Foundations for transformation: Building lived and living experience leadership in Victoria

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Acknowledgement

We acknowledge Aboriginal and Torres Strait Islander peoples as the First Peoples of Australia and the Traditional Owners and custodians of the lands and waters on which we live, learn, work and connect. We pay our respects to Elders past and present and acknowledge the strength, resilience, cultures and continuing contributions of Aboriginal and Torres Strait Islander peoples and communities.

Introduction

Foundations for transformation: Building lived and living experience leadership in Victoria (Foundations for transformation) traces the history of lived and living experience leadership in Victoria and its roots in wider social movements for human rights and justice. It recognises the global and local shifts and efforts to strengthen and advance lived and living experience leadership.

Foundations for transformation draws together that evidence and experience. It is written for readers who may be new to lived and living experience leadership but are ready to learn, lead and act. By setting out the basis for policy and systems reform, it aims to strengthen understanding of why lived and living experience leadership matters and how it can continue to grow and thrive across Victoria's mental health and wellbeing system and communities.

This document was developed in collaboration with representatives from lived and living experience-led peak bodies, organisations and system stewards, alongside a group of lived experience technical experts. This work involved lived and living experience-led research and engagement with people across a broad range of lived and living experience communities, sectors, and experiences. Cross-discipline and cross-sector leadership and expertise were embedded in its governance and development.

Foundations for transformation complements Victoria's *Lived and Living Experience Leadership Framework 2026–2036* (the *Leadership Framework*). Read together, these documents build collective understanding of the case for change as well as a shared agenda for supporting the growth of lived and living experience leadership, workforces and partnership across Victoria.

Definition and history

About lived and living experience

This section introduces and explores in depth the key concepts, values, principles and history of lived and living experience movements in Australia. Some of these are summarised under 'Key terms' and 'Glossary' in the *Leadership Framework*.

It is acknowledged that not all lived and living experience communities have been engaged in the development of this narrative. Please refer to the 'Development of the Leadership Framework' section in this document and 'Thank you: contributing voices to the Leadership Framework' in the *Leadership Framework* to learn about who has been involved.

This document is a starting point that will continue to review and reflect on the ways communities define their identities, experiences and histories as the *Leadership Framework* is implemented.

Lived and living experience

Lived and living experience refers to the personal knowledge and expertise gained through direct and personal experiences.

In the context of the *Leadership Framework*, the term applies to the mental health and wellbeing system (the system), which includes but is not limited to, mental health, alcohol and other drugs (AOD), harm reduction, suicide prevention and gambling harm services and programs. Other areas

where lived and living experience leadership exists or is emerging will be included over time. This means that the term lived and living experience is used in this context to refer to people who have experienced or are experiencing mental health challenges, psychological distress and/or substance use or addiction, suicidality and gambling harm and the people supporting them.

This definition encompasses experiences that have transformed life trajectories and altered perspectives, identities and worldviews (Byrne et al., 2021). A person with lived and living experience may access services and programs for support, and others may not. The provision of safe-enough environments and support has been inadequate for the needs of Aboriginal and Torres Strait Islander people and for people from different backgrounds, including intersectional backgrounds and identities due to racism, discrimination, stigma and exclusion.

Because of their shared experiences, many people with lived and living experience have formed communities and movements to provide support and to advocate to change the system and the cultures within it that perpetuate injustice, discrimination and harmful practices (see history of lived and living experience movements in Australia, below, for more information about some of these movements).

People with lived and living experience may choose to identify as someone with a particular perspective, they may identify with multiple perspectives, or they may not adopt these distinctions. Some may not distinguish between single perspectives because they come from collectivist cultures or for other reasons. They may identify with particular groups of people (for example, other service users) as well as experiences in particular parts of the system (e.g., settings).

In an AOD context, if people identify with the perspective of a consumer or service user, this means they have personal experience of substance use and/or addiction, either past or present. People may also identify as family – they have a significant personal relationship with a service user as a biological relative, non-biological relative, intimate partner, or ex-partner, through co-habitation, friendship, kinship or another form of relationship. Their loved one is in their own self-defined process of meaningful life change (Self Help Addiction Resource Centre, 2025).

In a harm reduction context, people who use drugs (PWUD) have living experience of drug use and risk of overdose. They face criminalisation and stigmatisation because of their drug use (Harm Reduction Victoria, 2025).

In a mental health context, if people identify with the perspective of a consumer/survivor, this means that they have used mental health services and have experienced marginalisation and systemic oppression within the mental health system and have survived. If they identify as a family, carer, kin or supporter, they are a person who has a significant, unpaid and personal role in the life of a person accessing services.

People with a lived experience of suicide have experienced suicidal thoughts, survived a suicide attempt, supported a loved one through suicidal crisis, or been bereaved by suicide (Roses in the Ocean, 2025).

While lived and living experience encompasses a range of experiences and different communities with distinct histories and approaches that must be honoured, many have united under common goals and values for some time. It is within this context that the *Leadership Framework* establishes a Victorian-first public policy direction for lived and living experience cross-discipline perspectives across the system with the aim of equitable advancement of all lived and living experience disciplines and perspectives.

Lived and living expertise

Lived and living expertise reflects the intentional development and integration of individual lived and living experience with:

- formalised discipline perspective, principles and practice.
- knowledge or experience of service and systems environments.
- engagement with historical and contemporary movements and advocacy.

Many people build this expertise through formal and informal lived and living experience practice, including community engagement, peer work and other lived and living experience work, such as advocacy. Their practice is informed by the collective knowledge base, values and principles of their lived and living experience community.

Although this may not always occur in a linear way, there is broad agreement that people build on their individual lived and living experience and translate this experiential knowledge into lived and living expertise. They also engage and identify with collective lived and living experiences and lived and living experience communities to identify common impacts and shared adversity.

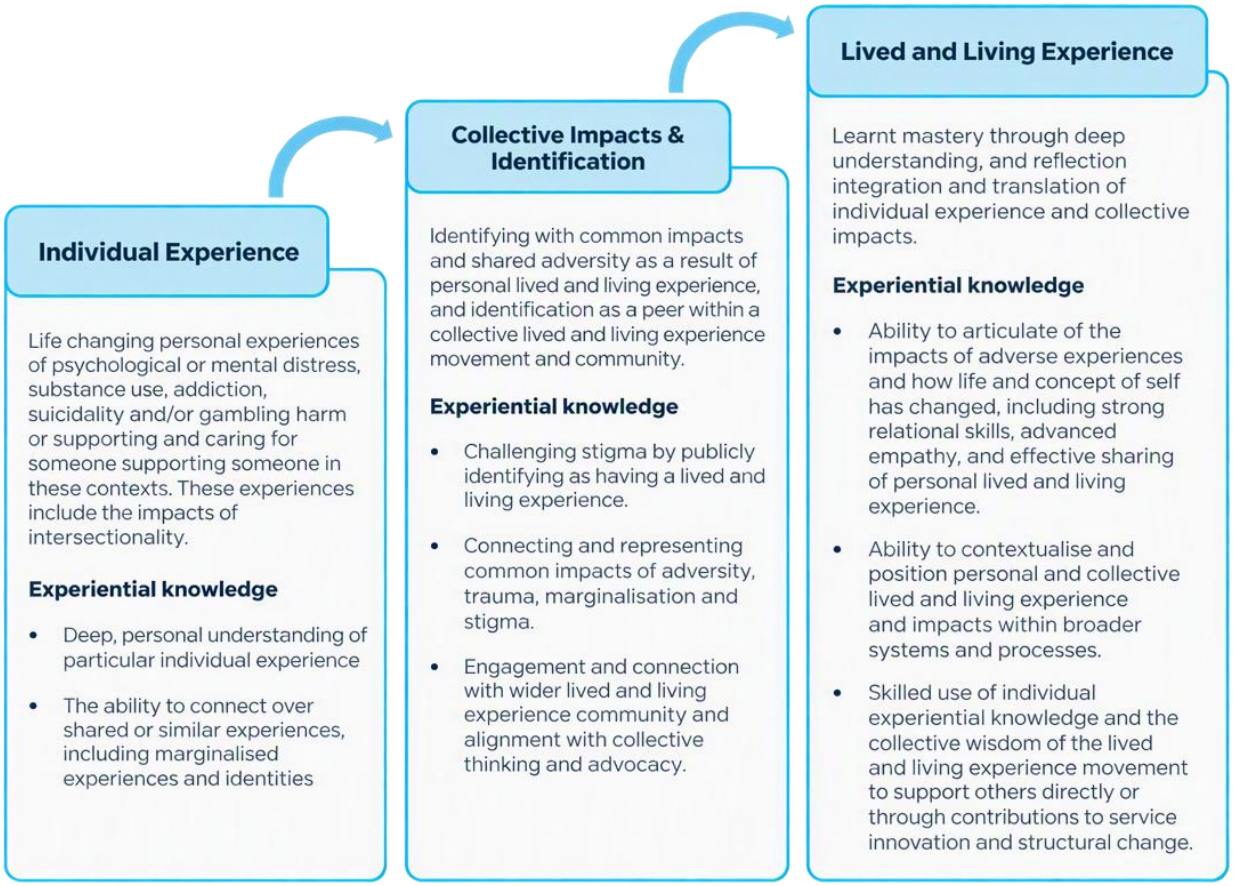


Figure 1: The lived and living experience expertise continuum. Adapted from Byrne & Roennfeldt (2025).

The pathways to building lived and living expertise should be flexible. The implementation of the *Leadership Framework* will aim to support people to understand these concepts and develop their lived and living expertise.

Lived and living experience workforces

Individuals are employed in a range of designated lived and living experience roles in mental health, AOD and harm reduction services. Both lived and living experience and experiential knowledge of systems and services are key areas of expertise in these roles.

Collectively, these individuals comprise the lived and living experience workforces. Within these workforces, lived and living experience perspectives and ways of working are informed by:

- Personal experience of mental health challenges, substance use and/or addiction, and/or suicidality as a consumer.
- Personal experience of mental health challenges, substance use and/or addiction, and/or suicidality from a peer perspective.
- Personal experience of supporting another person with mental health challenges, substance use and/or addiction, or suicidality as a family member, carer, kin or supporter, and/or personal experience of bereavement by suicide (Byrne et al., 2021).

Lived and living experience workers contextualise personal experience with broader lived and living experience principles, frameworks and lived and living experience workforce discipline practice to inform their work.

In 2025, Victoria released five Lived and Living Experience Workforce Discipline Frameworks developed in collaboration with lived and living experience peak bodies and workforces across mental health, AOD and harm reduction.

Figure 2: Lived and Living Experience Workforce Discipline Frameworks

Each framework highlights the foundational values and principles, theories and knowledge, and scope of practice essential to each lived and living experience discipline practice. They detail the types of roles within each workforce, including direct service roles, peer support, advocacy, education, policy, consultancy, leadership and research.

While these frameworks do not cover all the disciplines and perspectives in the lived and living experience workforces, including those relating to suicide, gambling prevention and eating disorders, the foundational values and principles are broadly applicable.

Lived and living experience leadership

Lived and living experience leadership can be understood as social movement leadership, in that leaders are part of a collective movement and use their lived and living expertise to bring about positive change for their community.

Many of Victoria's established lived and living experience leaders emerged from longstanding advocacy and engagement within lived and living experience movements across mental health, AOD, harm reduction, suicide prevention and gambling harm.

Because the development of lived and living experience leaders has been guided by the values of each movement, there is variation in lived and living experience leadership style and practices across sectors and communities.

This variation creates opportunities for lived and living experience leaders to build their leadership skills through education and by connecting with social and collective movements, which can strengthen and evolve collective lived and living experience leadership, while valuing the different forms and styles of leadership that have developed in each community.

Cultural and intersectional experiences such as racism and discrimination have often been overshadowed by a focus on traditional consumer movement issues, resulting in an under-representation of some perspectives.

Inclusive approaches and flexible definitions and practices enable lived and living experience leaders to use their expertise and systems knowledge to contribute to social justice and equity for multiple priority communities.

Lived and living experience leadership is underpinned by a commitment to responsive, adaptive and humane systems that reflect the needs and aspirations of the intended beneficiaries. This means striving to bridge the gap between policy-making and real-world challenges and enabling community leadership in driving local and systems-level change. It also demands a clear focus on inclusivity and equity.

Lived and living experience leadership is grounded in knowledge, perspectives, insights, and understanding gathered through diverse and collective wisdom as well as direct adverse experiences and injustice. It aims to benefit communities directly.

‘Lived and living experience leaders connect their personal, professional and socio-political worlds in unique ways to lead change, linking local experience with organisational and systems change endeavours. It operates both within and outside of roles, organisations and settings… Seeing ‘lived and living experience’ as a collective movement allows leaders to recognise that leadership is shared. Individual contributions are always built on the shoulders of others, and they pave the way for who leads with us today and after us tomorrow’ (Hodges et al., 2021, p. 1).

Lived and living experience leaders draw on their own experiential knowledge as a source of authority – sometimes called a ‘north star’ – while also valuing the distributed collective authority of other people’s experiences (Stewart et al., 2022). This is commonly understood and practised as centring lived and living experience, championing justice, mobilising strategically, standing up and speaking out, nurturing connected and collective spaces, and leading change (Hodges et al., 2023). While sharing common leadership values such as integrity, accountability and collaboration, lived and living experience leadership is distinguished by its relational approaches, its grounding in experiential knowledge, and its explicit commitment to shared power and refusal of power-over dynamics (Byrne et al., 2019).

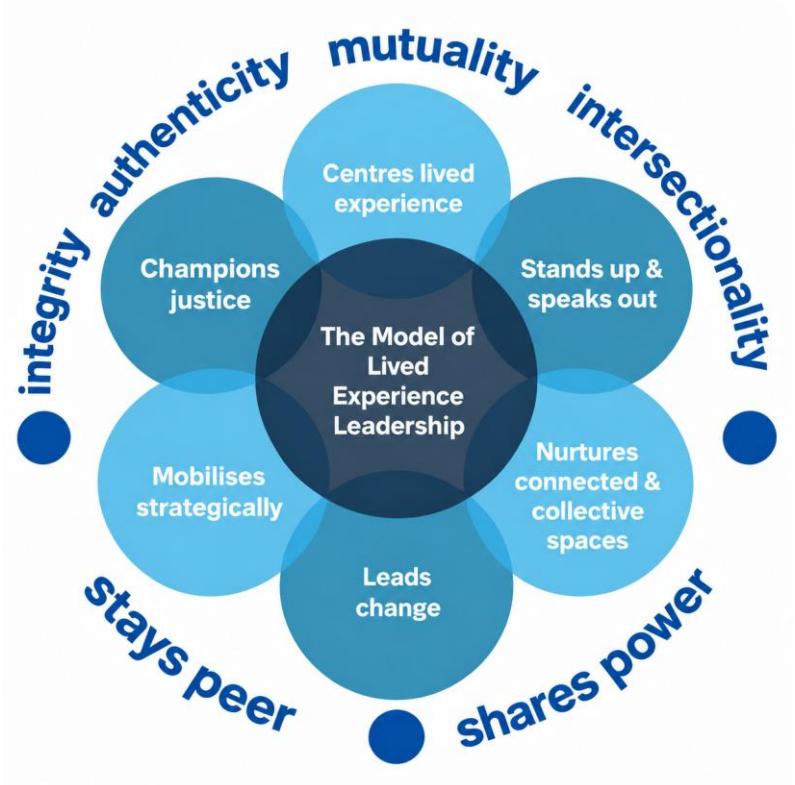


Figure 3: The model of lived experience leadership. Source: *Hodges et al. (2021).*

Lived and living experience leaders have the unique ability to translate personal experiences of systems into expertise which is in turn mobilised for systems change. Lived and living experience leaders are: 'change-makers, innovators and leaders who have activated their lived expertise to inform, shape and lead their… social purpose work... to directly benefit the communities they share those experiences with' (Sandhu, 2019, p. 3).

Drawing on this broad conceptualisation, the *Leadership Framework* focuses primarily on:

- formal, positional leadership roles held by individuals with lived and living experience at the program, service, organisational, community and government level
- lived and living experience-led organisations and those intentionally embedding lived and living expertise in a way that advances lived and living experience perspectives and contributes to system transformation.

However, it is recognised that lived and living experience leadership is practised in a range of roles and settings and is not reserved only for those in formal leadership roles.

Principles and values

The following values and principles have been developed through consideration of the literature both nationally and internationally, the perspectives of lived and living experience communities locally and work commissioned as a foundation for the development of the *Leadership Framework*. They outline the fundamental priorities and associated ways of being and working embodied by lived and living experience leaders in Victoria.

It is anticipated that these will be further developed over time alongside the maturation of lived and living experience leadership in our local context, across disciplines, perspectives, and roles.

Lived and living experience leadership principles and values

Community	
In context	Being credible and connected with the communities of which we are part, and proactively involving our communities in our leadership.
In practice	We privilege and value community building, fostering connection and collaboration with a view to individual and community liberation. We understand lived and living experience leaders are those who are leaders in the eyes of their communities and are accountable to these communities to influence and impact systems change. We continuously and reflexively seek the views, objectives and priorities of our communities, as contemporary leadership relies on concurrent evolution with the dynamic lived and living experience movement. We recognise, name and share power and knowledge with the many communities – including diverse identities, experiences and subgroups within them – of which we are part. We advocate for the elevation and preferencing of lived and living experience communities and expertise. This includes partnerships within and across lived and living experience communities, empowerment and shared decision-making and the proactive support of established and emerging leaders, organisations and services led by people with lived and living experience. We also advocate for people being supported to make their own choices when using services and recognise the fundamental role of agency, autonomy and self-determination.
Accountability	
In context	Being accountable to lived and living experience communities, within and across disciplines, and holding systems, services and governments to account in the pursuit of the vision, objectives and priorities of lived and living experience communities.
In practice	We act transparently, responsively, and consistently account to the lived and living experience communities who have endorsed us as leaders. We model the intentional mobilisation of lived and living expertise for systems change and embed accountability for this work within systems. We de-centre self and emphasise community voice and goals in decision-making.
Courage	
In context	Speaking and acting boldly, with diplomacy, in ways that maximise positive impact for lived and living experience led systems change.
In practice	We speak truth to power, with conviction, and are prepared to challenge the status quo and advance the goals and visions of lived and living experience communities. We challenge stigma, discrimination, and injustice where we find it. We hold space for uncertainty, navigating adversity, translating the interests and motivations of lived and living experience into systems contexts, and acting in service of lived and living experience communities. We productively and respectfully navigate conflict within and between lived and living experience communities and systems. We recognise the power dynamics and fragility of systems change work, maintain diplomacy and honour the personal costs that can result.

Equity	
In context	Recognising and responding to injustice based on background, identity, or experience, in a way that honours human rights, balances the scales, and positions people for equal outcomes.
In practice	We recognise the role and ongoing impact of power and privilege in centring some voices and diminishing others. We elevate and advocate for, from, and with, quiet or missing voices, recognising the silences (both active and passive) and gaps as harmful perpetuations of the status quo. We prioritise recognition of and investment in lived and living experience communities that are most impacted by systemic stigma, discrimination, and exclusion. We foreground different ways of working, pathways, and allyship across diverse and intersectional lived and living experience communities. We take a human rights approach in the pursuit of social justice for lived and living experience leadership, governance, workforce and partnerships.
Relationship	
In context	Prioritising relational ways of being and doing, and the sharing of power and knowledge, as the foundation for systems change.
In practice	We uphold the rights of all people to define their experiences and identities for themselves, and we speak out in the face of challenges to or denial of identities and experiences. We commit to building strong connections through mutual growth and co-learning about relational ways of working across communities, lived and living experience workforces, other disciplines, non-lived and living experience leaders, and across sectors. We work to build relational safety in our leadership and partnership endeavours and to actively call people and systems in where this is missing. We recognise that communities experience systemic oppression and marginalisation to differing degrees and practice cultural humility – and personal responsibility – in relationships.

How did we get here?

History of lived and living experience movements in Australia

Lived and living experience leadership in mental health, AOD, harm reduction, suicide prevention and gambling harm has been in existence for many decades in Australia and internationally.

Lived and living experience social movements emerged from grassroots activists and broader advocacy efforts to combat the harms experienced by communities through systemic human rights violations, isolation and marginalisation, and criminalisation, to reshape the institutions and systems that perpetuate these harms.

From this historical perspective, lived and living experience leadership can be understood as upholding human rights, pursuing social justice and driving systems and culture change. Lived and living experience advocacy has gradually evolved and grown into modern, values-based lived and living experience advocacy organisations, services and workforces across Australia.

Victoria has lived and living experience-led organisations and peak bodies that connect with and carry the legacy of their respective movements. These include the Victorian Mental Illness Awareness Council (VMIAC), Tandem, the Self Help Addiction Resource Centre (SHARC), and Harm Reduction Victoria (HRVic).

It is important to recognise and retain the intersections within and across lived and living experience communities as part of the collective vision for all lived and living experience.

Different lived and living experience communities and movements hold distinct identities, histories, traditions, connections, and practices.

Recognition and support for these distinctions will support diverse and intersectional lived and living experience leaders and communities to continue to evolve, deepening our understanding of lived and living experience practice, and helping to build more equitable and inclusive leadership.

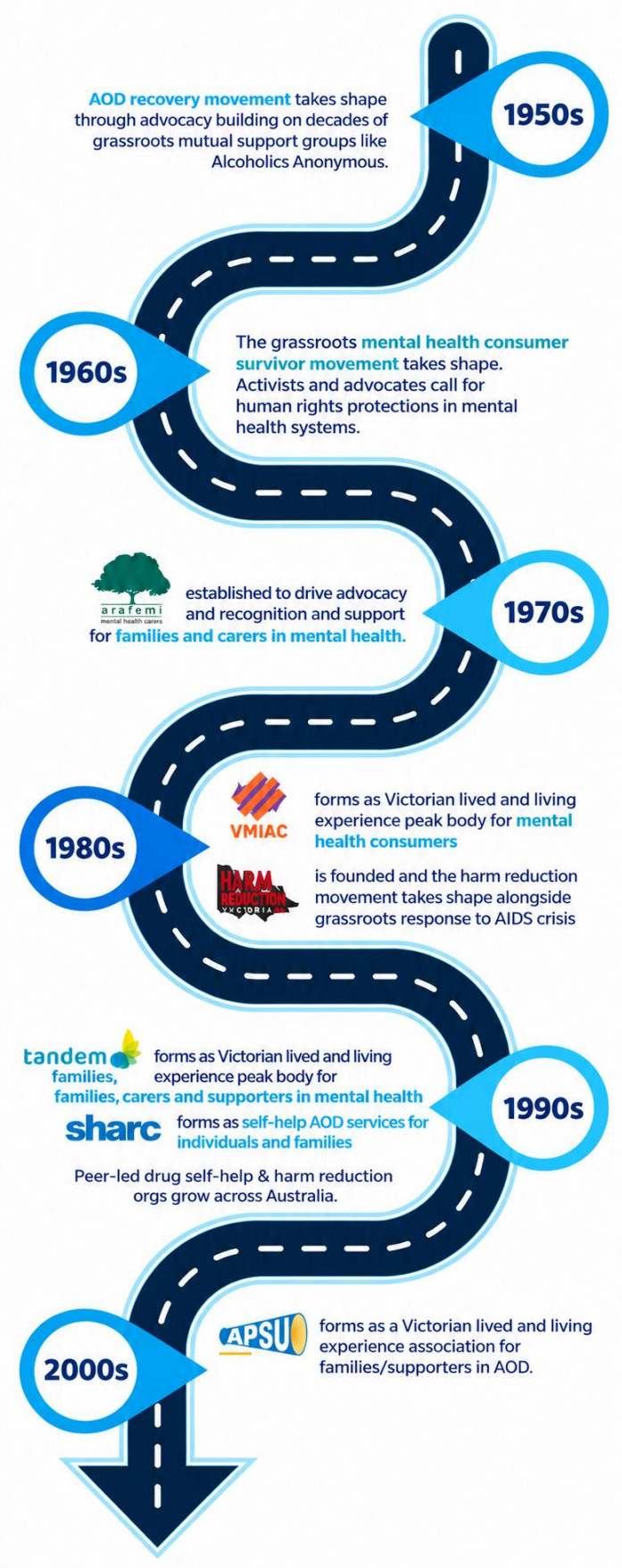


Figure 4: The evolution of lived and living experience leadership in Victoria

Current context

The global shift towards lived and living experience leadership

There is a wealth of evidence that demonstrates the effectiveness of lived and living experience-led organisations and peer-led programs in improving personal health outcomes and contributing to change for communities – including in law reform, community education, access to housing, employment and education (Loughhead et al., 2024; Royal Commission into Victoria's Mental Health System, 2019).

Globally, the unique value and importance of the expertise learned and gained through direct experience is growing. There is now an established 'global consensus that people with lived and living experience... play an integral role in influencing policy and processes in' mental health and wellbeing (Sartor, 2023, p. 1). The Heiloo Declaration (2024) on peer and lived experience leadership captures this consensus:

*'*Lived and living experience leadership is to be valued and respected. This expertise is to be used globally to transform systems, services, and societies to unlock the potential of recovery-based approaches and initiatives. We contribute to improving the lives of all who are impacted by challenges to their mental wellbeing and hold a lens of ensuring citizenship for all impacted by mental health and substance use challenges*'* (Global Leadership Exchange, 2024, p. 1).

The Australian context for change

Lived and living experience leaders and workforces are employed and engaged across state and commonwealth government-funded systems and services.

In Australia, state and territory governments are responsible for public hospitals, emergency departments, residential mental healthcare and community mental healthcare (Australian Institute of Health and Welfare, 2024). The Commonwealth government is responsible for Primary Health Networks and the National Disability Insurance Scheme. Private mental health services also employ lived and living experience workforces. Other lived and living experience-led organisations, including peak bodies and services, also employ people in designated lived and living experience roles.

The complexity of the system makes it challenging to see a complete picture of lived and living experience leadership and workforces in Victoria or nationally, as there is no central data collection or custodian.

Every state and territory in Australia is working to grow and support lived and living experience leadership and workforces, and there are a number of state-based frameworks and strategies related to mental health, AOD, and harm reduction either being implemented or in development.

The Commonwealth government is establishing national structures to grow and support lived and living experience leadership and workforces, amplify the voices of consumers, families and carers with lived and living experience, and drive equitable reform in mental health. This includes:

- The funding and establishment of consumer and carer peak bodies (Australian Government Department of Health, Disability and Ageing, 2025).

- The allocation of $7.1 million over four years to build and support the lived and living experience peer mental health workforce, through the establishment of a national professional association for peer workers, delivery of a national workforce census and the exploration of further training pathways.

In Victoria, the Royal Commission into Victoria's Mental Health System recognised the value of lived and living experience in its interim and final reports. The Commission's extensive consultation, findings, and subsequent recommendations have created the rationale and mandate for investing in lived and living experience leadership, workforce and partnerships in Victoria. More information about current investment is available in the *Leadership Framework* ('Foundations for implementation' section).

In 2021, the Victorian Auditor-General's Office (VAGO) released the *Reducing the harm caused by gambling* report, which included a range of recommendations (VAGO, 2021), including:

- Embedding lived experience in governance and service design: VAGO identified that Gambler's Help services lacked consistent mechanisms for incorporating consumer and lived experience perspectives in decision-making.
- Strengthening consumer voice in program development: The review recommended formal structures to ensure people with lived experience inform policy, planning and evaluation processes.
- Improving cultural safety and responsiveness: Greater involvement of lived experience was seen as critical to making services more inclusive and responsive to diverse communities, including culturally and linguistically diverse groups.
- Addressing gaps in peer workforce development: VAGO noted limited opportunities for peer roles and recommended expanding pathways for lived experience participation across the sector.
- Linking reforms to accountability and outcomes: The report emphasised that embedding lived experience should be tied to measurable improvements in service quality and harm reduction outcomes.

Victoria's Mental Health and Wellbeing System environment

Victoria's mental health and wellbeing system is complex, and our understanding of where and how lived and living experience leadership is operating across the system is not well developed. A Lived and Living Experience Leadership Mapping project being undertaken by the Victorian Centre for Mental Health and Wellbeing intends to provide rich data to support the implementation of this *Leadership Framework*. Key systems and entities of relevance are listed below with links to further information on each.

Mainstream mental health services

About Victoria's mental health services

Mainstream AOD and harm reduction services

Alcohol and other drug treatment services

AOD prevention and harm reduction

Suicide prevention services

Suicide prevention and response strategy

Gambling harm services

Gambling harm prevention and response in Victoria

Lived and living experience-led organisations and services

A number of lived and living experience-led organisations and peak bodies operate in Victoria's mental health, AOD, addiction and harm reduction sectors. Many of these started as peer-led groups – mutual aid, peer support networks, and self-help groups – in response to community need.

Lived and living experience-led organisations are distinct from programs and services that are designed and delivered by individuals with lived and living experience which are governed and operated by mainstream (non-lived and living experience) service providers. Lived and living experience-led organisations are typically governed and led by individuals from the communities they represent, with strong levels of representation by lived and living experience on boards, in executive teams and across their operations and program delivery. They also tend to have significant levels of member participation and decision-making within their structures.

Tandem

Victorian Mental Illness Awareness Council (VMIAC)

Self Help Addiction Resource Centre (SHARC)

Association of Participating Service Users (APSU)

Research

A small but growing number of lived and living experience researchers in Victoria are well-placed to lead and guide other research opportunities, including:

- Research is conducted, controlled and undertaken by leaders of lived and living experience-led organisations.
- The formation of consumer/peer and family/carer specific research groups within or supported by university environments to support mutual knowledge, education and guidance to strengthen lived and living experience-led research.
- Organisational development within and in partnership with universities to create welcoming and supportive spaces for lived and living experience researchers and advisors (Loughhead et al., 2024).

System stewards

System stewards are responsible for Victoria's public mental health and wellbeing system and the health and wellbeing outcomes of the diverse Victorians that access support, treatment and care through state-funded mental health and AOD services. They do this by providing strong oversight, leading system-wide change, and driving innovation and continuous improvement of system performance.

There are three key Victorian agencies that each play a role in stewarding Victoria's mental health and wellbeing system and improving outcomes for people experiencing mental health challenges, psychological distress and/or substance use or addiction, their families, carers, kin, supporters, the

mental health and wellbeing workforce and the broader community. These entities have separate but mutually reinforcing functions and responsibilities to support lived and living experience leadership, workforce and partnerships.

Department of Health – Mental Health and Wellbeing Division

Mental health and wellbeing

Leads and delivers Victoria's mental health and wellbeing reform agenda to build a stronger mental health and wellbeing system for all Victorians, including leading and implementing the recommendations of the Royal Commission into Victoria's Mental Health System and reforms to our AOD service system.

Victorian Collaborative Centre for Mental Health and Wellbeing

Victorian Collaborative Centre for Mental Health and Wellbeing

Works in partnership with people with lived and living experience to translate evidence into innovative and effective practice, to uphold human rights and to work with our mental health workforces and researchers towards our common goal of driving groundbreaking change to Victoria’s mental health and wellbeing system.

Mental Health and Wellbeing Commission

Mental Health and Wellbeing Commission

An independent statutory authority that holds government to account for the performance, quality and safety of Victoria’s mental health and wellbeing system.

Lived and living experience workforces also operate across and interact with other systems, such as community and public health, justice, forensic, housing and family violence systems. Although lived and living experience roles are also based in primary health and private settings, there is not yet a formal mechanism for collaboration and connection across all services and sectors.

Lived and living experience workforces in the current system environment

Some lived and living experience experts with specialisations across design, evaluation, technical expertise, advocacy and other areas choose to work independently and are engaged as consultants or contractors to lead and deliver work.

Key milestones and the evolution of lived and living experience leadership and workforces in Victoria are detailed in the Our Future report (Our Future Project Partnership, 2021).

Most members of Victoria’s lived and living experience workforces are peer workers operating in mainstream clinical and non-government service delivery settings. Peer workers are a critical component of lived and living experience workforces, and there is ongoing, expanding demand for them across crisis, clinical and community services (Royal Commission into Victoria's Mental Health System, 2021). There is a significant disparity in the numbers of mental health, AOD and harm reduction lived and living experience disciplines and family/carer and consumer/peer workers across the mental health and AOD service systems.

Existing data provides a limited view of current lived and living experience workforces. Additional quantitative and qualitative lived and living experience workforce data is needed to provide a more complete picture and inform implementation efforts. The key gaps in our data and knowledge about lived and living experience workforces include:

- Different lived and living experience perspective workforces and disciplines occupying lived and living experience roles across sectors, organisations and settings.
- Positional lived and living experience leadership roles and functions across sectors, organisations and settings.
- Lived and living experience roles in other settings and organisation types (e.g. academia, justice and forensic, lived and living experience and community-led organisations).
- Types of lived and living experience roles, functions and structures within and across settings, lived and living experience disciplines and perspectives.
- Demographic data, age, gender identity, cultural identity, disability.
- Data on Aboriginal and Torres Strait Islander lived and living experience workforce roles.
- Data on lived and living experience roles within suicide prevention and gambling harm.
- Qualitative and experiential data on lived and living experience workforce roles.

Initiatives to improve lived and living experience workforce data collection and address key evidence gaps are underway. This includes developing more systematic and comprehensive approaches which capture lived and living experience workforces operating across a range of settings and sectors.

Victoria's investment in lived and living experience leadership, workforce and partnerships

The Victorian Government and sector partners have undertaken significant work to ensure that lived and living expertise and leadership are central to designing, operating and strengthening the mental health and wellbeing system.

This includes (but is not limited to) investment in:

- Innovative service models such as The Peer Healing Space that is governed, led and delivered by people with lived and living experience.
- Centring and elevating lived and living experience leadership in the delivery and governance of the Mental Health and Wellbeing Connect centres by ensuring family/carer-led decision-making, co-evaluation and community engagement.
- Lived and living experience workforce investments to build, strengthen and sustain lived and living experience workforces, through training, supervision and early-career pathways.
- Programs to shift organisational culture to ensure lived and living experience leadership is valued, embedded, and sustained.
- Lived and living experience-led organisations and expertise that have a broad range of functions such as providing lived and living experience services and programs, discipline specific training, advocacy, research and evaluation.
- Lived and living experience roles and leadership in system steward organisations.

How the Lived and Living Experience Leadership Framework was developed

Led by the Department of Health, Mental Health and Wellbeing Division's Lived Experience and Diverse Communities Unit, the *Leadership Framework* was developed in collaboration with lived and living experience-led peak bodies, agencies, organisations, technical experts and system stewards. This work involved lived and living experience-led research and engagement with people across a broad range of lived and living experience communities, sectors, and experiences. Cross-discipline and cross-sector leadership and expertise were embedded in its governance and development.

Who worked on the Framework

Figure 5: Collaborating organisations

Six organisations made up the project's Steering Group, providing oversight and lived and living experience governance for development of the *Leadership Framework*: Tandem, Victorian Mental Illness Awareness Council, Self Help Addiction Resource Centre, Harm Reduction Victoria, the Victorian Collaborative Centre for Mental Health and Wellbeing, and the Mental Health and Wellbeing Commission.

A Lived and Living Experience Technical Expert Hub, coordinated by SHARC, engaged 14 lived and living experience technical experts with both consumer/peer and family/carer perspectives across mental health, AOD and harm reduction to work alongside the project team in developing the *Leadership Framework*.

Evidence and expertise informing the Leadership Framework

To make sure the *Leadership Framework* properly addresses the workforce and leadership needs of lived and living experience across sectors and disciplines, the development of the Framework drew on a range of quantitative and qualitative evidence through research, community engagement, and existing workforce data.

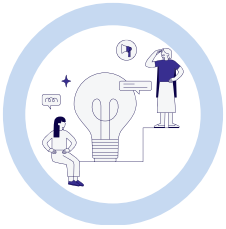
Lived and living experience-led research & evidence

Environmental scan & consultation

Lived and living experience-led analysis & synthesis

Lived and Living Experience Leadership Framework development workshops

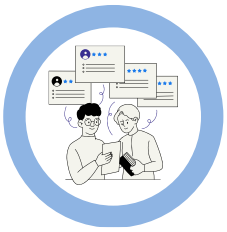
Key stakeholder core elements testing



Lived and living experience-led research and evidence

A series of lived and living experience-led projects were commissioned to gather and analyse existing local, national, and international evidence on lived and living experience leadership, workforce and partnerships to highlight key gaps, tell us what works, and identify what barriers and enablers that need to be articulated and addressed through the *Leadership Framework*:

- Royal Commission analysis of interim and final reports' narrative, directions and recommendations to bring together intentions for lived and living experience leadership and identify reform gaps – *led by SJ Haywood and Gareth Edwards*
- Literature Review of existing evidence and research on lived and living experience leadership, workforce and partnerships in the mental health and AOD and harm reduction contexts – *led by LELAN*
- Scoping organisational supports to provide details around the supports that organisations need to embed lived and living experience leadership and partnership – *led by Red Panther*
- Rapid Literature Scan of how lived and living experience leadership principles and values have been understood, defined, and practised – *led by lived and living experience technical experts.*



Environmental scan and consultation

It was important to understand the current state and future aspirations for lived and living experience leadership, workforce and partnerships from a wide range of individuals and organisations working in Victoria's public mental health and wellbeing system.

Our technical experts led an environmental scan and data analysis to evaluate the current context, identify the key challenges and opportunities, and determine where the focus of future efforts need to sit.

269 people working in a range of roles and organisations across mental health, AOD and harm reduction contributed to the Framework's development.

42
Focus groups & interviews

131
Survey responses

Lived and living experience-led analysis and synthesis

Technical experts analysed findings from our research and consultation and synthesised them into key findings and themes.

Lived and Living Experience Leadership Framework development workshops

Over a series of five workshops, the technical experts and members of the Steering Group developed the *Leadership Framework*'s vision and areas of focus, and informed and facilitated the engagement process to test its core elements more broadly.

Key stakeholder core elements testing

To make sure the Framework was on the right track, the *Leadership Framework*'s vision and strategic directions were tested with different stakeholders identified by lived and living experience technical experts and governance group members.

83 participants shared their perspectives.

Future directions for Aboriginal and Torres Strait Islander lived and living experience leadership

The terms 'Aboriginal and Torres Strait Islander' and 'First Nations' are used interchangeably throughout this section to respect the different preferences of terminology. It is acknowledged that the terms do not capture the unique or individual language groups and may differ from preferred terminology within different communities.

The voices, knowledge systems and leadership of Aboriginal and Torres Strait Islander peoples have been historically excluded from mental health structures and decision-making. Findings from the Yoorrook Justice Commission and other formal truth-telling processes reinforce the need to recognise the ongoing impacts of colonisation, including systemic racism, structural disempowerment and intergenerational trauma.

These injustices continue to shape the social, emotional and cultural wellbeing outcomes experienced by Aboriginal and Torres Strait Islander peoples, including those with lived and living experience of mental illness, distress, trauma, kinship and caring, recovery and healing.

The Royal Commission into Victoria's Mental Health System highlighted evidence from the Victorian Aboriginal Health Service that Aboriginal and Torres Strait Islander peoples continue to experience 'misinformed assumptions, negative judgement, overt and covert racism, and a lack of cultural understanding within mainstream services' (Victorian Aboriginal Health Service, 2019, p. 6). This evidence reiterates the importance of establishing supported and culturally responsive structures for Aboriginal and Torres Strait Islander peoples working within the lived and living experience workforce.

At present, there are no Aboriginal and Torres Strait Islander-specific lived and living experience supports in Victoria. Aboriginal and Torres Strait Islander lived and living experience workers continue to lead, support and care for one another through informal and often unseen structures without adequate recognition, funding or institutional support.

Important national and state-level strategies, such as Closing the Gap frameworks, call for the development and support of an Aboriginal and Torres Strait Islander health workforce, although statewide implementation has been limited due to under-resourcing and lack of systemic reform.

As a result, Aboriginal and Torres Strait Islander workers in designated lived and living experience roles are not consistently represented in leadership, governance or decision-making spaces. In addition, the distinct cultural, relational and community-based expertise is not systematically embedded within lived and living experience ways of working.

Aboriginal Community Controlled Health Organisations (ACCHOs) continue to demonstrate the strength, innovation and effectiveness of Aboriginal-led governance, care and workforce models. The expertise and leadership held within these settings, alongside those already working across the lived and living experience workforce, must be centred and resourced to inform a culturally grounded, anti-racist and self-determined future for Aboriginal and Torres Strait Islander lived and living experience workforce members.

Responding to the needs of Aboriginal and Torres Strait Islander peoples is a complex and sovereign space that requires time, care and genuine collaboration, led by Aboriginal and Torres

Strait Islander peoples themselves. Standalone First Nations-led work is currently being undertaken by the Centre for Mental Health Nursing Consumer Academic Program, ensuring it is governed by cultural integrity, lived expertise and accountability to community. This asserts Aboriginal and Torres Strait Islander peoples' right to define priorities, self-determined approaches, and shape decision-making, with a clear focus on ensuring lived and living experience leadership is recognised, resourced, respected and embedded.

This work will be developed in partnership with Aboriginal and Torres Strait Islander representatives across the lived and living experience workforce and the broader health and wellbeing sector, grounded in truth-telling, self-determination and shared accountability.

Progressing this is essential to meaningful and genuine reform. It is about addressing historical and ongoing injustice, rebuilding trust, and creating spaces for Aboriginal and Torres Strait Islander lived and living experience leadership to be appropriately acknowledged and elevated, not only within the lived and living experience workforce and mainstream services, but more broadly across Victoria's entire mental health and wellbeing system.

Glossary

A number of terms used in the *Leadership Framework* and this *Foundations for transformation* document are defined below. Definitions are drawn from a range of sources, including the five lived and living experience workforce discipline frameworks and other relevant frameworks. It is acknowledged that this is not an exhaustive list and that reviewing language and definitions to reflect the ways communities define their identities and experiences is important.

Term	Definition
Alcohol and Other Drugs (AOD) lived and living experience	AOD lived and living experience describes people who have personal experience of substance use and/or addiction, either past or present, that radically changes/changed their life and influences how they see the world. Living experience refers to someone who identifies as having ongoing experience of substance use. It can apply to current substance use and/or drug-related harms, to families whose experience of supporting someone with substance use are ongoing, and for those who choose to employ this term to reduce stigma associated with substance use and addiction. Family AOD lived experience refers to when a family member's loved one is currently in their own self-determined process of meaningful life change. Family AOD living experience refers to when a family member's loved one is currently experiencing the impact of substance use and/or addiction. In a harm reduction context, people with living experience who use and/or inject drugs are described as People Who Use Drugs (PWUD).
Allyship	Allyship refers to people in leadership or non-lived and living experience roles (such as clinicians or managers) actively supporting, enabling and resourcing people with lived and living experience working to dismantle barriers and share power.
Consumer (sometimes also consumer/survivor or ex-patient) and service user	The word 'consumer' is commonly used to describe people who have used mental health services. The term is not wholly accepted by all people who access mental health services. It can also be used to describe someone who uses, has used or is eligible to use AOD services. Consumer/survivors or ex-patients are a group of people who have survived experiences of marginalisation and systemic oppression within the mental health system. A service user is someone who uses, has used or is eligible to use AOD or harm reduction services. It includes both people who are refused services or those who refuse services.
Cultural safety	An environment that is safe for people – where there is no assault, challenge or denial of their identity or background, of who they are, of the discrimination or exclusion they experience and of what they need. Cultural safety is about shared respect, shared meaning, shared knowledge and experience of learning, living and working together with dignity and truly listening. Cultural safety is a key practice principle for providing person-centred, holistic and equitable mental healthcare and negotiating power in service encounters.

Term	Definition
Safe-enough	The word safe-enough is used to signify a person's felt sense of having enough safety to engage, which is individual and subjective. A place or environment in which people can feel confident that they won't be exposed to discrimination, criticism, harassment, or any form of emotional or physical harm is unfortunately impossible to create. Complete safety cannot be guaranteed, due to different points of view, challenges and biases (Mind Australia, 2024).
Designated roles	The term 'designated' indicates a role in which lived and living experience is an essential requirement, in addition to relevant training, skills, knowledge and expertise. Designated roles include all positions that require lived and living experience as key criteria, regardless of position type or setting.
Diversity	Diversity has different meanings. In the context of the *Leadership Framework,* it includes cultural identity, faith, ethnicity, gender, sexual orientation, age, ability and socio-economic status.
Family, carers, kin, supporters or service users	This term refers to people who have a significant personal support role in a consumer's or service user's life in an unpaid capacity. These relationships may include both family of origin and family of choice, and others who play a significant role in the person's life. Kin refers to complex networks of family, kin/kinship structures and friends. Family and kinship systems maintain interconnectedness through cultural ties and reciprocal relationships of sharing, caring, responsibilities and obligations. Some people may identify as a 'carer' in a person's life, while many others do not identify with that term but instead with the characteristic of their relationship (e.g. parent, child, partner, sibling or friend). The terms 'family' and 'carer' are not interchangeable. Service user includes family and supporters to people who use AOD and harm reduction services regardless of whether they directly use these or not.
Gambling harm lived and living experience	Gambling harm lived and living experience describes people who have personal experience of (or are family members, carers, kin or supporters of people who have personal experience of) gambling harms, either past or present, that radically change their life and influence how they see the world.
Harm reduction	Harm reduction refers to policies, programs and practices that aim to minimise the negative health, social and legal impacts associated with drug use, drug policies and drug laws. It is grounded in justice and human rights. It focuses on positive change and on working with people without judgement, coercion, discrimination or requiring that people stop using drugs as a precondition of support.

Term	Definition
Intersectionality	Kimberlé Crenshaw coined the term intersectionality in 1989 to describe multiple experiences of oppression experienced by people who have identities that are marginalised in society. Intersectionality acknowledges: • experiences of discrimination and inequality can shape a person's experiences across their life • experiences of discrimination and inequality can intersect, overlap and be interdependent • people experience multiple, intersecting forms of discrimination in our institutions and public settings (such as education, legal settings and workplaces) • our society, culture and relationships with others can enable discrimination and inequality to occur.
LGBTIQA+ communities	This umbrella abbreviation encompasses a range of sexualities, genders and sex characteristics, including lesbian, gay, bisexual, trans and gender diverse, intersex and/or queer. The '+' is for people whose gender identity or sexual orientation is not represented by the letters. Some Aboriginal communities use the terms 'sistergirls' and 'brotherboys'.
Lived and living experience of suicidality and bereavement	Lived and living experience of suicidality and bereavement describes people who have had or still experience suicidal thoughts and behaviours and/or survived a suicide attempt, or are family members, carers, kin or supporters of people who have experienced suicidal thoughts and behaviours and/or survived a suicide attempt, and/or died by suicide.
Lived and living expertise	Lived and living expertise reflects the intentional development and integration of individual lived and living experience with • formalised discipline perspective, principles and practice • knowledge or experience of service and systems environments, and • engagement with historical and contemporary movements and advocacy.
Mental health lived experience	Mental health lived experience describes people who have experienced or experience mental health challenges or psychological distress – whether they have a formal diagnosis, have used mental health services, or have been unable or chosen not to access them. It also includes people who are family members, carers, kin or supporters of people who have experienced or experience mental health challenges or psychological distress.
Multicultural communities	Includes people whose families have entered Australia through a variety of pathways, including through humanitarian, family, child and skilled migration. This term includes people from migrant, refugee and asylum seeker backgrounds regardless of visa status, type or pathway to Australia. It includes people from a wide range of cultures, ethnicities and faiths who speak a variety of different languages, and both well-established and more recently arrived communities.

Key Victorian mental health and wellbeing policies and strategies

Department of Health Strategic Plan 2023–2027

The *Department of Health Strategic Plan 2023–2027* sets out how the department seeks to deliver the best health, wellbeing, and care outcomes for communities across Victoria. It has a vision that Victorians are the healthiest people in the world. It creates many of the system reforms and enablers that will position this strategy to succeed, for example, building a stronger and more sustainable workforce, innovating and improving care, and the inclusion of harm reduction initiatives as a priority.

The next phase of reform – Mental Health and Wellbeing in Victoria

A central element of *Victoria's Department of Health's next phase of reform for mental health and wellbeing* is a strong commitment to supporting a system that embeds lived experience at every level. This approach is a key priority aimed at ensuring that individuals with direct personal experience of mental health challenges as consumers, family members, carers, kin or supporters are central to the design, delivery, and governance of services.

Mental Health and Wellbeing Outcomes and Performance Framework

A key goal of the *Mental Health and Wellbeing Outcomes and Performance Framework* is to ensure the workforce reflects the people and communities it serves. A major part of this initiative involves fully integrating the lived and living experience workforces with a focus on strengthening representation from multicultural and Aboriginal and Torres Strait Islander communities. Those with firsthand experience of the mental health system will have the authority to influence workforce practices and service design and are offered clear pathways for career progression and professional recognition.

Wellbeing in Victoria: A Strategy to Promote Good Mental Health 2025–2035

The *Wellbeing in Victoria strategy* articulates the needs and aspirations of Victorians in order to achieve individual and collective wellbeing. Recognising the need for long-term commitment and coordinated effort, the strategy sets the course for the first 10 years of change.

Alcohol and Other Drugs Strategy 2025–2035

The *Victorian Alcohol and Other Drugs strategy 2025–2035* aims to address drug-related harm in the Victorian community over the long term by ensuring Victorians can access the right information, support and care at the right time.

Diverse Communities Mental Health and Wellbeing Framework 2025–2035

The *Diverse Communities Mental Health and Wellbeing 10-Year Framework 2025–2035* is a commitment to building a safe, inclusive, and responsive mental health and wellbeing system that embraces the diversity of its population. The Victorian Government's framework for reform specifically focuses on improving outcomes for LGBTIQA+ Victorians, multicultural and multifaith Victorians, and Victorians living with a disability.

Victorian suicide prevention and response strategy 2024–2034

The *Victorian suicide prevention and response strategy 2024–2034* builds a systems-based, evidence-informed, whole-of-government and community-wide approach to suicide prevention and response. It responds to Recommendation 26 from the Royal Commission into Victoria's Mental Health System. The strategy has been developed in partnership with people with lived and living experience of suicide – including people who have survived a suicide attempt, live with suicidal thoughts, care for or support someone who is suicidal, or have lost someone to suicide.

Victorian eating disorders strategy 2024–2031

The *Victorian eating disorders strategy 2024–2031* aims to create a care system that is centred on the needs of people with eating disorders, their families, carers, kin and supporters. The aim is to build a system that is easy to navigate, has connected services and supports based on the best available evidence for people who need them, where they need them. It will be a system that helps prevent eating disorders, identifies and addresses issues early on and is designed and delivered with input from people who have experienced eating disorders themselves.

Balit Murrup: Aboriginal social and emotional wellbeing framework 2017–2027

Balit Murrup means 'strong spirit' in the Woi-wurrung language. It recognises that to reduce the growing mental health gap, new and different solutions are needed to address what has been described as entrenched mental health crises.

The vision of Balit Murrup is to support Victorian Aboriginal people, families and communities to achieve and sustain the highest attainable standard of social emotional wellbeing and mental health.

Balit Murrup's objective is to reduce the health gap attributed to suicide, mental illness and psychological distress between Aboriginal Victorians and the general population.

Victorian Aboriginal Health and Wellbeing Partnership Agreement and Action Plan

The *Victorian Aboriginal Health and Wellbeing Partnership Agreement and Action Plan* stipulates actions that must be taken in 2023–2025 to reform the healthcare system for Aboriginal people living in Victoria. This includes actions to strengthen cultural safety in mainstream health systems at all access points, ensuring cultural safety training, improving the identification of Aboriginal people in health services and strengthening the AOD sector to support Aboriginal people living in Victoria to have equitable access to health services. This strategy provides strategic directions and actions to prioritise the delivery of these actions as they relate to the AOD system.

Victorian Mentally Healthy Workplaces Framework

The *Victorian Mentally Healthy Workplaces Framework* aims to assist all Victorian workplaces and workers to thrive through improved safety, education, wellbeing, inclusion, and performance – for organisations, their teams and for all workers. This Framework provides priority areas for organisations to promote, protect and respond across leadership and accountability, culture, policies and practices, education and capability, inclusion, and risk prevention.

Our Workforce, Our Future

Our Workforce, Our Future is a capability framework for Victoria's mental health and wellbeing workforce. The framework puts consumers, families, carers, kin and supporters at the centre of care. It also acknowledges and values the breadth of expertise and experience across the workforce.

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