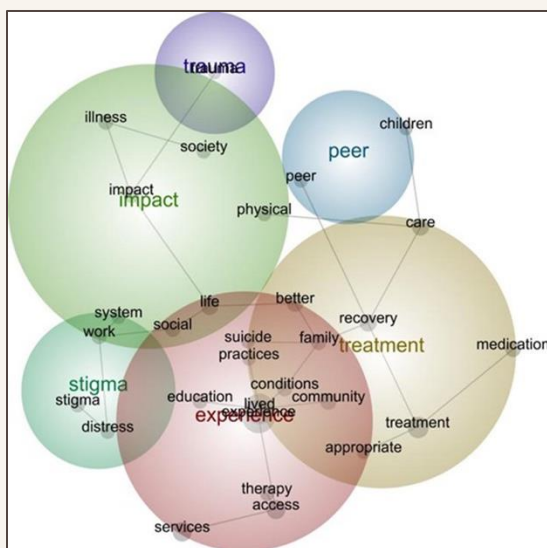


Lived Experience Must Take Centre Stage in Future Mental Health Research

This Quick Guide was created by current Co-Design Leads: Sam, Julia, Ali, Amit, Elise, Gregor, Nargis, Brenton and Tricia.

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Pictured is a Leximancer map of the six priority areas (themes; trauma, peer, treatment, experience, stigma, impact) and the priorities (concepts) shared by people with lived experience in the study. **Leximancer** is a tool that analyses text and displays the information visually. The space of each theme is represented by **coloured circles**. The concepts are the **words in black** and the lines link concepts semantically. Overlapping indicates semantic relation.

Connections and lived experience must be central to future research – and nuance is key

Why does this research matter?

For decades, experts have tried to establish priorities for mental health research and translation - where findings are applied to 'real world' settings. However, there has been limited progress in priority-setting.

Historically, priorities identified by researchers have focused on the integration of services, the role of social care and support, a need for peer-led models, recovery, and addressing the impacts of medication. **The priorities of people with lived experience of mental ill health have frequently been 'lost in translation'**. When people with lived experience have reported their priorities for research, researchers have interpreted them in a way that is different to how they were originally meant.

This research provides evidence that **experience is central** to driving mental health lived experience research priorities. The authors highlight the need for researchers and policymakers to listen carefully to the voices of people with lived experience and to prioritise research that addresses the complex, interrelated nature of mental health issues.


For whom does the research have relevance?

This review is most relevant for researchers and people involved in translating research into practice.


Primary Topic: Identifying and analysing the mental health research priorities from the perspective of people with lived experience in Australia.

Main Audience: Researchers, policy makers, advocacy groups and community organisations.


What was the focus of the research and who participated?

 207 Consumers 52 Carers 106 people who were both consumer and carers	The study used data from an Australian survey. Participants were asked to list three priorities for mental health research, and the responses were analysed using Leximancer software.	1,294 research priorities Ways people described gender: 77% female 18% male 4% another term 1% non-binary	Participants were aged from 20 to 93 years old	Led by lived experience researchers, who designed the study and collected the data and who worked collaboratively with an interdisciplinary research team to analyse and write the paper
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Whose perspectives were shared?

 A total of **365** people with lived experience of mental ill-health participated in the survey. Participants were from all Australian states and territories and from metropolitan, regional, and remote areas.

Key findings, why they matter and next steps

 Research has historically focused on the same priorities for people living with mental ill-health. However, this paper provides evidence to suggest there are different, more nuanced priorities for people with mental ill-health, namely **lived experience, treatment and its impacts, followed by social stigma, peer contact and trauma.**

This research is different because the researchers didn't just come up with a list of priorities, they were able to find out **how these priorities related to each other and the different aspects of the person** with lived experience. It is crucial that researchers and academics capture the direct speech of people verbatim instead of summarising, editing or 'cleansing' the data. **Failing to use the language of the person speaking is not acceptable.** This not only further marginalises and disempowers people, but it misinterprets the message. This results in the research not representing the true priorities of people with people living with mental ill-health.

What matters for us as co-designers with lived-experience of mental ill-health and carer, family and kinship group members

It matters to us that our voices are heard and what we view as priorities are centred.

"When I have taken the time to share my experience in my words and language, once the work is done and I read it and my words and language have been watered down and sanitised, that is no longer my story. I cannot see myself in those words. Which means, we are not on the same footing."

- Ali Haney

(Co-Lead of the Co-Design Living Labs Network, The ALIVE National Centre)

Citation and Full Paper:

Banfield, M., Gulliver, A., Jazayeri, D., Palmer, V. J and The ALIVE National Centre for Mental Health Research Translation Investigator Group. (2024). Experience is central and connections matter: A Leximancer analysis of the research priorities of people with lived experience of mental health issues in Australia. PLOS Mental Health 1(1). <https://doi.org/10.1371/journal.pmen.0000010>