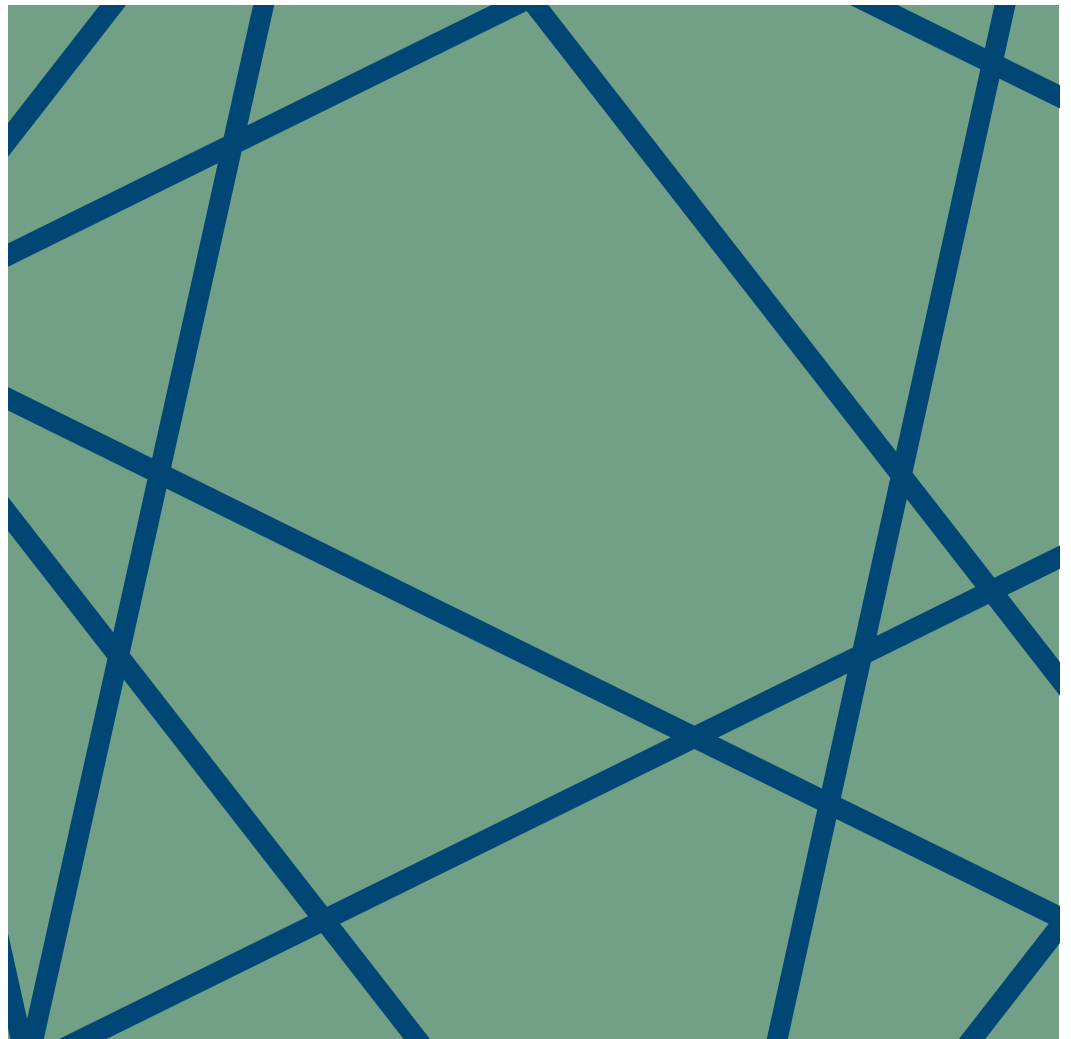


# Seven steps to develop an organisational lived expertise engagement framework



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**Facilitated by Mental Health Lived Experience Tasmania Inc. (MHLET) for Primary Health Tasmania.**

MHLET acknowledges the role of Mental Health Family and Friends Tasmania and Health Consumers Tasmania in supporting lived expertise to co-produce this document.

This document was co-produced by people with lived expertise from diverse backgrounds, together with primary care service organisations in Tasmania.

**Seven steps to develop an organisational lived expertise engagement framework  
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Terms in this document that carry specific meaning in the context of engaging lived/living experience are printed in **bold purple** the first time they are used in general text and defined further in the glossary section (from page 21).

Throughout this document the term **lived expertise** is used to describe people who provide expert advice to your organisation. Lived experts are also known interchangeably as lived experience representatives; consumer representatives; or lived experience consultants.


The term people with **lived/living experience** is used to describe a broader group of people with unique insights gained through personal experience.

Importantly, this document is designed primarily for engagement with your organisation's **consumers**; their family, friends and kin; and their communities. If your organisation is seeking to engage a lived experience workforce (or **peer workers**), this document may provide useful background, however your engagement will also be determined by employment laws, regulations, policies and practices that are beyond the scope of this document.

## Background

This document provides seven high-level steps for an organisation to develop a framework for engaging **consumers** with **lived expertise**.

The co-production of this document was facilitated by Mental Health Lived Experience Tasmania (MHLET) on behalf of Primary Health Tasmania. MHLET is an organisation managed and governed by people with **lived/living experience** from diverse backgrounds. MHLET proactively worked with lived expertise from within and outside its membership – together with service providers and government agencies – to facilitate the co-production.



The seven steps in this document provide a guide for organisations interested in co-producing a lived expertise framework, to enable best-practice, ongoing engagement with people with lived/living experience. If your organisation is interested in learning more about engaging lived expertise – but is not ready to develop a lived expertise framework – it will still find the content in this document useful for increasing understanding, building capacity, and improving practice.

This document was designed for organisations such as Primary Health Tasmania; peak bodies/funding organisations; and health and social care organisations across the Tasmanian primary care sector. It is designed to be consistent with lived/living experience approaches implemented by the Tasmanian Department of Health. It could also be applied by organisations in the broader community sector (such as housing, social support, health education and employment services).

The document has three main purposes:

1. To increase understanding of structured engagement with lived expertise.
2. To be a tool for organisations to establish a lived/living experience engagement framework and/or assess their current lived/living experience engagement practices.
3. To provide a consistent set of **principles** and **enactors** to inform engagement with lived expertise in Tasmania.

This document is purposefully designed to be a practical and implementable framework for use by any Tasmanian community service or primary care organisation.



The seven steps in this document are presented as checklists for your organisation to self-reflect on its capacity to implement a lived expertise framework. The checklists are not pass/fail assessments, and it is expected all organisations will find at least some of the items in each step challenging to implement. The checklists are designed to ensure your organisation's co-design with lived expertise is built on foundations of honesty, transparency, and trust. The most important success factor is your organisation's commitment to implement the steps, in genuine collaboration with lived expertise, and respectfully work together to deliver a lived expertise framework matched to your organisation's capacity.

For some organisations, a lived expertise framework using these seven steps may only be a starting point that leads to more detailed, complex and/or targeted approaches. In particular, your organisation is strongly encouraged to access the relevant additional resources provided in the literature review at the end of this document – and seek a strong, ongoing partnership with a well-established lived expertise organisation – if your organisation is implementing:

- consumer engagement requiring compliance with specific laws and government-mandated standards
- clinical practice guidelines
- **peer workforces**
- structured engagement with First Nations communities
- a transition to becoming wholly lived/living experience managed and governed.

This guide may be updated from time to time, including to provide extended tools and resources. This is **version 1.0**.

## Why develop a lived expertise framework?

An organisation would develop a lived expertise framework to establish and maintain effective, mutually respectful and long-lasting connections with one or more lived/living experience groups.

Usually this group – or groups – will be consumers of an organisation’s services (and/ or **carers**, family, friends, and kin of these consumers).

In some contexts, this group of consumers will be an organisation’s reason for being. For example, a counselling service for victim/survivors of family violence may exist solely to work with people with lived/living experience of such violence.

In other contexts, an organisation may need to engage with a specific cohort of consumers with distinct, additional experiences. For example, a health service organisation may need to apply the lived expertise of young people with ill-health, or the lived expertise of people with ill-health from migrant backgrounds.

For an increasing number of organisations, engaging lived expertise is a requirement of a funding contract, or a result of a commitment made in a grant application. For some organisations, the requirement to engage with lived expertise is a regulatory requirement. For example, for organisations that need to comply with the *National Safety and Quality Mental Health Standards for Community Managed Organisations*.

Some organisations seek to engage with lived expertise because it is fundamental to their values and their commitment to human rights. For example, many service organisations have committed to implementing the **disability** rights principle of nothing about us, without us.

Other organisations simply want to engage with lived expertise because it makes common sense. Often, these organisations have concluded: “who better to provide our organisation with expertise on how to work effectively with a priority group of clients, than experts from that same group?”

This document is designed to be a high-level guide for any organisation seeking to engage and apply lived expertise over the long term. It is not designed for one-off engagements, but instead to develop a flexible organisational framework that can be applied to different types of engagement over time. It can be used by organisations of any size, including those operating only in Tasmania, and those working more broadly.

The only prerequisite to applying the seven steps in this document is that an organisation genuinely and respectfully wants to achieve continuous positive change for and with people with lived/living experience.

The authors recognise that an organisation may already have existing lived/living experience frameworks that have been built with lived expertise and are working well. In these circumstances, the seven steps in this document may be useful to extend, or encourage reflection on, the organisation’s current framework.

As this guide is about developing a framework that can be applied by your organisation in many different contexts over the long term, please note:

it requires working with a group of lived experts to establish the framework, but can then be applied to engage individual lived experts for specific projects into the future

it requires co-production to establish the framework, but can then be applied to implement less intensive forms of lived expertise engagement, (such as consultation) into the future.



## Seven steps for developing a lived expertise framework

This document provides a basic guide and information on each of the following seven steps, and simple checklists to self-assess your organisation's capacity to develop a lived expertise framework.

1	<b>PRINCIPLES</b>	Consider your organisation's capacity, willingness and commitment to apply key principles for establishing and/or maintaining a lived expertise framework.
2	<b>ENACTORS</b>	Consider your organisation's capacity to apply enactors that implement and continuously improve a lived expertise framework.
3	<b>TYPES</b>	Consider the types of engagement with lived expertise your organisation is seeking to implement.
4	<b>POWER</b>	Consider the power relations your organisation might accept in each type of engagement.
5	<b>PREPARE</b>	Prepare for cultural change and values realignment across your organisation, and an investment of time and resources.
6	<b>CO-INITIATE</b>	Work with one or more lived expertise group(s) to ideate, discuss, and scope your lived expertise framework, including proposed remuneration.
7	<b>CO-PRODUCE</b>	Co-plan, co-design, co-deliver and co-evaluate your organisation's lived experience framework.

It is recommended that the people within your organisation who are responsible for developing a lived expertise framework work through each of the seven checklists presented below, in order.

Remember, the seven checklists are not a pass/fail test. They are designed to encourage your organisation to ask targeted questions about its knowledge of lived expertise; its capacity to engage lived expertise effectively; and what it wants to achieve by engaging lived expertise. With this information, your organisation will be in a position to start building lived/living experience engagement from transparent foundations, based on professional relationships of trust.

It is OK if your organisation is unsure about how to respond to a specific question or needs more information to make a considered assessment. These can be matters for discussion with lived experts in Steps 6 and 7.

## Step 1 PRINCIPLES

Consider your organisation's capacity, willingness and commitment to apply key principles for establishing and/or maintaining a lived expertise framework.

	Can your organisation...	Check
<b>SELF-DETERMINATION AND CHOICE</b> Related principles: Empowerment; Autonomy; Equality	recognise the rights of people with lived expertise to self-organise, and to support them to guide or inform the ways they would like to engage?	<input type="checkbox"/>
	have discussions about <b>power relations</b> and seek <b>substantive equality</b> between your organisation and the lived expertise group?	<input type="checkbox"/>
<b>INCLUSION</b> Related principles: Diversity; Intersectionality	acknowledge that lived experience is complex, varied and <b>intersectional</b> ?	<input type="checkbox"/>
	embrace, support and accept <b>diversity</b> within a lived experience group, including purposeful <b>inclusion</b> ?	<input type="checkbox"/>
<b>KINDNESS</b> Related principles: Empathy; Compassion	seek connections to a common humanity without judgement?	<input type="checkbox"/>
	listen, believe and validate with empathy?	<input type="checkbox"/>
	consider, acknowledge and accept the harm done to people with lived experience when engaging with services?	<input type="checkbox"/>
<b>PURPOSE AND ACCOUNTABILITY</b> Related principles: Transparency; Openness	genuinely share the primary purpose and intended outcomes of the engagement?	<input type="checkbox"/>
	commit to measuring and evaluating the outcomes, and sharing this information with the lived/living experience group?	<input type="checkbox"/>
	provide transparency on key elements of each engagement – including time, resources, information, requirements and constraints?	<input type="checkbox"/>
<b>EQUAL RELATIONSHIPS</b> Related principles: Reciprocity; Shared expectations; Partnership	commit to working with lived expertise in a multi-directional, mutually beneficial, and consensual manner?	<input type="checkbox"/>
	seek to make decisions in projects by agreement via constructive dialogue?	<input type="checkbox"/>
<b>DIGNITY</b> Related principles: Respect; Recognition	respect and incorporate lived expertise alongside other forms of evidence and data in policy and practice?	<input type="checkbox"/>
	acknowledge individuals with lived/living experience and respect their self-defined identities, and not be categorised by others?	<input type="checkbox"/>
<b>TRUST AND SAFETY</b> Related principles: Cultural safety	support people with lived/living experience to engage in environments of physical, emotional and <b>cultural safety</b> , without <b>stigmatising</b> their needs?	<input type="checkbox"/>
	accept that trust can take time to build, and as required, may need to facilitate multiple engagements?	<input type="checkbox"/>
<b>SUSTAINABILITY AND RESOURCING</b> Related principles: Central to design; Resilient	provide sufficient financing across all aspects of the agreed engagement?	<input type="checkbox"/>
	commit to consistent, stable, long-term arrangements rather than ad hoc approaches?	<input type="checkbox"/>
<b>FLEXIBILITY</b> Related principles: Agile; Responsive; Adaptive; Innovative	change established ways of thinking and doing when presented with challenging ideas or new information by people with lived experience?	<input type="checkbox"/>
	be <b>adaptive</b> enough to take a step back from current practice, in order to be responsive?	<input type="checkbox"/>
<b>CONTEXTUALITY</b> Related principles: Appropriate; Authentic	acknowledge engagement with and within each lived experience group will be different and ensure that inclusivity is prioritised?	<input type="checkbox"/>
	adapt approaches to different contexts including (but not limited to) locality, <b>culture</b> , language, age, health condition, socioeconomic status?	<input type="checkbox"/>

Carry through the results of this checklist to Step 5

## Step 2 ENACTORS

Consider your organisation's capacity to apply enactors that implement and continuously improve a lived expertise framework.

	Can your organisation...	Check
<b>ORGANISATIONAL CULTURE AND INTEGRATION</b>	examine <b>unconscious biases</b> , beliefs, judgements and practices, and how these influence your organisation's engagement with lived experience?	<input type="checkbox"/>
	seek a cultural shift that embeds effective engagement across the organisation?	<input type="checkbox"/>
<b>REMUNERATION</b>	standardise payment for lived expertise, based on the equivalent market rate, statutory allowance or award rate paid to other experts?	<input type="checkbox"/>
	negotiate the fair and appropriate type and quantum of payment to the agreed scope of the lived experience engagement?	<input type="checkbox"/>
<b>CAPACITY EXCHANGE; EDUCATION AND TRAINING; DEVELOPMENT</b>	ensure people in your organisation have skills to engage effectively and safely with lived experience?	<input type="checkbox"/>
	enable people with lived experience to build knowledge associated with the specific engagement?	<input type="checkbox"/>
<b>CARE AND SUPPORT</b>	include preparation, induction, and inclusive options for support in all lived experience engagements?	<input type="checkbox"/>
	ensure the risks and impacts of re-traumatisation are acknowledged, planned for, and minimised?	<input type="checkbox"/>
<b>EVALUATION, REFLECTION AND LEARNING</b>	involve lived expertise in co-evaluation, determining the way their contributions are used?	<input type="checkbox"/>
	share evaluation findings with people with lived/living experience, including information on how these findings will be applied?	<input type="checkbox"/>
<b>EQUITABLE ACCESS TO INFORMATION AND PROCESSES</b>	during a co-produced project, provide the same information to people with lived experience as is made available to your staff, unless legally prevented?	<input type="checkbox"/>
	ensure communication methods are inclusive of different needs?	<input type="checkbox"/>
<b>INTELLECTUAL PROPERTY AND CONFIDENTIALITY</b>	acknowledge that the intellectual property of people with lived experience includes personal stories, and the use of this property needs to be agreed?	<input type="checkbox"/>
	commit to the ongoing protection and/or permanent deletion of private and confidential information provided in an engagement?	<input type="checkbox"/>
<b>ADDRESS STIGMA</b>	acknowledge that stigmatisation of lived experience is likely to occur, and commit to dismantling stigma in its various forms?	<input type="checkbox"/>
	make an ongoing commitment to safety, learning, self-reflection, and improvement to minimise stigma?	<input type="checkbox"/>
<b>STRIVE FOR TRANSFORMATION</b>	approach lived experience engagement as an opportunity for progressive re-balancing of power and sustained change?	<input type="checkbox"/>
	keep an open mind about how resources are allocated, processes are originated, and structures formed across your organisation and/or sector?	<input type="checkbox"/>
<b>ASSESS; MATCH; PLAN</b>	assess organisational readiness to engage, and be clear with expectations about the role of people with lived expertise prior to engagement?	<input type="checkbox"/>
	commit not to set people up to fail, including by agreeing processes that match lived expertise to specific skills, experience and interest?	<input type="checkbox"/>

Carry through the results of this checklist to Step 5



## Step 3 TYPES

Consider the types of engagement with lived expertise your organisation is seeking to implement now, or in the immediate future.

PLEASE NOTE: Your lived expertise framework *can include some or all of these engagement types*. Further, your framework can be updated to include more or different types from time to time.

Organisations just beginning to formally engage people with lived/living experience may start with Types 1-2, before moving to Type 3. An organisation will be in a better position to engage in Types 4-5 if it has effectively implemented Types 1-3 within its own operations.

	Is your organisation seeking to...	Check
<b>INDIVIDUAL AND/OR FAMILY ENGAGEMENT</b>	share decision making in direct service delivery with consumers (and if appropriate their carer, family, friend or kin)?	<input type="checkbox"/>
	enable a consumer, or their advocate, to instigate a change or improvement to the way your organisation interacts with that person's lived experience?	<input type="checkbox"/>
<b>SERVICE OR PROGRAM ENGAGEMENT</b>	engage lived expertise in initiating, planning, designing, delivering and evaluating specific services, programs and initiatives?	<input type="checkbox"/>
	engage lived expertise in specific parts of service or program delivery (such as sitting on selection panels for key program roles)?	<input type="checkbox"/>
<b>ORGANISATIONAL CHANGE</b>	engage lived expertise to improve your organisation's governance, systems and structures?	<input type="checkbox"/>
<b>SYSTEMIC CHANGE</b>	engage lived expertise to improve the way a sector or jurisdictional system operates, including standards, policy, and applicable laws?	<input type="checkbox"/>
<b>TRANSFORMATIONAL CHANGE</b>	work with lived expertise to change dominant culture, build grassroots community-led movements and dismantle discrimination?	<input type="checkbox"/>

Carry through the results of this checklist to Step 5

<b>Step 4 POWER</b>		
Consider the power relations your organisation might offer in different types of engagement.		
	Is your organisation seeking to...	Check
<b>INFORM</b> people with lived/living experience	provide information to people with lived/living experience?	<input type="checkbox"/>
	increase awareness of services amongst people with lived/living experience using standard approaches?	<input type="checkbox"/>
	define the issue without necessarily engaging lived expertise?	<input type="checkbox"/>
	deliver an output or outcome your organisation has already determined?	<input type="checkbox"/>
<b>CONSULT</b> people with lived/living experience	ask people with lived/living experience for limited input on our approaches, recognising they will be impacted?	<input type="checkbox"/>
	ask questions that our organisation has determined?	<input type="checkbox"/>
	receive various inputs, of which lived expertise is only one?	<input type="checkbox"/>
	implement the output in a way that may, or may not, be influenced by the input provided by people with lived/living expertise?	<input type="checkbox"/>
<b>INVOLVE</b> people with lived/living experience	specifically invite people with lived/living experience to provide lived expertise and perspectives?	<input type="checkbox"/>
	work iteratively, testing and re-testing ideas with lived expertise?	<input type="checkbox"/>
	be transparent about how it used lived expertise?	<input type="checkbox"/>
	in the end, determine the output or outcome itself, whether or not lived expertise has significantly shaped the final result?	<input type="checkbox"/>
<b>CO-PRODUCE</b> with people with lived/living experience	partner with lived expertise to co-initiate solutions?	<input type="checkbox"/>
	share decision-making with people with lived/living experience, in all or clearly defined parts of the engagement?	<input type="checkbox"/>
	co-plan, co-design, co-produce and co-evaluate with lived expertise?	<input type="checkbox"/>
	genuinely and exhaustively seek to reach agreement with people with lived/living experience on the final output or outcome?	<input type="checkbox"/>
<b>TRANSFER POWER</b> to people with lived/living experience (also known as 'consumer-led')	allow issues and solutions to be defined by people with lived/living experience, with or without substantive input from your organisation?	<input type="checkbox"/>
	provide resources, authority, remuneration and time for people with lived expertise to do their agreed work?	<input type="checkbox"/>
	provide access to skills in addition to lived expertise, and access to the information required to do the agreed work?	<input type="checkbox"/>
	implement outputs or outcomes determined by people with lived experience?	<input type="checkbox"/>
<b>Carry through the results of this checklist to Step 5</b>		

*Note: while an organisation cannot establish a lived experience framework using levels 1, 2 and 3, these levels of power sharing may be appropriate when transparently delivered within the context of an existing framework.*

## Step 5 PREPARE

Prepare for cultural change and values realignment across your organisation, an investment of time and resources, and new partnerships.

Note: Your organisation *can still proceed* with developing a lived expertise framework, *no matter which items are checked in the list below*. By completing this process accurately, your organisation's structured engagement with lived expertise will start from a foundation of honesty and transparency, and have increased chance of success. A group of people with lived expertise can then decide to safely work with your organisation to address any of the identified gaps.

**Can your organisation...** Check

<b>PRINCIPLES</b>	agree to all the questions about principles in Step 1?	<input type="checkbox"/>
	agree to more than half of the questions about principles in Step 1?	<input type="checkbox"/>
	agree to less than half of the principles in Step 1?	<input type="checkbox"/>
<b>ENACTORS</b>	agree to implement all the enactors in Step 2?	<input type="checkbox"/>
	agree to implement more than half of the enactors in Step 2?	<input type="checkbox"/>
	agree to implement less than half of the enactors in Step 2?	<input type="checkbox"/>
<b>TYPES</b>	define the different types of engagement with lived/living experience set out in Step 3?	<input type="checkbox"/>
<b>POWER</b>	identify examples of having worked at least to level 3 (Involve) with external stakeholders or consumers in the past?	<input type="checkbox"/>
	commit to working at level 4 (Co-Production) for the purposes of developing a lived experience framework for your organisation?	<input type="checkbox"/>
<b>RESEARCH</b>	reflect on and articulate your organisation's previous engagement with lived expertise, current capacity to engage, and future needs for lived expertise?	<input type="checkbox"/>
	identify documentation in the literature review that may be relevant to your organisation?	<input type="checkbox"/>
<b>CHANGE</b>	develop a theory of change about developing and implementing a lived expertise framework?	<input type="checkbox"/>

Carry through the results of this checklist to Step 6

## Step 6 CO-INITIATE

Work with one or more lived expertise group(s) to ideate, negotiate, and scope your lived expertise framework, including proposed remuneration.

Is your organisation prepared to...

Check

**Work with a lived expertise group?**

The definition of lived expertise to be applied in the context of developing an organisational framework is: *groups of people who share experiences and can apply the expertise gained from their experience to achieve recognition, respect and positive change for their group(s).*

While individuals not associated with a group may have lived expertise relevant to your organisation, this document recommends organisations only develop, apply and evaluate a **lived expertise framework** with the support of **lived/living experience groups**. This is because key principles for ongoing engagement of lived expertise (such as inclusion, safety and sustainability) can only be implemented by engaging with a lived/living experience collective.

This document also acknowledges that lived expertise may extend beyond the direct consumer/service provider relationship – and particularly to the lived expertise of carers, family, friends, kin and significant others.

**Make the effort to connect with a lived/living experience group, recognising these groups may organise in many forms, or require support to organise?**

In the definition above, **groups** include:

- formal entities managed and controlled by people with lived/living experience
- where relevant formal entities do not exist or cannot participate, informal groups managed and controlled by people with lived/living experience
- people with lived expertise who require time, support and resources to formally or informally organise into a self-determining group
- different groups representing different lived experience working together.

A larger, well-established lived/living experience organisation may also organise a sub-group of lived expertise tailored to your organisational need. For example, if your organisation was seeking to specifically focus on young illicit drug users, a lived experience alcohol and other drugs consumer group could ensure the lived experts assigned to your project were young people. It is important to note that while a group of people may have shared experience, they will also have diverse perspectives, varied backgrounds, specific expertise and intersecting experiences.

**Acknowledge that 'context is critical', and that different groups may seek different approaches?**

This document has been authored by a group that has diverse lived expertise, primarily in the field of mental ill-health. The authors sought to learn from other communities or groups with lived experience and embrace the intersectionality of lived experience. While the authors believe the principles, enactors, and types of engagement set out above have common application, the authors acknowledge their perspectives may not be the same as those of other lived experience groups. For this reason, it is important for different organisations and services that engage with lived expertise to refine their framework in collaboration with relevant lived experience groups. For example, there will be different approaches adopted in the palliative care context when compared to the mental health context, or the family violence context (and so on).

**Identify the type(s) of lived expertise you need to engage?**

The types of lived expertise your organisation may wish to engage depending on context include (but are not limited to) the following communities represented by formal and informal groups in Tasmania and Australia:

- First Nations people, including Tasmanian Aboriginal people
- people living with disability
- migrants, refugees and asylum seekers
- people from culturally and linguistically diverse backgrounds
- victim/survivors of family and sexual violence
- people experiencing homelessness
- people experiencing poverty and unemployment
- LGBTQIA+ people
- people with experience of suicide
- victim/survivors of slavery
- injecting and illicit drug users
- sex workers
- people from age groups experiencing discrimination (youth; aged)
- former and currently serving defence force personnel
- former and currently serving emergency service first responders
- health consumers (including groups representing people with lived/living experience of specific health conditions and circumstances)
- mental health consumers
- carers, families, friends and kin of consumers, and their communities.



**Acknowledge the unique requirements of engagement with Aboriginal and Torres Strait Islander People?**

The authors specifically acknowledge that Aboriginal and Torres Strait Islander understandings of lived expertise are unique. The Black Dog Institute's Indigenous Lived Experience Centre (2023) website states: *A lived experience recognises the effects of ongoing negative historical impacts and or specific events on the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples. It encompasses the cultural, spiritual, physical, emotional and mental wellbeing of the individual, family or community... and takes into consideration Aboriginal and Torres Strait Islander people's ways of understanding social and emotional wellbeing.*



**Negotiate the terms for developing a framework?**

*Once you have connected with a group that can provide relevant lived expertise, it is recommended that your organisation reach written agreement with this group on how your organisation's lived experience framework will be developed. This will involve your organisation committing to reach agreement on:*

- who will be involved in the project
- how decisions will be made
- how disagreements or disputes will be resolved
- the premise, scope and limitations of the lived expertise framework
- the theory of change associated with the lived expertise framework
- how the lived expertise framework will be evaluated and improved
- the timeline for developing the framework
- the time commitments expected for each role in the project
- the methods of communication between people in the project
- how people with lived expertise have information to participate as equals
- ensuring safe spaces, and dealing with the risk of re-traumatisation
- respecting intellectual property, confidentiality and privacy
- acknowledging the contribution of lived expertise to your framework
- remuneration for lived expertise
- the participation of lived experts with caring responsibilities
- the participation of lived experts with limited access to technology
- the participation of lived experts with limited access to transport
- the participation of lived experts with disability and/or ill-health

**Carry through the results of this checklist to Step 7**

## Step 7 CO-PRODUCE

Co-plan, co-design, co-deliver and co-evaluate your organisation's lived expertise framework.

Is your organisation prepared to...

Check

### Re-examine conceptions of co-design?

The term co-design has become widely used, particularly in the context of governments and service providers working with consumers, communities, and people with lived/living experience. Unfortunately, co-design has been increasingly co-opted to describe all manner of engagement – including processes with little or no redresses of power imbalances (like customer surveys; feedback forms; and complaints processes).

The authors of this document suggest the term co-design should not be used to describe processes that are only at the inform, consult or involve levels of the power balance spectrum (see Step 4). Moreover, the authors believe that co-design is only one element in achieving the objective of **co-production**.

### Understand the key elements of co-production?

To develop an authentic lived expertise framework, it needs to be co-produced. **Co-production** involves co-initiating; co-planning; co-design; co-delivery; and co-evaluation.

Researchers Cath Roper, Flick Grey and Emma Cadogan – in their important, practical and easy-to-read guide on co-production (*see full citation in literature review below*) – identify three core principles underpinning co-production partnerships with lived/living experience consumers:

1. consumers are partners from the outset
2. power differentials are acknowledged, explored, and addressed
3. consumer leadership and capacity is developed.

Importantly, these researchers stress that what separates co-production from other forms of engagement is that it deliberately sets out to create a culture that values all expertise and knowledge, particularly the expertise and knowledge of the people that are most affected by the problem and solution. Consistent with this framework they identify that co-production recognises and seeks to address power differentials within partnerships and promotes and develops lived/living experience leadership which shifts away from an historical positioning of professionals as the experts that steer the agenda.

Remunerating lived expertise at the same rates as other experts is a key feature of co-production.

**Develop a structure for your co-produced lived expertise framework informed by the lived expertise group your organisation engages, and contemporary literature and practice?**

This document cannot prescribe the structure of your organisation's lived expertise framework. The structure will be different for every organisation, and uniquely shaped by the people with lived expertise that your organisation engages.

Nonetheless, as a starting point, **the template following provides a basic 10-section example of an organisational lived expertise engagement framework** that includes (but does not need to be limited to):

1. the lived expertise engaged via your framework
2. the environment in which your organisation engages with lived expertise (including any requirements that are externally mandated)
3. commitment to agreed **Principles** (see Step 1 above), including any actions required to re-align your organisation to one or more principles
4. commitment to agreed **Enactors** (see Step 2 above), including any actions required to activate one or more of the enactors
5. identification of **Types** (see Step 3 above) of engagement for different aspects of your organisation and its operations
6. identification of extent to which **Power** (see Step 4 above) will be shared for each of the different Types of engagement
7. a transparent plan for implementing each Type of lived/living experience engagement, with clear timelines, accountabilities, and levels of remuneration for lived expertise
8. a commitment to monitor, measure, evaluate and re-set the implementation of the framework, at least on an annual basis.

**Be open and transparent about its capacity to share power?**

Your lived expertise framework needs be clear and honest about engagement types. In some contexts, informing, consulting or involving people with lived/living experience is the most appropriate form of engagement – or the best that can be achieved with the available resources. In general, people with lived expertise will appreciate organisations being upfront about their capacity to share power. On the other hand, mislabelling a tokenistic process as co-production is likely to undermine relationships of trust between an organisation and its lived/living experience consumers. **The template following** provides examples.



## Allocate sufficient resources?

The resources required to develop a lived expertise framework should be something negotiated with a lived expertise group on a project basis in **Co-Initiation** (see Step 6 above).

The resources required to implement a co-produced lived expertise framework on an ongoing basis include:

- the time associated with people in your organisation who are responsible for actions in the framework
- remuneration of people with lived/living experience engaged via the framework, at the rates established in the framework and in a way that is flexible
- the costs associated with co-evaluating the framework on at least an annual basis
- the costs associated with specific actions in the framework (for example, a commitment to communicate with people with lived/living experience in a particular way).

Not allocating sufficient resources to implementation of the framework is highly likely to set it up to fail, resulting in loss of trust with people with lived/living experience. It is far better to reach agreement with lived experts on prioritising and resourcing the most important actions and building on this success.



**For more information and support to implement the seven steps, please feel free to contact Primary Health Tasmania or a Tasmanian organisation managed/controlled by people with lived/living experience.**

Please note: This 10-section template is provided as an example only and a starting point for discussion. Your lived expertise co-production partners may recommend an alternative approach.

## Basic template for an organisational lived expertise engagement framework

### **Section 1: Statements about the co-production of our organisation's framework**

For example, statements from your organisational leadership (CEO/Chairperson) and representatives of the lived expertise group that co-produced your framework, outlining the ways the framework was developed and the insights gained from the process.

### **Section 2: Key messages about the intended impacts of our organisation engaging lived expertise**

For example, brief messages to your organisation's key stakeholders about why your organisation developed a lived expertise framework – and the positive changes that it will bring for each stakeholder group. For example, the positive impacts on:

- our consumers
- the family, friends and kin of our consumers
- our staff
- our service partners
- our funders.

### **Section 3: Language and definitions**

Use of a brief glossary to make it clear how particular words and terms are used in the context of your organisation, its service sector(s), and the advice of lived experts.

### **Section 4: The scope of lived expertise covered in our organisational framework**

For example, an explanation of the way consumers and family/friends of consumers were engaged in developing the framework; the extent to which they included people from diverse backgrounds; and (for example) an explanation that some groups were not specifically engaged.

### **Section 5: Our service environment, and its impact on people with lived/living experience**

For example, a summary of your organisation's various services; the external environment in which they are delivered; and the way people with lived experience engage with these services. Consider including statements about the ways in which the service environment impacts people with lived experience, as well as the opportunities for improvements.

### **Section 6: Governance and continuous improvement of our framework**

For example, a description of the way decisions will be made about the framework into the future – including any co-governance arrangements with lived experts, and the way the implementation of the framework will be monitored and evaluated.

### **Section 7: Our organisation's commitment to principles of lived experience engagement**

For example, making brief statements about your organisation's commitment to each of the principles in Step 1 of this seven steps document (or different principles established by lived experts you engage).

### **Section 8: Our organisation's commitment to enactors of lived experience engagement**

For example, making brief statements about the ways in which your organisation can implement each of the enactors in Step 2 of this seven steps document (or different enactors established by lived experts you engage).

### **Section 9: Our organisation's remuneration of lived expertise**

For example, committing to a lived experience remuneration table, as set out below (or a different version agreed with lived experts).

### **Section 10: Our organisation's priority actions to engage lived expertise**

For example, an action plan (updated annually) for giving transparent, practical effect to your framework, including the types of ways lived experience is engaged; the level of power that lived experts have in each initiative; and the indicators of remuneration.

The template on the following page includes examples of actions across all five engagement types – noting your organisation and lived experts may agree to focus on fewer than five.

To reiterate, this template is provided as an example only – your lived experts may propose an alternative approach to implementation of your organisation's framework.

LIVED EXPERTISE REMUNERATION TABLE (EXAMPLE)

Level 1 Attendee	Level 2 Active Participant	Level 3 Adviser	Level 4 Consultant
(not expected to provide lived expertise)	(lived expertise provided as non-prepared responses in facilitated sessions/surveys)	(lived expertise provided as original analysis and/or advice)	(lived expertise provided in a contracted project with agreed deliverables)
<b>Example:</b>  Attendance at a sector conference organised by our organisation.	<b>Examples:</b>  Participant in a focus group; participant in a service design workshop.	<b>Examples:</b>  Member of a selection panel; reviewer of a policy paper; member of a standing advisory panel.	<b>Example:</b>  Contract with a lived expertise group to design a new program for consumers.
<b>Minimum position:</b>  Same payment as other general attendees (including no payment).	<b>Minimum position:</b>  Equivalent to hourly minimum award payment OR the same rate as other participants.	<b>Minimum position:</b>  Equivalent to hourly award payment of other staff involved in project OR rate established in guidelines for reimbursement of panel members.	<b>Minimum position:</b>  Market rate for consultants undertaking similar work.
<b>Preferred position:</b>  Preferred position: Provide sponsored places for lived expertise (waive fees; assist travel; assist childcare).	<b>Preferred position:</b>  Provide additional support for attendance (travel costs; childcare costs; technology support).	<b>Preferred position:</b>  As per Level 2, and provide additional hours for lived expert to familiarise themselves with content if other participants are applying prior knowledge.	<b>Preferred position:</b>  As per Level 3, and provide additional hours for lived experts to engage other people with lived experience at Levels 1-4 (as agreed in contract).

Engagement Type 1: Individual/family engagement			
Action 1.1		Power spectrum	Remuneration
Consumers invited to provide feedback on our services after each service interaction, with results and service adaptations communicated via website.		Mode 2: Consult	Level 1: No remuneration
Timing	Responsibility	Output measure(s)	Evaluation
Ongoing	Service manager	<ul style="list-style-type: none"> <li>• % consumers providing feedback</li> <li>• results communicated (Y/N)</li> </ul>	Monitored monthly; reported quarterly to Board; annually to stakeholders/consumers
<i>[Insert additional actions for Type 1 Individual/family lived experience engagement]</i>			

Engagement Type 2: Service or program engagement			
Action 2.1		Power spectrum	Remuneration
Undertake focus groups on our services A, B, and C with people with lived expertise. Report back results and actions arising.		Mode 2: Consult	Level 2: Voucher equivalent to minimum wage
Timing	Responsibility	Output measure(s)	Evaluation
2024-25	Quality manager	<ul style="list-style-type: none"> <li>• # of focus groups held</li> <li>• results communicated (Y/N)</li> </ul>	Focus group reports; Implementation of findings from focus group.
<i>[Insert additional actions for Type 2 Service or program lived experience engagement]</i>			

Engagement Type 3: Organisational change			
Action 3.1		Power spectrum	Remuneration
Establish and support lived expertise advisory group, providing advice to our leadership group.		Mode 3: Involve	Level 3: Board attendance fees
Timing	Responsibility	Output measure(s)	Evaluation
June 2024	Deputy CEO	<ul style="list-style-type: none"> <li>• advisory group established (Y/N)</li> <li>• % decisions implemented</li> </ul>	Advisory group members complete twice yearly assessment of group effectiveness.
<i>[Insert additional actions for Type 3 Individual/family lived experience engagement]</i>			

Engagement Type 4: Systemic change			
Action 4.1		Power spectrum	Remuneration
Work with lived experts to help ensure new state government sector policy embeds role of lived experience.		Mode 4: Co-produce	Level 4: Contract lived experts to produce policy paper
Timing	Responsibility	Output measure(s)	Evaluation
May-August 2024	CEO	<ul style="list-style-type: none"> <li>• Policy paper co-produced (Y/N)</li> </ul>	Assess level to which lived experience role has increased compared with current policy.
<i>[Insert additional actions for Type 1 Individual/family lived experience engagement]</i>			

Engagement Type 5: Transformational change			
Action 5.1		Power spectrum	Remuneration
Provide funding for lived experts to conduct community campaign on reducing stigma and discrimination.		Mode 5: Transfer power	Level 4: Contract to deliver campaign at market rate
Timing	Responsibility	Output measure(s)	Evaluation
May-December 2024	Contracted Lived Expertise	<ul style="list-style-type: none"> <li>• Contract executed (Y/N)</li> <li>• Campaign delivered (Y/N)</li> </ul>	As per contract terms on campaign performance metrics.
<i>[Insert additional actions for Type 1 Individual/family lived experience engagement]</i>			

## Glossary<sup>1</sup>

The following terms are directly used or indirectly applied throughout this framework, and/or may be used when you start developing your organisation's lived/lived experience framework with people with lived expertise.

### **Access and control of resources**

A concept that considers who has what within a relationship, and who makes decisions over that resource. Access to a resource means that someone can use that resource. Control is the power to decide how a resource is used and who can use it. The differences in access to and control of resources are a potential indicator of power imbalances experienced by lived/living experience groups.

### **Accessibility**

The design of products, devices, services or environments to be usable by people with the widest possible range of abilities, operating within the widest possible range of situations.

### **Accountability**

The obligation to accept responsibility for one's actions. Individuals are accountable for their own actions and obliged to explain and provide evidence of their choices and decision-making. The accountability of community and health service organisations include (but are not limited to) initiating, implementing, monitoring and evaluating systems that ensure the delivery of safe quality care, maintain and comply with legislated obligations, and meet standards and codes of conduct and practice that ensure consumers are better positioned to have their rights, choices and decisions respected.

### **Adaptive**

The ability of an organisation to perceive and adapt quickly and effectively to internal and external pressures and indicators for change and to identify and respond to potential and actual challenges to find the best outcomes. Adaptive organisational cultures promote better participation and engagement through transparent communication, equal responsibility and developing capacity for shared learning and integrated and effective decision making.

### **Capacity strengthening and capacity exchange**

A deliberate process to improve the ability of an individual, group, organisation, network, or system to enhance or develop new knowledge, skills, attitudes and structures to function effectively. In the context of lived/living experience, it is often implemented through capacity exchange, with knowledge, skills and attitudes being shared between an organisation and a lived/living experience group.

### **Carer**

A person who provides unpaid care and support to those who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, who are frail and aged, or otherwise require the exercise of caring responsibilities. A carer may be (or may prefer to be referred to as): family; friend; kin; supporter; or significant other.

<sup>1</sup> Terms in this glossary are drawn from World Health Organization (2023), *Framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions* and United Nations Women; United Nations Partnership on the Rights of Persons with Disabilities (2021), *Intersectionality Resource Guide and Toolkit: An Intersectional Approach to Leave No One Behind* and Hodges, E., Leditschke, A., Solonsch, L. (2023). *The Lived Experience Governance Framework: Centring People, Identity and Human Rights for the Benefit of All*. Prepared by LELAN (SA Lived Experience Leadership and Advocacy Network) for the National Mental Health Consumer and Carer Forum and the National PHN Mental Health Lived Experience Engagement Network.

## **Consumer**

A person who currently uses, or has used, or may use in the future, a service. People with lived/living experience may develop aspects of their expertise by being a consumer.

*Note: Lived experience (especially in the mental health sector) is frequently used as an umbrella term that combines the experiences of consumers with the experiences of carers, family, kin and other supporters of choice. While some people who have personal lived experience are also carers, and there are some issues where consumer and carer perspectives align, in some cases the interests of consumers are in clear opposition to those of carers. It is not possible for one person to authentically represent both positions at the same time with integrity. To avoid tokenism, both experiences must be recognised as independent and separate of each other and both be given opportunities for involvement and representation matched to the context and issue being explored.*

## **Consumer or person-directed care**

Builds on person-centred care and strengthens consumer choice and self-determination, where decisions about what services are required and desired are made by the consumer. It also emphasises the need for flexible and accessible services, with a focus on seeking supports to meet a wide variety of recovery interests. It promotes a dignity of risk or a risk-tolerant approach, emphasising a disability rights perspective that focuses on assessing an individual's capacity rather than relying on practitioner's capabilities to direct care.

## **Continuous improvement**

A progressive and incremental improvement of processes, systems, safety and quality of care. It is responsive to consumer and community needs and improving consumer and community experience and service outcomes. It is a continuous and ongoing effort to achieve measurable improvements in efficiency, effectiveness, performance, accountability, outcomes, regulatory compliance and other indicators of quality, performance and safety.

## **Culture**

May have different meanings depending on context. When referring to cultural groups and their connection to culture, it can be defined as a body of collectively shared values, principles, practices and customs and traditions and includes systems of knowledge, law and practices that comprise their heritage. When referring to an organisational culture, it refers to the shared values, beliefs, norms, practices, and behaviours that characterise an organisation and shape its collective identity, values, and way of functioning. It influences how people interact with one another, how decisions are made, and how work is conducted within the organisation.

## **Cultural safety**

- An understanding of a person's culture.
- An acknowledgement of difference, and requirement that services are actively mindful and respectful of difference(s).
- Informed by the theory of power relations.
- An appreciation of the historical context of colonisation, the practices of racism at individual and institutional levels, and their impact on First Nations peoples' living and wellbeing, both in the present and past.
- Acceptance that its presence or absence is determined by the person with lived/living experience and not defined by the service provider.

## **Culturally and linguistically diverse (CALD)**

A broad term used to describe communities with diverse languages, ethnic backgrounds, nationalities, traditions, societal structures and religions. A widely used definition of CALD refers to those people born overseas, in countries other than those classified by the Australian Bureau of Statistics as main English-speaking countries. However, people born in these main English-speaking countries and/or the descendants of people born overseas may identify with another culture or country, and may still face language and other barriers when interacting with service providers.

## Disability

Article 1 of the *Convention on the Rights of Persons with Disabilities* defines persons with disabilities as including those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. The full inclusion of people with impairments in society can be inhibited by attitudinal and/or societal barriers (such as discrimination), physical and/or environmental barriers (such as stairs), and policy and/or systemic barriers, which can create a disabling effect.

## Discrimination

Direct discrimination: when one person is treated less favourably than another because of their background or certain personal characteristics.

Indirect discrimination: when laws, policies and practices technically apply to everyone in the same way, and may appear neutral, but have a worse effect on some people than others.

Intersectional discrimination: the complex, multi-faceted dimensions of discrimination on the grounds of social categories or personal characteristics.

## Diversity

The demographic mix of a specific collection of people, taking into account elements of human difference. These differences include but are not limited to race, ethnicity, culture, language, gender, age, personality, religious beliefs, educational level, professional skills, work experience, socio-economic background, career obligations, and geographic location.

## Equality

Formal equality is the concept that all people should be treated the same regardless of difference.

However, this approach does not take systemic discrimination and individual difference into account and can result in indirect discrimination.

*Substantive equality* refers to *equality of outcomes* and takes the effects of discrimination and difference into consideration. It recognises that rights, entitlements, opportunities and access are not equally distributed throughout society and a one-size-fits-all approach will not achieve equality.

It requires the redistribution of resources, power and structures and increased access to resources and participation for those marginalised, including people with lived/living experience.

Inclusive equality is a substantive model of equality that incorporates:

- a) redistribution - addressing socioeconomic disadvantages
- b) recognition - combating stigma, stereotyping, prejudice
- c) participation - proactive inclusion
- d) accommodation - making space for difference.

## Enactor

An action (or coordinated series of actions) to facilitate and implement lived/living experience principles – through mobilisation of intellectual and material resources. *Related concept: enabler* (which may have negative connotations for some people with lived/living experience).

## Evaluation

A process that critically examines a program or service. It involves collecting and analysing information about a program or service's activities, characteristics and outcomes. Its purpose is to assess a program or service, to improve its effectiveness and to inform design and implementation decisions. It should be an ongoing process that links to continuous improvement, strategic planning, and risk management.

## Inclusion

The degree to which diverse individuals and groups are able to participate fully in the governance and decision-making processes about themselves, their own situation and about things that may impact them. The practice or policy of inclusion refers to providing equal access to opportunities and resources for people who might otherwise be excluded or marginalised to be included and participate in decision making.



## **Intersectionality**

The interconnected nature of identity, relationships, social constructs and categorisations such as race, ethnicity, skin colour, socioeconomic status, gender, sex, sexual orientation, nationality, migration status, language, religion, ability, age, housing status, residence, medical status and mental health as they apply to a given individual or group.

## **Lived/living experience**

In its broadest context, a person's direct and personal experiences and choices, positive and negative, the knowledge they have gained and the impact to them of these experiences and choices. This direct lived experience affords the person an authentic voice through their unique insight.

## **Lived expertise**

Knowledge, skills, attitudes and understanding gained by people with lived/living experience, that people who have only observed or learnt about such experiences do not have. With appropriate training and support, this expertise can be applied to bring about change and improvement to the systems that affect others with similar lived/living experience. *Related term: experts by experience.*

## **LGBTQIA+**

A diverse community including people who are lesbian, gay, bisexual, trans, queer, intersex, asexual and others who don't align or identify with being cisgender and heterosexual.

## **Peer worker**

Someone who works in a role that specifically designates the application of their lived/living experience to benefit others with lived experience at individual, program or systemic levels.

## **Power**

The ability to influence and control material, human, intellectual and financial resources to achieve a desired outcome. Power is dynamic, played out in social, economic and political relations between individuals and groups.

## **Power relations**

Recognition that processes and systems of power interact to shape experiences of privilege and disadvantage between and within groups. A person can experience power in some contexts and oppression in others.

## **Principle**

A fundamental proposition that serves as the foundation for a system of belief or behaviour or for a chain of reasoning. In relation to lived expertise these principles are often founded in decades of grassroots activism, research, practical experience, organisational development and demonstrated positive change in consumer outcomes.

## **Privilege**

Exclusive benefits given to people who belong to specific groups.

## **Process**

A series of actions or steps taken to achieve a particular goal.

## **Program**

An initiative, or series of initiatives, designed to deal with a particular issue, with resources, a timeframe, objectives and deliverables allocated to it.

## **Racism**

An ideological construct that assigns a certain race and/or ethnic group to a position of power over others based on physical and cultural attributes, including hierarchical relations in which those of one race exercise control over others.

## **Remuneration**

Payment for time spent doing agreed activities or providing a service. It may include wages, fees, allowances and various forms of 'in-kind' payment. It does not include reimbursement by the payer for actual costs incurred by the payee. It may be defined differently by different authorities (for example, different definitions of remuneration may be applied by the Australian Taxation Office and the Department of Social Services).



**Safe space**

Environment that is free of discrimination and stigmatisation, allowing individuals to share their perspectives, experiences and feelings in an open, supportive manner.

**Self-determination**

Choice in determining how one's life and/or actions are governed. This includes a right to recognition of group identities.

**Stigmatisation**

A complex, multi-level, social process that encompasses the elements of labelling, stereotyping, separation, status loss and discrimination in the context of a power situation.

**System**

The resources, policies, processes and procedures that are organised, integrated, regulated and administered to accomplish a stated goal.

**Theory of change**

A written description of how and why a desired change is expected to happen in a particular context (e.g. the positive change brought about for consumers by an organisation implementing a lived expertise framework). It can be expressed as a simple change hypothesis statement (If we do...; This will result in...; Leading to...). It can also be described via comprehensive program logic mapping of how service inputs lead to service activities; how service activities lead to service outputs; how service outputs lead to consumer outcomes; and how consumer outcomes lead to community impacts. It can also be used to test assumptions at each stage in the program logic (e.g. "we assume that our Service Inputs will be secured to maintain the Service Activities"). A detailed theory of change is useful for planning, implementation and evaluation.

**Trauma-informed**

Recognition by services and systems of the prevalence of trauma, by applying a common set of principles adapted to different contexts.

Re-traumatisation happens when people suffering from trauma are exposed to people, places, events, situations, or environments that cause them to re-experience past trauma.

**Unconscious biases**

Also known as implicit biases, are social stereotypes about certain groups of people that individuals form outside their own conscious awareness. These unconscious beliefs and prejudice about various social and identity groups, are often incompatible with one's conscious values.

## Literature review

Each of the following documents was considered in the development of the content above.

Literature Review Section A: Lived/Living Experience Frameworks, Guides and Tools (presented in order of publication date) Each of these publications may provide detailed, practical guidance for an organisation seeking to implement a lived expertise framework. <i>Note: Each of these documents can be accessed at no cost via an internet search engine (as at July 2023)</i>		
Publishing/commissioning entity	Year	Title
World Health Organization (WHO)	2023	<i>WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions</i>
Global Fund to End Modern Slavery and National Survivor Network (US)	2023	<i>Meaningful Engagement of People with Lived Experience: A framework and assessment for measuring and increasing lived experience leadership across the spectrum of engagement</i>
Tasmanian Council of Social Services	2023	<i>Community Voice Program (various online resources linked to TasCOSS website)</i>
National Mental Health Consumer and Carer Forum and the National PHN Mental Health Lived Experience Engagement Network	2023	<i>The Lived Experience Governance Framework: Centring People, Identity and Human Rights for the Benefit of All. [Prepared by LELAN (SA Lived Experience Leadership &amp; Advocacy Network) and authored by Hodges, E., Leditschke, A., Solonsch, L].</i>
National Mental Health Consumer and Carer Forum and the National PHN Mental Health Lived Experience Engagement Network	2023	<i>A Toolkit to Authentically Embed Lived Experience Governance: Centring People, Identity and Human Rights for the Benefit of All. [Prepared by LELAN (SA Lived Experience Leadership &amp; Advocacy Network) and authored by Hodges, E., Leditschke, A., Solonsch, L].</i>
Tasmanian Government	2023	<i>Long Term Plan for Healthcare in Tasmania 2040</i>
Roses in the Ocean	2022	<i>Lived Experience of Suicide Engagement, Partnership and Integration (LESEPI) Toolkit</i>
AMIDA (Action for More Independence and Dignity in Accommodation)	2022	<i>10 Top Tips: Practical information sheets to ensure people with cognitive disabilities have a real and equal Voice at the Table.</i>
World Wellness Group (Australia)	2022	<i>Multicultural Lived Experience Framework</i>
Mental health Complaints Commissioner (Victoria)	2022	<i>Lived Experience Engagement Checklist</i>

Sheila McKechnie Foundation	2022	<i>Unleashing Social Power: A guide to thinking differently about power for solidarity in social change</i>
Tasmanian Government	2022	<i>Healthy Tasmania Five-Year Strategic Plan</i>
Australian Commission on Safety and Quality in Health Care	2022	<i>National Safety and Quality Mental Health Standards for Community Managed Organisations</i>
Australian Commission on Safety and Quality in Health Care	2022	<i>National Safety and Quality Health Service (NSQHS) Standards - Partnering with Consumers Standard</i>
Co-Health	2022	<i>Lived/Living Experience Strategy 2021-26</i>
Lived Experience Leadership	2022	<i>What's in the National Lived Experience (Peer) Workforce Development Guidelines and Where to Find What You're Looking For</i>
Tasmanian Government	2022	<i>2022-23 Rethink 2020 Implementation Plan</i>
World Health Organization	2022	<i>Strengthening primary health care to tackle racial discrimination, promote intercultural services and reduce health inequities: research brief.</i>
CFE Research and The Systems Change Action Network	2022	<i>Coproduction: Principles in practice</i>
NSW Council of Social Service	2021	<i>NCOSS Lived Experience Framework: Principles and practices for Lived Experience partnerships</i>
Canadian Centre for Substance Use and Addiction (Canada)	2021	<i>Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends</i>
Mission Australia	2021	<i>Learning from Lived Experience: A Framework for Client Participation</i>
Department of Health and Human Services (US)	2021	<i>Methods and Emerging Strategies to Engage People with Lived Experience</i>
Mind Australia	2021	<i>Lived Experience Strategy (2021-2024); Participation and Co-design Practice Framework (2021)</i>
Swinburne Social Innovation Research Institute	2021	<i>15 practices of rural community co-produced mental health initiatives</i>
United Nations Women; United Nations Partnership on the Rights of Persons with Disabilities	2021	<i>Intersectionality Resource Guide and Toolkit: An Intersectional Approach to Leave No One Behind</i>
Australian Government National Mental Health Commission	2021	<i>National Lived Experience (Peer) Workforce Development Guidelines</i>
Australian Government National Mental Health Commission	2021	<i>Summary of Consultations for NLE(P)WD Guidelines</i>
Australian Government National Mental Health Commission	2021	<i>Lived Experience Roles for NLE(P)WD Guidelines</i>

Australian Government National Mental Health Commission	2021	<i>Roadmap' for NLE(P)WD Guidelines</i>
National Mental Health Consumer and Carer Forum	2021	<i>Advocacy Brief - Co-Design and Co-Production</i>
National Mental Health Consumer and Carer Forum	2021	<i>Advocacy Brief - Consumer and Carer Engagement</i>
World Health Organization	2021	<i>Nothing for us, without us: opportunities for meaningful engagement of people living with NCDs: meeting report.</i>
World Health Organization.	2021	<i>Mental health crisis services: promoting person-centred and rights-based approaches.</i>
Scottish Human Rights Commission	2021	<i>Paying people with lived experience for their participation.</i>
World Health Organization	2021	<i>Voice, agency, empowerment—handbook on social participation for universal health coverage.</i>
National Survivor User Network; Mind; Rai Waddingham	2021	<i>Lived Experience Leadership: Mapping the Lived Experience Landscape in Mental Health</i>
Western Australia Council of Social Service	2020	<i>Lived Experience Framework: Principles and practices for Lived Experience partnerships</i>
Domestic Violence Victoria	2020	<i>The Family Violence Experts by Experience Framework</i>
Mental Health and Suicide Prevention Research Group, University of South Australia	2020	<i>Lived Experience Engagement Framework</i>
CFE Research (UK)	2020	<i>The role of lived experience in creating systems change</i>
Canberra Health Services (ACT)	2020	<i>Canberra Health Services: Partnering with Consumers Framework 2020–2023</i>
Blue Knot Foundation	2020	<i>Organisational Guidelines for Trauma-Informed Service Delivery</i>
Consumers Health Forum of Australia	2020	<i>Consumer Commission Report: Making Health Better Together</i>
Tasmanian Government	2020	<i>Rethink 2020 - A state plan for mental health in Tasmania 2020-2025</i>
NSW State Insurance Regulatory Authority	2020	<i>Engaging with Lived Experience</i>
Australian Government Productivity Commission	2020	<i>Mental Health Inquiry Report (No.95) - Actions and Findings</i>
Victorian Mental Illness Awareness Council (VMIAC)	2020	<i>Consumer led transformational change</i>
Victorian State Government Mental Health Complaints Commissioner	2020	<i>Driven by lived experience – beginnings, present &amp; future</i>

Queensland Council of Social Service	2020	<i>Incorporating the consumer voice: How Queensland community organisations deliver consumer-centric services</i>
Tamarack Institute (Canada)	2019	<i>Engaging with People with Lived/Living Experience: A Guide for Including People in Poverty Reduction</i>
Alberta Health Primary Health Care (Canada)	2019	<i>Engaging Individuals with Lived Experience: A Framework</i>
Department of Health and Human Services (Victoria, Australia)	2019	<i>Mental health lived experience engagement framework</i>
Agency for Clinical Innovation (NSW)	2019	<i>A Guide to Build Co design Capability</i>
Office of the Advocate for Children and Young People (NSW)	2019	<i>Engaging children and young people in your organisation</i>
Tasmanian Office of the Chief Psychiatrist	2019	<i>The Tasmanian Mental Health Reform Program (Presentation)</i>
Mental Health Commission of NSW	2018	<i>Lived Experience Framework for NSW</i>
Queensland Health (Mental Health Alcohol and Other Drugs Branch)	2018	<i>Lived Experience Engagement and Participation Strategy 2018-2021</i>
The Centre for Best Practice in Aboriginal and Torres Strait Islander Suicide Prevention/Black Dog Institute	2018	<i>Indigenous Governance for Suicide Prevention in Aboriginal and Torres Strait Islander Communities: A Guide for Primary Health Networks</i>
Roper, C., Grey, F., Cadogan, E.	2018	<i>Co-production: Putting principles into practice in mental health contexts</i>
National Mental Health Commission (Australia)	2018	<i>Consumer and Carer engagement: a practical guide</i>
National Mental Health Commission (Australia)	2018	<i>Sit beside me, not above me: Supporting safe and effective engagement and participation of people with lived experience</i>
People with Disabilities WA; WA Government	2018	<i>Connect with Me</i>
NSW Aboriginal Affairs (Tony Dreise and Evalynn Mazurski)	2018	<i>Knowledge exchange, co-design and community-based participatory research and evaluation in Aboriginal communities: Literature Review, Case Study and Practical Tips</i>
Australian Commission on Safety and Quality in Health Care	2018	<i>NSQHS Standards User Guide for Health Services Providing Care for People with Mental Health Issues</i>
Wellways	2018	<i>Out Together Toolkit</i>
Australian National University/Black Dog Institute	2017	<i>Framework for the engagement of people with a lived experience in program implementation and research: Review and report prepared for the LifeSpan suicide prevention project</i>

Rethink Mental Illness (UK)	2017	<i>Progress through Partnership: involvement of people with lived experience of mental illness in CCG commissioning</i>
Australian Government	2017	<i>National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing 2017-2023</i>
Consumers Health Forum of Australia	2017	<i>Experience Based Co-Design Toolkit</i>
Australian Government	2017	<i>The Fifth National Mental Health and Suicide Prevention Plan</i>
Mental Health Australia	2017	<i>Co-Design in Mental Health Policy</i>
Lived Experience Advisory Council (Canada)	2016	<i>Nothing about us without us: Seven principles for leadership and inclusion of people with lived experience of homelessness</i>
The Royal Australasian College of Physicians	2016	<i>RACP framework for improving patient centred care and consumer engagement</i>
Consumers of Mental Health Western Australia (COMHWA)	2015	<i>Consumer Participation Policy</i>
Canadian Mental Health Association British Columbia (Canada)	2014	<i>Engage People with Lived Experience of Mental Health Conditions and Addictive Behaviours Workbook</i>
Merinda Epstein and Our Consumer Place	2013	<i>The Consumer Movement in Australia: A memoir of an old campaigner</i>
Our Consumer Place	2011	<i>Speaking Our Minds: A guide to how we use our stories (Our Consumer Place Resource Centre Booklet Two)</i>
Waitemata District Health Board (New Zealand)	2010	<i>Health Service Co-design: Working with patients to improve healthcare services guide and toolkit</i>
Disability Services Queensland	2009	<i>Walking the Talk: A framework for effective engagement with people with disability, families and people who support them</i>
Anglicare Tasmania Social Action and Research Centre	2009	<i>Experts by Experience: Strengthening the mental health consumer voice in Tasmania</i>
Tasmanian Government Mental Health Services (DHHS)	2006	<i>Consumer and Carer Participation Framework</i>

## Literature Review Section B:

Published research on lived/living experience

*Presented in alphabetical order of author*

Each of the following documents was examined in the development of the content above.

*Note: Access to most of these documents requires use (and potentially payment) via multiple databases including Informit, Scopus, EBSCO, and Google Scholar.*

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