

Participant Information Sheet/Consent Form

The University of Adelaide

Title	Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy [Community Consultations]
Protocol Number	HREC/91/SAH/14
Project Sponsor	National Health and Medical Research Council
Coordinating / Principal Investigator	Associate Professor Jaklin Elliott
Associate Investigator(s)	Dr Teresa Burgess, Prof. Ian Olver, Assoc. Prof. Terry Dunbar, Assoc. Prof. Bernadette Richards, Prof. Gregory Crawford, Dr Tanya Zivkovic, Dr Debbie Faulkner, Ms Michele McKinnon
Location	Adelaide, South Australia

Dear Participant,

You are invited to participate in a research project about Advance Care Planning.

What is the research about?

Advance care planning is the process through which individuals make plans for their future care, often through discussions with doctors, family members and important others. These plans are intended to guide medical care and decision-making if the individual loses the ability to make, or communicate, their wishes. Advance care planning has many benefits, offering people some control over their healthcare options and improving the quality of the end-of-life care they receive.

In this study, we are investigating what could and should be done to ensure that Advance care planning is meeting the needs and preferences of Australian patients from a range of cultural backgrounds, and those living with chronic disease.

Who is undertaking this research?

A number of experienced researchers from the University of Adelaide, University of South Australia, and the Australian National University are working together to undertake this research: **Associate Professor Jaklin Elliott** (School of Public Health), **Dr Teresa Burgess** (School of Public Health), **Professor Ian Olver** (School of Psychology), **Associate Professor Terry Dunbar** (Australian National University), **Professor Gregory Crawford** (School of Medicine), **Associate Professor Bernadette Richards** (Law School), **Dr Tanya Zivkovic** (School of Social Sciences) and **Dr Debbie Faulkner** (University of South Australia).

Why am I being invited to participate?

We are inviting participants from the Aboriginal and Torres Strait Islander, Italian, Vietnamese and Bhutanese communities, as well as individuals living with cancer, chronic obstructive pulmonary disease and dementia and their carers and health providers, to attend community consultations to discuss how advance care planning might best meet the needs of people within each of these groups. As a member of one of these communities, we would appreciate your contribution to this important discussion.

What will I be asked to do?

If you agree to participate, you will be invited to attend an interview (discussion) session, either by yourself or with similar others, depending on your preferences.. At this session, a member of the Research Team will ask participants to discuss issues around planning for the care at the end of life. This discussion will be audio and/or video recorded so that the research team can have an accurate record of all contributions. If you speak a language other than English, an interpreter will be available to ensure you can contribute fully to the discussion and have your perspectives heard.

For people living with COPD, cancer or dementia, your carer is welcome to attend the consultation with you to support your participation, or they may attend on their own to provide their own perspectives.

How much time will participation take?

The interviews will last approximately 60-90 minutes, and refreshments will be provided. We will work with you to schedule these at a time and place that is convenient for you. You will be offered a \$50 Coles/Myer voucher to acknowledge your participation.

Are there any risks associated with participating in this research?

As part of the discussion, we will be asking you about the care you may wish to have in the future or if you are no longer able to tell people what your wishes are. Talking about this can sometimes be upsetting. If you do become upset, the researchers will provide you with information about who you can talk to regarding any issues that may have distressed you.

What are the benefits?

Your participation in this project will help us to identify how community members understand and undertake advance care planning, and how this process might be improved to respect the rights of all Australians to discuss the care they may want in the future.

Can I withdraw from the research?

Participation in this research is completely voluntary. If you agree to participate in the community consultation, you do not have to answer any questions or discuss any topics that you do not wish to. You are also free to stop participating in the discussion at any time without any negative consequences. If you do withdraw from the discussion, it may not be possible for the researchers to remove the contributions you have made to the discussion prior to your decision to withdraw.

What will happen to my information?

All information collected electronically (consent forms and recordings of consultation discussions) will be safely stored in a password-protected file for as long as necessary for research purposes. All specifically identifying information, including names, will be replaced with numbers and/or false names, and we'll make sure that anything that can identify you will be changed or removed when we report on the outcomes of the project in conference presentations and journal articles. Any information provided in hard copy will be secured in a lockable filing cabinet at the University of Adelaide. We won't provide participants with full transcripts of consultation discussions, but if you would like us to, we can give you a summary of project results at the end of the project. All information and documents collected will be destroyed 5 years after the project has been completed (in accordance with University policy).

Complaints and compensation

If you get upset as a result of this research project, you can let us know as soon as possible. We will help you with finding support.

Who is organising and funding the research?

This research project is being conducted by a research team led by Chief Investigator A/Prof. Jaklin Elliott (University of Adelaide) and is funded by the National Health and Medical Research Council and 10 Partner Organisations. These partners are SA Health,

Northern Adelaide Local Health Network, the Northern Health Network, the Law Society of South Australia, Dementia Australia (SA), Multicultural Communities Council of SA, Aged and Community Services SA & NT, and Palliative Care SA.

None of the research team will receive a financial benefit from your part in this research project (other than their ordinary wages).

Who has reviewed the research project?

All research in Australia involving people is reviewed by an independent group called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the Department for Health and Wellbeing. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This National Statement has been developed to protect the interests of people who agree to participate in human research studies.

Further information and who to contact

The person you may need to contact will depend on what you want to know. If you want any further information concerning this project or if you have any problems about you and this research, you can contact:

Associate Professor Jaklin Elliott ph: (08) 8313 3855 or
Dr Katherine Hodgetts (Project Manager) ph: (08) 8313 4432

If you have any complaints about any aspect of the project, how it is going, or any questions about taking part in research in general, then you may contact:

Reviewing HREC name	SA Department for Health and Ageing Human Research Ethics Committee
HREC Executive Officer	Pip Stanford
Telephone	(08) 8226 8102
Email	Pip.stanford.sa.gov.au

Consent Form

Title	Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy
Protocol Number	XXXX
Project Sponsor	National Health and Medical Research Council
Coordinating Principal Investigator/ Principal Investigator	A/Prof Jaklin Elliott
Location	Adelaide, South Australia

Declaration by Participant

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 described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I agree to have my contributions to consultation discussions audio/video recorded.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my relationships with the researchers or the University of Adelaide. I understand that it may not be possible to remove my contributions prior to withdrawal from the audio/video record.

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

Name of Participant (please print) _____
Signature _____ Date _____

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures, and risks. I believe that the participant has understood that explanation.

Name of Researcher [†] (please print) _____
Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.



**Investigating the inclusion of vulnerable
populations in Advance Care Planning: Developing
complex and sensitive public policy**
NHMRC ID: APP1133407



Form for Withdrawal of Participation

Title	Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy
Protocol Number	HREC/91/SAH/14
Project Sponsor	National Health and Medical Research Council
Coordinating Principal Investigator/ Principal Investigator	A/Prof Jaklin Elliott
Location	Adelaide, South Australia

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my relationships with the researchers or the University of Adelaide. I understand that it may not be possible to remove my contributions prior to withdrawal from the audio/video record.

Name of Participant (please print) _____
Signature _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

--

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____
Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.