

# PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT - Survey -

# Delivering end of life law training in Australian primary and aged care services: A pilot study

**QUT Ethics Approval Number 7666** 

Research team

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# Why is the study being conducted?

This project is funded by the Australian Government Department of Health and Aged Care as a National Palliative Care Project.

The End of Life Law for Clinicians (ELLC) training program provides unique training to health professionals about end of life decision-making laws in all Australian States and Territories. Research has demonstrated that significant legal knowledge gaps exist amongst health professionals who work in palliative and end of life care, and that they want to know end of life law to help improve their clinical practice and manage legal risk.

The ELLC Implementation Pilot Study (the pilot study) involves implementing ELLC online training modules in a sample of general practices (primary care sites) and residential aged care facilities and/or home care services (aged care sites).

The objectives of the pilot study are to:

- Generate new evidence of training impact on participants' legal knowledge and confidence applying law in practice.
- Identify changes to primary and aged care practice (individual-level and service-level) as a result of completing the training.
- Identify barriers and facilitators to:
  - o training completion and application of new knowledge in practice, by participants (individual-level)
  - o training implementation in primary and aged care services (service-level).

You are invited to participate in this pilot study because you belong to one of the target pilot study groups who will complete the training: general practitioners, nurses, or allied and other health professionals working in general practice or aged care, or aged care managers.

As part of pilot study, you will be asked to complete seven online training modules and three short surveys:

- 1. A pre-training survey to assess your knowledge of end-of-life law and confidence in applying it.
- A post-training survey following completion of seven online training modules. This survey will
  assess whether your knowledge of law and confidence in applying it has improved, whether your
  practice has or will change as a result of completing the training, and seek your general feedback
  on the training.
- 3. A follow-up survey measuring knowledge of the law, confidence applying the law, and actual or intended practice change 6 months after completing the training.

#### What does participation involve?

The three anonymous surveys will each take up to 15 minutes of your time.

Questions will include:

- Knowledge of the law: Thinking about the law relating to palliative and end-of-life care. How
  much knowledge would you say you have? None; Very little knowledge; Some knowledge;
  Moderate knowledge; Considerable knowledge.
- 2. What did you like most about this training?
- 3. Have you made (or do you intend to make) practice change/s because of knowledge gained from ELLC?

Your participation in this pilot study is entirely voluntary. If you agree to participate, you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT. You will be able to review your responses before submitting the survey, and you can discontinue the survey any time by closing your internet browser. As data collected is anonymously, we will not be able to withdraw your survey responses once the survey has been submitted.

# What are the possible benefits for me if I take part?

It is expected that this pilot study will benefit you directly.

You will access training designed to increase your knowledge of end of life law and confidence and skills in applying the law in clinical practice. You may be able to claim Continuing Professional Development (CPD) points from your specialty College or professional organisation for undertaking the training.

To recognise your contribution, if you complete both the pre-and post-training surveys, the study team will provide you with a \$100 gift card. Once you have completed both surveys, you will be asked if you would like to be sent a gift card. To protect your anonymity associated with your survey responses, you will be taken to a different page to enter your email address and/or telephone number. Your identifying information will be used for the purposes of being sent a gift card and this information will be deleted once the gift card has been sent to you.

Once you have completed your third survey, you will also be asked if you would like to be included in an optional prize draw, for a chance to win one of five \$100 Visa gift cards. Please note the opening date for prize draw entries is 1 April 2025 (for primary care participants) and 1 January 2026 (for aged care participants). The draw for primary care participants closes on the prize draw date (1 June 2025) and the draw for aged care participants closes on the prize draw date (1 March 2026).

If you wish to be entered into the prize draw, you will be asked to acknowledge the Terms and Conditions of the draw. These Terms and Conditions are provided on page 5 and can also be located at:

https://survey.gut.edu.au/survey-data/67/67667/media/62/6254.pdf

Submitting an online form with your contact details (email address and/or telephone number) fulfils the conditions of entry into the prize draw. Your identifying information will be used for the purposes of the prize draw only and will be deleted once the prizes have been allocated.

#### Other benefits include:

- The opportunity for aged sites to participate in an ELLC workshop on end of life decision-making (CPD points may be claimed).
- Access to free legal resources that support optimal end of life decision-making.
- The opportunity to be part of Australian-first research that can improve the end of life experiences of health professionals, patients/residents and families.
- Showcase continuous improvement and excellence in quality, safety, and patient-centered care
- Support your organisation to meet accreditation requirements under the RACGP Standards for General Practices or the Strengthened Aged Care Quality Standards.
- Improved pain and symptom management for patients/residents at the end of life.
- Prevention of avoidable hospital admissions and emergency department visits for treatment of end of life issues.
- Reduced complaints and disputes at the end of life.
- Better end of life experiences for staff, patients/residents and families.
- Improved end of life and palliative care service delivery.

Survey results (deidentified) will be provided to each participating organisation through summaries and reports.

#### What are the possible risks for me if I take part?

There are minimal risks associated with your participation in this pilot study. The main foreseeable risk is inconvenience (e.g. giving up time to participate in the pilot by completing three short surveys).

There is a possibility that you may feel some discomfort about completing surveys on end-of-life legal training given the potentially emotional nature of end-of-life care. The level of discomfort is likely to be small (if any) given the lack of focus on clinical practice in surveys. Survey questions related to clinical practice are focused on the impact of training and intended or actual practice change and you will not be asked to provide any details regarding specific decisions you have made or care you have provided. If any discomfort arises, you can choose to not complete the survey question or to pause or discontinue the survey.

QUT provides for limited free psychology, family therapy or counselling services for research participants of QUT research projects who may experience discomfort or distress as a result of their

participation in the research. Should you wish to access this service please call the Clinic Receptionist on 07 3138 0999 (Monday–Friday only 9am–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.

# What about privacy and confidentiality?

All aspects of the study, including results, will be strictly confidential. The surveys are anonymous and do not collect any identifying information. Details of clinical practice are not sought in any of the responses. No third parties will have access to the data obtained during the pilot study.

The surveys will be distributed using the email you provided on the ELLC training website. Only the Study Team, and website developers for ELLC will have access to the information collected by the training website, except as required by law. The website developers will have access to data in the training website to perform their contract with QUT. The website developers are employed by a professional organisation that is bound by appropriate privacy regulations.

Any data collected as part of this pilot study will be stored securely as per QUT's Management of research data policy. We plan to publicly present and publish the results of this research, however, the findings are based on anonymous data that will not identify you.

# How do I give my consent to participate?

Submitting the completed online surveys is accepted as an indication of consent to participate in the research project.

#### What if I have questions about the research project?

If you have any questions or require further information, please contact one of the researchers listed below.

Ben White bp.white@qut.edu.au (07) 3138 4066 Penny Neller penny.neller@qut.edu.au (07) 3138 2230 Rachel Feeney rachel.feeney@qut.edu.au (07) 3138 4553

# What if I have a concern or complaint regarding the conduct of the research 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 research project you may contact the QUT Research Ethics Advisory Team on 07 3138 5123 or email <a href="mailto:humanethics@qut.edu.au">humanethics@qut.edu.au</a>. 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 PILOT STUDY PLEASE KEEP THIS SHEET FOR YOUR INFORMATION.

# **Terms and Conditions of Entry into a Prize Draw**

- 1. The Promoter is Queensland University of Technology (QUT) ABN 83 791 724 622 having its principal place of business at 2 George Street, Brisbane, Queensland 4000.
- 2. By entering the competition connected to the research project named in the attached Participant Information Sheet and Consent Form, participants agree to be bound by these Terms and Conditions.
- 3. Submitting a survey fulfils the conditions of entry into the competition.
- 4. The opening and closing dates of the competition are listed on the attached Participant Information Sheet and Consent Form. The prize winner will be selected by random draw which will take place at QUT on the prize draw date as listed in the attached Participant Information Sheet and Consent Form.
- 5. The first entry drawn randomly will receive the prize listed on the attached Participant Information Sheet. The prize is not transferable, refundable, exchangeable, and cannot be taken as cash.
- 6. The Promoter will use reasonable efforts to notify the prize winner by no later than two weeks post the prize draw date. If a winner cannot be contacted or refuses the prize it will be offered to the next randomly drawn entry. The promoter's decision is final as to the winner of the prize and binding and no correspondence will be entered into in relation to the conduct of the competition or otherwise.
- 7. The prize will be available for collection by the winner at a time organised as suitable for the winner.
- 8. If this competition is interfered with in any way or is not capable of being conducted as anticipated due to any reason beyond reasonable control of the Promoter, the Promoter reserves the right, in its sole discretion, to the fullest extent permitted by the law to (a) disqualify any participant; or (b) subject to any written directions from a regulatory authority, to modify, suspend, terminate or cancel the competition, as appropriate.
- 9. All entries become the property of the Promoter and will not be returned to participants.
- 10. Except for any liability that cannot be excluded by law, the Promoter (including its officers, employees and agents) excludes all liability (including negligence), for any personal injury or any loss or damage (including loss of opportunity), whether direct, indirect, special or consequential, arising in any way out of the competition, including but not limited to, where arising out of the following: (a) any technical difficulties or equipment malfunction (whether or not under the Promoter's control); (b) any theft, unauthorised access or third party interference; (c) any entry or prize claim that is late, lost, altered, damaged or misdirected (whether or not after their receipt by the Promoter) due to any reason beyond the reasonable control of the Promoter; (d) any variation in prize value to that stated in these Terms and Conditions; (e) any tax liability incurred by a winner or entrant; or (f) use of the prize.
- 11. Each participant indemnifies and keeps indemnified the Promoter against all claims, losses, damages and expenses suffered by the Promoter or any third parties arising out of the breach of these Terms and Conditions by the participant, the conduct of the participant in the competition, the use of information supplied by the participant or the use of the prize.

12. Under the applicable Privacy Laws, the Promoter must tell participants when it collects personal information about them and how it plans to use it. If a participant chooses to enter or take part in the competition, the participant will be required to provide the Promoter with personal information such as the participant's name and email address. The Promoter collects participants' personal information in order to conduct the competition and associated research study. QUT's Privacy Policy is available at:

https://www.qut.edu.au/additional/privacy