
Participant Information Statement

Project Title: The experience of Australian multidisciplinary specialist palliative care teams caring for people with intellectual disability (ID) who are dying.

Project Summary: We are interested in understanding the experiences of NSW multidisciplinary palliative care teams caring for people with intellectual disability who are dying.

If you are working in an Australian multidisciplinary specialist palliative care team and are a:

- Physician,
- Nurse,
- Social worker, or
- Pastoral care worker

and

- have cared for, or anticipate that you might one day care for, a person with intellectual disability who is dying,

you are invited to participate in a research study. The study is being conducted by:

- **Dr Michele Wiese**
School of Social Sciences & Psychology, Western Sydney University
- **Professor Roger Stancliffe**
Centre for Disability Research & Policy, Sydney University
- **Associate Professor Josephine Clayton**
Northern Clinical School, Sydney University; and HammondCare
- **Dr Nathan Wilson**
School of Nursing & Midwifery, Western Sydney University, and
- **Ms Bernadette Curryer**
School of Social Sciences & Psychology, Western Sydney University.

How is the study being paid for?

The research is funded by a Western Sydney University Women's Fellowship awarded to Dr. Michele Wiese.

What will I be asked to do?

We will ask you to complete a demographic form, comprising questions like your age, education and experience. You will then be interviewed for about 30 – 45 minutes and asked questions about your experiences or opinions re a) caring for people with intellectual disability who are dying, b) the facilitators and barriers to care, and c) any team future needs. You can be interviewed over the phone or in-person. The interview will be recorded. About two weeks after the interview you will receive a copy of the interview transcription which we will ask you to check. At completion of the research we will send you a summary of the findings.

How much of my time will I need to give?

In total about one and a half hours.

What benefits will I, and/or the broader community, receive for participating?

The study will not benefit you directly. The results will offer an understanding of the experiences of Australian multidisciplinary specialist palliative care teams caring for people with intellectual disability (ID) who are dying.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?

We do not anticipate any risk or discomfort to you arising from participation in the study.

How do you intend to publish or disseminate the results?

The results will be published in peer-reviewed scientific journals, industry newsletters, and presented at relevant conferences and industry forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. The demographic information and your responses to interview will have all identifying details removed. All your data will be labelled with an identity code number only.

Will the data and information that I have provided be disposed of?

Only the researchers will have access to the raw data you provide. The data will be stored indefinitely and may be used in other related projects, for example combined with data collected in future projects which aim to ensure equitable access to palliative care for this potentially vulnerable group. The data may also be subject to secondary data analysis by future research students.



Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time without giving reason. If you do choose to withdraw, any information that you have supplied will be destroyed.

Can I tell other people about the study?

Yes, you can talk to anyone you wish about the study. You can tell other people about the study by offering Dr Michele Wiese's details (Dr Wiese is the chief investigator of the study). They can contact Dr Wiese to discuss their participation in the research project and obtain a copy of the information sheet.

What if I require further information?

Please contact Dr Michele Wiese should you wish to discuss the research further before deciding whether or not to participate (email: m.wiese@westernsydney.edu.au; phone: 4736 0067)

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you are asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H12024

THIS INFORMATION SHEET IS FOR YOU TO KEEP