



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

HREC Project Number: 15666

Research Project Title: Exploring healthcare consumers' lived experience during climate-related disasters in Australia

Chief Investigator: Prof Enrico Coiera

Co-investigators: Dr Hania Rahimi-Ardabili, Prof Farah Magrabi, Dr Zerina Tomkins, Prof Yvonne Zurynski, Dr K-lynn Smith, Kalissa Brooke-Cowden, A/Prof Annie Lau

You are invited to take part in this research project because you were managing a health condition (as a patient or a carer) during climate-related disasters in Australia (i.e. floods, bushfires). This study aims to explore the healthcare consumers' lived experience during climate-related disasters in Australia to learn from the challenges they faced and how they responded to them, to prepare the health system and communities for future crises.

This Participant Information Sheet/Consent Form tells you about the research project, and what is involved. Knowing what is involved will help you decide if you want to participate. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or a friend.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to the tests and research that are described
- Consent to the use of your personal information as described.

You have already received a copy of this Participant Information and Consent Form via email to keep.

1. What is the purpose of this research?

This study aims to explore healthcare consumers' lived experiences during climate-related disasters, such as floods and bushfires in Australia. Information collected in this study will allow us to understand the gap in the current health system in responding to climate-related disasters.

2. What does participation in this research involve?

This research is open to disaster-affected communities who were managing a health condition during climate-related events in Australia.

Participant inclusion criteria:

- From disaster-affected communities and managing a health condition (as a patient or a carer) during recent climate-related disasters in Australia (e.g. flood)
- Able to attend a 45-60 minute interview (online, by phone or in-person)
- Able to read and speak in English.

Prior to participation, you will be asked to indicate your consent by signing and returning this form via email to the research team. A research team will later contact you to schedule a one-on-one interview with you online using the Microsoft Teams platform, over the phone or in-person at your preferred time and date. The interview will take about 45-60 minutes and be conducted in a place of your choice. During the interview, you will be asked questions about challenges you faced during the disaster events when you were managing a health condition (as a patient or a carer), and your responses to them. The interview will be audio and video recorded. You can participate with audio alone by choosing to join the call without a camera/video function. Your permission will be sought before the commencement of the audio/video recording.

Permission to view the recording will be restricted to the investigators listed on this project, and the video/audio records will be saved in a password-protected folder on a safe server. Typed notes will be de-identified and saved into the same folder. Only the audio part of the records will be stored after the completion of the study, for five years, on a Macquarie University password-protected drive and then will be deleted.

You will receive two reminder emails after the initial invitation from us.

There are no costs associated with participating in this research project, and if you complete the research project, you will receive a \$100 GiftPay e-Gift Card (includes 100+ in-store and online brands), as a token of our appreciation.

3. Other relevant information about the research project

This study is an exploratory study that aims to explore healthcare consumers' experiences during climate-related disasters in Australia.

We may contact you in the future and invite you to participate in a subsequent study with your permission.

4. Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you need to indicate your consent by signing this Participant Information and Consent Form and returning it by email.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Macquarie University or any organisation involved in this study or research team members.

5. What are the possible benefits of taking part?

If you complete this study, you will receive a \$100 GiftPay e-gift Card (includes 100+ in-store and online brands) as a token of our appreciation.

We further hope that your participation will help us identify the health needs during climate-related crises and to develop strategies to support consumers.

6. What are the possible risks and disadvantages of taking part?

You may feel that some of the questions raise issues that are stressful or upsetting. However, the interviews will be conducted in your place of choice, where you feel safe and comfortable. During the interview, if you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. You are welcome to take a break, reschedule or terminate the interview at any point if you experience distress. In the case that you experience excessive distress during the interview or need support, we will intervene and refer you to sources of support. If you experience distress after the interview, we recommend the following resources which are available for support: Australia: Lifeline (telephone 13 11 14; lifeline.org.au) is a national charity providing all Australians experiencing a personal crisis with access to 24-hour crisis support and suicide prevention. International: Befrienders Worldwide (befrienders.org) is an international service where members and trained volunteers around the world provide confidential support to people in emotional crisis or distress. Alternatively, you can discuss it with your general practitioner.

7. What if I withdraw from this research project?

After you consent to participate, you may still withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team. A copy of the withdrawal of Consent form is provided at the bottom of this document for your information.

If you decide to leave the research project, the researchers will not collect additional information from you, although personal information already collected up to the time you withdraw will be retained to ensure that the results of the research project can be measured properly and to comply with the law. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project by marking the relevant box in the Withdrawal of Consent form.

8. What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. The research team will

store the data collected from you for this research project for a minimum of 5 years on a Macquarie University password-protected drive after the publication of the research results. Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law. The information collected will be de-identified. All potentially identifying information will be removed (such as names of people, specific locations) and will be coded with categories to ensure that the meaning of the information is retained.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your explicit permission. In accordance with relevant Australian and/or New South Wales privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team.

You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

9. Complaints and compensation

Any complaints about this project should either be directed to investigators Dr Hania Rahimi-Ardabili (E: hania.rahimiardabili@mq.edu.au), Prof Enrico Coiera (E: enrico.coiera@mq.edu.au), or directly to the ethics secretariat of the Macquarie University Human Research Ethics Committee (ethics.secretariat@mq.edu.au).

10. Who is organising and funding the research?

This project is funded by Macquarie University.

11. Who has reviewed the research project?

The ethical aspects of this research project have been approved by an Ethics Committee at Macquarie University.

12. Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on (02) 9850 9419 or any of the following people:

Research contact person

Name	Role	Email	Phone
Hania Rahimi-Ardabili (NSW)	Lead investigator and research coordinator	hania.rahimiardabili@mq.edu.au	+61 2 9850 9419
Kalissa Brooke-Cowden (NSW)	Research coordinator	kalissa.brooke-cowden@mq.edu.au	+ 61 2 9850 6051
Zerina Tomkins (VIC)	Research coordinator	zerina.tomkins@monash.edu	+ 61 3 9905 0819
Enrico Coiera	Chief investigator	enrico.coiera@mq.edu.au	+61 2 9850 2403

If you have concerns or complaints about any aspect of the project and do not wish to contact the research team, you are able to directly contact the authorising Ethics committee; the details are:

Complaints contact

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone: (02) 9850 7854; email: ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.

Declaration by Participant

I have read the Participant Information Statement.

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 freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project, withdrawal will not affect my relationship with any of the named organisations and/or research team members.

I understand that I have received a copy of this document via email to keep.

- I want to receive a summary of the findings of the study on the completion of the project
- I am happy to be contacted for an invitation to future research participation

Participants Name

Date

Withdrawal of Consent

I wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** affect my relationship with Macquarie University, or any organisation named in this study or research team members.

Please select either:

- I am withdrawing my consent, I would like any personal information collected about me which I have provided for the purpose of this research study withdrawn.

OR

- I am withdrawing my consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

Name:	Hania Rahimi-Ardabili
Email:	Hania.rahimiardabili@mq.edu.au
Phone:	(02) 9850 9419
Postal Address:	Level 6, 75 Talavera Road Macquarie University NSW 2109