|  |  |
| --- | --- |
|  | **PARTICIPANT INFORMATION SHEET** |
| **PALLIATIVE CARE WORKFORCE CAPABILITIES FRAMEWORK: CONSUMER INTERVIEWS**  **QUT Ethics Approval Number 5740** | |

**Research team**

|  |  |
| --- | --- |
| Principal Researcher: | **Distinguished Professor Patsy Yates**  Executive Dean, Faculty of Health, Queensland University of Technology |
| Associate Researchers: | **Kylie Ash**  National Project Manager PCC4U, Queensland University of Technology  **Joanna Rego**  Senior Research Assistant, Palliative Care Education & Training Collaborative, Queensland University of Technology  **Sharon Wetzig**  Learning and Development Coordinator, Palliative Care Education & Training Collaborative, Queensland University of Technology |

**Why is the study being conducted?**

The purpose of this research is to identify a set of skills and attributes of healthcare providers that are necessary to provide quality palliative care across health and aged care settings. The information you provide is important to enable us to understand your experience and expectations, so that we can better prepare health providers for this important work. The information gathered from this study will guide the development of education programs to ensure that the future workforce is adequately prepared to provide high quality palliative care. This research will ensure that we are not missing components important to you and other people who require palliative care services.

**What does participation involve?**

Your participation will involve attending one group interview with approximately 5-8 other participants for a duration of approximately 60 minutes. The interviews will be conducted online via the Zoom platform. If you prefer, instead of a group interview, we can conduct the interview with you on your own either online or by phone*.* To participate in this research project, you therefore will need to have access either to a computer or phone. Prior to the interview we will provide you with some brief background information about what is currently known about the skills and attributes required of health professionals who provide palliative care. During the interview we will ask about your perceptions of what is involved in quality palliative care, your experiences of care, and your expectations of health professionals who are involved in providing palliative care services.

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

It is not expected that this research project will benefit you directly. However, it is envisaged that your perspectives will assist us to identify the skills and attributes that should be the focus of future education programs for health care providers. This should help to improve the care and support provided by health services to patients and their families in future. We hope that involvement in this study will be a rewarding experience. Some people also find it helpful to have the opportunity to share difficult experiences such as illness and loss with someone who is not directly involved in providing care.

To recognise your contribution to the project, the research team is offering you a Mastercard prepaid gift card to the value of $100 to compensate for your time and input.

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

There are some risks associated with your participation in this research project. Some questions may pose discomfort or distress as they will refer to palliative care which is a sensitive topic, both, at a personal and professional level. Serious illness naturally causes anxiety and distress for patients and their families. It is possible that you or your family may feel distressed at some times during the interviews and beyond.

To minimise any possible risk of distress, the facilitator will ensure discussions proceed at the pace set by the group or individuals. Breaks during interviews will be taken as deemed necessary and appropriate. You will not be under any pressure to answer questions or talk about topics that you prefer not to discuss. Other risks will include inconvenience and minor discomfort and/or fatigue from sitting and viewing a computer screen. Breaks can be offered if required and interviews will be conducted at a time convenient to you.

If you find some of the discussions raise concerns for you, you can contact QUT Psychology and Counselling Clinic, which offers limited free psychology, family therapy or counselling services (face-to-face or telehealth consultations available) for research participants of QUT 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 9777** (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. For young people aged between 5 and 25, you can also call the Kids Helpline on **1800 551 800**.

**What about privacy and confidentiality?**

All comments and responses will be coded with a unique code so that you cannot be recognised. Data will be re-identifiable by the research team, only if needed. All group interview participants will be asked to keep discussion and comments confidential. Findings from this research will be reported in such a way that you will remain anonymous. Any data collected as part of this research project will be stored securely as per QUT’s Management of research data policy. Data will be stored for a minimum of 5 years, and can be disclosed if needed to protect you or others from harm, if specifically required by law, or if a regulatory or monitoring body such as the ethics committee requests it.

**How do I give my consent to participate?**

We would like to ask you to sign a written consent form (below) to confirm your agreement to participate. If you would like to receive a paper copy of this information sheet and consent form, please call or email Joanna Rego on 07 3138 0135 or [j.rego@qut.edu.au](mailto:j.rego@qut.edu.au). We will also send you pre-paid envelope, so you will be able to post your consent back to us. Your decision to participate, or not participate, will in no way impact upon your current or future relationship with QUT or organisations you are associated with. If you do agree to participate you can withdraw from the interviews without comment at any time. Any data obtained from individual interviews will be destroyed, however, individual data from group interviews, might not be possible to be removed.

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

If you have any questions or require further information, please contact:

Dr Joanna Rego [j.rego@qut.edu.au](mailto:j.rego@qut.edu.au) 07 3138 0135

**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. If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the QUT Research Ethics Advisory Team on +61 7 3138 5123 or email [humanethics@qut.edu.au](mailto:humanethics@qut.edu.au).

**Thank you for helping with this research project.**

|  |  |
| --- | --- |
| A blue rectangle with white text  Description automatically generated with low confidence | **CONSENT FORM** |
| **PALLIATIVE CARE WORKFORCE CAPABILITIES FRAMEWORK: CONSUMER INTERVIEWS**  **QUT Ethics Approval Number 5740** | |

**STATEMENT OF CONSENT**

**By signing below, you indicate that you:**

* have read and understood the Participant Information Sheet regarding this research project;
* consent to participate in the online zoom group or individual online meetings or individual phone interview;
* understand that data collected and analysed will be only published in collated, anonymous form to support further research on this topic;
* understand that interviews will be recorded for the purpose of data analysis;
* understand that participation in the study is voluntary;
* understand that the data from this study may be published;
* understand that if you have any additional questions, you can contact the research team; and
* understand that you are free to withdraw from group or individual interviews without comment at any time.
* understand that the final version of the palliative care capability framework will be publicly available. If you would like a copy to be emailed or mailed to you, please tick this box

QUT is committed to research integrity and the ethical conduct of research projects. Note: if at any time you have questions about your rights as a research participant, please contact the QUT Office of Research Ethics and Integrity on 61 7 3138 5123 or by email at [humanethics@qut.edu.au](mailto:humanethics@qut.edu.au).The QUT Office of Research Ethics and Integrity is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

**First and Last Name:**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Signature:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Date:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**PLEASE RETURN THE SIGNED CONSENT FORM TO**

[pcc4u@qut.edu.au](mailto:pcc4u@qut.edu.au) or return via mail in pre-paid envelope provided