

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

QUT Ethics Approval Number 1800001027

RESEARCH TEAM

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Australian Commission on Safety and 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 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 the research team 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.

WHAT IS A DELPHI STUDY?

The Delphi technique seeks to obtain consensus on the opinions of experts and stakeholders, termed panel members, through a series of structured surveys. As part of the process, the responses from each round are fed back in summarised form to the participants who are then given an opportunity to respond again to the emerging data. The Delphi is therefore an iterative multi-stage process designed to combine opinion into group consensus.

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.

The purpose of this Delphi study is to achieve consensus of opinion on the optimal processes and outcomes for meeting the end-of-life care actions in the Comprehensive Care Standard of the second edition of the NSQHS standards as per a panel of experts. This will lead to nationally relevant recommendations.

PARTICIPATION

Your participation will involve completing three confidential online surveys, over a period of 6 weeks.

Every 2 weeks we will send you an email asking you to answer a survey. Each of the three surveys will take approximately 30 minutes to complete. Surveys do not have to be completed in one sitting. You can save your answers and complete it later.

If you agree to participate, you will be asked to review responses from the national survey regarding processes and outcomes to address the end-of-life care action and you will be asked to quantitatively rate the appropriateness of each response in your opinion. You can also provide free-text data to explain your answer or suggest new processes and/or outcomes. In surveys 2 and 3 you will see how the rest of the study participants rated each item and have a chance to change your answers if you wish to do so. Your opinions will be captured using a five point Likert-type scale rating responses to statements from 'entirely disagree' to 'entirely agree', and via free-text responses. There will be no face-to-face communication and you will not be identifiable to others who are taking part. This process will continue until group consensus is achieved or three Delphi rounds have been completed. In order to allow timely conclusion of the study we would respectfully request a response time of 1 week for completion of each round.

We will send you one reminder and then if we haven't heard from you we will assume that you don't wish to take part and remove you from the list of participants (for each of the 2nd and 3rd surveys we will send up to two reminders).

If you agree to participate, please do not discuss your involvement with your colleagues until data collection is complete. You will be required to complete each item of the survey before being permitted to advance. You will also be permitted to revisit an item 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 QUT or ACSQHC. 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

All comments and responses are confidential unless required by law. Survey responses will be collated confidentially using an identifying number known only to the participant and principal investigator. Direct quotes to free-text answers may be used as part of the study report or later Delphi iterations, but these will not be traceable back to you. Survey responses will be collected online using a secure online survey platform (RedCap®), utilising an encrypted internet server.

Any data collected as part of this project will be stored securely as per QUT's Management of Research Data policy. Please note that de-identified 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/

This research is funded by a National Health and Medical Research Council (NHMRC) Centre for Research Excellence in End-of-Life Care (ELC). NHMRC CRE-ELC 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. You will also be provided by a copy of the published results from the study if you nominate that you would like to be sent a copy.

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 one of the listed researchers:

Prof Patsy Yates 07 3138 3835 p.yates@qut.edu.au
Dr. Elise Button 07 3138 6125 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. 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.