

Participant Information Sheet

Researcher

My name is Jane Desborough and I am a researcher at the Australian National University (ANU) College of Health and Medicine. I am leading a team that includes health services researchers, health economists, and people with lived experience of chronic illness. Together we aim to understand how out-of-pocket costs of healthcare and medicines are experienced by people with chronic illnesses on low, middle, and high incomes. Other team members who will be directly involved in this part of the research are Ms Jillian Kingsford Smith, Dr Anne Parkinson and Dr Elisabeth Huynh.

Project Title: The Real Price of Health: Experiences of Out-of-Pocket Costs in Australia.

General Outline of the Project

Despite Australia having a universal health insurance scheme, out-of-pocket costs for healthcare and medicines are often high. Individual Australians are the third largest contributor to healthcare financing in Australia behind federal, state and territory governments. Much of this is spent on consultations with doctors and other health care providers, medications, and diagnostic tests. This has the potential to create barriers to access at the frontlines of the health system, where the greatest gains from prevention and early intervention can be sourced.

Understanding the impact of out-of-pocket costs on the day-to-day lives of people with chronic illness, and in relation to their income level, will provide important new knowledge, and an opportunity to improve the equity of financing of healthcare in Australia. This study will explore the challenges people experience in managing the affordability of certain health services or medicines. It will also describe the choices that people make, which are reflective of the value they place on aspects of their health and life.

This project aims to:

1. Understand how out-of-pocket costs of healthcare and medicines are experienced by people with chronic illnesses on low, middle, and high incomes.

To help us to understand a wide range of experiences, we aim to interview about 60 people living with chronic conditions about the impact of out-of-pocket costs on their day-to-day lives. You have been invited because you are a person with one or more chronic health conditions and can use your life experiences to help us better understand this. You will have an opportunity to learn about the outcomes of the research you have contributed to via your peer support group and any publication(s) / conference presentations we produce will be made available to these groups to share with their members. The outcomes will also be shared on our research website:

<https://nceph.anu.edu.au/research/projects/real-price-health-experiences-out-pocket-costs-australia>

This project is funded the Australian Research Council, Discovery Early Career Researcher Award #DE220100663, The Real Price of Health: Experiences of Out-of-Pocket Costs in Australia.

Participant Involvement

Your participation is **voluntary**. It is completely up to you if you want to be involved in this research. All information you provide will be de-identified. You can change your mind at any time and pull out of the research without telling me why. To do this you can contact me using the details provided at the bottom of this information sheet. If you do pull out of the research before the work is prepared for publication, I will not use any of the information that you have given me, unless you are happy for me to do so.

You will be invited to take part in an interview. The interview will be prepared and facilitated by experienced interviewers with the aim of learning about your experience of managing the out-of-pocket costs of health care and medicines, including choices that you make.

What personal information will we ask you to discuss?

During the interview, we will ask you to discuss the following information:

- Your age and sex
- About your chronic illness – what it is and if you have more than one condition
- Financial and other costs directly and indirectly related to your health
- Your approximate income
- Your racial or ethnic origin

We **will not** ask you to name individual doctors or health services.

How will this information be used in the research?

This information will help us to understand and compare how different people, including those from low, middle and high incomes are impacted by the cost of health care and medicines. It will also help us to understand the choices and trade-offs that people make; for example, sometimes people will choose to pay for a medication instead of going to the movies. We will use this information to develop a survey that will be used in the second part of the study, where people will be presented with options related to their health and will be asked to choose between these. The information from this survey will help us to understand the value that people with chronic conditions place on aspects of their health and life, and help us to inform policy related to this.

The interview is expected to take about 60 - 90 minutes. If possible, the interview will be conducted face to face at a time and location that is convenient for you. If face to face interview is not possible, it will be conducted online via Zoom or Webex. We will ensure you have access to the required technology before the interview takes place. If you speak little or no English, we will conduct your interview using the Translating and Interpreter Service (TIS National). The interpreter will not have access to your full name if you do not wish them to.

With your permission, the interview will be recorded and transcribed for analysis. The video content will be deleted after the interview, and you will be sent a copy of the interview transcript to read and confirm that the information is correct before we use it for our analysis. You will be remunerated \$42 per hour for

your time. This is the rate suggested by Health Consumers NSW: <https://www.hcnsw.org.au/for-health-consumer-organisations/remuneration-and-reimbursement-of-health-consumers/>. This will be provided as either cash or a gift card.

About six months after the interview, I will upload a summary of the research and provide you with a link to this summary.

Are there any risks if you participate?

There are limited risks of participating in this research; however, given that the topic of discussion is your experience of managing out-of-pocket costs, there is a chance that the discussion could raise topics that could be sensitive or emotional. Should this occur during the interview, you may step out, ask for support and/or feel free not to continue the interview. Should this happen after the interview has finished, please contact one of the support services listed below under questions and concerns.

There is a small risk that information you provide may identify you. To avoid this, we suggest that you avoid discussing information that is confidential or that could harm you or someone else. We will not ask you to name individual health care providers or health services.

In accordance with COVID-19 safety at the time of the research, masks will be worn and hand sanitiser available for face-to-face interviews. If necessary, all interviews will take place using telephone, Zoom or another safe, online methods.

What are the anticipated benefits?

This project addresses an important issue for people with chronic conditions, who often experience out-of-pocket costs for health care and medicines. It is unlikely that you will personally benefit as a result of taking part in this research, although the study aims to eventually benefit Australians through informing health care policy and the equity of health care and medicines financing in Australia

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. If you have any concerns about your privacy, please contact us to discuss the matter. All data will be stored in password protected folders at the ANU and on the ANU OneDrive. Only people directly working on this project and named on ethics protocols will have access to these data. Your personal details from this Statement of Informed Consent will in no way be connected to the information from the interview. (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/ppi/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 develop online resources and filmed hypothetical consultations, and they may be published in peer reviewed journals. Participants will not be identifiable in any of the above project outputs.

Data Storage:

All data will be stored in electronic format in secure, password protected folders at the ANU. No identifying information will be recorded in this process. On completion of the study interview, with your permission data will be preserved as audio recordings and/or as de-identified transcripts. The dataset will be stored at the ANU Data Commons repository and made available on request for genuine researchers.

Queries and Concerns:

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

Jane Desborough
National Centre for Epidemiology and Population Health,
Australian National University
Telephone: (02) 6125 6545
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 2022/856). 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

The Real Price of Health: Experiences of Out-of-Pocket Costs in Australia

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 this interview being recorded YES NO

I agree to the audio 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 the audio 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:

Pseudonym (alias) YES NO

No attribution YES NO

Signature:.....

Date:.....