Austin Health

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(This document must be scanned into the Austin Health SMR once the participant has consented)

Participant Information Sheet/Consent Form

Qualitative Study (Physician) – *Adult providing own consent*

Title	Patients' and physicians' perspectives on the use of domiciliary oxygen therapy in interstitial lung disease
Short Title	Domiciliary oxygen therapy in interstitial lung disease
Protocol Number	LNR/15/Austin/46
Project Sponsor	Not applicable
Principal Investigator	Prof Christine McDonald
Associate Investigators	Dr Yet Hong Khor A/Prof Anne Holland Dr Nicole Goh
Location	Austin Health

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project as you look after patients with interstitial lung disease. The research project aims to explore your views and experience with the use of oxygen in interstitial lung disease.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the tests and treatments involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your local doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:
• Understand what you have read
• Consent to take part in the research project
• Consent to have the interview that is described

You will be given a copy of this Participant Information and Consent Form to keep.

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2 What is the purpose of this research?

Interstitial lung disease is an important lung problem that can make people breathless, tired and unwell. Oxygen may be used as a treatment for some people with this condition. We want to learn about your views on the use of oxygen in patients with interstitial lung disease and why the patients may or may not want to use oxygen as part of their treatment. We also want to know more about how oxygen is prescribed in patients with interstitial lung disease. This knowledge might help us to learn how to improve the use of oxygen in this illness.

The results of this research will be used by Dr Yet Hong Khor to obtain the degree of Doctor of Philosophy.

This research has been initiated by Professor Christine McDonald.

This research has been funded by Institute for Breathing and Sleep.

3 What does participation in this research involve?

Procedures
We are inviting you to take part in this research project which is aimed at helping us to learn more about the experience and prescription of the use of oxygen in patients with interstitial lung disease. If you agree to be involved, you will be asked to participate in an interview with one of the researchers mentioned above.

Ideally, the interview will take place with you in a comfortable place at the Austin Hospital. However, if it is better for you, the interview can take place over the telephone. If there are any questions you do not wish to answer during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except the researchers of this study will have access to the information documented during your interview. The entire interview will be tape-recorded, but no one will be identified by name on the recording. The recording will be kept so that the information is recorded accurately. The recordings will be destroyed at the end of the study.

Duration
The research will involve a single interview lasting about 30 minutes.

4 Do I have to take part in this research project?

Your participation in this research project is entirely voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

5 What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research; however, your participation is likely to help us to find out more about the use of oxygen in people with interstitial lung disease.

6 What are the possible risks and disadvantages of taking part?

We are asking you to share with us some personal and confidential information. If you feel uncomfortable talking about some of the topics, you do not have to answer the questions. You do not have to give us any reason for not responding to the questions during the interview.

7 What if I withdraw from this research project?

You do not have to take part in this research if you do not wish to do so. You may stop participating in the interview at any time that you wish. The interviewer will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with the notes or if the interviewer did not understand you correctly.

8 What happens when the research project ends?

At the end of the research, each participant will receive a summary of the results. We will also publish the results at the end of the research so that other interested people may learn from the research.

Part 2 How is the research project being conducted?

9 What will happen to information about me?

By signing the consent form you consent to the study doctor and relevant research staff collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Any information about you will have a number on it instead of your name. Only the researchers of this study will know what your number is and we will lock that information up with a lock and key at the Austin Health Department of Respiratory Medicine (Bowen Centre). Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in

such a way that you cannot be identified, except with your permission. All information will be published anonymously and nothing will be attributed to you by name.

In accordance with relevant Australian and Victorian privacy and other relevant laws, you have the right to request access to your information collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

11 Complaints and compensation

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

12 Who is organising and funding the research?

This research project is being conducted by Professor Christine McDonald and funded by the Institute for Breathing and Sleep.

13 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of Austin Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

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14 Further information and who to contact

The person you may need to contact will depend on the nature of your query.

If you want any further information concerning this project or if you have any medical problems which may be related to your involvement in the project (for example, any side effects), you can contact the principal study doctor on 03 9496 3845 or any of the following people:

Clinical contact person

Name	Dr Nicole Goh
Position	Associate Investigator
Telephone	03 9496 5390
Email	Nicole.Goh@austin.org.au

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	Dr Sianna Panagiotopoulos
Position	Manager, Office for Research
Telephone	03 9496 4090
Email	ethics@austin.org.au

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Consent Form – *Adult proving own consent*

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Associate Investigator(s)	Dr Yet Hong khor A/Prof Anne Holland Dr Nicole Goh
Location	Austin Health

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I understand that information collected during the interview will remain confidential.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the study without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Name of Witness* to Participant's Signature (please print) _____

Signature _____ Date _____

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older.

Declaration by Study Doctor/Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher† (please print) _____

Signature _____ Date _____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.