Government of **Western Australia**
Mental Health Commission

Developing Lived Experience Outcome Indicators

Key Considerations for Developing Lived Experience Outcome Indicators for the WA State Priorities Mental Health, Alcohol and Other Drugs 2022 – 2024 Outcomes Measurement Framework

This report has been developed by the Centre for Social Impact The University of Western Australia, in collaboration with the System-Wide Data Working Group. This report presents the key learnings from discussions with the System-Wide Data Working Group and lived experience experts about engaging lived experience representatives to inform the development of outcomes indicators.

May 2022

DEVELOPING LIVED EXPERIENCE OUTCOME INDICATORS

Key Considerations for Developing Lived Experience Outcome Indicators for the WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 Outcomes Measurement Framework

Lisette Kaleveld, Renée Gardiner and Professor Paul Flatau
Centre for Social Impact The University of Western Australia

With shared expertise from Lived Experience Academics, Kerry Hawkins, Lyn Mahboub and Amanda Waegeli, and members of the System-Wide Data Working Group

January 2022

Government of **Western Australia**
Mental Health Commission

Acknowledgement of Country
In the spirit of conciliation, the Centre for Social Impact The University of Western Australia (CSI UWA) and the Mental Health Commission (MHC) acknowledge that their operations are situated on Noongar land, and that Noongar people remain the spiritual and cultural custodians of their land, and continue to practice their values, languages, beliefs and knowledge. We acknowledge the Traditional Custodians of Country throughout Australia and their connections to land, sea and community. We pay our respect to their elders and extend that respect to all Aboriginal and Torres Strait Islander peoples.

Acknowledgement of lived experience
We acknowledge the individual and collective expertise of people with a living or lived experience of mental health, alcohol and other drug issues, and the families and carers who provide support and have their own lived/living experience. We recognise the vital contribution and value the courage of individuals who have shared their perspectives and personal experiences for the purpose of learning and growing together to achieve better outcomes for all.

Authors
Lisette Kaleveld, Renée Gardiner, Paul Flatau
Centre for Social Impact The University of Western Australia (CSI UWA)

Key words Mental health; Alcohol and Other Drugs; Outcomes Measurement; Measurement and evaluation; Impact
Publisher Centre for Social Impact UWA, Business School, Perth, Australia
DOI 10.25916/jxhq-4469
Format Printed; PDF online
URL https://www.csi.edu.au/research/project/mental-health-commission-lived-experience-report/

Suggested citation Kaleveld, L., Gardiner, R. & Flatau, P. (2022). *Developing Lived Experience Outcome Indicators: Key Considerations for Developing Lived Experience Outcome Indicators for the WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 Outcomes Measurement Framework*. Centre for Social Impact UWA: Perth. https://doi.org/10.25916/jxhq-4469

Address for correspondence
Professor Paul Flatau
Director, Centre for Social Impact The University of Western Australia
Business School
The University of Western Australia
35 Stirling Hwy, Crawley, WA, 6009 Australia
paul.flatau@uwa.edu.au

Acknowledgements
CSI UWA would like to thank the MHC for giving us the opportunity to undertake the project. In particular, we thank Kim Lazenby, Amanda Harrison and Rebecca McKelvie from the MHC and their staff for supporting us throughout the project and to members of the System-Wide Data Working Group (SWDWG), as well as invited participants who participated in the workshops and consultations, and supplied information on which the present report was built. We would also like to thank Lyn Mahboub, Kerry Hawkins, and Amanda Waegeli, lived experience academics and experts who contributed their valuable expertise to this initial piece of work in developing the WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 Outcome Measurement Framework.

BACKGROUND

Strategic context

In Australia and internationally, lived experience is increasingly being recognised as key to informing the design, delivery and evaluation of mental health, alcohol and other drugs (AOD) services, ensuring that services more adequately meet the needs of service users and communities, and that mental health outcomes are enhanced.

The value of lived experience for improving mental health and AOD outcomes for Western Australians is well-recognised within the Mental Health Commission (MHC). The MHC's Corporate Governance and Policy Framework includes a commitment to partnering with lived experience experts, representatives, service users, carers and family members in policy development and service design and delivery. The work of developing an Outcomes Measurement Framework (OMF), initiated by the MHC, represents a further opportunity to integrate perspectives of those with lived experience into the overall functioning of the mental health system.

The development of an Outcomes Measurement Framework

"The OMF will be used to inform government, key stakeholders, service providers and the Western Australian community of the achievements of publicly funded initiatives against desired outcomes."

- Mental Health Commission

The Centre for Social Impact University of Western Australia (CSI UWA) was engaged by the MHC to assist the System-Wide Data Working Group (SWDWG) with the first stage of developing an OMF for the WA State Priorities Mental Health, Alcohol and Other Drugs 2020-2024 ("WA State Priorities"). The OMF will guide a system-wide approach to reporting and provide an opportunity for the continual improvement of publicly funded mental health and AOD services.

The initial stage, as scoped by the MHC, was to develop a reporting template and specification guide to enable the public reporting of outcomes anticipated from the WA State Priorities, and a set of principles to guide the development of lived experience outcomes. The six principles are as follows:

1. The lived experience of consumers, carers and families is valued and guides the development of the OMF.
2. The OMF will reflect the six guiding principles identified in Working Together: Mental Health and Alcohol and Other Drug Engagement Framework 2018-2025, which are Safety, Authenticity, Humanity, Equity, Diversity and Inclusivity.[1]
3. The OMF will take into account the information needs and interests of a variety of stakeholders across government and the community.
4. The OMF will include a focus on consumers' diverse experiences of mental health and AOD services and their satisfaction with their personal outcomes from engaging with the service.
5. The development of the OMF will take into account other reporting frameworks, including the measures already in place within agencies, and avoid unnecessary reporting burden.
6. New or alternative indicators and measures will be considered when necessary, to ensure the above principles are reflected in the OMF.

The project adopted an iterative approach through a modified Delphi methodology, involving desktop research, collecting feedback through stakeholder workshops and consultations, and integrating these learnings throughout the course of the project. Feedback was sought from the SWDWG, including from lived experience representatives, clinical and other health and social services experts and peak bodies.

In addition to these feedback processes, a small group of lived experience academics partnered with CSI UWA for more focused discussions to consider, in depth, questions relating to defining 'lived

---

[1] Mental Health Commission, *Working Together: Mental Health and Alcohol and Other Drug Engagement Framework, 2018-2025*, https://www.mhc.wa.gov.au/media/2532/170876-menheac-engagement-framework-web.pdf

experience', as well as to unpack what meaningful outcomes would look like, from a lived experience perspective.

How to use this document

This document presents the key learnings from these discussions about engaging lived experience experts and representatives to inform the development of lived experience outcome indicators in the context of publicly funded mental health and AOD services in Western Australia. It should be noted that the development of lived experience outcome indicators has not yet been operationalised by the MHC and, therefore, the ideas presented here are based on discussions with the SWDWG and lived experience academics and experts.

We outline a strategic approach to what needs to be considered when developing outcome indicators based on lived experience perspectives. It is intended to be used as a general reference, to guide thinking. This may benefit any agency interested in developing, measuring, and improving mental health and AOD outcomes reporting, including mental health, AOD or other social support services, other government agencies where mental health and/or AOD outcomes are relevant, and, wherever a diverse range of perspectives is of value for service improvement.

The broadest understanding of outcomes measurement underpins this work, with whole-of-person, whole-of-life and whole-of-population changes in scope. This means that to maximise the mental health and AOD outcomes for the Western Australian population, measurement needs to include changes that happen for individuals and their families, within projects, programs, and services, across the mental health and AOD system, and for the population as a whole.

Outcome measurement initiatives should be based around broad understandings of 'lived experience'. Ideally, lived experience perspectives would include those of lived experience experts and academics, representatives who can speak to the needs of specific cohorts (for example, young people), representatives who can understand experiences with certain vulnerabilities (such as experiences of homelessness), experiences of services and service-users, carers, and family members, as well as the views of non-service users.

The SWDWG acknowledges that while this scope is incredibly ambitious and may not be able to be achieved in the short term, these ways of thinking can nonetheless add value and meaning at the micro, meso and macro levels, as we work towards more holistic outcomes and measurement practices.

KEY CONSIDERATIONS FOR DEVELOPING LIVED EXPERIENCE OUTCOME INDICATORS

This section outlines what is important to consider in the development of lived experience outcome indicators.

1 – Recovery includes more than symptom reduction

In the world of impact measurement, problem formulation is an important foundational step. Problem formulation underpins measurement as it helps define the change expected and the outcomes and indicators that will help us know we are making a difference. In the mental health and AOD sector, it is fair to say that much of problem formulation has been built around clinical expertise and centred on diagnostic models, with success measures largely based on symptom reduction.

> *Whole-of-person outcomes are increasingly important, as evidence emerges of the social determinants of mental health and AOD issues, and the impact of trauma on people's experiences of wellbeing, distress, and mental ill-health.*

However, we learned through our extensive workshop program and consultations that treatment success, as defined by clinicians may be distinct from (and sometimes not congruent with) quality-of-life outcomes and the personal sense of meaning an individual may experience in their life. Whole-of-person outcomes are increasingly important as evidence emerges of the social and systemic determinants of mental health and AOD issues (for example, deep and entrenched poverty, long-term unemployment, affordable housing access barriers and housing stress, and prejudice and deep discrimination), and the impact of trauma on people's experiences of wellbeing, distress, and mental ill-health.

This paradigm shift away from a world underpinned only by clinical models, to one that is more deeply informed by a person's social context is increasingly reflected in the co-design of services and programs in which lived experience plays its part. Our evaluation frameworks and outcomes measurement practices must also reflect this expanded focus. The lived experience lens provides an opportunity to define change in the mental health and AOD space more broadly and holistically. Lived experience perspectives are more likely to shed light on the root causes of mental health and AOD issues, and point to the most meaningful indicators of recovery in the context of people's lives.

2 – 'Lived experience' varies and perspectives are distinct

In setting out to develop lived experience indicators, one of the early insights gained from this project was establishing a shared understanding of what we mean by 'lived experience'. Whose lived experiences are we talking about, and what makes their lived experience meaningful and relevant to consider? There are very few established definitions of lived experience to draw upon, and the term can be interpreted in ways that could, at times, dilute the concept or the power of a 'lived experience' perspective.

A proposed typology of the various kinds of lived experience perspectives is outlined below.

- **Lived experience academics and experts:** People with personal mental health and AOD experience, as well as knowledge and understanding of lived experience discourse within the global community of practice.
- **Lived experience and cohort representatives:** People with a personal experience of mental health and/or AOD issues whom either represent themselves by using their personal lived experience and may represent a specific cohort (such as an Aboriginal perspective) or collective of people with lived experience.
- **Service-users:** People who are engaging with a service, or have previously used a service, for support with their mental health and/or AOD needs.
- **Carers and family members:** People who care for people who are experiencing or have experienced mental health and/or AOD issues, which may also include the individual's family members.
- **Non-service users:** People who have a mental health and/or AOD condition, but who are not currently engaging with a service or support (potentially through lack of awareness, barriers to access, personal choice, or past negative experience of services).

Recognising each of the above as distinct types of lived experience, can support a more deliberate selection of whose perspective is important and why it is important.

3 – Lived experience perspectives, knowledge and insights can inform outcomes in a variety of ways

Lived experience knowledge and perspectives can inform outcomes measurement in a range of ways. It is important to consider and define the purpose for seeking a lived experience perspective. For example, do we need the lived experience perspective to provide a critical review of the overall measurement framework, its balance and focus? Do we seek feedback on the language used? Or maybe we are looking at experiences of a service, or more nuanced understandings of personal change and recovery? Or of understanding how broader systemic forces impact on peoples' lives including how they may interact with treatment programs?

Such perspectives can help to understand the extent to which needs are met (and which needs are unmet), and the extent to which services are trauma-informed and functioning with the dignity of its clients at the centre.

An outline of some of the ways lived experience can inform measurement is proposed below.

- **Lived-experience-informed outcome indicators:** Outcomes measurement frameworks and practices can benefit from critical review by lived experience experts, who may, for example, bring a more holistic perspective to problem formulation. In building an OMF, lived experience

perspectives can bring in factors beyond traditional (often clinical) measures of success such as an understanding of choice, or even some legitimate reasons not to engage with services. Lived experience perspectives may also see gaps; for example, in terms of needs that should be addressed that might not be typically measured by mental health or AOD services (such as income levels, debts, or housing and homelessness conditions).

- **Felt experiences of service users:** Capturing felt experiences of service users helps to unpack the experiences of service users in terms of a sense of safety, empowerment, self-efficacy, and agency. Such perspectives can help to understand the extent to which people perceive how a service contributes to individual outcomes, meets needs (such as aligning with personal values) and provides opportunities for engagement, choice, decision-making and empowerment. Service users are in the best position to understand the extent to which services are trauma-informed (given various sources of trauma and their impacts) and functioning with the dignity of its clients at the centre.
- **Personal experiences of the impact of service support:** The individual's experience of how they felt a service enabled their recovery needs to be captured alongside the clinical perspective of their recovery. Service-user perspectives can shed light on needs that remain unmet and how within the context of a service these needs can be addressed to drive improved outcomes for individuals. Through a person's experience of receiving a service or support, we can understand the extent to which they were given the tools, resources and skills to support their recovery, while recognising that recovery is a multidimensional process that may extend beyond these needs and vary for individuals who require a higher-level of support to help improve the quality of their life. In this context, it is important to recognise that not all those receiving support are always in a position to fully self-determine their recovery process and draw on tools, resources and skills effectively. Understanding the diversity in backgrounds, needs and circumstances including their capabilities to express their personal experiences of service is an important part of developing lived experience measures and lived experience outcomes measurement.

A person's experience of a mental health or AOD condition does not begin when they enter a service and does not end when they exit.

- **Personal recovery journeys:** Understanding what it is like to develop, experience, manage and recover from a mental health and/or AOD issue is critical for developing system-level measures that speak to preventing and addressing the causes and consequences of mental health and AOD issues, and meeting the need for sustained, ongoing recovery support. A person's experience of mental health or AOD condition does not begin when they enter a service or program and does not end when they exit.
- **Cohort-specific measures:** Outcomes measurement falls over when it is built on assumptions about an 'average person', without considering the diverse needs that actually exist. Lived experience representatives come from a diverse range of cohorts or may have specific vulnerabilities or experiences (such as young people, people who are a part of the LGBTIQ+ community, Aboriginal and/or Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, and people with experiences of homelessness or domestic violence). For example, Aboriginal people may find it important to measure the extent to which a support addresses interpersonal relationships, social networks, spirituality, connection with the environment and Country, and is delivered in a culturally appropriate way as factors that can significantly impact recovery and healing. Measurement activities that are informed by specific cohort experiences, as well as administrative activities that track the level of engagement of specific cohorts help to ensure the service system is inclusive, accountable, and equitable.

4 – Processes for meaningful engagement need to be open, relational, and iterative

Engaging people with lived experience in the development of outcome indicators helps to shift focus away from traditional transactional approaches to data, in which an 'expert group' collects information about a client group. Rather, the voice and wisdom and worldviews of those who participate as clients is just as valued.

To honour this principle, the processes for engaging with lived experience representatives is just as important as the results of the partnership. Participatory methods aim to draw on the shared knowledge and wisdom of a collective. Discussions with the SWDWG highlighted the need for

agencies and services to partner with lived experience representatives through participatory co-design and co-production, and also consider ways that lived experience representatives can be involved in decision-making. For example, lived experience representatives may participate as decision-making members in quality improvement teams, take part in hiring decisions, or develop and provide staff training.

Partnerships with lived experience experts, representatives, service users, carers and family members as well as non-service users, should be open, generative and relational. Ideally, there should be enough space and time (and resources available) to build trust and establish group processes that are safe and inclusive. There should be time and space for discussion, consultation and information gathering from multiple stakeholders, and, importantly, the time, energy, and facilitation skills to resolve any disagreements, tensions, or dissonance in order to reach consensus and/or the best version of a shared vision.

Allowing multiple voices to be heard and tensions to be understood and resolved leads to enhanced measurement frameworks that are more likely to resonate and provide quality, meaningful data.

The quality of partnerships will, of course, still be constrained by various factors including insufficient time, budget, and resources as well as organisational skills, training, and support. While acknowledging these challenges, there are strategies and practices available to support the inclusion of best practice approaches, and when applied consistently, will enhance a movement towards true partnerships that result in better outcomes for all those involved.

5 – Engagement needs to be equitable, diverse and inclusive

In seeking the lived experience perspective, it is essential to realise that there is not only one perspective. Socio-demographic dimensions, such as age, culture, gender and sex diversity, profoundly impact experiences of mental health and wellbeing, barriers to engagement with services, experiences of recovery, as well as the social and structural determinants of mental health and wellbeing.

Purposefully seeking diverse views, and the perspectives of people representing different cohorts, is a central component of the work.

For example, in the AOD space there have been deliberate efforts to work more closely with Aboriginal people to measure social and emotional wellbeing, as Aboriginal people understand and experience it. This measurement helps to inform what is culturally safe and effective for Aboriginal people or communities.

Equity, diversity and inclusivity is also important when considering data collection and analysis. Datasets should be examined to ensure demographic data adequately captures diversity (and can be disaggregated for sub-population analysis). If participants of priority groups are unable to be identified or information is limited in the data collection, then the question should be asked, why not? The processes used to collect measures must also be tested to ensure they do not present barriers for people from specific groups, or people in specific circumstances, to respond.

6 – Instruments and data collection processes should be humanising, strengths-based and trauma-informed

Lived experience expertise can help to inform the careful selection of instruments and methods that feel safe and appropriate for people, and that do not add to an excessive reporting burden for clients or services.

There are currently many measures used in the mental health system that are clinically robust, and also align with mandatory state and national reporting frameworks for services (for example, the National Outcomes and Casemix Collection (NOCC) protocol and reporting requirements).

However, in our workshops and consultations we have heard that some people have negative experiences with some of the mandated questionnaires and tools. They can be seen as a burden to undertake, impacting peoples' sense of self and sense of agency, while also not accurately capturing one's experience. Less common, but worse, is that poorly designed instruments may impact people's desire to seek support for their mental health and AOD issues.

Lived experience experts call for more strengths-based approaches that can more effectively capture gains made by individuals (even though this may not be as easily defined, measurable or quantifiable).

This shift in the sector's desire to have more measures that capture personal recovery processes is starting. However, the pace of change is slow. Three international measures have been developed from the perspective of lived experience, and are validated as tools for assessing individual outcomes across various programs and services:

- Recovery Self-Assessment (RSA), Yale School of Medicine[2]
- Citizenship Measure, Yale School of Medicine[3]
- INSPIRE – long and short surveys[4]

There is also a measure that has been designed to measure the psychological and social empowerment of individuals within the context of Aboriginal health, social and wellbeing services:

- Growth and Empowerment Measure (GEM)[5].

Consideration will need to be given to the application and validity of these measures as they translate to the Western Australian population. This also includes looking at current statutory, contractual and licencing requirements that may apply and what additional reporting burden these measures may cause if captured as an additional data source to current mandatory state and national reporting frameworks.

CREATING THE CONDITIONS FOR LIVED EXPERIENCE-INFORMED OUTCOMES AND MEASUREMENT

The key considerations for developing lived experience outcome indicators, as outlined in this document, are not exhaustive, but do reflect the potentially pivotal role of lived experience perspectives in informing measurement.

One final learning that emerged from discussions with the SWDWG and lived experience academics was the importance of involving lived experience experts in the design of measurement frameworks (not just the outcome indicators), ideally using co-design, co-production, and citizen-led approaches.

Critical review by lived experience expertise can inform the focus of the outcomes measurement framework, and help to establish more meaningful and holistic outcome domains, and get the balance right between viewpoints. For example, through balancing the perspectives of service users and non-service users, the clinical and non-clinical perspective, individual outcomes verses population-level measures, as well as considerations around tracking the social determinants of mental distress, and diverse support needs across the population.

Consideration 6 above ("Instruments and data collection processes should be humanising, strengths-based and trauma-informed") speaks to the notion of an 'authorising environment' in which outcome indicators and measures of success are typically developed and used. As discussed above, various statutory, contractual and licensing requirements demand specific measures, as do the mandatory state and national reporting frameworks for services. However, considerations about what is meaningful to the people who are served by the mental health and AOD system, and what the best indicators of an effective service from the client's point of view, should have equal currency in deciding what outcomes should be measured and tracked.

In Western Australia, the MHC is taking a leadership position in respect of lived experience outcomes measurement. Through our work during the first stage of developing an OMF for the WA State Priorities, we have begun to learn what lived experience outcomes measurement might look like. Reframing measures based on lived experience perspectives will require resources, including research and access to literature, as well as sustained engagement and consultation processes with diverse lived experience representatives.

---

[2] For more information visit Yale School of Medicine, Department of Psychiatry, Yale Program for Recovery and Community Health, https://medicine.yale.edu/psychiatry/prch/tools/rec_selfassessment/

[3] For more information visit Yale School of Medicine, Department of Psychiatry, Yale Program for Recovery and Community Health, https://medicine.yale.edu/psychiatry/prch/.

[4] Williams, J., Leamy, M., Bird, V., Le Boutillier, C., Norton, S., Pesola, F., and Slade, M. (2015). *Development and evaluation of the INSPIRE measure of staff support for personal recovery*, Social Psychiatry and Psychiatric Epidemiology,**50**, 777-786. https://doi.org/10.1007/s00127-014-0983-0

[5] Haswell, M., Gaskin, S., Kavanagh, D., Ardler, I., Bloxsome, T., Billingham, M., and Oolong House Nowra (2017) Growth and Empowerment Measure: Its story and how can it assist in empowering people?, https://insight-prod.s3.ap-southeast-2.amazonaws.com/public/uploads/20171018.pdf.

Measurement is most powerful when it can be applied consistently, for example, across the mental health, AOD and other intersecting systems. There is a need to develop a whole-of-government, and system-wide approach to embedding lived experience outcomes and measures across different systems. For this, research and evaluation expertise is also recommended, to help develop a balanced approach that can benefit from the rigour of standardised methods and practices, as well as the value of capturing the nuanced and individualised changes reflected in the diverse experiences of people with mental health and AOD issues.

Despite the complexity of this work, there is increasing interest in Western Australia, as well as across Australia and internationally, in incorporating the lived experience perspective into how mental health and AOD service and system outcomes are measured, evaluated and reviewed. With a view to continual improvement in service design, commissioning and delivery, engaging diverse perspectives in how we define and measure success can only increase our confidence that public investment is meeting community needs and enhancing mental health and wellbeing outcomes for all.