



Respectful risk management: Ethics and mental health research

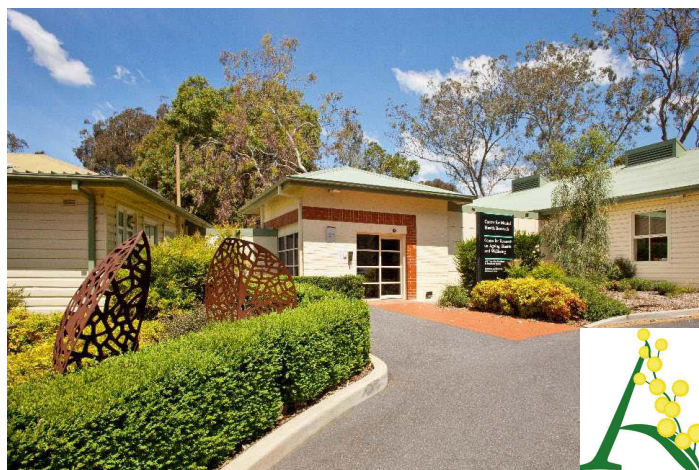
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My perspective



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Chapter 4.5: People with a cognitive impairment, an intellectual disability, or a mental illness

- Capacity to consent
- Ability to participate
- Vulnerability to discomfort and stress


Why this presentation?

...people deserve to be protected, to be able to tell their story and get it out, to be able to influence policy and services and our understanding of mental illnesses. But I think in doing that and in having lived experience that you need to acknowledge that it can be a very tough journey. It can be a very tough life.

Carer

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Why this presentation?

Some people might argue that that's positive discrimination, to safeguard someone that's vulnerable - where I say no, it's just discrimination, it's creating a stereotype and stigmatising a particular person based on a certain clinical list of symptoms.

And so I don't think they should be treated any differently to someone who is also not mentally ill... I wouldn't like to be involved in research and [have] someone say, "Hey, like you can't do this 'cause you can't give informed consent because you have experience with a mental health issue." Um like, sure I can.

Consumer

Consumer


[Morse et al. (2019) *JERHRE* 14]

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Vulnerability



VS



[Luna (2009) *IJFAB 2*]

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Ethical considerations highlighted by:

Ethics procedures	Lived experience
<ul style="list-style-type: none">• Capacity to consent• Susceptibility to discomfort or distress	<ul style="list-style-type: none">• Respectful risk management• Privacy and confidentiality• Benefits of research

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Capacity to consent – Research indicates:

- Most people with lived experience of mental illness have the capacity to consent to research
 - Particularly in community settings
- Capacity may be reduced in certain circumstances and settings, e.g.
 - People with cognitive difficulties
 - People who are hospitalised (coercion)
- Poor consent processes are a barrier to all participants



[DuBois et al. (2011) *AJOB Primary Research*; Roberts & Roberts (1999) *Biol Psych*; Yanos et al (2009) *Psychiatr Serv*]

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Strategy: Clear Communication

- Poor information sheets are a barrier to **all participants**
- A good information sheet:
 - Concise
 - Clear
 - Appropriate for your audience



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General Outline of the Project:

- **Description:** Carers of people with a chronic mental illness have a story to tell. But whose story is it? Do carers have the right of ownership of their carer's journey? Or is it intrinsically linked to the consumer's story and therefore not theirs to tell within ethical boundaries? This research project will investigate the guidelines for research involving people with chronic mental illness, investigate consumer and carer views on these guidelines and propose a framework that supports ethical research on the carer experience.
- **Taking part:** We are inviting mental health consumers and carers living in the ACT to take part. Taking part is voluntary. The study involves an interview that will take 60-90 minutes. We understand that not everyone relates to the term 'carer', or shares the same definition. For the purposes of this project we are using the term carer to refer to a family member or friend who provides informal support to someone with a mental illness. A consumer is someone who identifies as having a lived experience of mental illness themselves.
- **Use of Data and Feedback:** This study will contribute to the development of ethical guidelines for engaging mental health carers in research. Inclusion of consumer and carer perspectives in the process of policy development will allow us to create ethical guidelines that are meaningful and relevant to the lived experiences of consumers and carers. Our feedback should help to improve mental health research practices. We will also prepare an academic paper on our findings. A plain language summary will be available to participants and included in our newsletter. Insight (<http://nimhr.anu.edu.au/research/projects/acacia-act-consumer-and-carer-mental-health-research-unit/newsletter>).
- **Project funding:** This project is being conducted by ACACIA: The ACT Consumer and Carer Mental Health Research Unit. The project is funded by the Australian Capital Territory Government Health Directorate, ACT Government Contract Number 2013.21920.590. This project is part of a wider initiative to involve mental health consumers and carers in research processes and its dissemination.


Your Involvement

- **Voluntary Participation & Withdrawal:** Taking part in this study is voluntary. You don't have to take part in the interview and you don't have to answer all questions. You can withdraw at any time before findings are published without giving a reason and without penalty. If you do withdraw, your answers up to that point will not be included in the study unless you ask us to keep them.
- **What is involved?** If you decide to take part in the study you are agreeing to be interviewed by one of our research officers. The researcher will take notes while talking to you, but if you agree we would also like to record the interview. This will make sure we don't miss anything. You will be asked whether you agree to being recorded on the consent form.



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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.



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.



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Understanding Participation: Measuring the value and impact of consumer and carer voices in services and policy

Participant Information Sheet


Meet the research team:
This research project is being conducted by Dr Alyssa Morse (the principal investigator), Dr Amelia Gulliver, and Dr Michelle Banfield. The research team are part of ACACIA: The ACT Consumer and Carer Mental Health Research Unit at the Centre for Mental Health Research, ANU. We are working in partnership with Health Care Consumers' Association, The ACT Mental Health Consumer Network, Carers ACT, the ACT Health Directorate and Canberra Health Services.

Key information:

- **What's the study about?** How does participation work in practice (tokenism versus real involvement)? How is the consumer and carer voice integrated into policy and services? How are their contributions valued, and what indicators exist to demonstrate how their voice is used? We are interested in finding out the answers to these high-priority research questions developed by consumers and carers in the ACT. Our ultimate goal is to co-create a set of consumer- and carer-developed principles for lived experience participation, value and impact. We would also like to create a matching measurement tool that can be used in the ACT health sector. To explore these questions and help achieve these goals, we are interviewing people who have experience working in, or with, lived experience participation.
- **Who can participate?** We are looking for up to 35 participants who have experience working in, or working with, lived experience participation in the ACT. This includes, for example, consumer representatives, carer representatives, service providers and policy advisors. Interview participants will be recruited from within community organisations (10 participants), the ACT Health Directorate and Canberra Health Services (10 participants), and from the broader ACT community (15 participants).
- **How will you use my data?** The findings of the research project will be published in peer-reviewed journals and presented at academic conferences. A plain language summary of the results will be published on the ACACIA website (<http://cmhr.anu.edu.au/acacia>) and in ACACIA's *Insight* newsletter. The findings may also be disseminated via the newsletters and mailing lists of our partners on this project (listed above).
- **How is the study funded?** This research project is funded by an RSPH Excellence in Population Health Research Award. Two of the researchers (AM and AG) are funded by an ACT Government Deed of Grant. Under this Grant, they have no contractual obligations regarding the collection and use of data, or the publication of findings. MB is supported by a Medical Research Future Fund fellowship.


How the study works:

- **Participation is voluntary:** Participation in this study is voluntary. It is completely up to you whether or not you participate. If you do participate, you don't have to answer all the interview questions. You can withdraw from the study at any time before the results are prepared for publication without giving a reason and without penalty. If you do withdraw, your answers up to that point will not be included in the study unless you ask us to keep them.




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Discomfort and distress – Research indicates:

- Some people with a mental illness may be more susceptible to some forms of discomfort or distress.
- Consider context:
 - Focus/methods of project
 - Specific participant group



[DuBois et al. (2011) *AJOB Primary Research*; Roberts & Roberts (1999) *Biol Psych*; Yanos et al (2009) *Psychiatr Serv*]

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Lived experience perspectives on vulnerability

- Participants did not believe that experiencing a mental illness increased their risk of psychological harm
- Some circumstances may increase risk
 - Acutely unwell
 - Power imbalances

So I think maybe it's not so much about singling out mental health consumers, I think it's about a trauma informed approach to the topic of research. So acknowledging that there are certain types of research that don't involve mental health consumers that... could actually traumatise a person who has no history of mental illness but has a history related to that research.

Consumer

[Morse et al. (2019) *JERHRE* 14] 13

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Respectful risk management

- Safeguards can facilitate participation
- Emphasis on autonomy and choice
 - Supportive measures responsive to needs
 - Provide options
 - Avoid imposing blanket measures
- How can you design acceptable safeguards?
 - Evaluation, consultation and co-design!



[Morse et al. (2019) *JERHRE* 14; DuBois et al. (2012) *American J Public Health*] 14

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Strategy: Relevant support resources

Study:

- Online survey
- Young people (16+)
- ACT residents only

Support service details tailored to this audience.

Support Service Contact Details

If you are currently feeling upset or distressed, there are services to help you. Please talk to a trusted adult (e.g., parent, guardian, teacher), your school psychologist, General Practitioner (GP), or contact one of the services below:

Lifeline Australia: 13 11 14 (24 hours), www.lifeline.org.au

Kids Helpline (for people aged 25 and under): 1800 55 1800 (24 Hours)
<https://kidshelpline.com.au/>

Suicide call-back service: 1300 659 467 (24 hours), www.suicidecallbackservice.org.au

Beyond Blue: 1300 22 4636 (24 hours), www.beyondblue.org.au


SANE: 1800 187 263 (9-5), www.sane.org

Headspace: <http://www.headspace.org.au/>

If you need immediate support and assistance, please call Access Mental Health on 1800 629 354 or 02 6205 1065. Access Mental Health offer mental health services that are available 24 hours a day, 7 days a week. These services give you access to assessment and treatment services and offer advice and information on a range of mental health issues.

If your situation is life-threatening, call Triple 000 immediately for help or visit your nearest Emergency Department.

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Strategy: Distress protocol

- A plan for action in the event of a participant:
 - Experiencing psychological distress
 - Disclosing thoughts about suicide, self-injury or other harmful indicators
- Developed with researcher, clinician and consumer input

ACACIA participant distress protocol

Flow Chart

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Strategy: Prepare for difficult conversations

- Training is available:
 - Mental Health First Aid
 - Lifeline Accidental Counsellor Training
 - Question, Persuade, Refer (QPR) training
 - <https://www.chnact.org.au/mental-health-programs-hp>
- Discuss or role-play with team



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Privacy and confidentiality

If a third party were to suddenly have that information and be able to say OK... I know who that person is, that does become a problem because it's no longer between me and the person who's directly involved.

Consumer

Yeah, and I think it [research] can be more anonymous too. I don't know that I'd want to identify myself in a study... I'm not comfortable with people knowing widely that I've been through this.

Consumer

[Morse et al. (2019) *JERHRE* 14]

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Strategy: Clear communication

- What information will you collect?
- What information will you share and how?
 - Open and realistic about possible identification
- Allow participants to review transcripts and draft results
- Take care in reporting results



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Benefits: Participation can be positive!

...like even when I have been mentally ill I guess, and been involved in research, I've always found it quite positive, and quite empowering to be able to talk about my own experiences.

Consumer



The more that I think that it's actually like going to make a difference the more time I'd be happy to put into it.

Consumer

[Morse et al. (2019) *JERHRE* 14]

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Take home messages

- Think through realistic challenges and risks of your project:
 - National Statement and other guidelines
 - Empirical evidence
 - Community consultation and/or co-production
- Design and implement appropriate, acceptable and respectful safeguards.
 - Consider individual needs and context
- Clear communication



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Acknowledgements

Lived Experience Research Unit

Prevention, Promotion and
Educational Systems Unit

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Helpful references

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