

## Participant Information Form

### Health/Social Science Research

<b>Title:</b>	MOSAIC-Aus
<b>Project ID:</b>	42717
<b>Co-ordinating Principal Investigator:</b>	A/Prof Natasha Smallwood
<b>Associate Investigators:</b>	Dr Anne Walker, Prof Anne Holland, A/Prof Donald Sullivan, Prof Phan Tien Nguyen
<b>Location:</b>	Monash University

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#### **Part 1 What does my participation involve?**

##### **1. Introduction**

You are invited to take part in this research project, which is called “*MOSAIC-Aus: Models of Supportive Care in Lung Cancer - Australian Healthcare Provider Perspectives*”. You have been invited because we recognise that you are a clinician working in lung cancer care in Australia.

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 verbally asked to consent prior to commencing the interview. In doing so, 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?**

Providing palliative and holistic symptom management to people with lung cancer can be challenging. The current implementation and service delivery across Australia and New Zealand is unknown. There is no defined optimal model of care, to effectively and efficiently address the palliative and symptom needs of people with lung cancer and their carers.

This project, initiated and led by Dr Annie Walker (Monash University), aims to evaluate the current system, access, attitudes, barriers and facilitators to palliative care and symptom management for people with lung cancer. It aims to identify clinicians' perspectives on optimizing service provision and role allocation in palliative care in the modern era of lung cancer care.

##### **3. What does participation in this research involve?**

Verbal consent will be obtained and recorded prior to any study assessments being performed.

Participation in this project will involve:

- Participating in an interview via videoconferencing, telephone or face-to-face with trained member(s) of the research team, at a time which is convenient for you. The interview will take about 30-40 minutes.
- The researcher(s) will ask you to describe your experience in providing care for people with lung cancer and the integration with palliative care. Topics discussed will include facilitators, barriers and how to best optimize the model of care in the context of the modern treatment landscape in lung cancer. These questions will guide the discussion, but you will have the freedom to respond with what you feel is important and relevant as we are interested in hearing what you have to say.
- No personal or identifiable information will be collected. However, you will be asked some demographic questions that will help us to understand who is participating in our research and to ensure we obtain a balanced sample of participants.
- Interviews will be audio recorded, with only audio files being kept. Audio recording will be used to transcribe the recording verbatim with all identifying information removed. Monash University Zoom live AI closed captioning may be used to assist in transcriptions. Human transcription and dictation services may be used to assist in transcribing interview scripts. The audio recording will be deleted after transcription has been completed. You may request to review and amend any transcripts of your participation. If you wish to review your transcript, this request must be made to the interviewer or another member of the research team within two weeks of completing your interview.
- Any video recording made as a part of the video-conferencing process will be immediately deleted at the conclusion of the interview.

This study will run over the course of 2024-2025, while we aim to recruit a total of approximately 24 participants. However, you will only be actively involved at the time of your interview.

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 Central Clinical School (Alfred Hospital), Monash University, Melbourne. Respiratory, palliative care or oncology doctors or specialised lung cancer nurses, from around Australia who are eligible to participate in this study will be identified through the profession and research 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.

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 other affiliated organisations and institutes involved in this research.

## **6. What are the possible benefits of taking part?**

It is possible that there will be no direct benefit to you for taking part in this study. The wider potential of this research may benefit the future optimization of palliative and symptom management for people with lung cancer. This research can help identify gaps and barriers in current provision model of palliative care and understand service providers perspectives in improving this model of care.

## **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 interview immediately. You will not be paid for your time. 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 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 2024-2025. 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 providing verbal consent prior to the interview, 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. Monash University Zoom live AI closed captioning may be used to assist in transcriptions. Human transcription and dictation services may be used to assist in transcribing interview scripts. 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 computers of the research team for at 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.

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 experience level or other demographics will be given as averages for each 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 being conducted by Dr Anne Walker. It is supported by an Australian Government Research Training Program Scholarship.

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 HREC of Monash University.

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>Dr Annie Walker</i>
Position	<i>Consultant Respiratory and Sleep Physician. PhD Candidate, The Alfred Hospital, Central Clinical School, Monash University</i>
Telephone	<i>+61 3 9903 8735</i>
Email	<i>Anne.Walker@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>