Participant Information Statement

[Participant group – Stage 2: focus group]

Research Study – Palliative Paramedicine: Delphi Study and Focus Group with Experts on Implementation Strategies

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You are invited to participate in this research project titled, "Palliative Paramedicine: Delphi Study and Focus Group with Experts on Implementation Strategies".

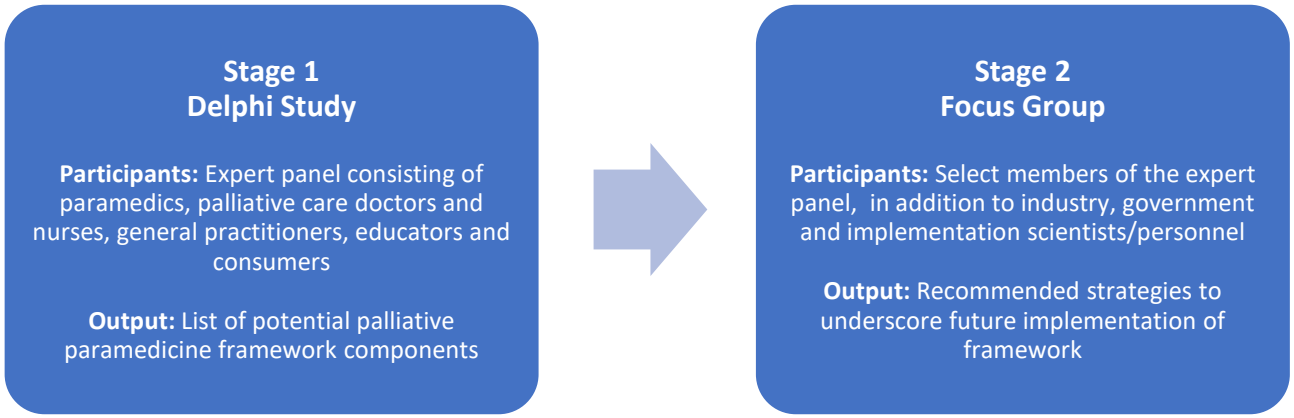
This Participant Information Statement tells you about the research project and explains what is involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything you don't understand or want to know more about. Participation in this research is voluntary, so it's up to you whether you wish to take part or not.

1. What is this study about?

We are conducting a research study about palliative paramedicine, employing a two-stage approach to develop a best practice framework for Australian paramedics to deliver palliative and end-of-life care, which will be suitable for national implementation.

In the first stage, a Delphi study, we gained consensus from an expert panel regarding the framework components considered most essential for improving paramedics' role in community-based palliative and end-of-life care. You will have received a copy of the framework to review. In the second stage we will conduct a focus group with select members of the expert panel, alongside industry, government and implementation specialists, to understand barriers and elicit recommended strategies to underscore the future national implementation of the framework.



Taking part in this study is voluntary.

Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

The study is being carried out by the following researchers:

- Professor Josephine Clayton; Professor of Palliative Care, University of Sydney Northern Clinical School; Senior Specialist Palliative Care Physician and Director of Palliative Care Research and Learning, Greenwich Hospital and The Palliative Centre, HammondCare.
- Dr Madeleine Juhrmann; Research Fellow, Flinders University Research Centre for Palliative Care Death and Dying (RePaDD) and School of Paramedicine; Honorary Research Fellow, The Palliative Centre, HammondCare; and Adjunct Research Fellow, University of Technology Sydney Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)
- Professor Emerita Phyllis Butow; Professor of Psychology, University of Sydney School of Psychology
- Associate Professor Mark Boughey; Associate Professor of Palliative Care, University of Melbourne Medical School; Director of Palliative Medicine, St Vincent's Hospital; and Deputy Director St Vincent's Hospital Centre for Palliative Care
- Associate Professor Paul Simpson; Associate Professor of Paramedicine and Director of Paramedicine Programme, Western Sydney University; Intensive Care Paramedic, New South Wales Ambulance
- Professor Meredith Makeham; Professor of General Practice, University of Sydney Faculty of Medicine and Health
- Dr Oluwatomilayo Omoya; Research Associate, Flinders University College of Nursing and Health Sciences; and Emergency Nurse, Queen Elizabeth Hospital
- Ms Sophia Flanagan-Sjoberg; Honours candidate, Flinders University College of Nursing and Health Sciences; and Paramedic, South Australian Ambulance Service

3. Who can take part in the study?

We are inviting clinicians, educators, consumers, policy experts and research personnel with lived experience and/or expertise in palliative paramedicine to participate in this study.

You have been invited to participate in this study because you are a participant of our previous Delphi study that has indicated interest to participate in this next stage, a member of our palliative paramedicine collegial network, and/or an opinion leader with a publicly available email address.

4. What will the study involve for me?

If you decide to take part in this study, you will be asked to participate as part of a select expert panel in an online focus group via Zoom. The semi-structured focus group will take as long as the participants require (maximum commitment 120 minutes). All participants will complete a short demographic questionnaire to allow the sample to be described and differences between subgroups to be explored.

The research team will share the framework Delphi study (stage 1) with the participants prior, and you will be asked during the focus group to share your perceptions on the barriers and enablers for implementing the framework into policy and practice. The focus group will be video and audio-recorded and transcribed verbatim. The video recording will be deleted immediately following the session. A deidentified transcript will be generated from the focus group and will be thematically analysed by the research team. Your personal information will remain confidential at all times.

Participants will be given the optional opportunity to review information generated from the focus group prior to publication of the findings.

Can I withdraw once I've started?

Being in this study is completely voluntary and you do not have to take part.

We do not anticipate your decision will affect your current or future relationship with the researchers or anyone else at The University of Sydney. If you take part in the focus group, you are free to stop at any stage or to refuse to answer any of the questions. However, since it is a group discussion, it may not be possible to withdraw individual comments from records once the discussion has started".

5. Are there any risks or costs?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study. However, it is possible that reflecting on palliative and end-of-life care may be upsetting for some participants. Participants who express feelings of distress when expressing their perspectives will be referred to support services Lifeline '13 11 14' and Beyond Blue '1300 22 46 36' and will be advised to see their general practitioner for further review and support. If distress is evident, participants will be offered the opportunity to pause or cease participation in the focus group completely.

6. Are there any benefits?

This study is significant as developing an evidence-based implementation strategy will inform the future translation of the framework into sustainable policy and practice. However, we cannot promise or guarantee that you will receive any direct benefits from participating in this study.

7. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you for the purposes of this study.

Any information you provide us will be stored securely and we will only disclose it with your permission unless we are required by law to release information. We are planning for the study findings to be published.

You will not be individually identifiable in these publications. Quotations will be labelled with occupation or family member/carer (e.g., paramedic). However, if you agree to, you will be acknowledged as part of the expert panel in these publications by checking the tick box on the consent form.

Electronic copy data will be stored on the University's enterprise edition of OneDrive during the project. OneDrive is a cloud file storage service that stores data on secure servers within New South Wales. Hard copy data in the form of consent forms will be stored in a locked cabinet in the research team's office in New South Wales. After the approved retention period of five years, both hard copy and electronic data will be disposed of. Electronic data will be deleted from the server and hard copy data shredded.

8. Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. Participants can indicate they are interested in receiving feedback by providing your contact details on the consent form. This feedback will be in the form of a brief lay summary.

9. What if I would like further information?

When you have read this information, the following researcher/s will be available to discuss it with you further and answer any questions you may have:

- Dr Madeleine Juhrmann, Research Fellowmadeleine.juhrmann@flinders.edu.au, 08 8432 4191

10. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [2022/914] according to the *National Statement on Ethical Conduct in Human Research (2007).*

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep