INFORMATION SHEET AND CONSENT FORM FOR STUDY 4: TRANSCULTURAL HEALTH WORKER INTERVIEWS

Identifying the mental health effects on and support needs of people bereaved during and following COVID-19: Mapping the experience of Culturally and Linguistically Diverse (CALD) communities
[UTS HREC REF NO. ETH21-5923]

What is the research study about?

The COVID-19 pandemic has disrupted literally every aspect of life, including how we die and how we grieve. We are doing this research to understand the grief experiences and support needs of people from CALD communities who have experienced a death from any cause during the COVID-19 pandemic. CALD communities include those people who are living in Australia who were born overseas, have parents or grandparents who were born overseas, and are mostly from non-Western or non-English speaking countries.

We want to understand the grieving experiences of CALD communities over time; any support they needed during bereavement and the effect of the pandemic's public health measures on grief, including lockdown, limitations in visiting hospitals or aged care facilities, and attending funerals and other rituals.

You have been invited to participate in this study because you are a transcultural health worker who has supported someone who experienced a death during 2020 and/or 2021.

Who is conducting this research?

My name is Professor Elizabeth Lobb and I am a bereavement counsellor and academic at UTS.

Other investigators on the study are:

Dr. Fiona Maccallum – University of Queensland
Professor Meera Agar – University of Technology Sydney
Professor Jane Phillips – University of Technology Sydney
A/Professor Lauren Breen - Curtin University
Dr. Tim Luckett – University of Technology Sydney
A/Professor Michelle DiGiacomo – University of Technology Sydney
Professor Jennifer Philip – University of Melbourne
Professor Jennifer Tieman – Flinders University
A/Professor Annmarie Hosie – University of Notre Dame Sydney

Who can take part?

Before you decide to participate in this research study, we need to ensure that it is OK for you to take part. We need you to:

a) Be an Australian transcultural health worker who has supported someone who has experienced a death from any cause during 2020 and/or 2021;
b) Have sufficient English language skills to understand this information and participate in an interview.

If I say yes, what will it involve?

If you decide to participate, it will involve completing a 30-40 minute phone or ZOOM interview. The interview will be conducted by a UTS researcher employed for the project and will be audio-recorded to ensure answers are recorded accurately. Topics will include visiting restrictions, funerals, social supports, mental health supports and the impact of restrictions and social distancing on cultural practices. This information will help us to identify the bereavement support needs of people from CALD communities.

Do I have to take part in this research study?

Participation is completely voluntary. It is completely up to you whether or not you decide to take part. Please read this information carefully to decide.

You can change your mind at any time and stop the interview without having to give a reason, and your decision will be respected.

What if I withdraw from this research project?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason by contacting the project manager, Dr. Serra Ivynian (Serra.Ivynian@uts.edu.au).

If you decide to leave the research project, we will not collect additional personal information from you (e.g. name, address, date of birth etc.), although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want the UTS research team to do this, you must tell project manager Dr. Serra Ivynian before you join the research project.

Are there any risks/inconvenience?

Yes, there are some risks. We understand that the nature of the questions could evoke strong feelings for you. The interview will cover questions about death and grief of the people you have supported during the COVID-19 pandemic. You may find some of the questions upsetting to answer. You don't have to answer the questions if you don't want to. You can also finish the interview at another time or stop it altogether. However, if any feelings raised in the interview don't go away over the next few days, we suggest you seek further support from the services listed at the bottom of this form.

What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using personal information about you for the research project. The interview transcripts will be de-identified, meaning that you will be given a participant number for your name, and the names of any other people or places mentioned in the interview will be removed. The interview recordings and transcripts will be stored on a secure UTS network drive. Only the researchers involved in the study will have access to the interview recordings and transcripts. At the completion of the study, all participant numbers will be removed and data will be stored in a non-identifiable manner.

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.

We plan to publish the results in peer reviewed journals and we are required to provide a report to our funding body. We also plan to present the findings to relevant stakeholders in heath and community services at the completion of the project to support the development of a National Bereavement Action Plan to inform future pandemics. In any publication, information will be provided in such a way that you cannot be identified.

What if I have concerns or a complaint?

If you have concerns about the research that you think we can help you with, please feel free to contact the Chief Investigator for this research project, Professor Liz Lobb (Liz.Lobb@health.nsw.gov.au) or the project manager Dr. Serra Ivynian (Serra.Ivynian@uts.edu.au) on (02) 9514 4822.

If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on (02) 9514 9772 or Research.ethics@uts.edu.au and quote this number [UTS HREC Approval No. ETH21-5923]

The researchers deeply appreciate your agreeing to take the time to contribute to this very important study and your contribution is highly valued.

For assistance with your grief

- First and foremost, discuss your feelings with someone close to you.

- Visit GriefLine, which offers online and telephone counselling between 6am and 2am AEST 7 days a week.
- The MyGrief App which is produced by the Australian Centre for Grief and Bereavement and is available here www.grief.org.au
- Read the UTS self-help counselling resources for information about other helplines and ways to look after your mental health.
- Talk to your GP who can refer you on to counselling with a psychologist if you need it. The government has increased the number of sessions to 20 in response to COVID-19 because they've recognised the heightened distress that people are experiencing during the pandemic;
- If you prefer, you can also get in touch with our researcher Dr. Serra Ivynian, who can guide you towards appropriate bereavement counselling services.

CONSENT FORM

[UTS HREC REF NO. ETH21-5923] - Identifying the mental health effects on and support needs of people bereaved during and following COVID-19: Mapping the experience of CALD communities

I _____ [participant's name] agree to participate in the research project being conducted by [give name, UTS address and contact telephone.]. I understand that funding for this research has been provided by the Medical Research Future Fund.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

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 without affecting my relationship with the researchers, the University of Technology Sydney or the NSW Multicultural Health Communication Service.

I agree to participate in the interview with the understanding that it will be audio-recorded.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

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

I am aware that I can contact Professor Elizabeth Lobb (Liz.Lobb@health.nsw.gov.au) or the project manager Dr. Serra Ivynian (Serra.Ivynian@uts.edu.au) on (02) 9514 4822 if I have any concerns about the research.

_____ ____/____/____

Name and Signature [participant] Date

_____ ____/____/____

Name and Signature [researcher or delegate] Date