

Participant Information Sheet (consumers of workshop)

Researcher

My name is Mingming Zhou and I am a PhD candidate at the Australian National University (ANU) College of Health and Medicine. My supervisors for this project are Associate Professor Jane Desborough, Dr Anne Parkinson and Dr Julia Dray.

Project Title: Consumer remuneration practices in Australian health research: a mixed methods study

General Outline of the Project

Engagement of consumers, including patients, caregivers, and service users, in health research is gaining increasing recognition as a fundamental element in advancing patient-centered and high-quality research outcomes. These individuals bring unique perspectives and lived experiences that can significantly enhance the relevance, accountability, and effectiveness of health research endeavours.

However, researchers may face a substantial challenge in effectively engaging a diverse spectrum of consumers and appropriately acknowledging their contributions to the research process. An important aspect of this challenge relates to the issue of remuneration – the compensation offered to consumers in recognition of their invaluable contributions in terms of time, skills, and expertise to research project. This remuneration can take various forms, including direct compensation and reimbursement for out-of-pocket expenses such as travel, parking, meals, and childcare. Offering remuneration may allow consumer partners from different socioeconomic population groups to be engaged in research and thus encouraging the inclusion of diverse perspectives.

This project is a collaboration between the National Centre for Epidemiology and Population Health (NCEPH), Australian National University and Research Australia (RA). It is comprised of two stages. Stage 1 has recently been completed: a survey of Research Australia member organisations to identify how health organisations and researchers currently recognise consumers for their contributions to research, and to understand the experiences and attitudes of health organisation members and researchers regarding financially remunerating consumers in health and medical research.

Stage 2 involves a number of deliberative workshops to explore the feasibility and generalisability of proposed models of consumer remuneration, which have been informed by the results of our recent survey of Research Australia members in Stage 1.

You will have an opportunity to learn about the outcomes of the workshop you have contributed to via a concise report that summarises the research findings in an easy-to-understand format around July 2024 after the completion of this study, and any publication(s) / conference presentations we produce will be made available around 2025. You could choose to receive them via email or mail (Indicated in the consent form).

Participant Involvement

As you are a health care consumer, you have been invited to take part in an online deliberative workshop, which will be comprised of three groups of 6-8 people to be jointly held by ANU and Research Australia. Two groups will include people representing their organisations which are members of Research Australia, and one group will include health care consumers such as yourself. You will be presented with a report detailing 2-3 consumer remuneration models which have been informed by the results from the survey of Research Australia members in Stage 1 of this project. This will be followed by a facilitated discussion of the content. For example, we would like to discuss which model you believe is more feasible for current practice and how might we generalise this model in different contexts. Each group will work with a facilitator in a structured process of group reflection. The workshop will run for approximately 2 hours (with a break included). The workshop will be conducted online using the Zoom platform and will be video/audio recorded, and transcribed. When the Zoom session is initiated, a message will be displayed advising participants that the workshop will be video/audio recorded. You will be asked to complete and sign a “Statement of Consent” if you wish to participate and consent to be video/audio recorded. (see attached to this information sheet).

Voluntary Participation & Withdrawal

Your participation is **voluntary**. It is completely up to you if you participate or not. You are free to withdraw at any time without any reason or any cost to you. As this is a group workshop, we cannot guarantee anonymity although names of individual participants will be de-identified in reports or publications arising from this research.

Remuneration

Consumer participants will be remunerated \$40 each for their contributions in accordance with rates suggested by Health Consumers NSW: <https://www.hcnsw.org.au/for-health-consumer-organisations/remuneration-and-reimbursement-of-health-consumers/>.

Are there any risks if you participate?

There are few risks of participating in this research. This is a workshop in which you will be asked about the practices and guidelines in use for consumer remuneration. We will keep your information confidential, but other members of the workshop will hear what you say or may know you personally. Please try not to mention any confidential or defamatory information, or information about illegal activities [as applicable] during workshop, and please keep workshop discussions confidential. However, all participants will be de-identified in reports and publications arising from this research. If you have any further concerns about confidentiality and anonymity, please raise the issue prior to, or during, the course of the workshop.

What are the anticipated benefits?

It is unlikely that you will personally benefit from participation in this research. However, the output from this study is aimed to benefit both researchers and consumers in health research. The anticipated models of consumer remuneration that will be developed as a result of this research will support researchers as a guide to consumer remuneration and will also provide consumers with a clear understanding of accepted rates for their contribution to health research.

Confidentiality

Your privacy is important to us. Any personal information that is obtained in connection with this study will remain confidential as far as the law allows. Recording of this workshop will include video and audio, but that only the audio recording will be retained. Your personal details from this Statement of Informed Consent will in no way be connected to the information from the workshop that you participate in. (That is, your name will not be linked with any information you provide).

Privacy Notice

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. 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.

The findings will be used to write a report and may be published in peer reviewed journals. Participants will not be identifiable in any publications.

Data Storage:

All data will be stored in electronic format in secure, password protected folders at the ANU. Data will be stored for five years following publication.

Handling of Data following the required storage period:

After the storage period, all identifying details will be removed from the data and the non-identified data will be archived in the ANU Data Commons for use in later research, including potentially by other researchers.

Queries and Concerns:

Should you have any questions or concerns about this project, please contact:

Ms Mingming Zhou

National Centre for Epidemiology and Population Health, Australian National University

Telephone: (04) 6624 0189. Email: mingming.zhou@anu.edu.au

Or

Associate Professor Jane Desborough (primary supervisor)
National Centre for Epidemiology and Population Health, Australian National University
Email: jane.desborough@anu.edu.au

Should you feel stressed or emotional after the interview, we recommend you contact someone from one of the groups listed below: Lifeline's 24-hour crisis support team on 13 11 14 or Beyond Blue's 24-hour support service on 1300 659 467.

Who should I contact if I have concerns about the conduct of this study?

The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol H/2023/1263). If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager, The ANU Human Research Ethics Committee, Australian National University
Telephone: +61 2 6125 3427 Email: Human.Ethics.Officer@anu.edu.au

If you would like to take part in the study, please read and sign the 'Statement of Informed Consent' below.

CONSENT FORM for research participants

Consumer remuneration practices in Australian health research: a mixed methods study.

I have read and understood the Information Sheet you have given me about the research project, and I have had any questions and concerns about the project (listed here)

addressed to my satisfaction.

I agree to participate in the project. YES NO

I agree to be video/audio recorded. YES NO

I agree to this video recording being stored in a secure repository at the ANU and being used for future research. YES NO

I agree to having a transcript of this video recording being stored in a secure

repository at the ANU and being used for future research. YES NO

I agree to be identified in the following way within research outputs (e.g., reports and academic articles):
Pseudonym (alias)e.g., Participant 1, Participant 2 YES NO

I agree to receive the results of this study via email or mail. YES NO

Email or mail address: _____

Signature:.....

Date:.....