consent to researchers using the information you provide for the purpose of the research outlined above.
You will have the option of providing your contact information at the end of the questionnaire if you are happy to be contacted in future to participate in further research associated with the development of this project.

6. Possible benefits and risks to participants

It is possible that there will be no direct benefit to you for taking part in this study. The wider potential of taking part in this research is that the information gathered from physicians who deal with ILD may provide a better understanding of the barriers associated with implementing best practice in clinical settings outside tertiary centres. Such findings will be important for the development of approaches for reducing the inequity in ILD care across Australia.

We do not expect this study to cause any harm or discomfort. If you have any concerns about the study or your participation, you can contact the Chief Investigator Professor Anne Holland: see contact details below.

7. Confidentiality

The questionnaire distributed is through an anonymous link. Therefore, respondents cannot be identified unless they voluntarily provide their contact information as part of the questionnaire. However, all data collected through the questionnaire will be de-identified for the purposes of analysis and subsequent reporting of findings at conferences and/or the publication in international peer-reviewed journals.

8. Storage of data

All data will be stored securely on the secure research drive at Monash University. Access to this drive is via an authorised password and the names of those with access is kept by the University.
We will keep your information for a minimum of 5 years from the date that the results are published. After this time, we will destroy all the data. The storage, transfer and destruction of the data will be undertaken in accordance with Monash University’s Data Storage and Retention policies.

9. Results

As the findings from this initial phase of the research will guide the development of the next stage, it is anticipated that the results will be form part of the reporting of the overall body of work that will be published in peer-reviewed journals and presented at conferences.

10. 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

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Thank you,

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