aves
MENTAL HEALTH
Non-Profit Organisation (NPO 212-449)
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Position Statement: Integrating Lived Experience as a Core Methodology for Mental Health Research in the Asia-Oceania Region

Introduction

The Asia-Oceania Region of aves Mental Health (formerly Global Mental Health Peer Network) hereby issues this position statement addressing the need to incorporate the voices of persons with lived experience in mental health research.

Over the past few years, Mental Health Research has increasingly recognised the need for Lived Experience Engagement; however, that has often limited participation to single-session consultations, advisory positions, and, in many contexts, treating people only as research subjects [1]. Historically, Mental Health research has been carried out within colonial frameworks that heavily rely on the biomedicalisation of mental health. While there is a change in the ecosystem, many countries in Asia-Oceania continue to perpetuate that model of understanding mental health purely from a pathological lens [2].

This position statement recognizes that the region is not a monolith and actively calls for Mental Health Research to integrate intersectional, context-specific, and culturally sensitive Lived Experience engagement as a core methodology to its projects.

Background Information

Marked by substantial cultural, economic, and political diversity, the region has a highly varied national response to mental health as a public health concern [3]. This heterogeneity shapes how mental health is prioritised, resourced, and governed across the region. To date, 43 countries in the region have ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), reflecting a growing commitment to rights-based approaches in mental health governance [4]. This shift has been accompanied by increasing efforts to involve people with lived experience in decisions that affect their lives, signalling an important, though uneven, transition toward more inclusive and participatory mental health systems.

The shift in terminology also substantiates this progress. Today, lived experience is no longer regarded as a peripheral or contested concept. It is now widely recognized as a prerequisite and core expectation across many research and funding institutions, as reflected in the revised Declaration of Helsinki guidelines, commitments by funding bodies such as the Wellcome Trust, leading scientific journals including The Lancet Group and PLOS, and the 2023 framework on Lived Experience Inclusion issued by the World Health Organization [5]

What do we mean by lived experience in mental health research?

At aves Mental Health, “Lived experience” refers to people who have gone through mental health conditions in a deep, sustained, and often painful way, not just the common stresses or challenges that everyone faces at times. It includes those who have used mental health services, as well as those who haven’t been able to access them - whether by choice, due to barriers, or because services simply weren’t available.

Within Mental Health research, Lived Experience represents an epistemology recognising first-hand experience of mental health conditions as valid knowledge, insight, and expertise [6]. Rejecting the purely academic and top-down expertise, Lived Experience in Research calls for community first and intersectional engagement. It is cognizant of social determinants and overlapping stressors based on identity markers (such as age, gender, race, culture, sexuality, socioeconomic status, disability, geographical location, and more) that inform the health, access to care, and social systems for people and views first-hand experience as valid knowledge to inform agendas, methodologies and projects [7].

Statement of Concern

While progress at a policy and governance level, as well as new international nomenclature, is acknowledged, this rarely translates into active practice in many countries within Asia-Oceania. Biomedical, colonial, and hierarchical frameworks continue to dominate mental health research across the region. These systems exclude the lived realities of people and dismiss community-based knowledge while actively championing the Eurocentric system that treats people as *patients in need of care*, devoid of their humanity.

Lived experience engagement has also often been confined to advisory roles or one-off consultations. While these approaches can provide value, they are insufficient to achieve meaningful partnership and risk becoming tokenistic. This tokenism has multiple harmful effects: it reinforces stigma, turns labour into an extractive practice devoid of economic parity, and acts as a means of retraumatization. This is especially severe in settings where advocates are forced to function without any institutional protection.

In societies shaped by decades of social inequalities, often as a result of colonial influence, the failure to prioritize lived experience results in epistemic injustice and risks co-option, where lived experience perspectives are included superficially to legitimize existing agendas, without granting genuine influence or decision-making power. Excluding the voices of people with lived experience can produce ineffective and culturally unsafe interventions [8]. It can also weaken community trust and uptake of services and undermine reform credibility[9]. We are therefore deeply concerned that without a radical shift in power will simply continue to perpetuate what they are trying to fix.

Principles and Values

aves Mental Health is an international lived experience organisation that provides a platform for people with lived experience of mental health conditions to exercise their right to speak up, provide perspectives and recommendations on matters directly affecting them. Our rights-based approach to mental health requires that services and processes are grounded in core principles such as transparency, accountability, equality, dignity, and respect for human rights. These principles are not optional ideals but foundational values that determine whether systems truly serve the people they are meant to support.

In the Asia-Oceania region, where mental health systems vary widely in resources and governance, upholding these values is essential to ensuring that individuals with mental health conditions are treated as full citizens with agency, rights, and voice. For us, lived experience is not a peripheral add-on but a source of insight, wisdom, and expertise essential to improving the mental health landscape.

Our regional chairs for the term share their experiences in their own words, highlighting the power of lived experience in shaping more inclusive mental health systems.

"The integration of lived experience within research often remains confined to documentation rather than meaningful engagement and change. There is a continued lack of effort to understand our worlds. Stories are often flattened into suffering, ignoring the meaning we hold. So the question remains- where is the shift truly taking place? Beyond informed consent and tokenism, we need systems that hold accountability and genuinely care." – Souradeep Chakraborty (India)

"Lived experience-informed research impacts macro-level systems. During this period of political uncertainty, the voices, rights, and dignity of our communities are under threat. To build social interventions that do not perpetuate harm, we have to continue bringing our perspectives to the table. We will survive, we have survived." – Shreyus Sukhija (India)

Call to Action

Mental health research stands at a critical turning point. To produce research that is ethical, equitable, and rooted in impact, lived experience must move from the margins to the methodological core of how we design, conduct, and evaluate mental health research across Asia-Oceania, honoring the region's diversity and heterogeneity.

1. Bridge the Gap Between Technical Expertise and Lived Reality

- Funders and Researchers must actively centre community knowledge systems as valid expertise
- Platform intersectional lived experience of people from the region, and ensure that these insights are translated and integrated as valid forms of knowledge within traditionally academic spaces.

2. Embedding lived experience as a core methodology is an act of institutional responsibility

- This includes actively creating pathways for meaningful engagement, which include but are not limited to capacity strengthening programmes, remunerated roles, and opportunities for true co-production, right from the grant investment till after the dissemination of the research.
- Lived experience experts must be integrated across design, governance, strategy, implementation, and evaluation.

3. Share Power Across the Research Lifecycle

- This requires fair compensation, equitable partnerships, transparent roles, and shared ownership of outcomes.
- Leadership at all levels must amplify marginalized voices, address systemic misallocation of resources, and commit to institutional safeguards for people with lived experience involved.

Efforts toward meaningful engagement inevitably carry risks and challenges, and these must be acknowledged with honesty and care. However, they also present a significant opportunity for institutions, researchers, and funders to form genuine partnerships with people who bring lived experience expertise. When approached intentionally and grounded in principles of ethical inclusion, such collaboration can move us beyond symbolic representation and toward meaningful co-design.

Policy Recommendations

As part of broader efforts to decolonise global mental health, State Parties across Asia-Oceania have a responsibility to address entrenched power imbalances that marginalise the knowledge and leadership of people with lived experience. Moving from rhetoric to structural reform requires clear policy commitments that redistribute power, institutionalise participation, and uphold the dignity and expertise of lived experience experts.

1. Redistribute Power Through Rights-Based Participation

- State Parties should formally recognise participation of people with lived experience as a human right.

- This requires redistributing decision-making power from hierarchical, top-down systems toward participatory governance models.
- Clear accountability mechanisms should be established, including designated lived experience leadership roles with authority and oversight responsibilities throughout project and policy lifecycles.

2. Ensure Intersectional and Inclusive Representation

- Participation mechanisms in policy and research must be guided by intersectionality.
- State Parties should ensure representation across age, ethnicity, gender, sexuality, disability, socioeconomic status, Indigenous identity, and other historically marginalised identities within global health processes.
- Selection and engagement processes must be transparent and designed to reach communities that have been systemically excluded.

3. Guarantee Formal Recognition, Compensation, and Participatory Infrastructure

- Lived experience expertise must be formally recognised and compensated at levels equivalent to technical and professional counterparts [8].
- Transparent and detailed budgeting should be established at the outset of any initiative, clearly defining roles, remuneration, and responsibilities [8].
- State Parties should create diverse participatory approaches, including open public forums (e.g., citizen assemblies, town halls), consultative mechanisms (e.g., stakeholder dialogues, focus groups), deliberative processes (e.g., citizen panels, consensus conferences), and formal governance structures with fixed seats for lived experience representatives.

Mental Health Research does not exist outside of state responsibility. By embedding rights-based participation, dismantling discriminatory systems, ensuring intersectional representation, and resourcing lived experience leadership equitably, State Parties across Asia-Oceania can move toward truly meaningful engagement.

Conclusion

The Asia-Oceania Region of aves Mental Health affirms that lived experience must be embedded as a core methodology in mental health research across the region. While global frameworks and institutions increasingly recognise lived experience as essential to ethical and rights-based practice, research in many Asia-Oceania contexts remains dominated by biomedical, hierarchical, and colonial models that marginalise community knowledge and perpetuate tokenistic engagement. Given the region's vast cultural, linguistic, and socioeconomic diversity, there is both an obligation and an opportunity to shift from consultation to genuine power-sharing. We call for intersectional, culturally grounded, and rights-based approaches that formally recognise and resource lived experience expertise; integrate it across all stages of research and governance; and dismantle discriminatory structures to ensure meaningful engagement.

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