

Participant Information Form

Health/Social Science Research

Title: Exploring Current Needs, Knowledge, and Perspectives of Singing for Breathing (SFB) Programs Among People with Chronic Respiratory Disease (CRD) and their Informal Caregivers

Project ID:

Co-ordinating Principal Investigator: Prof Natasha Smallwood

Associate Investigators: Ms Stefanie Zappino, Prof Anne Holland,
A/Prof Jeanette Tamplin, Dr. Amy Pascoe

Location: Monash University

Part 1 What does my participation involve?

1. Introduction

You are invited to take part in this research project, which is called “*Exploring Current Needs, Knowledge and Perspectives of SFB Programs Among People with CRD and their Informal Caregivers*”. You have been invited because you have a diagnosis of Chronic Obstructive Pulmonary Disease (COPD), Interstitial Lung Disease (ILD) or thoracic malignancy or are an informal caregiver of someone with COPD, ILD or thoracic malignancy.

This Participant Information Form tells you about the research project. It explains the processes involved with taking part. 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.

Participation in this research is voluntary. If you don’t wish to take part, you don’t have to.

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 be involved in the research described

2. What is the purpose of this research?

There is growing interest in group singing interventions for lung disease, known as Singing for Breathing programs with research showing promise for improving symptom management and

quality of life. Despite this, a considerable lack of consistency has been noted in how programs are delivered and structured. Additionally, no such programs have been investigated within an Australian context and minimal research has investigated programs in New Zealand.

This project is led by Prof Natasha Smallwood (Respiratory Physician and Director of Respiratory Medicine at Alfred Health and Monash University). The research will be conducted Ms Stefanie Zappino (as part of PhD program at Monash University) and aims to evaluate the current needs, knowledge, and perspectives of people with chronic respiratory disease and their caregivers relevant to Singing for Breathing programs delivered in Australia and New Zealand. It also aims to explore the current knowledge, attitudes, and perspectives of people with chronic respiratory disease and their caregivers towards Singing for Breathing programs to enable us to consider how to best design and deliver programs that effectively address the needs of people with chronic respiratory disease.

3. What does participation in this research involve?

You will be asked to read and sign a consent form prior to any study assessments being performed. Participation in this project will involve:

- You will be asked to take part in an interview via videoconferencing or telephone with a trained member of the research team (Stefanie Zappino – Monash University, PhD Candidate) at a time that is convenient for you. The interview will take about 30-40 minutes.
- The researcher will ask you to describe your knowledge and perspectives on singing for breathing programs for people with chronic respiratory disease and explore your opinion on where they fit in the current treatment landscape of chronic respiratory disease. This discussion will include the potential benefits and barriers to group singing interventions for people with chronic respiratory disease, the settings they are delivered in, and the facilitation of programs. These questions will guide the discussion, but you will have the freedom to respond with intro you feel is important and relevant as we are interested in hearing what you have to say. Prior knowledge or experience of singing for breathing programs is not needed to participate.
- No personal or identifiable information will be collected. However, you will be asked a few demographic questions (disease you are diagnosed with, age, gender, location) to ensure we obtain a balanced sample of participants.
- Interviews will be audio recorded, with ONLY AUDIO files being kept. Any video recording made as a part of a video-conferencing process will be IMMEDIATELY deleted at the conclusion of the interview.

This study will run over the course of 2025-2026, and we aim to recruit a total of 15-20 participants. However, you will only be actively involved at the time of your interview.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids researchers or participants jumping to conclusions.

There are no costs associated with participating in this research project. You will not be asked to specifically attend any location for a research project visit. You will not be paid for your time.

4. Other relevant information about the research project

This project is being undertaken at the School of Translational Medicine (Alfred Hospital), Monash University, Melbourne. Those living with or caring for someone with chronic respiratory disease eligible to participate in this study will be identified through advertising through consumer advocacy groups and patient facing organisations (e.g. Lung Foundation Australia and the Asthma and Respiratory Foundation New Zealand).

5. Do I have to take part in this research project?

Participation in any research project is 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. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect, your relationship with professional staff or your relationship with Monash University.

6. What are the possible benefits of taking part?

We cannot guarantee that participants will receive any benefits from this research. The results from this study may benefit group singing interventions service provision and the people who use non-pharmacological support therapies in the hospital and community setting by contributing to the development of a model of care for singing for breathing programs. The findings from this study will be used to inform future work to support people with chronic respiratory disease to maintain and improve quality of life and symptom management.

7. What are the possible risks and disadvantages of taking part?

We do not foresee any risks associated with participation in this project. If you do feel that one or some of the questions, we ask are stressful, then you do not have to answer. Instead, you may skip the question and go to the next question, or you may stop the interview immediately. If you have any concerns about the study or your participation, you can contact the Complaints Person, see details below.

8. What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional information from you, although information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You

should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9. Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as failure to recruit sufficient participants or staffing changes within the research team.

10. What happens when the research project ends?

Interviews will be completed over 2025-2026. Once sufficient information has been collected to complete the study, the study will end with no further interviews undertaken. It is anticipated that the first results from this study will be published within 1-2 years. If you would like to receive a summary of the results from this research study, please select this option on the consent form. We will then ensure that you are posted the results summary as soon as this is available.

Part 2 . How is the research project being conducted?

11. What will happen to information about me?

By signing the consent form you consent to the research team 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.

Some information (such as any notes written during the interview) may be collected on paper and transferred to electronic format for analysis. Paper data notes will then be destroyed. Your interview will be recorded, as this allows the interviewer to listen to you properly. The audio recording will be transcribed to an electronic document, which will not include your name or any identifiable data. Once transcribed the audio recording will be destroyed so that your interview is anonymous. Transcribed, anonymous interviews will be analysed by members of the research team to look for themes.

No identifiable information will be recorded on the transcribed interview. Each participant will be allocated a unique research record number which will be assigned to the interview. This record number will not be linked to your name or any identifiable data, so that data collected in this study will not be re-identifiable.

Anonymous, electronic data (from the transcribed interview) will be stored on the password-protected work computer of the research team for at least 5 years after study completion. Only the researchers involved in analysing the results will have access to anonymous electronic data.

Any information obtained in connection with this project and that can identify you will remain confidential and will not be passed to any other organisation. 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. Therefore, information related to age or disease severity will be given as averages for each patient group and not for individuals. Similarly, only anonymous quotes will be used in the publications/presentations, so it will not be possible to identify you.

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

12. Complaints and compensation

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), details below. In the event of loss or injury, the parties involved in this research project have agreed to sit and discuss any concerns with participants. Please note, this study will be asking all participants the same questions.

13. Who is organising and funding the research?

This research project is led by Professor Natasha Smallwood and her research team at Monash University, including Ms Stefanie Zappino (PhD candidate), who's supported by an NHMRC-funded Centre for Research Excellence for Pulmonary Fibrosis.

No financial benefits are anticipated from this research study. No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14. 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 Monash University Human Research Ethics Committee (MUHREC). 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.

15. 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 questions relating to your involvement in the project, you can contact the following people:

Clinical contact person

Name	<i>Ms Stefanie Zappino</i>
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Position	<i>Senior Music Therapist, PhD Candidate, The Alfred Hospital, Central Clinical School, Monash University</i>
Telephone	<i>TBC voice mail to be set up on Monash office phone</i>
Email	<i>Stefanie.zappino@monash.edu</i>

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Name	<i>Monash University Human Research Ethics Committee</i>
Position	<i>Executive Officer</i>
Telephone	<i>+61 3 9905 2052</i>
Email	<i>muhrec@monash.edu</i>

Consent Form - Adult providing own consent

Title: Exploring Current Needs, Knowledge and Perspectives of Singing for Breathing Programs Among People with Chronic Respiratory Disease and their Informal Caregivers

Short Title: Knowledge and Perspectives of People with CRD and their Caregivers

Project Sponsor: Investigator initiated

Project ID:

Co-ordinating Principal Investigator: Prof Natasha Smallwood,

Associate Investigators: Ms Stefanie Zappino, Prof Anne Holland, A/Prof Jeanette Tamplin and Dr Amy Pascoe

Location: Monash University

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 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 project without affecting my future care.

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

I consent to the interview being audio-recorded (please tick the box)

I would like to receive a copy of the results summary (please tick the box)

Name of Participant (please _____)	
Signature _____	Date _____

Declaration by 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 Researcher [†] (please print)	
Signature _____	Date _____

[†] An appropriately qualified 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.

Form for Withdrawal of Participation - Adult providing own consent

Title: Exploring Current Needs, Knowledge and Perspectives of Singing for Breathing Programs Among People with Chronic Respiratory Disease and their Informal Caregivers

Short Title: Knowledge and Perspectives of People with CRD and their Caregivers

Project Sponsor: Investigator initiated

Project ID:

Co-ordinating Principal Investigator: Prof Natasha Smallwood

Associate Investigators: Ms Stefanie Zappino, Prof Anne Holland, A/Prof Jeanette Tamplin and Dr Amy Pascoe

Location: Monash University

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers

Name of Participant (please _____ Signature _____ Date _____

In the event that the participant’s decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

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Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

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Name of Researcher (please print)	
Signature _____	Date _____

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project. Note: All parties signing the consent section must date their own signature.