

PARTICIPANT INFORMATION SHEET FOR PRE-TEST INTERVIEWS

Project Title: Social Value of Health Gains

You are invited to take part in a research study funded by the MRFF Targeted Health System and Community Organisation Research Grant. This research study is being conducted by a team led by Professor Emily Lancsar at the Australian National University. Please read this Participant Information Sheet carefully before deciding whether to participate in this research.

General Outline of the Research Study:

Description: This research study aims to improve how governments make decisions about funding medicines, treatments, and health services for children and young people. We are interested in finding out from young people and adults about how they think such decisions are made and what they think can be done to improve such decisions. This will assist policy makers allocate health care funding in a way that has the greatest public support.

Participants: We are looking for adults aged 18 years and older and young people aged between 15 to 17 years to complete an online survey on their own, and (iii) parents of a 15-17 year old that would be interested to complete an online survey together with their child.

Participant Involvement:

What does participation in this research study involve?

Short Online Screening Survey

To express your interest in the study, we kindly ask that you complete a short online survey which includes questions such as your age and preferred method of contact and will take one to two minutes of your time.

Semi-Structured Interview

Following the survey, we may invite you to participate in an interview via a video-conference session (on Zoom platform). This session will be recorded and will take up to an hour of your time. You will first be asked to complete an online survey which will involve (i) watching some video information about health funding decisions, and (ii) making choices among a series of hypothetical scenarios which will involve different people who would benefit from the treatment and health care should the treatment and health care be prioritised by the government. You will then be asked some questions about your answers to the survey. ANU will reimburse you for the time taken to complete the interview and send you one AUD\$35 gift card at the conclusion of the study.

Is my participation in the research study voluntary?

Your participation is entirely voluntary. Your decision to participate or not participate will not impact your current or future relationship with ANU or any other organisation(s) you are employed by. You can withdraw anytime *during* the interview. If you withdraw during the interview, you will be able to decide what happens to the data you have already provided. You can also withdraw from the research study *after* the interview, at any time until we commence writing of the report and drafting of research publications (at which point we will no longer be able to remove any information you have provided during your participation).

How will this information and data be used?

We will use the information from our research study to write research publications and provide recommendations for governments. When the research study is complete, you are encouraged to contact the researchers listed below for a summary of our findings. Summary reports will also be made publicly accessible via the TORCH website: <https://www.torchstudy.com>.

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

The outcomes of the research study could benefit children and young people, carers, and health professionals through improved government decision-making about the use of health and care services in children and young people.

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

This study aims to explore participants' perspectives about how money should be spent on health care for children and young people. As this relates to participant's broader perceptions about this topic, the risks to participants are minimal, other than inconvenience for the time taken to participate. However,

there is a small chance that participants may experience some discomfort if the topic involves them thinking about their own experience with illness or other family members experience with illness. Similarly, some discomfort or anxiety may be generated through developing an understanding of healthcare decision making, and the possibility of treatment not being provided in some circumstances, which they may not have previously considered. We expect the chance of psychological risk occurring is small.

Contact Details if in Distress: If you find any of the questions stressful, you may consider contacting;

- Lifeline's 24-hour crisis support team on **13 11 14**;
- Beyond Blue's 24-hour support service on **1300 659 467**; or
- Kids Helpline on **1800 551 800**.

What about privacy and confidentiality?

In collecting your personal information within this research, the ANU must comply with the Privacy Act 1988. The ANU Privacy Policy is available at https://policies.anu.edu.au/ppl/document/ANUP_010007 and it contains information about how a person can:

- Access or seek correction to their personal information;
- Complain about a breach of an Australian Privacy Principle by ANU, and how ANU will handle the complaint.

In the Short Online Screening Survey, we will ask you to provide your preferred contact method. This information will only be accessible to the research team and will only be used to contact you about recruitment and reimbursement. It will be stored separately on a password-protected database, from any other data including the survey responses, interview recordings and transcript.

We will not ask you to reveal confidential information, and you have the right to refuse to answer any question. All of the comments and responses provided will be coded to de-identify any possible identifiable information, such as your name or location. As mentioned, the re-identifying code will be stored separately to personal information and will only be accessible to the research team, should you request your data be removed from the study. Any data collected as part of this research study will be stored on a secure and project-specific ANU folder in which only members of the research team can access. Once the project is completed, the data will be archived and deposited to the Australian Data Archive (ADA), based in the ANU Centre for Social Research and Methods (CSRM) at the Australian National University (ANU). ANU's Research Data Storage Service will be used to archive the research data. After 5 years from the date of publication of the study, all data relating to this study stored on the data storage service will be permanently deleted.

As the research project involves an audio recording:

- You will have the opportunity to provide feedback and comment on a summary of your interview to ensure the results reflect the spectrum of your views.
- The recording will be retained for the minimum retention period of 5 years after the date of publication of the study.
- It is not possible to participate in the research project without being recorded.

Every effort will be made to ensure that the data you provide cannot be traced back to you in reports, publications and other forms of presentation. For example, we will only include the relevant part of a quote, we will not use any names, or names will be changed, and/or details such as dates and specific circumstances will be excluded. Nevertheless, while highly unlikely, it is possible that if you are quoted directly your identity may become known.

The research study is funded by a 2020 MRFF Targeted Health System and Community Organisation Research Grant. The funder will not have access to the data obtained during the study.

What if I have any questions about the research study?

If you would like any more information about this research study, please contact:

Professor Emily Lancsar/ Dr Elisabeth Huynh/ Dr Marcus Sellars

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The Australian National University

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Australian
National
University

What if I have any concern or complaint regarding the conduct of the research project?

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol 2021/124). If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager

The ANU Human Research Ethics Committee, The Australian National University

Telephone: +61 2 6125 3427

Email: Human.Ethics.Officer@anu.edu.au

Thank you for helping with this research project. Please keep this sheet for your information.