

Participant Information Form

Health/Social Science Research

Title: Needs, knowledge, and perspectives of people with chronic respiratory disease and their caregivers regarding Singing for Breathing programs

Project ID:

Co-ordinating Principal Investigator: A/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 “*Needs, knowledge, and perspectives of people with chronic respiratory disease and their caregivers regarding Singing for Breathing programs*”. You have been invited because you have a diagnosis of chronic obstructive pulmonary disease, interstitial lung disease or thoracic malignancy, or are an informal caregiver of someone living with one these lung conditions.

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 provide consent via the first survey question, “Do you consent to participant in this online survey?”. By selecting yes, 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?

Participation in this project will involve completing an online questionnaire. The questionnaire will ask you about your condition and symptoms, or the condition and symptoms of the person you care for, and basic demographic details, such as your age, gender and geographic location. The survey is designed to explore the current needs, knowledge, and perspectives of people with lung conditions and their caregivers regarding Singing for Breathing programs and will also ask questions about your general engagement with music and current strategies for symptom management. The questionnaire can be completed by clicking on the link and should take 10-15 minutes to complete. The study will run over the course of 2025. There are no costs associated with participating in this research project, nor will you be paid.

4. Other relevant information about the research project

This project is being undertaken at the School of Translational Medicine (Alfred Hospital), Monash University, Melbourne. People with a diagnosis of chronic obstructive pulmonary disease, interstitial lung disease, or thoracic malignancy and their informal caregivers eligible to participate in this study will be identified via the Lung Foundation Australia, the Asthma and Respiratory Foundation New Zealand and networks of the research team.

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. You are free to withdraw from the project at any stage by leaving the survey. If you do decide to take part, you will be asked to tick the consent box at the beginning of the online survey.

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 or any of the affiliated organisations and institutes involved in this research.

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 inform future work to support people with lung conditions 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, harms or discomfort 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

survey. 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 by leaving the survey. 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?

Data from the survey will be collected during 2025. It is anticipated that the results from this study will be published and publicly available within 1-2 years. If you would like to receive a summary of the results from this research study, please contact the research team through the details below. 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 selecting the consent box at the beginning of the online survey you consent to the research team collecting and using the information provided for the research project. Any information obtained in connection with this research project will remain confidential. The questionnaire is distributed through an anonymous link. Therefore, respondents cannot be identified unless they voluntarily provide their contact information as part of the questionnaire.

Electronic survey data will be stored in secure Monash University cloud-based, password-protected folders for a least 5 years from the date of publication. After this time, we will destroy all the data. Only the researchers involved in analysing the results will have access to anonymous electronic data.

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 clinical service and provider perspectives will be given as averages, and not for individuals. Similarly, only anonymous quotes will be used in any publications or 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

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|-----------|---|
| Name | <i>Ms Stefanie Zappino</i> |
| 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

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

