

Nothing about us without us

VMIAC's brief guide to Lived Experience engagement in research

Rights | Acknowledgement | Expertise Self-Determination | Choice | Diversity Safety | Respect | Fairness | Information

Read VMIAC's Lived Experience-led Research Strategy

https://www.vmiac.org.au/research

Experts in our own lives

The expertise of people with lived experience of mental health challenges is highly valuable and needs to be central to all mental health research. Too often, lived expertise has been undervalued, underresourced, and taken for granted by researchers and research agendas. We know what needs to be prioritised in mental health research.

People with lived experience who are involved in research must be valued, acknowledged, and paid fairly for our work and contributions, whether as participants, advisors, or researchers. Traditional power imbalances in research practice must be acknowledged and transformed.

A right to self-determination& information

People with lived experience have a right to be fully informed about any research project we choose to be involved in as participants, advisors or researchers. Research participants should have the choice to be kept informed about project outcomes and impact, while maintaining confidentiality, and exercising this choice must be simple.

Recognise diversity

People with lived experience are diverse. Our experience of mental health challenges is varied and intersectional. We also have diverse views about mental health services and interventions.

The relevance, quality, and validity of mental health research has suffered from failing to identify, acknowledge, and address diversity.

Diverse and priority groups must be adequately represented in research planning, teams, and as participants. Inclusion is best achieved through promoting, supporting, and resourcing lived experience leadership and engagement in all aspects of mental health research.Autonomy & choice

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Is unpaid participation fair?

Some people may refuse payment for participation. While voluntary, unpaid participation may also sometimes be appropriate (e.g., for key projects with large samples and low demands).Voluntary participation should not be standard practice.

What about vouchers?

Vouchers should only be offered as payment if that is participants' choice, not the choice or policy of researchers.

Ethics

Organisations doing research should have policies to uphold the rights of people with lived experience that outline procedures for safe, fair engagement.

Safety

Is your research practice traumainformed? Have you included adequate support for lived experience researchers and participants?Is unpaid participation fair?

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