

Whose Story Is It?

We know that involving consumers and carers in research is becoming increasingly important.

Clear ethical guidelines about including consumers in mental health research exist, but there are no equivalent guidelines for carers or consumer-carer relationships.



What we did

This study investigated mental health consumer, carer and researcher perspectives on mental health research ethics. It was conducted in three stages:

- 1) survey of international researchers,
- 2) discussion forum with consumers, carers and lived-experience researchers
- 3) in-depth interviews with consumers and carers.

What we found

Key issues raised in relation to carer research and telling shared stories in research were: *ownership of story*, and *privacy and confidentiality*.

Risks and conflicts caused by these issues could be resolved by better communication between researchers and participants, and within consumer and carer relationships.



What we learned

Based on the results, we make these recommendations for research practice:

- *Consider the boundaries of story ownership when stories are shared by more than one person*
- *Manage the risks of information sharing for relationships by educating participants*
- *Manage research risks respectfully and protect participants' rights to make decisions*

Want to learn more?

For more information about ACACIA's research projects, head to the "Our Research" page on the ACACIA website:

<http://cmhr.anu.edu.au/acacia>

