THE NORTHERN TERRITORY MENTAL HEALTH LIVED EXPERIENCE ENGAGEMENT FRAMEWORK



NORTHERN TERRITORY GOVERNMENT

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Minister's Foreword

HON SELENA UIBO
MINISTER FOR MENTAL HEALTH AND SUICIDE PREVENTION

The Northern Territory Government is committed to ensuring that people who have lived and living experience of mental health issues are central in the design of care and treatment services that affect them. Amplifying the voices of those who have navigated the mental health care system as a consumer or caregiver is essential for creating safe and responsive services that are aligned with the diverse and evolving needs of the community.

The Nothern Territory Mental Health Lived Experience Engagement Framework draws on core principles of the Victorian Mental Health Lived Experience Engagement Framework (2019) and is informed by frameworks in other Australian jurisdictions, the Gayaa Dhuwi (Proud Spirit) Declaration (2015) and contemporary research about lived experience participation in service design. Importantly, it is also informed by a process of public consultation to ensure the Framework reflects the NT context.

The Northern Territory boasts a diverse range of cultures and recognising this diversity is crucial for promoting best practice across clinical and non-clinical community, health and mental health services. Inclusive engagement involves considering the experiences and opinions of a wide range of stakeholders, ensuring that the unique voices of Territorians are heard. The Framework aims to provide an outline of expectations for decision makers and service providers to use inclusive engagement pathways to ensure that people who have lived experience of mental health issues are acknowledged as vital to achieving health outcomes.

The Framework is intended to be a living document that will be updated and revised over time to ensure its ongoing relevance and accuracy, ensuring it remains valid to the needs of Territorians.

As we navigate the complex landscape of health outcomes, the authentic perspectives of those with lived experiences serve as a compass, guiding us towards comprehensive and empathetic solutions. By fostering a collaborative approach that actively includes these voices, we not only enrich our understanding of mental health challenges but also cultivate a healthcare system that is responsive, inclusive, and genuinely committed to improving the well-being of all individuals. Together, through shared experiences and collective insights, we pave the way for a more compassionate and effective future in mental health care.



Acknowledgements

NT Health acknowledges the Traditional Owners of the Northern Territory (NT) and pays respect to all Aboriginal and Torres Strait Islander people and their cultures, their Elders past, present and emerging, and to future generations. We recognise Aboriginal peoples' continuing connection to their lands, waters and communities in which we live.

We acknowledge the impact colonisation has had on the health and wellbeing of Aboriginal Territorians and we are committed to strengthening partnerships between Aboriginal and non-Aboriginal individuals, families and communities of the NT to improve health outcomes.

The Framework recognises the great diversity of nations within Australia and the term Aboriginal should be taken to be inclusive of Torres Strait Islander people[1].

NT Health also acknowledges people with lived and living experience of mental distress, mental health issues or illness as well as those impacted by suicide, their families, carers and support people. We recognise the importance of lived experience voices in the development, review and redesign of mental health services and suicide prevention initiatives.

People who have experienced a mental health issue and/or illness and have recovered, or who currently have a personal lived experience of mental health issues and/or illness and are on their recovery journey, are referred to as 'people with lived experience of mental health issues' in this Framework. This also includes people who have a lived experience of suicidality.

The Framework also uses language that acknowledges the lived experience of carers, families, kinship groups and friends supporting people with lived experience of mental health issues. When speaking collectively, the Framework refers to the lived experience of people with mental health issues and carers, families and kinship groups.

1. Introduction

The NT Mental Health Lived Experience Engagement Framework (the Framework) outlines the expectation that all clinical and non-clinical community, health and mental health services will use inclusive engagement pathways to ensure that people who have lived experience of mental health issues are recognised as integral to service design and achieving health outcomes.

Inclusive engagement considers the experiences and opinions of the widest range of stakeholders possible, ensuring the diverse voices of Territorians are heard. This includes those who are harder to reach or traditionally excluded such as those in rural and remote locations. Inclusive engagement minimises the risks associated with an over-reliance on a small number of regular experts and shapes and designs services alongside the community it serves.

Inclusive engagement leads to:

- Health system and organisational decision making that is better informed by a wide range of opinions and experiences
- Establishment of foundations for mutual respect, understanding, and collaboration, leading to more robust agreements
- Evidence based programs, policies and services with improved service delivery
- Improved health outcomes for health care service consumers

As demand for mental health services continues to increase and reforms are initiated, the contribution of people with lived experience is essential to ensure services are fit for purpose and address the unique needs of each community.

The Framework will ensure that lived experience voices across mental health and suicide prevention are central to service planning and that individuals are at the forefront of their health and community care. By amplifying the voices of those who have navigated mental health and caregiving challenges, the Framework aims to guarantee that services are not only responsive but also genuinely aligned with the diverse and evolving needs of the community.

The NT is home to a rich tapestry of cultures and recognising the diversity within and between Aboriginal communities and those from culturally and linguistically diverse (CALD) backgrounds is paramount to fostering best practice. This Framework will be implemented by each service area, region and/or organisation based on specific local needs.

All Australian jurisdictions have mental health lived experience engagement frameworks with similar core principles plus adaptation to the local context. Foundations of this framework have drawn from the Victorian Mental Health Lived Experience Engagement Framework (2019)[2] as the most contemporary example, and the Gayaa Dhuwi (Proud Spirit) Declaration (2015)[3]. Frameworks in other jurisdictions were also reviewed in the development process.

2. Purpose

The Framework seeks to provide guidance and support for health services and organisations, encouraging active engagement and collaboration with individuals who have lived experience. By fostering engagement opportunities with those who have firsthand knowledge, services will be meaningfully improved for the people who use them. This includes the lived experience workforce, the broader community and particular subsets such as carers, family and friends, as well as people from specific population groups who will hold varying perspectives. The Framework is intended to be a broad, adaptive document that will evolve over time.

The Framework will:

- Ensure that mental health services and suicide prevention responses are meaningful, culturally safe, respectful and accessible
- Build on NT Health's existing principles of consumer engagement and cultural responsiveness
- Offer an overview of engagement approaches, resources and supports
- Promote best practice by placing consumers and carers at the centre of policy and practice change by engaging them through co-design and participation
- Provide evidence-informed support for the most vulnerable groups of people in suicide prevention and post suicide care responses
- Build stronger communities that have increased capacity to respond to and prevent suicidality through raising awareness and reducing stigma over time. With the long-term goal to eliminate stigmatisation of mental illness



3. Aboriginal Peoples and lived experience



In the NT, Aboriginal Territorians are disproportionately represented in the health system overall and this includes mental health outcomes.

Cultural responsiveness is the term used to describe the capacity to respond to care issues of individuals and provide patient-centred care (taking into account cultural, linguistic, spiritual and socio-economic background)[1]. NT Health acknowledges that experiences for Aboriginal Territorians and communities are significantly different than those of non-Aboriginal Territorians and are impacted by the ongoing effects of colonisation, genocide, dispossession, forced removal of children, high incarceration rates, racism and accumulative grief, loss and trauma.

It is important that Aboriginal Territorians and communities are actively leading solutions and policies that impact them. When engaging Aboriginal Territorians, the acknowledgement of the cultural diversity between and amongst Aboriginal communities must be recognised. It is vital to ensure engagement processes are culturally safe so people feel respected and that their voices and heard.

From an Aboriginal perspective, mental health, or connection to mind and emotions, is viewed as only one aspect of the Social and Emotional Wellbeing (SEWB) concept of wellness. Other aspects include connection to body, to family and kinship, to community, to culture, to country, and to spirit, spirituality and ancestors. All aspects are equally important and must be considered[4].

Gayaa Dhuwi (Proud Spirit) Australia's vision is for Aboriginal leadership, excellence and presence across all parts of the Australian mental health system and the achievement of the highest attainable standard of SEWB, mental health and suicide prevention outcomes for Aboriginal Territorians[3].

There are five key principles which underpin the Gayaa Dhuwi Declaration and its implementation plan[3]:

1. Aboriginal concepts of Social and Emotional Wellbeing (SEWB), mental health and healing should be recognised across all parts of the Australian mental health system, and in some circumstances specialised areas of practice should be supported.

    - The holistic concept of SEWB in combination with clinical approaches should guide all Aboriginal mental health, healing and suicide prevention policy development and service and program delivery.

Figure 1: SEWB Diagram adapted from Gee et al (2014).[5]



2. Aboriginal concepts of SEWB, mental health and healing combined with clinical perspectives will make the greatest contribution to the achievement of the highest attainable standard of mental health and suicide prevention outcomes for Aboriginal people.

    - All parts of the Australian mental health system should be guided by concepts of SEWB, mental health and healing in combination with clinical approaches when working to heal and restore the wellbeing and mental health of Aboriginal people.

3. Aboriginal values-based SEWB and mental health outcome measures in combination with clinical outcome measures should guide the assessment of mental health and suicide prevention services and programs for Aboriginal people.

    - Led by Aboriginal people, all parts of the Australian mental health system should use Aboriginal values-based SEWB and mental health outcome measures in combination with clinical measures when developing evaluation frameworks for Aboriginal mental health and suicide prevention services and programs.

4. Aboriginal presence and leadership is required across all parts of the Australian mental health system for it to adapt to, and be accountable to, Aboriginal people for the achievement of the highest attainable standard of mental health and suicide prevention outcomes.

5. Aboriginal leaders should be supported and valued to be visible and influential across all parts of the Australian mental health system.

    - All parts of the Australian mental health system should support Aboriginal leaders to practice culturally informed concepts of leadership.

4. Key messages

Four key themes are critical to the success of the engagement processes:

1. People with lived experience of mental health issues have the right to be recognised, respected and included in policy decision making.
2. Fit-for-purpose engagement methods for people with lived experience of mental health issues are important to help drive ongoing system reform in the NT. These include consultations, focus and working groups, consumer-led research and co-design.
3. Lived experience engagement activities will address issues of safety, safe storytelling and power to promote, support and uphold meaningful and productive lived experience participation.
4. Staff working in mental health, suicide prevention and community services in the NT will have a clear understanding of expectations, roles and responsibilities when undertaking engagement activities and will be supported accordingly. Management will oversee processes to ensure appropriate processes are followed.



5. Policy context

NT Health is committed to working with people with lived experience to ensure mental health and suicide prevention services involve Territorians as active partners in their care. This involves providing timely, quality, patient-focused, culturally safe and evidence-based care with the aim to maintain optimal functionality and wellness.

The Framework builds on our existing Patient Experience and Consumer Engagement Framework[6] that promotes:

- Fostering a responsive organisational culture
- Creating a safe environment
- Building consumer engagement strategies and systems
- Developing a skilled and empowered multi-disciplinary workforce

Suicide is a significant challenge for the NT and this Framework should be considered in conjunction with the NT Suicide Prevention Implementation Plan 2023-2028[7]. Those bereaved by suicide and people who have made previous suicide attempts offer valuable lived experience insight, especially important for the design of community prevention programs.

A strong Framework and underpinning culture allows improvement across all aspects of care including appropriate service design, mental health workforce planning and lived experience workforce development. The Framework supports the NT Health Aboriginal Cultural Security Framework 2016-2026[1] which prioritises enhanced consumer and community engagement and participation so that Aboriginal Territorians and communities partner in the planning, development, provision and evaluation of services. This approach acknowledges and builds on the research and evaluation that has taken place in the NT previously.

Cultural safety identifies that consumers are safest when service providers have considered power relationships, cultural differences and consumer rights. Culturally safe services are respectful, inclusive and enable specific population groups to participate in decision-making. Critically, cultural safety is defined by the experience of the consumer, not the professional providing the service.

The Framework will assist staff to meet responsibilities under the Mental Health and Related Services Act 1998[8], the Carer Recognition Act 2006[9] and associated NT Carers Charter[10].

6. Engagement process

People with lived experiences navigating mental health services in the NT possess valuable insights that deserve recognition, respect, and inclusion in the decision making processes of policies and programs. Engagement efforts are most effective when conducted at individual, service, sector and system levels. A rich array of engagement methods exist, both nationally and internationally, and employing multiple approaches is essential to capture the diverse perspectives within the community.

Table 1: Engagement principles.

Be purposeful	Clearly define the purpose and anticipated outcomes of each engagement activity involving lived experiences. Ensure roles and expectations are well-communicated to foster focused, scoped and outcome-driven engagement.
Be prepared	Initiate lived experience engagement early in the planning process, considering historical context and experiences. Minimise risks of over consultation, duplication, or ill-informed messaging. Recognise the history and impact of colonisation and trauma in consultations, particularly with Aboriginal communities.
Be genuine	Actively seek input and collaboration with consumers and carers. Empower those with lived experiences to play central roles in policies and programs. Cultivate resilient relationships by prioritising open communication, sharing information and providing opportunities for choice and control.
Be inclusive	Design processes that maximise inclusivity to engage a wide range of Territorians, including those traditionally underrepresented. Identify opportunities to engage with diverse demographics, seeking agreement and understanding of processes and outcomes from all involved.
Use open communication	Maintain regular communication throughout the engagement process, providing updates and closing the feedback loop. Build trust and genuine relationships with lived experience stakeholders, striving for a shared understanding of issues and potential solutions. Be accountable to people with lived experiences, the community, and services by sharing learnings and ensuring sufficient information for meaningful contributions to the decision making process.

7. Foundations for effective engagement

The International Association for Public Participation (IAP2) public participation spectrum is an international standard for engagement that describes engagement along a continuum[11]. The continuum describes what level of engagement is requred for different types of stakeholders, from informing people of work that is being undertaken to co-production, where people with lived experience have significant opportunity to inform the work and its outcomes.

Figure 2: The IAP2 engagement continuum.

INCREASING IMPACT ON THE DECISION

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Public participation goal	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
Promise to the public	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible	We will implement what you decide.

8. Lived experience participation

The NT has a unique population that is diverse and distributed over a large geographical area. Currently the NT has a range of unfunded networks representing a wide range of perspectives including regional diversity and specific populations, such as veterans, people identifying as LGBTQIA+, young people and men's groups.

Individuals with lived experience can undertake a range of roles in different service settings and may be referred to as a range of titles to best define their roles, though there may be crossover in functions in any one position[12]. Table 2 provides some examples of work that people with lived experience may be involved in.

Table 2: Examples of work that people with lived experience members may be involved in (adapted from Mental Health Peer Workforce Literature Scan, Health Workforce Australia 2014)[12].

ACTIVITY	TASK EXAMPLE
Direct work with individuals regarding advocacy and system navigation	Referrals, attending appointments with consumers, patients or carers, liaising with services, sourcing community resources, providing information, general education and advocacy.
Lived experience support	One-on-one work, encouragement, providing hope, role modelling, skills building, sharing of personal experience, safe storytelling.
Systems improvement	Participation in safety and quality projects, policy and process review and design, advisory groups and/or steering committees, training delivery.
Skills and therapy groups	Health promotion, group co-facilitation, skills encouragement, hearing voices groups.
Co-ordination and management	Team leader management of lived experience workforce and resources.
Consumer Consultant	Contracted as needed. Participation on job interviews, service reviews, redesign, involvement in boards and reference groups
Cultural change	Everyday influencers of cultural change within organisations.

In addition to the examples in Table 2, lived experience participants can assist in many others areas such as peer education, recovery planning and identification of preferred support mechanisms as well as training and vocational pathways and support measures for lived experience participants and facilitators.

Training will support increased capacity and greater participation of the peer-led mental health workforce. Developing the lived experience workforce comprises part of the national and NT workforce plans. Considerations include the manner in which the existing workforce positions would be realigned to accommodate an increase in lived experience staff roles.

From time to time mental health consumers and carers opt to independently pursue their own issue or need, including developing, delivering and evaluating any necessary response. Government often supports these activities with funding and other resources, but is not involved in undertaking the decision making. This is referred to as a 'community-owned' or 'consumer-and-carer-owned' initiative. In community- and consumer-and-carer owned initiatives, mental health consumers and carers may lead the process to define their own issue or need, then design and provide the solution, delivery and evaluation within existing mainstream mental health or community services.



9. Creating lived experience capacity outside of government services

The development of two national representative bodies is creating distinct lived experience voices for consumer representation and family, carer and kin representation. These bodies will help provide national direction for building capacity outside of government services.

Lived experience peaks in other jurisdictions currently take on many different forms and those in operation are outlined in Appendix A.

Investment in the creation of an independent, NT-wide lived experience collaborative organisation will enhance the contributions of people with lived experience to the mental health system and services. Creating such an organisation requires significant co-design through engagement of people with lived experience with diverse voices from multiple locations across the Territory.

The NT has unique characteristics including a diverse population, wide geographical distribution and an evolving mental health service sector. A key feature of a NT-Wide Lived Experience Organisation will be to provide a collaborative networking base. This will create an alliance of entities that are largely autonomous, diverse and geographically distributed but that collaborate to achieve common or compatible goals. Interaction would be supported by a shared IT network. This approach allows the widest possible representation and participation across the NT, and flexible location of supported local representatives.

Potential roles for the organisation will be to act as a central point of contact for existing consumer-led groups and networks, facilitating two-way communication. It will work with consumers to achieve and support systemic change through:

- Training: capacity building for consumers and workplaces
- Consultation and representation: stakeholder engagement, awareness raising and promotion of consumer issues
- Policy: advocacy and consultation

Building capacity in the community involves:

- Developing and building knowledge, skills, confidence and capacity to support people as local and regional advocates
- Increasing knowledge and capacity for people to make their own choices about treatment, care and support
- Promoting the rights, dignity and autonomy of people living with mental illness or psychological distress
- Reducing stigma and increasing awareness of mental illness
- Contributing to the governance of service providers to ensure the consumer and carer voice is represented
- Assisting service provides with organisational readiness training and recruitment support
- Supporting consumer and carer self-care
- Providing peer mentoring support and a community of practice

10. Remunerating lived experience representatives

In line with the principle of valuing lived experience expertise, where a service invites a lived experience representative of a community to participate in service activities, it is expected that the participant will be remunerated. Consumers or carers who participate as part of their paid employment do not require remuneration.

Services are encouraged to develop paid participation policies using the National Mental Health Commission (NMHC) Paid Participation Policy[13] as a guide.



11. Safe and meaningful engagement

The effectiveness of lived experience participation processes hinges on the unique organisational structures of each entity, interwoven with other decision-making processes within the organisation[14]. The essence of lived experience participation and engagement lies in the core principles of person-centred care, which treat each individual with profound respect, recognising them not merely as a condition to be treated, but as a unique person. Person-centred care stands as a widely acknowledged cornerstone for attaining high-quality healthcare, leading to improved outcomes and enhanced experiences for patients, caregivers and families.[15]

Individuals with lived experience, at times, grapple with a significant loss of influence in their treatment journey, particularly when subjected to involuntary treatment. The initial stride toward meaningful engagement involves acknowledging the distinctive needs, perspectives and values that individuals with lived experience bring to the table, whether in roles such as a lived experience consultant, focus group member, lived experience employee, or another capacity. Attention must be paid to amplifying the voices of smaller and unique cohorts, such as neurodivergent and gender-diverse individuals, including the Aboriginal rainbow community, within the context of lived experience in the NT.

It is essential for all services to acknowledge and prioritise Aboriginal learning styles and ways of doing business. Services also need to ensure that any services provided are based around person-centred care and that the engagement of people with lived experience holds genuine significance. Building a relationship of trust is paramount in understanding the primary engagement concerns of mental health consumers, caregivers and sector stakeholders. Table 3 outlines the key barriers to engaging lived experience participants, accompanied by identified enablers and suggested solutions.



Table 3: Barriers to engagement of lived experience participants, identified enablers and suggested solutions (adapted from the Victorian Mental Health Lived Experience Engagement Framework)[2].

BARRIER	ENABLERS AND SOLUTIONS
Feeling unsafe	Create a safe space by identifying potential issues and implementing pre-emptive measures well before the commencement of engagement. This is especially crucial in mental health contexts where re-exposure to disempowering experiences can be harmful.
Feeling intimidated	Rebalance power dynamics by adopting co-production principles that shift decision-making back to service users. Address any intimidating aspects of government culture by finding ways to make community members feel more welcome and fully engaged.
Lack of support	Connect consumers and carers with lived-experience support to ensure emotional distress or feelings of being burdened are addressed, either during or after an engagement activity.
Using overly complex language	Use plain English to enhance common understanding, especially when engaging consumers and carers. If complex language is unavoidable, provide pre-reading briefings and opportunities for clarification throughout the engagement process.
Consultation fatigue	Develop clear objectives and processes, set expectations around outcomes, and recognise that engagement may be challenging unless feedback is incorporated, aligning with co-production principles.
Emotionally triggering content	Provide trigger warnings before meetings to minimise the impact of emotionally challenging content. This includes topics like involuntary treatment, experiencing restraint and seclusion in treatment, or the separation or death of a loved one. Establish discreet pre and post-briefings to support individuals in dealing with traumatic experiences.
Poorly defined issues	Provide clear definitions for aims and scope, articulate roles and responsibilities, and incorporate reporting and feedback mechanisms into the consultation process to ensure clarity and effectiveness.

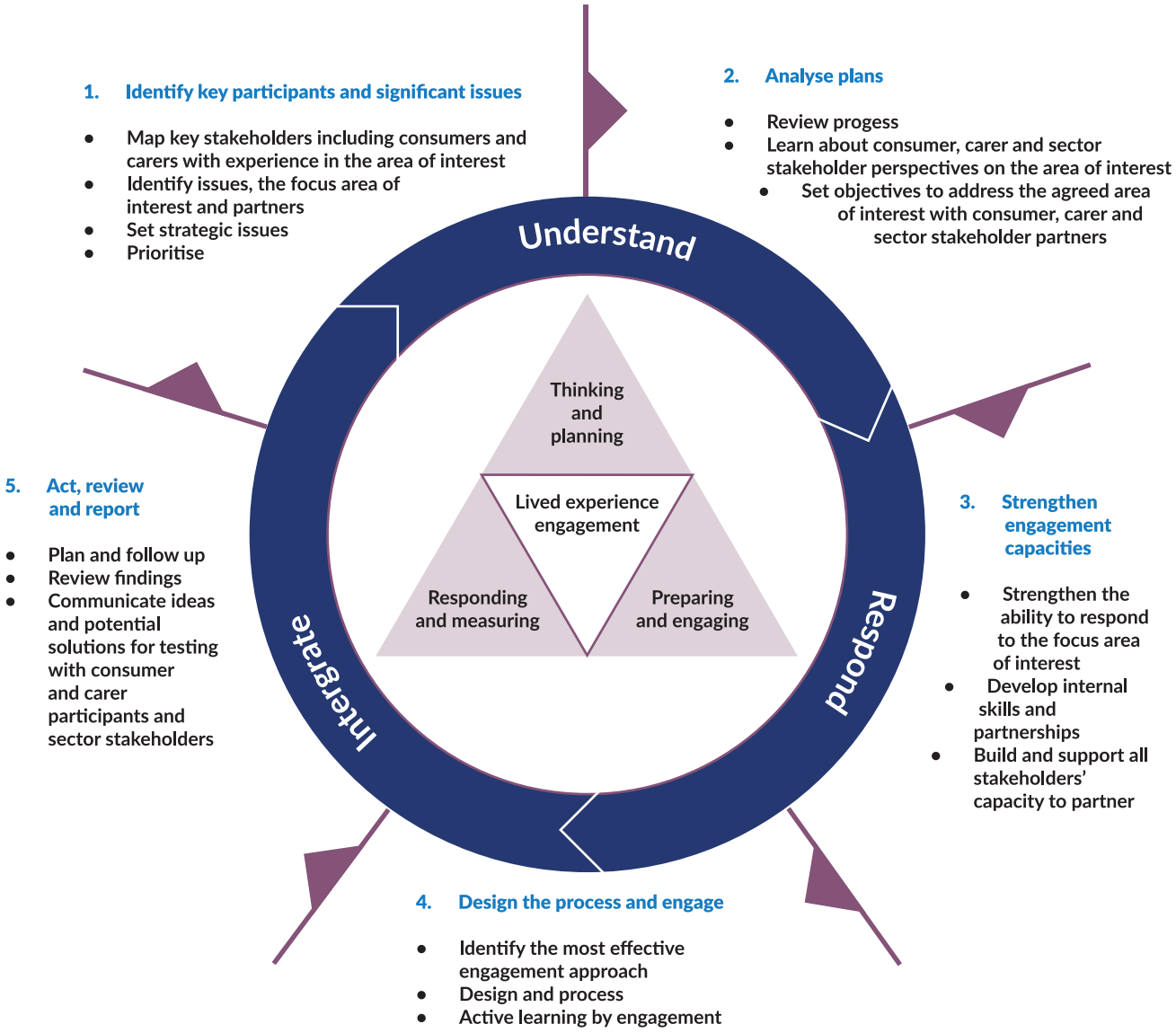
Specific initiatives to provide training and support for staff working in mental health, suicide prevention and community services to ensure they have a clear understanding of their roles and responsibilities in the engagement process should be addressed in workforce development plans. Ongoing training in cultural safety and trauma informed care is also central to success.

12. Tools for engagement

Each project is unique and therefore engagement can take many forms. However, following certain steps will ensure consideration has been given to include the lived experience perspective.

The model shown in Figure 3 provides a useful reference for engagement. The model is action-oriented, outlining initial preparatory work through to delivery.

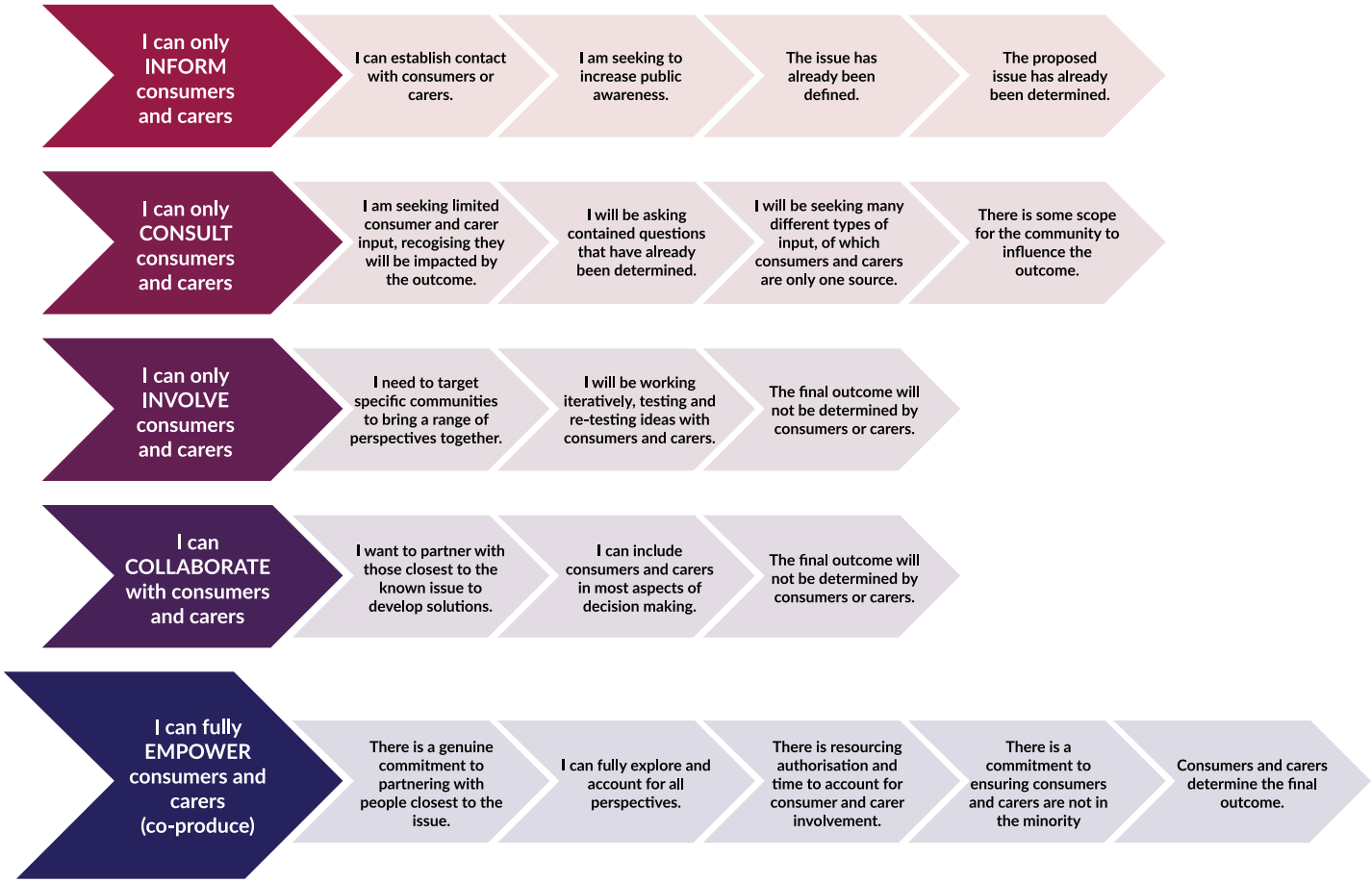
Figure 3: The engagement model from the Victorian Mental Health Lived Experience Engagement Framework[2].



Each organisation is responsible for ensuring that staff are adequately equipped to engage with lived experience stakeholders and to work in a culturally safe and trauma-informed manner. Similarly, organisations are also responsible for providing context-specific information and training to lived experience staff to ensure they have a clear understanding of their roles and responsibilities.

The Engagement decision tool shown in Figure 4 is designed to help determine where a project sits along the engagement continuum. The tool reflects the principle of empowering Territorians to take an active part in shaping their services.

Figure 4: Engagement decision tool from the Victorian Mental Health Lived Experience Engagement Framework[2].



13. Indicators of success

Table 4 provides a framework for evaluating lived experience engagement using key engagement principles. Each principle has suggested goals, with suggestions for how engagement might be done well (or not so well). The last column offers general evidence parameters that can be used to develop indicators of success.

Table 4: A framework for evaluating lived experience engagement using engagement principles (adapted from the Victorian Mental Health Lived Experience Engagement Framework[2])

ENGAGEMENT PRINCIPLE	GOAL	LOW ENGAGEMENT	MEDIUM ENGAGEMENT	HIGH ENGAGEMENT	EVIDENCE
We are purposeful	The problem has been identified	No or little lived experience engagement to identify the problem	Initial lived experience engagement analysis conducted	Project sponsor facilitates additional time/resources following lived experience engagement analysis	Consensus between the department and people with lived experience about the nature of the problem
	Relevent consumer and carer participants with required expertise have been identified	Relevant consumer and carer participants not identified	Consumer and carer participants with required expertise identified	A wide range of consumer and carer participants with required expertise identified	Percentage of specific practice suggestions made by consumer and carer participants that have been adopted in whole or part
	Strategic lived experience engagement activity aligned to strategic intent as outlined in business plans	Lived experience engagement activity not aligned to strategic intent	Lived experience engagement activity aligned to strategic intent	Lived experience engagement activity aligned to strategic plan that was developed in collaboration with key consumer and carer participants	Communications with consumer and carer participants are documented
We are prepared	Lived experience engagement plan has been endorsed and communicated to stakeholders at the outset of planning	No specific type of lived experience engagement endorsed	A level of engagement identified in project endorsement	Lived experience stakeholders are involved in establishing the type of engagement	Communications to all stakeholders clearly states project intent and type of engagement
	There are clear processes in place to support effective engagement	The role for engagement is undefined, and consumers and carers are unclear about the overall process	Aspects of engagement are defined	Consumers and carers are engaged, with a clear understanding of project processes, how they will be contributing, and to whom they can raise concerns	Governance structures are documented and include specific reference to consumer and carer engagement
	Engagement techniques identified to support lived experience interests and needs	No demonstrated understanding of lived experience interests or needs	Demonstrated understanding of lived experience interests or needs	Knowledge of lived experience interests or needs based on consumer and carer participant input	Issues identified, lived experience engagement strategies in place and communicated to all stakeholders prior to any escalation

ENGAGEMENT PRINCIPLE	GOAL	LOW ENGAGEMENT	MEDIUM ENGAGEMENT	HIGH ENGAGEMENT	EVIDENCE
We are genuine	Commitment to understanding current concerns, values and interests of consumer and carer participants	No understanding of current concerns, values and interests of consumer and carer participants	General understanding of concerns, values and interests of consumers and carers, but barriers have limited specific understanding of current concerns	Barriers to consumer and carer participation have been identified and efforts made to overcome them to ensure thorough understanding of current concerns, values and interests	Techniques are aligned to determine consumer and carer participants current concerns, values and interests
	Promote a culture of innovation and learning in policy advice and practice responses by incorporating the lived experience perspective	Lived experience input not in incorporated into policy advice	Policy and practice demonstrates more or less of the same approaches despite lived experience input	Consumer and carer participant input influences new approaches to policy and practice	Lived experience requirements are revisited and adjusted throughout the duration of the project
	Improved access to emerging lived experience issues	Lived experience engagement techniques do not elicit emerging lived experience issues	Lived experience engagement techniques reveal emerging lived experience issues	Lived experience engagement techniques inform strategic policy and practice change to address emerging issues	Proposed solutions reflect the contributions of consumers and carers
We are inclusive	Enhanced lived experience engagement and participation	No or little lived experience engagement analysis conducted	Initial lived experience engagement analysis conducted	Project sponsor facilitates additional time/resources following lived experience engagement analysis	Significant barriers identified and addressed before they impact on confidence; Demonstrate how the participants influenced the process for the project; Appropriate ongoing relationships with specified stakeholder groups
	Consumer and carer participants able to advise on the most suitable ways to engage	Assumptions on engagement techniques made without consumer or carer participant input	Reasonable efforts made to seek feedback on potential engagement processes with all stakeholder groups including lived experience	Lived experience input sought for engagement methods	Consumer and carer input can be clearly articulated and documented
	Communication is tailored appropriately for audiences	Standard language and collateral offered across all communications	A range of communication channels are offered based on good practice and previous experience	Consumer and carer participants have been actively engaged to identify appropriate communications	Reports from consumers and carers such as formal minutes and evaluation data reflect an endorsement of communication approaches

ENGAGEMENT PRINCIPLE	GOAL	LOW ENGAGEMENT	MEDIUM ENGAGEMENT	HIGH ENGAGEMENT	EVIDENCE
We are inclusive	Enhanced two-way communication skills between all participants	No, or only token, changes in capacity to influence based on consumer and carer participant identified needs or issues	Minor changes in capacity to influence based on consumer and carer participant identified needs or issues	Significant changes in capacity to influence based on consumer and carer participant identified needs or issues	Recorded outcomes reflect a high level of influence from consumers and carers
We communicate	Clearly demonstrate how consumer and carer participant input has influenced the process	Little or no feedback is offered or promised to consumer and carer particpants	All feedback is collated and made available to consumer and carer participants and staff determine next steps	Opportunities are provided to consumer and carer participants to explore the feedback in depth, discuss its implications and determine future steps	Statement of feedback provided to all participants

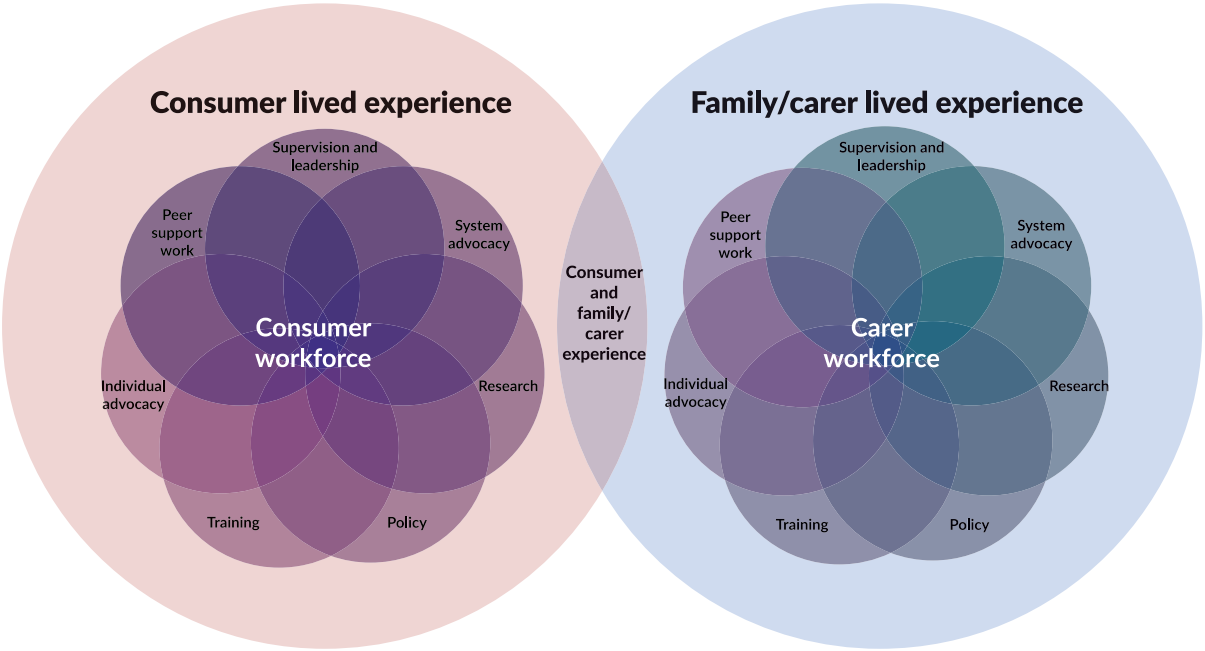
From 2024-25, progress against the Framework and lived experience engagement should be reported on annually by each organisation.

14. Identifying people with lived experience

There are many different ways to engage with consumers and carers with diverse expertise. Key to this is ensuring consumers and carers with lived experience bring knowledge and understanding most relevant to the issues being addressed. For example, if the project is questioning how to provide a service to people with an eating disorder, then participants selected will be able to bring this particular personal knowledge and experience to inform their contribution, rather than a more general experience of mental health issues.

Care should be taken to differentiate the perspectives of employees with lived experience of mental illness (consumer workforce) or as caregivers (carer workforce). Some services may utilise one person to cover both perspectives in their engagement process. It is important to separate the roles to ensure that there is a distinct focus between consumer and carer experiences. Figure 5 demonstrates that there is an area of overlap but each lived experience role has a discrete focus. The development of two national peak bodies is creating distinct lived experience voices for consumer representation and family, carer and kin representation, which reflects this.

Figure 5: Consumer and carer lived experience work from the Centre for Mental Health Learning - Introduction to Lived Experience Roles.[16]



There are many ways to recruit and engage people with a lived experience in service planning and reform activities including recruiting from:

- Aboriginal Community Controlled Health Organisations (ACCHOs)
- The mental health community sector and treatment system
- Peak bodies
- Individuals who are employed in mental health services
- Lived experience academics
- Lived experience networks
- People who have used other parts of the health system or other social services

15. Glossary

TERM	DEFINITION
Carer/s	Someone who is actively supporting, assisting or providing unpaid care to a consumer. A carer may or may not live with the consumer. A carer may be a family member or family of choice, friend or other person, including a child or young person, who has a significant role in the life of the consumer. Carers include people in the consumer's support networks who play a meaningful support role, providing ongoing personal care, support, advocacy and/or assistance for a person with mental illness. This role differs from the role of a paid carer, who is a person employed to care for someone. Not everyone who provides unpaid support to consumers identifies as a carer; rather, they prefer to be associated by the characteristic of their relationship (such as partner or sibling).
Co-design	Co-design is an inclusive approach to designing, planning, and evaluating services, programs and interventions in which consumers, carers and health professionals work collaboratively. The approach is guided by awareness of, and actions towards balancing power dynamics and an understanding that the outcomes must effectively respond to consumer and carer experience and priorities.
Community engagement	Community engagement refers to the processes and connections between government, communities and consumers in the development and implementation of policies, programs, services and projects. It encompasses a wide variety of government-community interactions ranging from information sharing to community consultation and in some instances, active participation in government decision making. It incorporates public participation, with people being empowered to contribute to decisions affecting their lives, through the acquisition of skills, knowledge and experience.
Consumer/s	A consumer is someone who has an experience of mental illness, and who has received, is receiving, or is seeking treatment and/or a diagnosis and support from mental health or social and emotional wellbeing services. Consumers include people who have a formal diagnosis and have engaged with services, as well as people who have not engaged with services or received a diagnosis. In other words this may include people who are service users, peers, a person with lived (or living) experience, or survivors.
Consumer/ carer advocate	A consumer or carer advocate is an individual or organisation who works to support, promote and defend the interests of lived experience consumers and/or carers. Advocates focus on addressing the unique challenges and concerns faced by consumers and carers, advocating for policies and services that enhance their well-being. They may support an individual or stand up for a just cause or a specific position.

TERM	DEFINITION
Cultural responsiveness	Culturally responsive care is about the 'centrality' of culture to people's identity and working with them to determine what culturally safe care is for them as individuals. It goes beyond notions of cultural awareness and cultural respect.[17]
Cultural safety	Cultural safety is determined by Aboriginal and Torres Strait Islander individuals, families and communities. Culturally safe practise is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism[18]. To ensure culturally safe and respectful practice, health practitioners must: • Acknowledge colonisation and systemic racism, social, cultural, behavioural and economic factors which impact individual and community health • Acknowledge and address individual racism, their own biases, assumptions, stereotypes and prejudices and provide care that is holistic, free of bias and racism • Recognise the importance of self-determined decision-making, partnership and collaboration in healthcare which is driven by the individual, family and community • Foster a safe working environment through leadership to support the rights and dignity of Aboriginal and Torres Strait Islander people and colleagues
Family	Family includes the consumer and those with a significant personal relationship with the consumer. This includes biological and non-biological relatives, intimate partners, those with kinship responsibilities, chosen family and others who play a significant role in the consumer's life.
Feedback loop	A feedback loop refers to an ongoing process of communication and interaction between an organisation and its stakeholders. It involves regularly seeking input, opinions, and responses from stakeholders, incorporating that feedback into decision making processes and then communicating how their input has been considered and applied. This continuous loop fosters collaboration, transparency, and the development of more inclusive and effective strategies or initiatives that align with the needs and expectations of the stakeholders involved.

TERM	DEFINITION
Kinship group	A kinship group refers to the social structure, relationships, roles, responsibilities and obligations of many Aboriginal people based on familial relationships, shared ancestry, and cultural connections within communities. Kinship relations and culture are not easily understood in terms of relationships in the Western definition of family. An important aspect of kinship care are responsibility concerns and how people can appropriately be involved in a person's care.
Lived experience	Lived experience relates to someone who has an experience of mental illness, and who has received, is receiving, or is seeking treatment and support from mental health or social and emotional wellbeing services. It encompasses the perspectives of living experience, consumers and carers.
Mental health system	Mental health is a state of wellbeing that enables you to deal with what life throws at you. It is about feeling resilient, enjoying life and being able to connect with others.[19] The NT mental health system is the sum of all resources that seek to improve mental health including self-help resources, primary health care, community providers and the tertiary services.
Stakeholder	A stakeholder is any individual, group, organisation or political entity with an interest or stake in the outcome of a decision. Stakeholders can be consumers, family members or carers, other community members, policymakers, service providers or other organisations involved with an interest, motivation or need to participate.
Social and emotional wellbeing	In broad terms, social and emotional wellbeing is the foundation for physical and mental health for Aboriginal Territorians. It is a holistic concept which results from a network of relationships between individuals, family, kin and community. It also recognises the importance of connection to land, culture, spirituality and ancestry, and how these affect the individual.[5]
Peer worker	A peer worker is an individual who has personal lived experience of mental health challenges and has undergone specialised training to provide support and assistance to others facing similar issues.
Person-centered care	A person-centred approach treats each person respectfully as an individual human being, and not just as a condition to be treated. It involves seeking out and understanding what is important to the patient, their families, carers and support people, fostering trust and establishing mutual respect. It also means working together to share decisions and plan care.[20]

TERM	DEFINITION
Recovery	Recovery refers to the process through which individuals with mental health challenges achieve a better quality of life, well-being and personal fulfilment. The recovery approach to mental illness is about helping individuals take control of their own lives. They decide what is important for them and what they would like their life to look like, not just in terms of mental illness symptoms, but holistically.
Regular expert	The term regular expert refers to an individual who consistently provides insight, advice or opinions on a particular subject. This person is considered an expert due to their continuous and reliable contributions in a specific area of knowledge or expertise. Relying too heavily on regular experts has risks including limited perspectives and them feeling burdened by responsibility leading to burnout or task fatigue.
Suicidality	Suicidality refers to a range of thoughts, behaviours, and actions related to suicide. It encompasses a person's contemplation of suicide, the desire to engage in self-destructive acts, or the act of attempting or completing suicide. Suicidality is a complex and serious mental health concern that may manifest along a continuum, ranging from fleeting thoughts of death to more persistent and severe suicidal ideation, planning and attempts.
Suicide	Suicide is death caused by self-directed injurious behaviour with any intent to die as a result of the behaviour. Many factors can contribute to someone considering, attempting or dying by suicide (including loss, addictions, childhood or other forms of trauma, depression, serious physical illness, mental illness and major life changes).[7]
Trauma informed	Trauma informed is the understanding that individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual to be physically or emotionally harmful or life threatening and that has lasting, adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being.[21] Trauma-informed care is a strengths-based service delivery approach that asks "what has happened to you?" rather than "what is wrong with you?"[22]

16. Appendix A: Lived experience representation in other jurisdictions

JURISDICTION	NAME	SCOPE	GOVERNANCE	FUNDING MIX
QLD Consumer Network	Mental Health Lived Experience Peak Queensland	Provides policy advice and systems advocacy for consumers of mental health services. Focus on building capacity and empowering mental health consumers to participate as consumer representatives in the mental health sector.	Board: 2 Co-chairpersons, 2 Ordinary Members. Lived Experience Advisory Group: Network of mental health consumers that leads the development of any work from start to end.	Queensland Government.
QLD Workforce Network	Queensland Lived Experience Workforce Network	Supports the lived experience workforce by providing sector leadership, opportunities for skills development and systems advocacy.	Board: Chairperson, Vice Chairperson, Treasurer, Secretary, 4 General Members.	Membership fees.
NSW Consumer Network	BEING - Mental Health Consumers	Policy: advocacy and consultation. Training: capacity building for consumers and workplaces. Consultation and representation: stakeholder engagement, awareness raising and promotion of consumer issues. Research; organisational and governance development.	Board, including Audit and Risk Committee.	NSW Government, donations, sponsorship packages, membership fees.

JURISDICTION	NAME	SCOPE	GOVERNANCE	FUNDING MIX
NSW Carer Network	Mental Health Carers NSW	Advocates for government and non-government organisations to engage people with lived experience. It runs free training and education sessions for carers.	Board: President, Vice President, Treasurer, Secretary, 6 ordinary members.	NSW Government, other grants, donations.
VIC Consumer Network	VMIAC	Advocates for individual consumers, develops resources for consumers, works on committees, projects and policy reviews with government and the mental health sector, education sessions for consumers, NDIS advocacy and support service.	Committee of Management: Chair, Deputy Chair, Treasurer, Secretary, 5 Ordinary Members.	Donations, other unspecified revenue.
VIC Carer Network	Tandem	Advocates for family and friend involvement in planning and care, provides information, education and training to carers, awareness raising, input into research and policy development, administers Carer Support Fund (financial assistance to carers).	Board: Chair, Treasurer, 7 Ordinary Members	VIC Government, Merri Health, donations, other unspecified income.

JURISDICTION	NAME	SCOPE	GOVERNANCE	FUNDING MIX
ACT Consumer Network	ACT Mental Health Consumer Network	Supports consumers to become Consumer Representatives to: participate on government and non-government committees; participate in research programs; lobby government and mental health service providers; facilitate education programs for consumers and the broader community.	Board: Chair, Deputy Chair, Treasurer, Secretary, 7 Ordinary Members.	ACT Government, membership fees for associate organisations.
WA Consumer Network	Consumers of Mental Health WA	Represents consumers by engaging in consumer consultation and participation in Systemic Advocacy and Reform, Education and Awareness Raising, Research, Growing Peer Leadership and Support, Individual Advocacy.	Board: Chair, Vice-Chair, Treasurer, Secretary, 5 Ordinary Members.	WA Government, other grants, education and training programs, membership fees for consumer groups, associate individuals and associate organisations.
TAS Consumer Network	Mental Health Lived Experience Tasmania Inc.	Works to formalise the participation of mental health consumers in the Tasmanian Government's mental health system, especially in decision-making fora such as working groups and committees.	Board: Chair, Deputy Chair, Treasurer, 5 Ordinary Board Members.	Tasmanian Government, donations.

JURISDICTION	NAME	SCOPE	GOVERNANCE	FUNDING MIX
TAS Carer Network	Mental Health Families and Friends Tasmania	Advocacy including panels and submissions. Engagement including expos, presentations, social media and e-news. Representation including representative training program. Group support including peer support sessions and a proposed mentoring program. Education and information including workshops and toolkits; Referral help.	Board: President, Secretary, 6 Ordinary Members	Tasmanian Government, Commonwealth Government, other grants.
SA Consumer Network	Lived Experience Leadership and Advocacy Network	Develops workshops and training for people with lived experience as well as those that work with and support them, linking people with lived experience to advocacy and representative opportunities, connects and supports lived experience advocates and representatives at regular conversation sessions, consults with and advises organisations on partnering with people with lived experience, contributes to policy development, provides organisational representation and collective lived experience perspectives on high-level committees.	Board: Chair, Deputy Chair, Treasurer, Secretary, 6 Board Members.	Membership fees, other unspecified revenue.

17. Appendix B: Guidance and Resource Documents

Improving lived experience engagement, co-design and participation

- 'Sit beside me, not above me'. National Mental Health Commission. 2017. https://www.mentalhealthcommission.gov.au/publications/sit-beside-me-not-above-me
- Western Australian Lived Experience (Peer) Workforces Framework. WA Mental Health Commission. Government of Western Australia. https://www.mhc.wa.gov.au/about-us/major-projects/lived-experience-peer-workforce-project/
- Partnering with Consumers Standard. Australian Commission on Safety and Quality in Health Care. https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard
- Consumer and Carer Engagement: A Practical Guide. National Mental Health Coalition. Australian Government. https://www.mentalhealthcommission.gov.au/lived-experience/consumer-and-carers/consumer-and-carer-engagement-%281%29
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- Lived Experience Framework for NSW, Mental Health Commission of NSW. 2018. https://www.nswmentalhealthcommission.com.au/report/lived-experience-framework-nsw
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- Lived Experience (Peer) Workforce Guidelines (2021) and Companion Documents (2023). National Mental Health Commission. Australian Government. https://www.mentalhealthcommission.gov.au/lived-experience
- A CMHDARN Best Practice Guide to Enabling Consumer and Carer Leadership in Research and Evaluation. Community Mental Health Drug and Alcohol Research Network. 2015. https://cmhdaresearchnetwork.com.au/resource/ask-the-experts/

- User Guide for Health Services Providing Care for People with Mental Health Issues. National Safety and Quality Health Service Standards. Australian Commission on Safety and Quality in Health Care. 2018. https://www.safetyandquality.gov.au/sites/default/files/2019-05/nsqhs-standards-user-guide-for-health-services-providing-care-for-people-with-mental-health-issues_0.pdf
- A Practical Guide for Working with Carers of People with a Mental Illness. Lived Experience Australia, 2016. https://www.livedexperienceaustralia.com.au/_files/ugd/907260_566ddf1b630c4592b55e2b74e86a7a31.pdf
- LifeSpan Lived Experience Framework. Black Dog Institute. 2017. https://www.blackdoginstitute.org.au/wp-content/uploads/2020/04/bdi_lived-experience-summit-2018_final.pdf?sfvrsn=2
- Co-production: Putting Principles into Practice. Cath Roper, Flick Grey & Emma Cadogan. University of Melbourne. 2018. https://healthsciences.unimelb.edu.au/__data/assets/pdf_file/0007/3392215/Coproduction_putting-principles-into-practice.pdf
- Co-Design Toolkit. West Australian Council of Social Services (WACOSS). 2017. https://www.wacoss.org.au/library/co-design-toolkit/
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- Principles of Co-design. NSW Council of Social Service (NCOSS). 2017. https://www.ncoss.org.au/wp-content/uploads/2017/06/Codesign-principles.pdf
- Lived Experience Framework, Principles and practices for Lived Experience partnerships. West Australian Council of Social Services (WACOSS). 2020. https://www.wacoss.org.au/partnerships/lived-experience-framework/
- A Guide to Build Co-Design Capability. Agency for Clinical Innovation. NSW Government. 2019. https://aci.health.nsw.gov.au/__data/assets/pdf_file/0013/502240/Guide-Build-Codesign-Capability.pdf
- Experience Based Co-Design Toolkit. Australian Healthcare and Hospitals Association. 2021. https://ahha.asn.au/experience-based-co-design-toolkit
- NRID Codesignkit. A Co-Design Toolkit for those with complex needs. Metro-regional Intellectual Disability Network NSW. 2014. http://codesignkit.org.au/

Cultural Responsiveness and best practice in Aboriginal social emotional wellbeing, mental health and suicide prevention

- Gayaa Dhuwi (Proud Spirit) Declaration. National Aboriginal and Torres Strait Islander Leadership in Mental Health, 2015. https://www.gayaadhuwi.org.au/resource/the-gayaa-dhuwi-proud-spirit-declaration/
- National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social Emotional Wellbeing 2017-2023. Australian Government. https://www.niaa.gov.au/sites/default/files/publications/mhsewb-framework_0.pdf
- Culturally Responsive Aboriginal Healthcare Framework Guide 2018-2020. Hunter New England and Central Coast Primary Health Network, NSW. 2018. https://hneccphn.imgix.net/assets/src/uploads/resources/Aboriginal-Health/frwk-culturally-responsive-aboriginal-healthcare.pdf
- User Guide for Aboriginal and Torres Strait Islander Health. National Safety and Quality Health Service Standards. Australian Commission on Safety and Quality in Health Care. 2017. https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-User-Guide-for-Aboriginal-and-Torres-Strait-Islander-Health.pdf
- Partnering with Aboriginal Community Controlled Organisations to deliver trusted services with stronger outcomes for Aboriginal people. West Australian Council of Social Service and Noongar Family Safety and Wellbeing Council. 2019. https://create.org.au/wp-content/uploads/2019/06/WACOSS-Submission-Partnering-with-Aboriginal-Community-Controlled-Organisations-to-deliver-trusted-services-with-stronger-outcomes.pdf

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THE NT MENTAL HEALTH LIVED EXPERIENCE ENGAGEMENT FRAMEWORK

NORTHERN TERRITORY GOVERNMENT