

ACACIA



Whose Story Is It?

Mental Health

Research Opportunity

*ACACIA: The ACT Consumer and Carer
Mental Health Research Unit*

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Whose Story Is It?

Mental Health Research Ethics

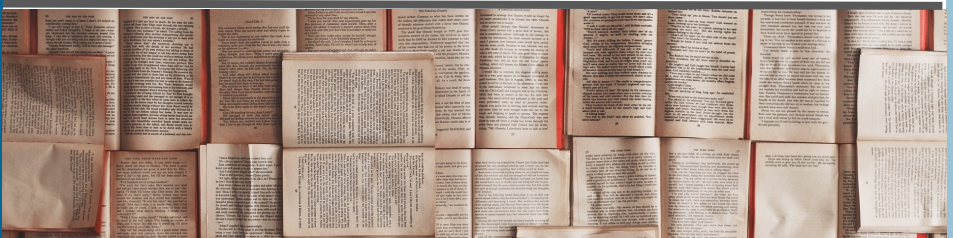
Research can ask people to tell deeply personal stories. In mental health research we are interested in learning about the stories of people who have experienced a mental illness and the stories of the people who support them. How can we help people tell these stories safely?

Research words

In this brochure, we will refer to people who have a lived experience of mental illness as “**consumers**”. We use the term “**carer**” to describe the friends and family members who provide informal support to someone with a mental illness. You can also think of carers as “support people” if that term is more relevant to you.

Who can participate?

We are looking for mental health carers and mental health consumers to participate in an interview exploring the ethics of mental health research. Participants must be at least 18 years old.



What is the project about?

ACACIA is conducting research to understand how mental health consumers and carers see their role in research participation. We are interested in learning about how consumers and carers feel about the issues that university ethics committees think about when they assess a planned research project. We will focus on the ethical issues that are related to research when mental health consumers and carers are participants.

Last year we ran a public forum to get an idea of the kinds of ethical issues that are important to consumers and carers. This interview follows on from that event, and aims to broaden our understanding of some of the key topic areas.

The main focus of the interview will be talking about carer participation in research, as the ethical guidelines for interviewing carers are unclear. We will also talk about the ethical issues of doing research with participants with a lived experience of mental illness more generally.

We are interested in learning about your thoughts, feelings and ideas about how carers and consumers can participate in research safely, together and separately.



Participating

What will I be asked to do?

If you choose to participate you will be asked some questions about these topics in a one-on-one interview setting. An interview will take about 1 hour to 1.5 hours to complete.

During the interview, you can answer with as much or as little information as you would like. You don't have to answer all the questions and you can stop the interview at any time without giving a reason and without penalty.

How will participating help?

Your contribution in this interview will help us to design research that is safe for consumers and carers to participate in. We aim to use the results of this project to develop guidelines for how to do safe and ethical research with consumers and carers. We will also write up the results as an academic paper.

We value your contribution!

We value you sharing your time, thoughts and ideas with us. As a thank you for your time and effort all participants will be given a \$20 Wish (Woolworths group) gift card.



Participating

Are there any risks?

We hope that participating in this interview will be a good experience. But sometimes talking about your experiences can be difficult or upsetting. Remember you are free to pause or end the interview at any time. We will also give you a pamphlet that has information about some organisations you can contact if you would like some support.

Your choice to participate, withdraw or not participate in the study will not affect your access to services, or the access of the person you support.

When and where is the interview held?

The interview will be held at ACACIA's offices at the Australian National University (ANU). Or we can arrange to hold the interview at a more convenient location for you. There is parking or appropriate reimbursement for public transport expenses available.

Interviews will be held on weekdays during business hours. Exact times are flexible, contact us to arrange a time that suits you. Our contact details are on the back of this brochure.

Participating is voluntary

Participating in this study is completely voluntary. You do not have to participate and you can withdraw from the study at any time before results are published.

What will you do with my information?

The data we collect during these interviews will be used to help develop ethical guidelines for involving carers in research. We also plan to write an academic paper and a plain language summary about our findings.

Keeping your personal information confidential

We will protect your confidentiality to the full extent allowed by law. This means that we will not disclose your personal information unless it is necessary in a serious emergency or we are required to do so by law. Only the research team will have access to the personal information collected in the study. Interview recordings will be typed up without names.

How will we store the data we collect?

Data will be kept on password protected computers on ANU campus that only the research team can access. All records will be kept for five years after results are published.

Privacy

This research is compliant with the Privacy Act 1988 and ANU's privacy policy, which can be found at https://policies.anu.edu.au/ppl/document/ANUP_010007

The ANU privacy policy 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 has information about how ANU will handle the complaint.

How do I find out more?

Would you like to participate in an interview? Or would you like some more information? Please contact the ACACIA research team using the details on the back of this brochure.



Meet the research team!

The researchers working on this project are part of the ACACIA team at the Centre for Mental Health Research, ANU.

Dr Michelle Banfield, Research Fellow

Alyssa Morse, Research Officer

Owen Forbes, Research Support Officer

Rebecca Randall, Research Officer

John Gosling, Research Officer

Mearon O'Brien, Research Officer

Ethics Committee Clearance

The ethical aspects of this study have been approved by the ANU Human Research Ethics Committee (Protocol #2015/247). 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

T: +61 2 6125 3427

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

ACACIA: The ACT Consumer and Carer Mental Health Research Unit

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