

Lived Experience Engagement Framework

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A word from our Executive Director

“It is my pleasure to share the Mindgardens Lived Experience Framework, the next stage in our organisation’s commitment to embedding lived experience perspectives throughout all our ground-breaking translational research work.

Full inclusion of lived experience is transformative. People who live with mental health, drug and alcohol and neurological disorders, and their families and carers, have unique insights that challenge the way health systems have traditionally operated; when we implement their ideas within services, through truly collaborative co-design processes, we promote recovery, autonomy, equity and human potential.

At Mindgardens Neuroscience Network, our lived experience colleagues have central roles across the full spectrum of our activity, participating equally alongside clinical and health system professionals in shaping our research priorities, developing project protocols that properly embody consumers’ needs, and building capacity to integrate this thinking throughout the service system.

This Framework documents our approach and sets a high bar for the future. I hope it will provide clarity for all our collaborators about Mindgardens’ expectations in working together, while also providing leadership for our sector.”



Professor Jackie Curtis
Executive Director
Mindgardens Neuroscience Network

What is Mindgardens?

Mindgardens Neuroscience Network was established to improve the lives of people who experience mental health, drug and alcohol and neurological disorders. We were established by founding Members South Eastern Sydney Local Health District, UNSW Sydney, Black Dog Institute and Neuroscience Research Australia (NeuRA) to bridge the gaps that have held our sector back. We are tackling decades-long delays between original discoveries and changes to practice. We are amplifying missing voices, including those of consumers, so they can challenge conventional thinking. We are breaking down barriers between academic researchers and people working at the coalface. And we are scaling up pilot programs into efficient, responsive models of care.

Integrate, Collaborate, Innovate

Mindgardens acts as a catalyst to change the way mental health, drug and alcohol and neurological healthcare services are designed and delivered. We are bringing together people with lived experience, clinicians, researchers, health managers and the community in an integrated environment to focus on outcomes, co-designing new models of care and real system change.

Our Strategic Goals

01

Drive better outcomes through research and innovation translation.

02

Maximise the impact of collaboration, co-design and partnerships.

03

Build a learning healthcare ecosystem.

MindLabs

MindLabs is a Mindgardens initiative that supports researchers to develop skills and capacity to translate their original findings into actions that make a real difference in people's lives. This includes setting and maintaining best practice standards for lived experience engagement across Mindgardens research programs. MindLabs is available to assist Member organisations and other partners to improve the quality, safety and effectiveness of their lived experience inclusion in:

- Research design, budgeting, ethics and funding applications
- Co-design planning and practice
- Cross-disciplinary collaboration, skill matching and mentoring

Please contact MindLabs to explore how we can support your organisation or project. mindlabs@mindgardens.org.au

Acknowledgement of Lived Experience

Mindgardens acknowledges the contribution and the power of people with lived experience of mental health, drug and alcohol and neurological challenges, along with their carers, families and loved ones, to inform, influence and enhance research. We hold a thought today for all of those who are currently experiencing challenges associated with mental health, drug and alcohol or neurological disorders.

Acknowledgement of Black Dog Institute

Mindgardens wishes to thank Black Dog Institute (BDI) for sharing their Lived Experience Framework, which was co-designed by people with a lived experience along with the BDI Lived Experience Resource Network team.

About the Lived Experience Engagement Framework

This Framework describes Mindgardens' approach to inclusive and effective participation of people with lived and living experience across the organisation, to deliver the best possible outcomes while aligning with Mindgardens' core values and areas of focus. It offers guidance for anyone working with Mindgardens to transform support for mental health, drug and alcohol and neurological disorders to engage effectively and safely with people with a lived or living experience, their carers, and support people.

Why do we need this Framework?

Working with people with a lived and living experience is beneficial only when engagement is safe and effective for everyone involved. The Framework has been developed to ensure Mindgardens consistently adheres to best practice and its own values as a translational research organisation focused on disorders involving the brain, emotions, nervous system, and thinking processes. It also clearly articulates Mindgardens' expectations to our research partners.

- Mindgardens aims to respect and include lived experience perspectives authentically, transparently and consistently, and to demonstrate the importance of working this way.
- We are committed to building our own and our partners' organisational capacity to include lived experience perspectives in all aspects of our work.

Language and definitions

The words we use and the way we communicate are important.

Mindgardens' commitment to the National Communications Charter for the mental health and suicide prevention sectors guides us in using strength-based, respectful, inclusive, jargon-free and recovery-oriented language that conveys hope and optimism.¹

The Charter includes the following principles:

- It is best not to make assumptions – if you don't know, ask.
- Labelling people by their diagnosis is not helpful; use person-first language, eg 'a person with a schizophrenia diagnosis' not 'a schizophrenic'.
- We all have different ways of communicating. Respect the recovery-oriented language a person chooses about themselves.

Mindgardens recognises that the language about lived experience is more developed in mental health, compared to drug and alcohol and neurological disorders. This reflects a more advanced culture of lived experience inclusion in mental health. We are committed to contributing to the development of lived experience practice and language across all domains of our research and innovation work.

The following definitions are useful in describing what we mean:

Lived experience (mental health challenge):

- People with lived and living experience identify either as someone who is living with (or has lived with) mental health challenges or someone who is caring for or otherwise supporting (or has cared for or otherwise supported) a person who is living with (or has lived with) mental health challenges.²

Lived and/or living experience:

- Unless otherwise specified, when Mindgardens uses these terms we are referring to the lived and/or living experience of people with mental health, drug and alcohol or neurological challenge(s) and their carers, families and kinship groups.

Safe and Effective Lived Experience Engagement:

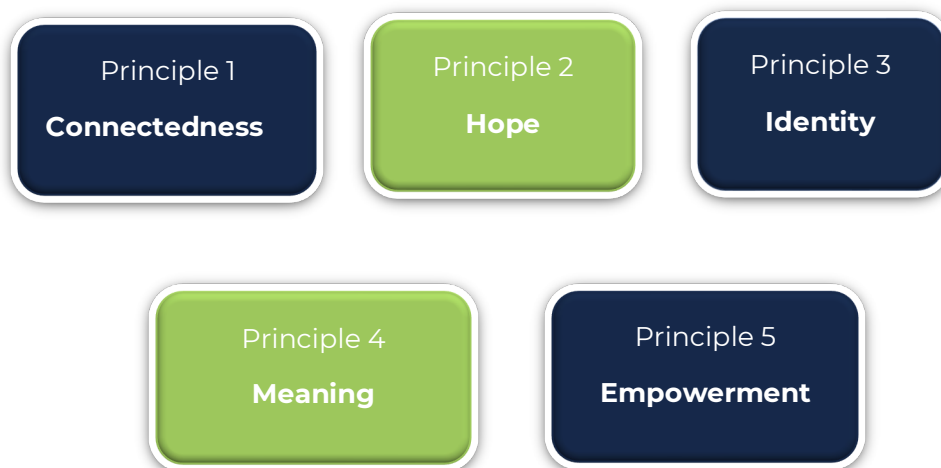
- Understood by MindLabs as an approach to planning, conducting and evaluating lived experience engagement that aligns with our Principles of Lived Experience Engagement.

Lived experience engagement: the principles

In developing this Framework, Mindgardens has drawn from guidance produced in Australia and overseas about how to work safely and effectively with people with lived experience. These principles address, at a high level, essential lived experience values. At an operational level, they describe how to embed these values appropriately within different types of work.

Mindgardens supports the recovery-oriented, trauma-informed principles contained in the Connectedness, Hope & optimism, Identity, Meaning, and Empowerment (CHIME) framework:³

- Connectedness: having positive relationships and strong social networks from peer support, community groups or friends & family.
- Hope and optimism are crucial for believing that recovery is possible and developing.
- Identity: regaining a positive sense of self and identity and overcoming stigma.
- Meaning: living a meaningful and purposeful life, as defined by the person (not others).
- Empowerment: having control over life, focusing on strengths, and taking personal responsibility.



Applying the principles in participation and engagement

Lived experience participation and engagement occur on a spectrum of extent and depth – ranging from minimal or tokenistic inclusion to the deepest, most respectful collaboration.

Mindgardens believes people with lived or living experience should always be engaged at the highest possible level of this spectrum considering the characteristics of a project or activity.

We follow the Western Australian Mental Health Commission’s Participation Spectrum, which characterises levels of lived experience involvement according to their extent and depth.⁴ Projects that do not share power between clinicians and those with lived experience, or in which products or services are developed without lived experience input, are at the lowest end of the participation spectrum. Peer-led programs, co-produced services, or lived experience-led training programs are at the upper end.

At individual, service, program, organisational, policy or strategy levels, Mindgardens and the MindLabs team use the Participation Spectrum and current literature to determine the best fit-for-purpose approaches and methodology.



National Mental Health Commission, 2017

Recommended resources

In addition to the foundational principles described above, Mindgardens recommends the following resources.

[**NSW Health: All of Us**](#)⁵

The All of Us guide's purpose is to provide positive and respectful experiences for consumers, carers, communities and staff working together to design, improve or innovate in health. The framework supports engagement activities across NSW Health, ensuring a positive impact and not harm to consumers, carers or communities.

[**Mental Health Commission of New South Wales: Lived Experience Framework**](#)⁶

This Framework encourages efforts to be brave, generous and curious in spirit, to seek out opportunities to learn and improve, and for people with lived experience of mental health issues and caring, families and kinship groups to work together with service providers as equal partners.

The framework responds to the call for embedding lived experience across the mental health sector and in system processes, encouraging service providers to embrace the rich knowledge that lived experience can bring to service design, delivery, monitoring, evaluation and improvement activities.

[**National Mental Health Commission: Consumer and carer engagement: a practical guide**](#)⁷

The guide is intended to provide a clear framework and set of principles for best practice in consumer and carer engagement and participation. It is hoped that this guide will be read and used by mental health consumers and carers and by people working within the mental health system at all levels.

[**National Health & Medical Research Council: framework for Effective Consumer and Community Engagement in Research**](#)⁸

Key requirements for partnering with people with a lived and living experience, including descriptions of phases and types of engagement and their alignment to the strategic objectives of the research.

[**NSW State Insurance Regulatory Authority: Lived Experience Engagement Framework**](#)⁹

This Framework outlines principles for engaging lived experience – partnership, respect, inclusion, authenticity, transparency, and improvement.

References

- ¹ Everymind, *National Communications Charter: A Unified Approach to Mental Health and Suicide Prevention*, 2021. <https://lifeinmind.org.au/the-charter>
- ² National Mental Health Commission, *The Fifth National Mental Health and Suicide Prevention Plan*, 2017. <https://www.mentalhealthcommission.gov.au/getmedia/0209d27b-1873-4245-b6e5-49e770084b81/Fifth-National-Mental-Health-and-Suicide-Prevention-Plan>
- ³ Leamy, Mary, Victoria Bird, Clair Le Boutillier, Julie Williams, and Mike Slade. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry* 199, no. 6 (2011): 445-452.
- ⁴ National Mental Health Commission, *Consumer and carer engagement: a practical guide*, 2017. <https://www.mentalhealthcommission.gov.au/getmedia/afef7eba-866f-4775-a386-57645bfb3453/NMHC-Consumer-and-Carer-engagement-a-practical-guide>
- ⁵ NSW Health, *All of Us: A guide to engaging consumers, carers and communities across NSW Health*, <https://www.health.nsw.gov.au/patients/experience/all-of-us/Pages/default.aspx>
- ⁶ Mental Health Commission of New South Wales, *Lived Experience Framework*, <https://www.nswmentalhealthcommission.com.au/report/lived-experience-framework>
- ⁷ National Mental Health Commission, *Consumer and carer engagement: a practical guide*, <https://www.mentalhealthcommission.gov.au/getmedia/afef7eba-866f-4775-a386-57645bfb3453/NMHC-Consumer-and-Carer-engagement-a-practical-guide>
- ⁸ Australian Government National Health and Medical Research Council, *Expectations and Value – Framework for effective consumer and community engagement in research* <https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Consumer%20Community%20Engagement/Expectations-and-Value.pdf>
- ⁹ NSW Government, *Engaging with Lived Experience: A strategic framework for guiding our work impacting mental health*, <https://www.nsw.gov.au/sites/default/files/2021-08/engaging-with-lived-experience-framework.pdf>