MONASH University

# Participant Information Sheet/Consent Form

**Non-Interventional Study** - *Adult providing own consent*

**Gippsland Health Alliance (GHA) participants**

| | |
|---|---|
| **Title** | Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals. |
| **Principal Investigator** | Dr Susan Lee (Monash University) |
| **Associate Investigator(s)** | Anita Raymond (Monash University)<br>Dr Melissa Bloomer (Deakin University) |
| **Location** | Gippsland Health Alliance (GHA) website. |

## Part 1 What does my participation involve?

### 1 Introduction

You are invited to take part in this research project titled 'Nurses' roles in bereavement care during end-of-life care of dying patients in acute non-metropolitan hospitals'.

You have been invited to participate in this research project as you are a registered nurse working within an acute non-metropolitan hospital who has had experience in providing end-of-life care to patients and their families. Your experience of end-of-life care is highly valued in this research as it is during this period, that nurses are also providing early bereavement care to families.

This Participant Information Sheet and Consent Form tells you about the research project. 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. 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 the use of the personal information as provided by you.

You will be given a copy of this Participant Information and Consent Form to keep.

## 2 What is the purpose of this research?

Bereavement is defined as the entire experience including the anticipation, death, and subsequent adjustment following the death of a loved one. Nurses' providing end-of-life care for patients in hospitals, are also providing early bereavement care to families encountering grief and bereavement. The quality of bereavement care provided to families within hospitals can have a significant influence on grief and the subsequent bereavement process.

Acute care refers to treatment within a hospital setting, where a patient receives active but short-term treatment for acute injury or episodes of illness with intent to restore health. Death within acute care can therefore be an unexpected event with the resultant grief and bereavement for families of dying patients more pronounced. Limited research currently exists in Australia and specifically in non-metropolitan hospitals, surrounding nursing bereavement care for families.

The aim of this study is to better understand the roles of registered nurses in the provision of bereavement support during end-of-life care in acute non-metropolitan hospitals. This research will help identify what bereavement care measures are put into place for grieving families. The findings of this research will also help better inform clinical practice, generate role awareness of nursing bereavement care and positively impact on the grief and bereavement experienced by families, following the death of a loved one within a hospital.

The results of this research will be used by the researcher Anita Raymond to obtain a Doctor of Philosophy qualification through Monash University and publish in peer reviewed journals. This research is not being funded.

## 3 What does participation in this research involve?

Participation in this research involves taking part in a semi-structured interview with the researcher. The researcher would like to discuss your experience of nursing dying patients in hospitals and will seek to clarify exactly what the nursing roles and responsibilities are during end-of-life care, particularly relating to families and bereavement care. The interview will take approximately 1 hour and the session will be audio-recorded. Although it is anticipated that only one interview is necessary, if the researcher requires further clarification of any issues discussed you may be contacted at a later date and invited to participate in a second interview. The interview will be conducted at a time and a location agreed on by you and the researcher.

## 4 What do I have to do?

Read this Participant Information and Consent form in its entirety. If you are interested, please make contact with the researcher – Anita Raymond and a mutually convenient date and time for an interview will be determined.

## 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. Your decision whether to take part or not, or to take part and to withdraw will not affect your relationship with your employer.

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

We cannot guarantee or promise that you will personally receive any benefits from this research. Participation in this study does however give you the opportunity to share your experiences and contribute to the outcomes of this study, with the goal of improving bereavement care in non-metropolitan acute hospital settings.

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

No risks to health are anticipated for participants who agree to take part in this project. However, given the topic of this study, there is a chance that you could become emotional or distressed during the interview. If you do feel distressed or become upset, the interview will be paused or terminated as determined by you. You can also choose not to answer any question you feel uncomfortable discussing. It should also be advised that if you become upset or distressed the researcher may call on the support of the Employee Assistance Program (EAP) for further counselling.

### 8 What if I withdraw from this research project?

You can withdraw at any time by notifying the researcher, who will provide you with a withdrawal of participation form to sign.

### 9 What happens when the research project ends?

On completion of this research project all data will be analysed to generate finding themes. It is anticipated that following data analysis, end-of-life care and specifically bereavement care will be well defined from a nursing perspective and in the context of a non-metropolitan acute hospital setting. All data findings will be in de-identified form and summary findings and clinical recommendations will be communicated back to participating hospitals.

Other reports generated from the study will be used for journal publication, conference presentation and as chapters within a thesis to meet the requirements of PhD.

## Part 2 How is the research project being conducted?

### 10 What will happen to information about me?

By signing the consent form you consent to the relevant research staff collecting and using your information for this research project.

No information obtained in connection with this research project will allow for your identification. Your identity will remain anonymous and any information you provide will be confidential.

Consent forms and all audio recordings will be stored securely in a locked filing cabinet within the locked office of the researcher, Anita Raymond and will be accessible only to the research team named in this application. The electronic database containing research findings will be saved on a password protected computer and will only be accessible to the research team.

At completion of the project all the data will be transferred to disks and stored in a locked filing cabinet in a locked office of the School of Nursing Midwifery at Monash University and will be accessible only to the research team named in this application. In accordance with research and ethics policy, all information will be destroyed after a period of five years.

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. You will remain entirely anonymous and de-identified when reference is made to any relevant data from this research investigation.

## 11 Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics committee of Latrobe Regional Hospital, West Gippsland Healthcare Group and Monash University. The 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.

## 12 Further information and who to contact

If you would like any further information about any aspect of this study, please contact:

| | |
|---|---|
| Name | Dr Susan Lee |
| Position | Principal Investigator |
| Telephone | +61 3 9904 4204 |
| Email | susan.lee@monash.edu |

If you would like to participate in this study please contact the researcher below:

| | |
|---|---|
| Name | Anita Raymond |
| Position | Associate Investigator |
| Telephone | 03 51 22 6977 |
| Email | agmic1@student.monash.edu |

For complaints relating to this research project please contact the Monash University - Human Ethics Office below:

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|---|---|
| Name | Dr Souheir Houssami |
| Position | Executive Officer - Advice and/or complaints about projects |
| Telephone | +61 3 990 52052 |
| Email | souheir.houssami@monash.edu |

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| **Location** | Gippsland Health Alliance (GHA) website. |

**Declaration by Participant**

I have read the Participant Information Sheet.

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.

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

Name of Participant (please print) _____

Telephone contact _____ Email contact _____

Signature _____ Date _____

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# Form for Withdrawal of Participation - *Adult providing own consent*

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**Declaration by Participant**

I wish to withdraw from participation in the above research project

Name of Participant (please print) _____

Signature _____ Date _____

Researcher will need to provide a description of the circumstances below.