**Australian Mental Health Consumer and Carer Perspectives on Ethics in Adult Mental Health Research**

[Alyssa R. Morse](https://journals.sagepub.com/doi/10.1177/1556264619844396), [Owen Forbes](https://journals.sagepub.com/doi/10.1177/1556264619844396), [Bethany A. Jones](https://journals.sagepub.com/doi/10.1177/1556264619844396), ...

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Barriers to research arise when national ethical guidelines governing the inclusion of consumers in mental health research are implemented at the local level. Equivalent guidelines for research involving carers are not available. A social science investigation of Australian mental health consumer and carer perspectives on research ethics procedures was conducted in two interlinked stages: (a) a discussion forum with consumers, carers, and lived-experience researchers and (b) in-depth interviews with consumers and carers. Data collection and analysis drew strongly on methodological features of grounded theory. Privacy, confidentiality, and stigmatizing ethics procedures were key issues for consumer and carer participants. Recommendations for research practice include the following: considering the impact of information sharing on participants’ relationships and adopting individual-focused approaches to managing research risks.

**Mental health research priorities in Australia: a consumer and carer agenda**

Michelle A. Banfield, Alyssa R. Morse, Amelia Gulliver & Kathleen M. Griffiths

https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-018-0395-9

Background

The perspectives of mental health consumers and carers are increasingly recognised as important to the development and conduct of research. However, research directions are still most commonly developed without consumer and carer input. This project aimed to establish priorities for mental health research driven by the views of consumers and carers in Australia.

**Australian Mental Health Consumers’ Experiences of Service Engagement and Disengagement: A Descriptive Study**  
Sharon Lawn, Christine Kaine, Jeremy Stevenson, and Janne McMahon  
  
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8508315/

Abstract

Mental health issues are a severe global concern with significant personal, social, and economic consequences and costs. This paper reports results of an online survey disseminated across the Australian community investigating why people with mental health issues choose particular mental health services over others, what causes them to disengage from services, and what factors and qualities of services are important to consumers to support their continued engagement or re-engagement with mental health services. The importance of GPs was evident, given their key role in providing mental healthcare, especially to those referred to as “the missing middle”—consumers with mental health issues who fall through the gaps in care in other parts of the healthcare system. The study found that many respondents chose to engage with mental healthcare providers primarily due to accessibility and affordability, but also because of the relational qualities that they displayed as part of delivering care. These qualities fostered consumers’ sense of trust, feeling listened to, and not being stigmatized as part of help seeking and having their mental health needs met. Implications for education and practice are offered.

Engaging consumers in health research: a narrative review

Ania Anderst, Karena Conroy, Greg Fairbrother, Laila Hallam, Alan McPhail, Vicki Taylor

<https://www.publish.csiro.au/ah/pdf/AH19202>

Abstract.

Objective. Consumer and community engagement (CCE) in research is increasingly valued in a contemporary healthcare environment that seeks to genuinely partner with consumers and the wider community. Although there is widespread agreement at research governance levels as to the benefits of CCE in research, there is little available research-based guidance as to how best to proceed with CCE organisationally and how to manage and overcome barriers. The aim of this narrative review was to draw together the available research, review findings and relevant governance-related material and to discuss these in light of a case series among research-engaged consumers in order to chart a practical way forward.