PLAIN LANGUAGE STATEMENT

Plain Language Statement

Date: 22nd September, 2025

Full Project Title: The provision of end-of-life care in intensive care for children and young people

Principal Researcher: Dr Laura Brooks (Deakin University)

Associate Researchers: Professor Melissa Bloomer (Deakin University, Griffith University), Dr Rebecca Thornton (Deakin University), Assoc. Prof. Kristen Ranse (Queensland University of Technology), Ms Alysia Coventry (Melbourne University, Australian Catholic University), Dr Ashleigh Butler (La Trobe University), Assoc. Prof. Stephen McKeever (Swinburne University), Ms Jessie Rowe (Royal Children's Hospital Melbourne), Ms Shontelle Thomas (Queensland Children's Hospital)

TO: ACCCN members

Am I eligible to participate?
You are eligible to participate in this study if you have been:

- A current Australian College of Critical Care Nurses member, and
- Involved in providing end-of-life care of at least one child or young person in an Australian critical care setting, and
- A registered nurse with a postgraduate nursing qualification in intensive care or critical care OR have at least three years' experience working in intensive care or critical care settings.

Reason for this research
End-of-life care has been identified as a nursing research priority in paediatric intensive care, warranting greater examination. This is because in developed countries, most paediatric and neonatal deaths occur in intensive care settings, typically following a decision to limit or cease life-sustaining treatment. Paediatric end-of-life care is a core component of critical care nursing practice, continuing beyond the point of death. Yet, given that paediatric critical care nurses are a constant presence at the bedside, simultaneously caring for the critically ill child, their family, and balancing competing clinical priorities, the provision of end-of-life care can be particularly challenging.

For parents and other family members, their experience of a child's critical illness is important, as is their need for support from nurses and other clinicians across the child's illness trajectory. The manner in which end-of-life care is provided and how the child died is important, and may result in significant and long-lasting impacts, with multiple layers of loss. Thus, how paediatric critical care nurses provide end-of-life care is key to supporting parents and the wider family. Therefore, the aim of this research is to develop evidence-based practice recommendations for the provision of end-of-life care for children and young patients in Australian critical care practice settings.

What does the research involve?

Participation in this research involves completing an online survey and taking part in an online panel focus group. There are two steps to participation. The first step is an online survey where you will be asked: (1) demographic information, including your age, how long you have worked in intensive and/or critical care, and your role in intensive and/or critical care, (2) to read and evaluate a number of evidence-based practice recommendations for the provision of end-of-life care for children and young people, and (3) to provide your contact details for confirmation of the online panel focus group. This activity should take approximately twenty (20) minutes. The second step is to participate in an online panel focus group, with other critical care registered nurses. The aim of the online panel focus group is to discuss the practice recommendations until there is agreement about the acceptability and meaningfulness of each recommendation, amongst all participants. This activity should take approximately forty-five (45) minutes. The topic to be explored in the survey and online panel focus group include:

- End-of-life care for children and young people in intensive care

What are the benefits associated with participating in this study?

There are no direct benefits to you, but your participation will contribute to the development of evidence-based practice recommendations that are expected to lead to improvements in care.

Participation is Voluntary.
Your participation in this research project is completely voluntary. If you don't wish to take part, you don't have to. Your decision whether or not to participate in this research, or whether to withdraw from this research, will not affect your relationship with the researchers, Deakin University, or the Australian College of Critical Care Nurses.

Once you have read and understood this plain language statement, please complete the survey if you wish to participate. You are able to pass on the survey link or contact details of the lead researcher (m.bloomer@griffith.edu.au) to other ACCCN members that you believe may be interested in participating in the study. If you choose to forward the survey link or pass on the contact details, then those nurses can access the survey link, read and understand this plain language statement, then complete the survey if they wish to participate. Participation involves completion of the survey and participation in an online panel focus group. At the end of the survey you will be asked to provide your contact details so that the research team can make contact with you to arrange your participation in the online panel focus group. There may be more than one online panel focus group, potentially allowing for flexibility for you to select a time that suits you. Your survey responses will remain confidential, only accessible by the research team. If you are unable to attend the online panel focus group, please contact the lead researcher who may then make email contact with you after the online panel focus group to share with you the final draft evidence-based recommendations and ask you to provide any final comments via email return. Your completion of the survey will be taken as your implied consent to participate in the study, inclusive of the survey and subsequent online panel focus group, and for the research team to use the information that you share with us. At the beginning of the online panel focus group you will be asked whether you provide your verbal consent to participate.

Can I withdraw my participation from this study at any time?
Yes, you can withdraw at any stage before you submit your survey, you are free to do so without prejudice, and withdrawing will not jeopardise your relationship with Deakin University or the Australian College of Critical Care Nurses. To withdraw from the study all you need to do is close the window that you have open. If you withdraw from the survey by closing the browser, the data will

not be used, as only complete surveys will be used. It is not possible for you to withdraw once you have submitted the survey as survey data are de-identified and only aggregate data will be analysed and presented in the results. Participation involves completion of both the survey and online panel focus group for the purposes of validating the evidence-based practice recommendations. You can withdraw before participating in the online panel focus group by contacting the research team at m.bloomer@griffith.edu.au. You may withdraw before the online panel focus group, or during the online panel focus group by ceasing your participation in the online group by contacting the research team as identified above. You cannot withdraw after the online panel focus group as the survey data will have been analysed and the online panel focus group data are collected and transcribed in a way that does not link you to the data.

Will my participation involve any risk or inconvenience?
We recognise that spending approximately sixty five (65) minutes participating in this study may be an inconvenience. While participants will be advised in the online panel focus group that they should not share anything discussed during the panel focus group with anyone outside of the panel focus group. The anonymity or confidentiality of participants cannot be guaranteed due to the presence of other participants in the online panel focus group. It is acknowledged that participants or interviewers could personalise their own end-of-life care experiences when given the opportunity to reflect on practice recommendations, thereby triggering an emotional response or emotional discomfort. In recognition of this, participants will be able to contribute to or skip any question in the online panel focus group without explanation or cease their involvement at any time. If a level of discomfort is observed where the participant is not able to form thoughts or express opinions, with permission, the interviewer will offer to cease an individual's participation in the focus group. A follow-up email will be placed to the participant within 48 hours, to check-in, and ensure they are aware of the available supports and resources.

Will I receive compensation for my participation in this study?
You will not be compensated for participating in this study.

How will the research findings be published?
We aim to publish the results of this study in a high-quality academic journal and present the findings at conferences. We will always maintain your confidentiality.

How will my privacy and confidentiality be protected?
In any publication arising from this work, your data will not be provided on its own. Information will only be published for overall group scores. Any references to demographic information that might allow someone to guess your identity will be removed. The online panel focus group will be recorded; no identifiable details will be used in publication of the results. The Zoom online platform will be used for the online panel focus group. The recordings will be deleted when downloaded and stored in a password protected file on Syncplicity. The online panel focus group transcripts will be transcribed and deidentified prior to publication of results.

Where will my data be stored?
Your de-identified study data will be kept securely on a password protected folder on the Sycplicity secure server for five years from the date of the last publication that reports on the data after which, it will be destroyed. The numerical key for re-identification will be kept securely by the data custodian on a password protected computer file in the School of Nursing and Midwifery at Deakin University. Only the researchers listed on this plain language statement will have access to the raw data for the purposes of analysis. The data custodian is Dr Laura Brooks, Deakin University, who will manage the storage of and access to the data.

This research is being undertaken by Deakin University with a research team who are from several institutions to ensure expertise within the team. To ensure the research is conducted within the Australian Code for the Responsible Conduct of Research, the project team conducting collaborative research across institutions comply with the Deakin University Research Data Management Procedure and have discussed and agreed on a Data Management Plan and its requirements.

Will participation prejudice me in any way?
No, participating will not prejudice you in any way.

Can I receive a summary of the findings?
A written summary of the findings and final evidence-based practice recommendations will be made available to participants, sent as an email attachment from the lead researcher Professor Melissa Bloomer. You will be given an option at the end of the survey to select whether you would like to be sent a summary of the results.

Further Information or Queries
If you require further information, or if you have any questions for the research team about this research and what participation in this study entails, or if you have any problems concerning this project you can contact the research team using the details provided below.

Professor Melissa Bloomer
Telephone: +61 402 472 334
Email: m.bloomer@griffith.edu.au

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

The Human Research Ethics Office, Deakin University,
221 Burwood Highway, Burwood, VIC, 3125
Telephone: 9251 7129, **research-ethics@deakin.edu.au**

Please quote project number 2025/HE000066**.**