

**QUANTum study**  
**QUALity CompreheNsive End-of-Life Care: STandard Five study**

**QUT Ethics Approval Number: 1800001027**

**RESEARCH TEAM**

**Principal Investigator:** Dr. Elise Button

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**Australian Commission on Safety & Quality in Health Care (ACSQHC)**

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**INTRODUCTION**

This Participant Information Sheet tells you about the research project. It explains the processes involved in 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. Participation in this research is voluntary. If you don't wish to take part, you don't have to.

**DESCRIPTION**

The main aim of this project is to optimise application of the end-of-life actions and to ultimately provide data to help create a framework for continuous improvement in the quality and effectiveness of the delivery of end-of-life care in acute settings.

We would like to conduct a national survey of acute care health services across Australia pre-implementation of the second edition of the NSQHS standards to:

- Describe current processes and outcomes, and experienced barriers and challenges;
- Explore planned processes and outcomes, and potential barriers and challenges; and
- Understand what facilitators would help hospitals to implement the end-of-life care actions in the Comprehensive Care Standard in the second edition of the NSQHS Standards.

**PARTICIPATION**

Participation will involve completing a confidential online survey that will take approximately 30 minutes of your time. If you agree to participate, you will be asked about your hospital's policy and practice for implementing comprehensive end-of-life care in acute health care settings at your institution.

The survey will include a combination of multiple choice responses and open-ended questions. You will also have the opportunity to provide free-text responses should the available items not be applicable to you in the multiple-choice responses.

The survey will comprise four sections:

- In the first section, you will be asked to provide data on the characteristics of your hospital.
- Section two will ask about current or planned practices (and associated barriers and challenges, and facilitators) that engage or will engage in processes or measure outcomes at your hospital associated with the end-of-life care actions in the Comprehensive Care Standard.
- Section three will ask about current or planned practices (and associated barriers and challenges, and facilitators) that engage or will engage in processes or measure outcomes associated with key domains that are considered to be important by patients and families that are not fully covered in the NSQHS standard.
- In Section four, you will be asked to provide any general comments that may be relevant to this research around the end-of-life care actions in the second edition of the NSQHS Standards (2nd ed) and also the domains of end-of-life care that are important to patients and families.

You will be required to complete each item of the survey before being permitted to advance. You will also be permitted to revisit items and to change your responses. This will be possible during completion of questions and prior to the final confirmation step. Your participation in this project is entirely voluntary. Your decision to participate or not participate will in no way impact upon your current or future relationship with Queensland University of Technology or the Australian Commission on Safety and Quality in Healthcare. If you do agree to participate you can withdraw from the research project during your participation without comment or penalty.

### **EXPECTED BENEFITS**

It is expected that this project will not benefit you directly. However, this study will optimise application of the end-of-life actions and to ultimately provide data to help create a framework for continuous improvement in the quality and effectiveness of the delivery of end-of-life care in acute settings. This work will contribute to improved delivery of safe and high-quality end-of-life care in Australia.

### **RISKS**

There are no anticipated risks beyond normal day-to-day living associated with your participation in this research.

If you feel that you need to talk to someone confidentially about any distress you have experienced as a result of this study, you can contact the QUT Health Clinics as QUT provides limited free psychology, family therapy or counselling services (face-to-face only). Should you wish to access this service please call the Clinic Receptionist on **(07) 3138 0999** (Monday to Friday between 9am and 5pm), QUT Psychology and Counselling Clinic, 44 Musk Avenue, Kelvin Grove, and indicate that you are a research participant. Alternatively, Lifeline provides access to online, phone or face-to-face support, call **13 11 14** for 24 hour telephone crisis support.

### **PRIVACY AND CONFIDENTIALITY**

If you wish to participate in this study, any responses you make within the survey will be collected in a potentially re-identifiable form. All comments and responses are confidential unless required by law. The research team will have access to the data, but will de-identify it prior to analysis. No identifiable information will be published.

All comments and responses are anonymous and will be treated confidentially unless required by law. The personal details of individual persons (such as names, email addresses or telephone numbers) are not required in any of the responses. Any data collected as part of this project will be stored securely as per QUT's Management of Research Data policy.

Please note that non-identifiable data from this research project may be used as comparative data in future research projects or stored on an open access database for secondary analysis. Data will be used for publication to inform health services planning and policy making. All data will be archived for seven years for verification purposes in accordance with the University Sector Retention and Disposal Schedule and the Queensland State Archives General Retention and Disposal Schedule, available from [http://www.governance.qut.edu.au/rms/retention\\_disposal/](http://www.governance.qut.edu.au/rms/retention_disposal/).

Survey responses will be collected online using a secure online survey platform (RedCap®), utilising an encrypted internet server.

This research is funded by a National Health and Medical Research Council Centre for Research Excellence in End of Life Care. National Health and Medical Research Council Centre for Research Excellence in End of Life Care can access the final aggregated research report, but will not have access to the individual data obtained during the project.

We plan to discuss and publish the aggregated results in academic journals or reports to inform health services planning and policy making. However, you will not be identified in any document. Publications will be prepared for internationally peer-reviewed journals and abstracts will be prepared for relevant meetings and conferences and a summary report may be published on the ACSQHC website.

### **CONSENT TO PARTICIPATE**

Submitting the completed online survey is accepted as an indication of your consent to participate in this project.

### **QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT**

If have any questions or require further information please contact the research team member below.

**Prof Patsy Yates** (07) 3138 3835 [p.yates@qut.edu.au](mailto:p.yates@qut.edu.au)

**Dr. Elise Button** (07) 3138 6125 [e.button@qut.edu.au](mailto:e.button@qut.edu.au)

### **CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT**

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project you may contact the QUT Research Ethics Advisory Team on (07) 3138 5123 or email [humanethics@qut.edu.au](mailto:humanethics@qut.edu.au). The QUT Research Ethics Advisory Team is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

**THANK YOU FOR HELPING WITH THIS RESEARCH PROJECT.**

