

# Understanding the Lived Experience Governance Framework and Aligned Toolkit

Ellie Hodges | Chief Executive and Founder of LELAN © 2024

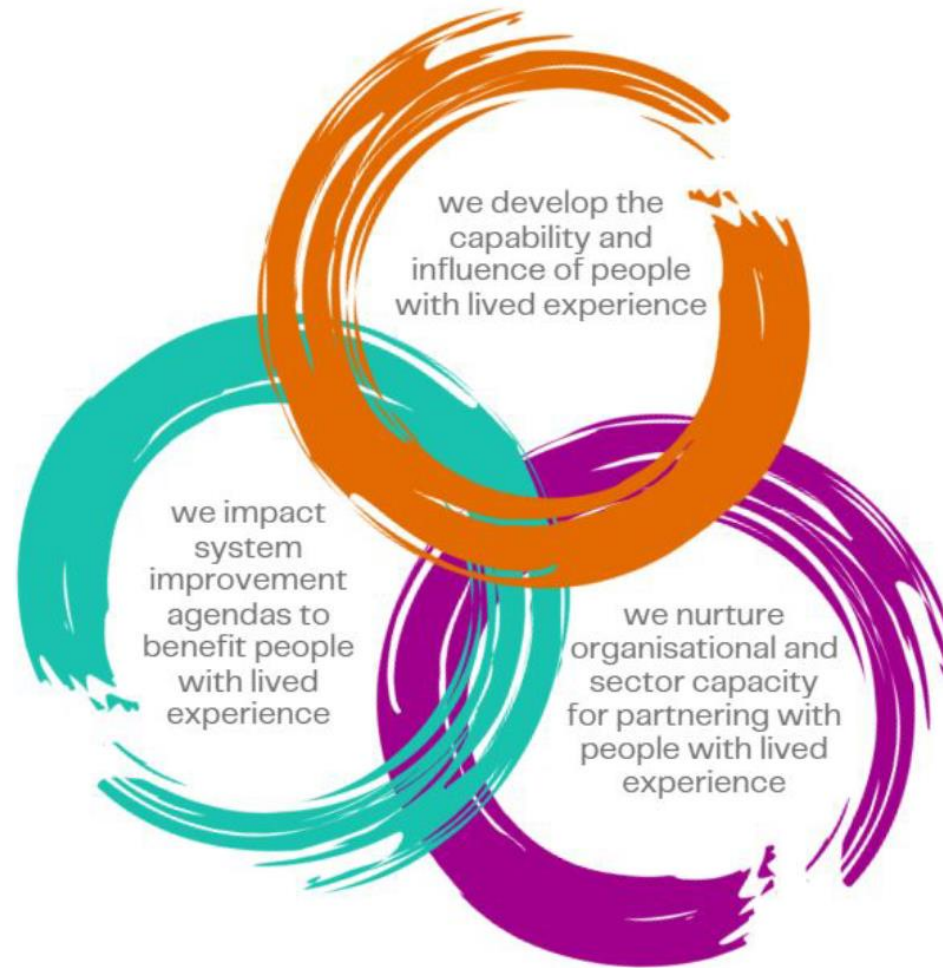


we gather on the  
unceded lands of  
First Nations  
people



# About LELAN

# our strategic pillars and impact targets

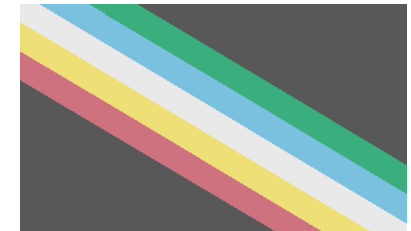
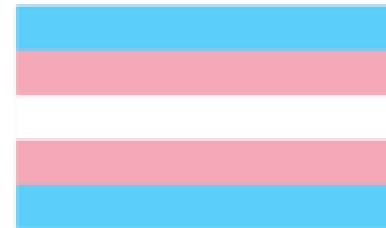


LELAN's systemic advocacy targets the mental health and social sectors in South Australia.

Our thought leadership and innovation for lived experience expertise, leadership and governance is borderless.

# a deep commitment to Lived Experience

- We recognise the lives and work of people with lived experience, particularly those that passionately, intentionally and skilfully use their lived expertise for change. It matters.



# How 'Lived Experience Governance' Came to Be

commissioned  
2022 and  
published July  
2023



Mental Health Lived Experience Engagement Network  
National Mental Health Consumer & Carer Forum

### Pathways For Supporting The 'Not Negotiable' Lived Experience (Peer) Workforces To Thrive

A scoping paper for formal lived experience expertise training programs and supports

Prepared by [LELAN logo] 2022

Mental Health Lived Experience Engagement Network  
National Mental Health Consumer & Carer Forum

### The Lived Experience Governance Framework

Centring People, Identity and Human Rights for the Benefit of All

Prepared by [LELAN logo] July 2023

Mental Health Lived Experience Engagement Network  
National Mental Health Consumer & Carer Forum

### A Toolkit to Authentically Embed Lived Experience Governance

Centring People, Identity and Human Rights for the Benefit of All

Prepared by [LELAN logo] July 2023



*embodying the principles of co-production*



reviewing literature and existing governance frameworks



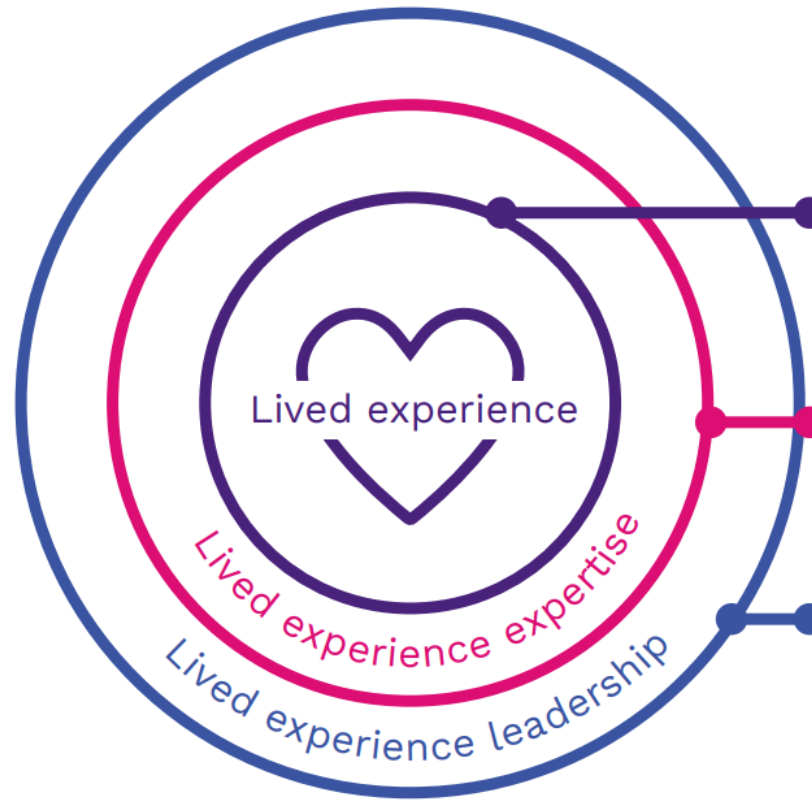


# (y)our connection to Lived Experience Governance

- A **thought or question** you have about Lived Experience Governance and how to make use of it in your role, organisation and/or life.
- What you **really want to know** about Lived Experience Governance and how to make use of it in your role, organisation and/or life.
- How you would **like to engage with co-production** with Lived Experience Governance and how to make use of it in your role, organisation and/or life.

# A Quick Introduction to Lived Experience Governance

# the nuance of Lived Experience and its application in the Framework and aligned Toolkit



## Lived experience

To reimagine and redefine ourselves, our place in the world and our future plans<sup>49</sup>

## Lived experience expertise

To use those experiences in a way that's useful to other people<sup>50</sup>

## Lived experience leadership

To speak up to influence community awareness, organisational culture, policy and politics; create space, pathways and inclusion with others; prompt and support change<sup>51</sup>

# Aboriginal and Torres Strait Islander Lived Experience

- 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.*
- People with lived or living experience of suicide are those who have experienced suicidal thoughts, survived a suicide attempt, cared for someone through a suicidal crisis, been bereaved by suicide or having a loved one who has died by suicide, *acknowledging that this experience is significantly different and takes into consideration Aboriginal and Torres Strait Islander peoples ways of understanding social and emotional wellbeing.*

[2020 Black Dog Institute Aboriginal and Torres Strait Islander Lived Experience Centre accessed at [www.blackdoginstitute.org.au/education-services/aboriginal-and-torres-strait-islander-network](http://www.blackdoginstitute.org.au/education-services/aboriginal-and-torres-strait-islander-network)]

# defining Lived Experience Governance

- *Lived experience governance intentionally embeds organisational cultures and systems that give primacy to centring or being led by lived experience perspectives, principles, and ways of working in the decision-making, oversight and evaluation of systems, structures, policies, processes, practices, programs and services.*

# why a Lived Experience Governance approach is needed at this time



There is an unrepentant demand for a shift from words to deeds. But that begs the question, what would a system governed on the basis of lived experience, equity, human rights and justice look like? What is involved in getting there? Who do we need at the table? What kinds of tables do we need?

Interview Participant



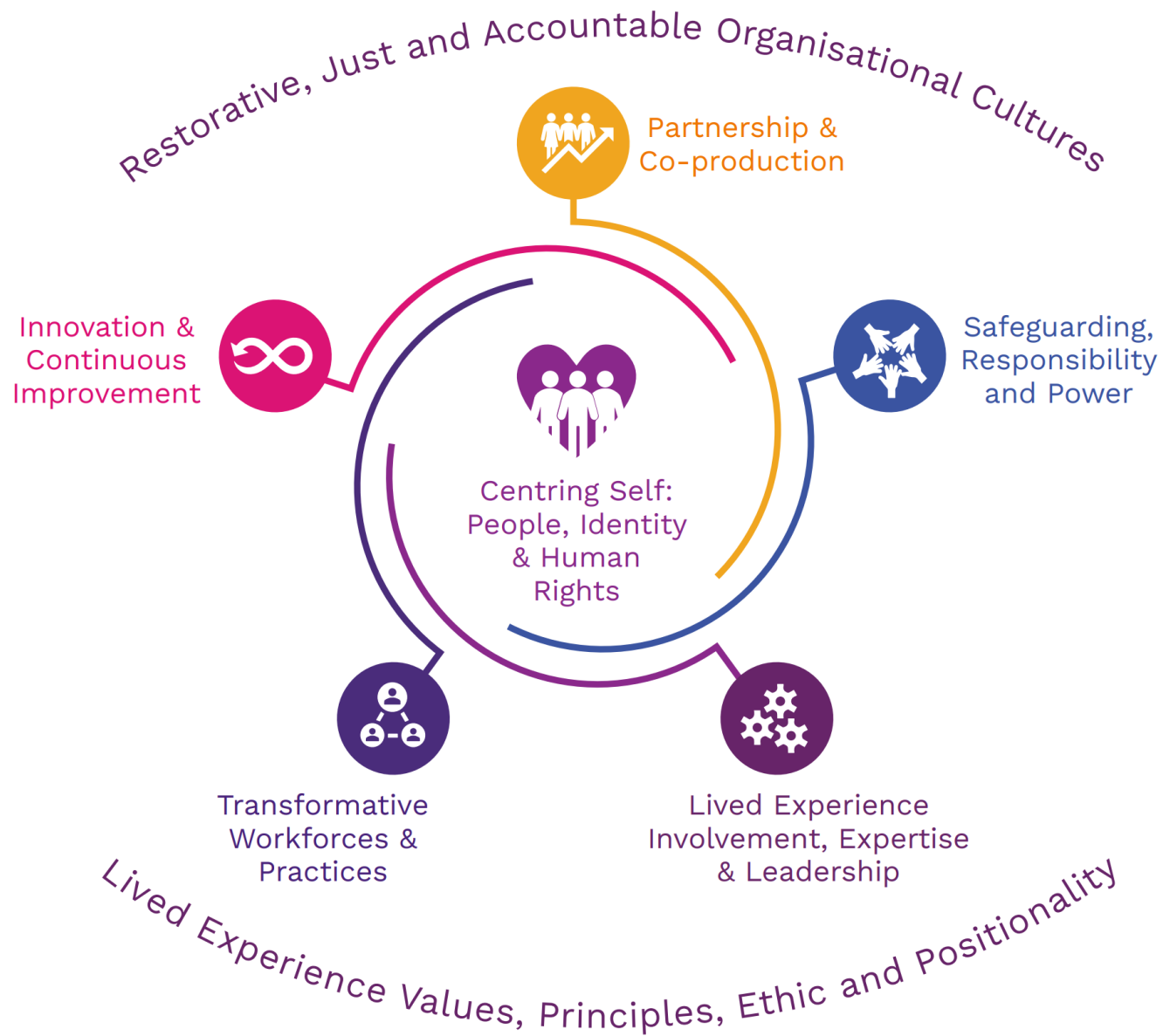
*Good governance is saying this current system that has been built is what is causing harm. And we need to be creating and affirming values and practices that resist that abuse and oppression and encourage safety, encourage accountability. We need to encourage self-determination, encourage mentoring, and encourage other ways to continue to be part of this movement.*

Thinktank Participant

# tensions and approaches to risk and decision-making

- *The Lived Experience Governance Framework provides a guidepost across the interrelated foundational concepts and domains to assist leaders, organisations and systems to transform practice and navigate the complexities that exist in this space.*
- *Safety cultures and practices across organisations and services that promote connection, choice and responsibility to and not for or over people are imperative.*

the essential components of Lived Experience Governance [domains, foundations and core]





# Lived Experience Governance values and principles

## Core Lived Experience Values

Hope  
Equality/Equity  
Mutuality  
Empathy  
Choice  
Respect  
Authenticity  
Belonging/Inclusion  
Interdependence/  
Interconnectedness  
Justice/Human Rights

## Core Lived Experience Principles

Lived experience as expertise  
Self determination  
Recovery-focused  
Person directed  
Strengths based  
Relational  
Trauma informed  
Humanistic  
Voluntary  
Culturally responsive

# where Lived Experience Governance fits with other governance approaches



Understanding how lived experience governance sits and fits in relation to other forms of governance is essential for successful implementation.

Lived experience governance exists as a separate and equally important component of an organisation's corporate governance and strategic processes and structures.

Lived experience governance is aligned with and complementary to other essential corporate governance mechanisms that support safe, effective, person-centred practice and decision-making<sup>10</sup>.

All governance should be person-centred and underpinned and informed by lived experience values, principles and perspectives.

# how Lived Experience Governance aligns with existing accreditation processes

## The National Safety and Quality Health Service (NSQHS) Standards

The Australian Commission on Safety and Quality in Health Care, National Safety and Quality Health Service Standards (NSQHS standards) exist to prevent health services from causing harm and ensure quality care. Of the eight standards, four are based upon clinical practice and have been excluded, while the remaining four standards are more broadly about quality of care, the structure of the service and the experience of the person at the centre of care.

| The National Safety and Quality Health Service (NSQHS) Standards | Lived Experience Governance Framework Domains   |                                     |  |   |                                       |
|--|---|-------------------------------------|--|---|---------------------------------------|
|  | Partnership & Coproduction  | Safeguarding Responsibility & Power | Lived Experience Involvement, Expertise & Leadership | Transformative Workforces and Practices | Innovation and Continuous Improvement |
| <b>Clinical Governance Standard</b>                              | <b>Standard action items numbers aligned with lived experience governance domains</b> |                                     |  |   |                                       |
| Governance, leadership and culture                               | 1.01.1.02   | 1.01.1.02                           | 1.01.1.02  | 1.01.1.02                               | 1.01.1.02                             |
| Organisational leadership  | 1.03.1.04.1.05  | 1.03.1.04.1.05                      | 1.03.1.04.1.05                                       | 1.03.1.04.1.05                          | 1.03.1.04.1.05                        |
| Clinical leadership  |   |                                     |  | 1.06                                    | 1.06                                  |
| Policies and procedures  |   | 1.07                                |  |   | 1.07                                  |
| Measurement and quality improvement                              | 1.08.1.09   | 1.08.1.09                           | 1.08.1.09  | 1.08.1.09                               | 1.08.1.09                             |
| Risk management  | 1.10  | 1.10                                | 1.10   | 1.10                                    | 1.10                                  |
| Incident management systems and open disclosure                  | 1.11.1.12   | 1.11.1.12                           | 1.11.1.12  | 1.11.1.12                               | 1.11.1.12                             |
| Feedback and complaints management                               | 1.13.1.14   | 1.13.1.14                           | 1.13.1.14  | 1.13.1.14                               | 1.13.1.14                             |
| Diversity and high-risk groups                                   | 1.15  | 1.15                                | 1.15   | 1.15                                    | 1.15                                  |
| Healthcare records   | 1.16  | 1.16                                | 1.16   | 1.16                                    | 1.16                                  |
| Safety and quality training                                      | 1.19.1.21   | 1.19.1.21                           | 1.19.1.21  | 1.19.1.20.1.21                          | 1.19.1.20.1.21                        |
| Performance management   |   |                                     |  | 1.22                                    | 1.22                                  |
| Credentialing and scope of clinical practice                     |   |                                     |  | 1.23.1.24                               | 1.23.1.24                             |
| Safety and quality roles and responsibilities                    |   | 1.26                                |  | 1.25.1.26                               | 1.25.1.26                             |
| Evidence-based care  | 1.27  | 1.27                                | 1.27   |   | 1.27                                  |
| Variation in clinical practice and health outcomes               | 1.28  | 1.28                                | 1.28   | 1.28                                    | 1.28                                  |
| Safe Environment   | 1.29.1.30.1.31.1.32.1.33  | 1.29.1.30.1.31.1.32.1.33            | 1.29.1.30.1.31.1.32.1.33                             | 1.29.1.30.1.31.1.32.1.33                | 1.29.1.30.1.31.1.32.1.33              |

## National Safety and Quality Mental Health Standards for Community Managed Organisations

The Australian Commission on Safety and Quality in Healthcare, National Safety and Quality Mental Health Standards for Community Managed Organisations (CMO Standards) has been created with the aim to protect the public from harm and to continuously improve the quality of service provision<sup>1</sup>.

| National Safety and Quality Mental Health Standards for Community Managed Organisations | Lived Experience Governance Framework Domains   |                                     |  |   |                                       |
|---|---|-------------------------------------|--|---|---------------------------------------|
|   | Partnership & Coproduction  | Safeguarding Responsibility & Power | Lived Experience Involvement, Expertise & Leadership | Transformative Workforces and Practices | Innovation and Continuous Improvement |
| <b>Practice Governance Standard Items</b>   | <b>Standard action items numbers aligned with lived experience governance domains</b> |                                     |  |   |                                       |
| Practice governance, leadership and culture   | 1.01.1.02.1.03  | 1.01.1.02.1.03                      | 1.01.1.02.1.03                                       | 1.01.1.02.1.03                          | 1.01.1.02.1.03                        |
| Care leadership   |   |                                     |  | 1.04.1.05                               | 1.04.1.05                             |
| Legislation, regulations, policies and procedures                                       |   | 1.06                                |  |   | 1.06                                  |
| Measurement and quality improvement   | 1.07.1.08   | 1.08                                | 1.07.1.08  | 1.07.1.08                               | 1.07                                  |
| Organisational risk management  | 1.09  | 1.09                                | 1.09   | 1.09                                    | 1.09                                  |
| Incident management systems and open disclosure   | 1.10  | 1.10                                |  | 1.10                                    | 1.10                                  |
| Feedback and complaints management and resolution                                       | 1.12.1.13   | 1.11.1.12.1.13                      | 1.11.1.12.1.13                                       | 1.11.1.12.1.13                          | 1.11.1.12.1.13                        |
| Consumer care records and information   |   | 1.14                                | 1.14   | 1.14                                    | 1.14                                  |
| Safety and quality training   |   |                                     |  | 1.15                                    | 1.15                                  |
| Workforce qualifications and performance management                                     | 1.18  |                                     | 1.18   | 1.16.1.17.1.18                          | 1.18                                  |
| Safe environment  | 1.21.1.22.1.23  | 1.19.1.21.1.22.1.23.1.25            | 1.21.1.22.1.25                                       | 1.21.1.22.1.24.1.25                     | 1.21.1.22                             |
| Privacy   | 1.26.1.27   | 1.26.1.27                           | 1.26.1.27  | 1.26.1.27                               | 1.26.1.27                             |

## National Safety and Quality Primary and Community Healthcare Standards

The Australian Commission on Safety and Quality in Health Care, National Safety and Quality Primary Community Healthcare Standards<sup>2</sup> are designed for health providers in primary and community settings in order to ensure the quality and safety of services. Since May 2023 accrediting agencies can evaluate and approve organisations on the basis of compliance to the standards, which may be a requirement for funding/commissioning bodies of health services.

| National Safety and Quality Primary and Community Healthcare Standards | Lived Experience Governance Framework Domains   |                                     |  |   |                                       |
|--|---|-------------------------------------|--|---|---------------------------------------|
|  | Partnership & Coproduction  | Safeguarding Responsibility & Power | Lived Experience Involvement, Expertise & Leadership | Transformative Workforces and Practices | Innovation and Continuous Improvement |
| <b>Clinical Governance Standard</b>                                    | <b>Standard action items numbers aligned with lived experience governance domains</b> |                                     |  |   |                                       |
| Governance, leadership, and culture                                    | 1.01  | 1.01                                | 1.01   | 1.01                                    | 1.01                                  |
| Policies and procedures  | 1.02  | 1.02                                | 1.02   | 1.02                                    | 1.02                                  |
| Measurement and quality improvement                                    | 1.03  | 1.03                                | 1.03   | 1.03                                    | 1.03                                  |
| Risk management  | 1.04  | 1.04                                | 1.04   | 1.04                                    | 1.04                                  |
| Incident management and open disclosure                                | 1.05.1.06   | 1.05.1.06                           | 1.05.1.06  | 1.05.1.06                               | 1.05.1.06                             |
| Feedback and complaints management                                     | 1.07.1.08   | 1.07.1.08                           | 1.07.1.08  | 1.07.1.08                               | 1.07.1.08                             |
| Patient populations and social determinants of health                  | 1.09.1.10   | 1.09.1.10                           | 1.09.1.10  | 1.09.1.10                               | 1.09.1.10                             |
| Healthcare records   | 1.11  | 1.11.1.12                           | 1.11   | 1.11.1.12                               | 1.11.1.12                             |
| Safety and quality training  | 1.16  | 1.15.1.16                           | 1.16   | 1.15.1.16                               | 1.15.1.16                             |
| Safety and quality roles and responsibilities                          |   |                                     |  | 1.17                                    | 1.17                                  |
| Evaluating performance   | 1.18  | 1.18                                | 1.18   | 1.18                                    | 1.18                                  |
| Scope of clinical practice   |   |                                     |  | 1.19                                    | 1.19                                  |
| Evidence-based care  |   | 1.20                                |  | 1.20                                    | 1.20                                  |
| Variation in care delivered and health outcomes                        |   | 1.21                                |  | 1.21                                    | 1.21                                  |
| Safe environment   | 1.22.1.23   | 1.22.1.23                           | 1.23   | 1.22.1.23                               | 1.22.1.23                             |

## NDIS Code of Conduct and Practice Standards and Quality Indicators

The National Quality and Safeguards Commission NDIS Practice Standards<sup>3</sup> specify the quality standards to be met by registered NDIS providers to provide supports and services to NDIS participants. Together with the NDIS Code of Conduct<sup>4</sup>, the NDIS Practice Standards build NDIS participants' awareness of what quality service provision they should expect from registered NDIS providers. The following table outlines the conduct statements in the NDIS's Code of Conduct and standards and quality indicators in the NDIS Core Practice Standards and Quality Indicators.

| NDIS Code of Conduct and Practice Standards and Quality Indicators  | Lived Experience Governance Framework Domains                              |                                     |  |   |                                       |
|---|--|-------------------------------------|--|---|---------------------------------------|
|   | Partnership & Coproduction   | Safeguarding Responsibility & Power | Lived Experience Involvement, Expertise & Leadership | Transformative Workforces and Practices | Innovation and Continuous Improvement |
| <b>Code Of Conduct</b>  | <b>Conduct statements aligned with lived experience governance domains</b> |                                     |  |   |                                       |
| Act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with applicable laws and conventions        | ✓  | ✓                                   | ✓  | ✓                                       | ✓                                     |
| Respect the privacy of people with disability   | ✓  | ✓                                   | ✓  | ✓                                       | ✓                                     |
| provide supports and services in a safe and competent manner, with care and skill.  |  | ✓                                   | ✓  | ✓                                       | ✓                                     |
| Act with integrity, honesty and transparency  | ✓  | ✓                                   | ✓  | ✓                                       | ✓                                     |
| Promptly take steps to raise and act on concerns about matters that may impact the quality and safety of supports and services provided to people with disability | ✓  | ✓                                   | ✓  | ✓                                       | ✓                                     |
| Take all reasonable steps to prevent and respond to all forms of violence against, and exploitation, neglect and abuse of, people with disability                 | ✓  | ✓                                   | ✓  | ✓                                       | ✓                                     |
| Take all reasonable steps to prevent and respond to sexual misconduct   | ✓  | ✓                                   | ✓  | ✓                                       | ✓                                     |

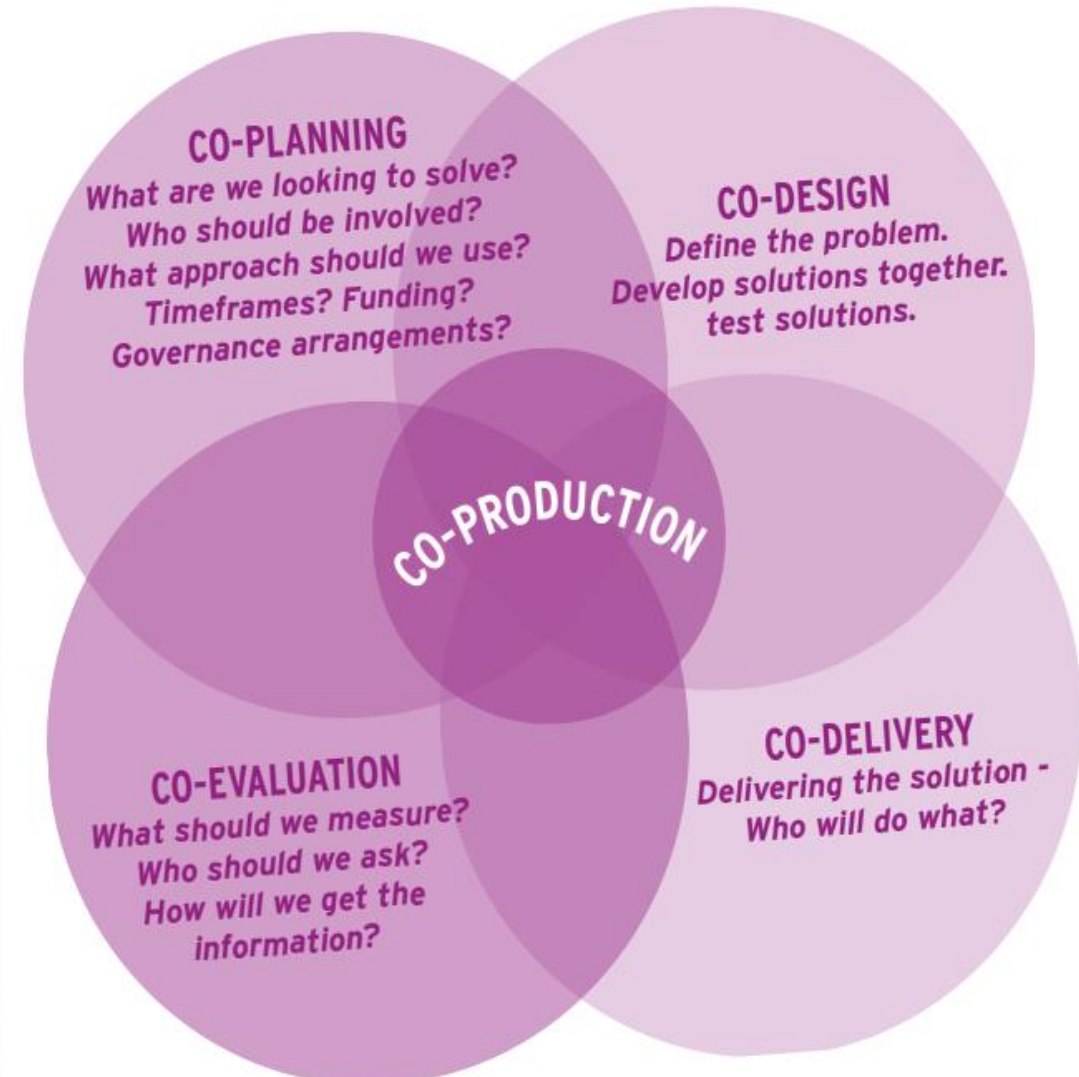
what will be  
experienced and  
seen in  
governance  
systems and  
processes

- [Domain 1] **Partnership and Co-production:**
  - Prioritised and Embedded.
  - Adequate Resourcing.
  - Two-way Communication Pathways.
  - Relational not Transactional.
  - Person-Defined Impacts.
  - Lived Experience-Initiated Opportunities.
  - Co-produced Performance Measures.

co-everything,  
everywhere with  
everyone. as much  
as you can



Burkett, I. *An Introduction to Co-design*.



Roper, C., Grey, F., & Cadogan, E. (2018). Co-production: Putting principles into practice in mental health contexts.

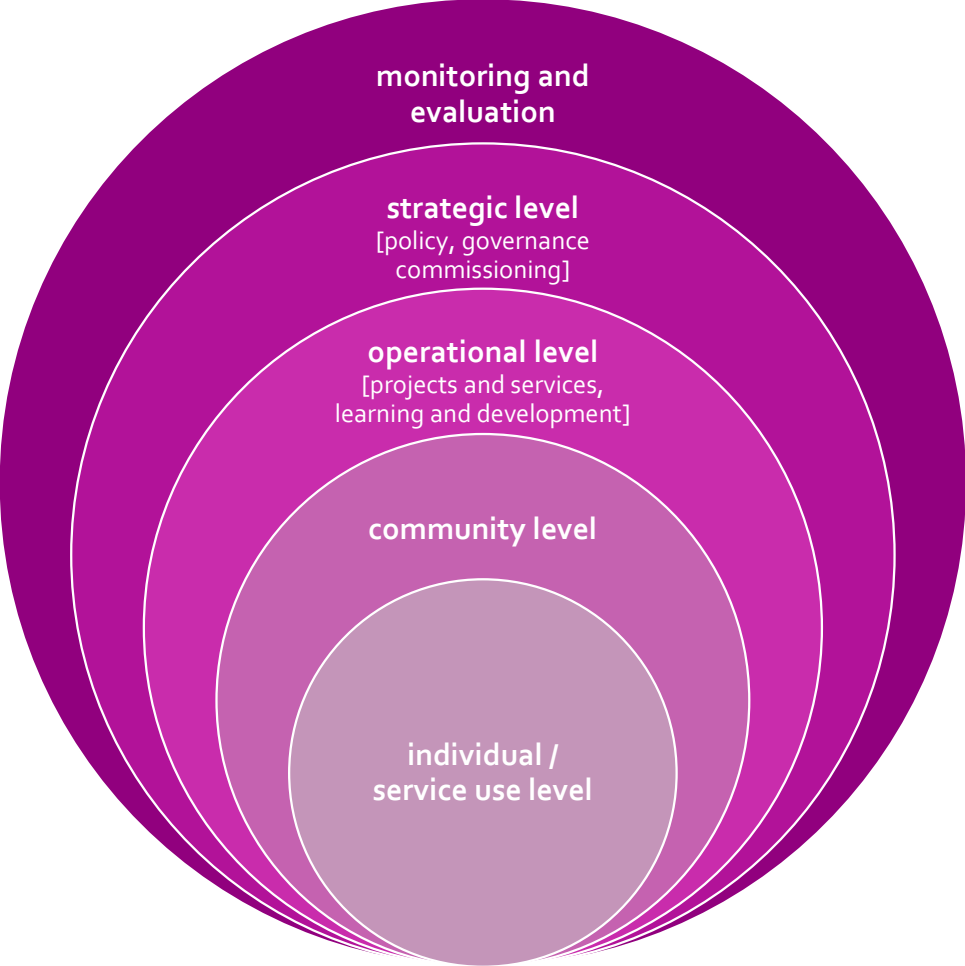
what will be  
experienced and  
seen in  
governance  
systems and  
processes

- [Domain 2] **Safeguarding, Responsibility and Power:**
  - Rights are Upheld.
  - Dignity of Risk.
  - Responsibility To, Not For or Over.
  - Decision-Making Transparency.
  - Redistribution of Power.
  - Capacity to Exercise Power.
  - Measures that Matter.

what will be  
experienced and  
seen in  
governance  
systems and  
processes

- [Domain 3] **Lived Experience Involvement, Expertise & Leadership:**
  - Strategic Recognition and Action.
  - Opportunities and Integration.
  - All Levels, in Diverse Roles.
  - Presence and Authority.
  - Resourced to Leverage.
  - Lived Experience-led Change.
  - Critical Reflection.

# across your agency, at all levels




Increasing level of public impact

|                | INFORM  | CONSULT   | INVOLVE   | COLLABORATE  | EMPOWER  |
|----------------|---|---|---|--|--|
| <b>GOAL</b>    | To provide balanced and objective information in a timely manner. | To obtain feedback on analysis, issues, alternatives and decisions. | To work with the public to make sure that concerns and aspirations are considered and understood.             | To partner with the public in each aspect of the decision-making.                                      | To place final decision-making in the hands of the public. |
| <b>PROMISE</b> | "We will keep you informed."                                      | "We will listen to and acknowledge your concerns."                  | "We will work with you to ensure your concerns and aspirations are directly reflected in the decisions made." | "We will look to you for advice and innovation and incorporate this in decisions as much as possible." | "We will implement what you decide."                       |



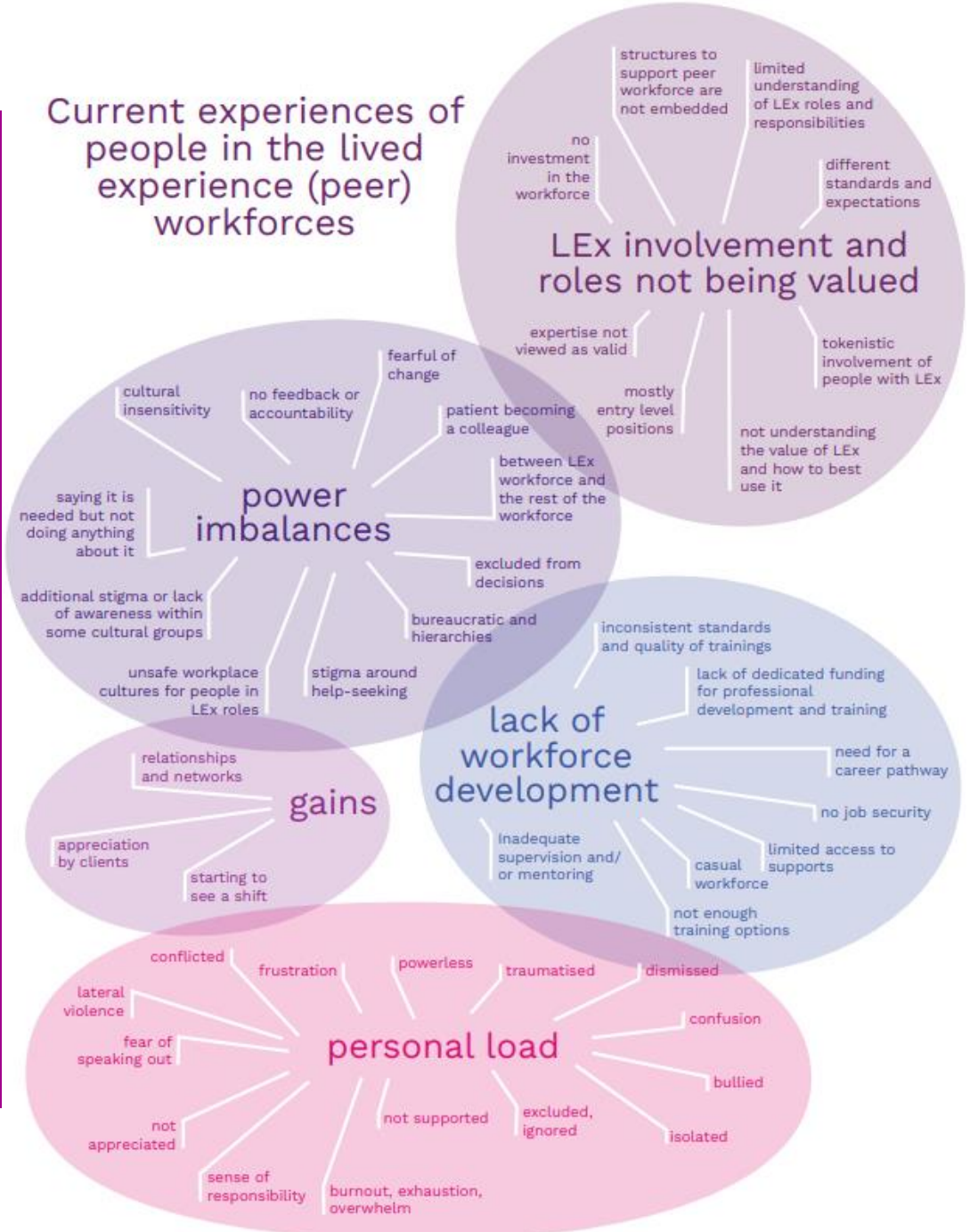
## some caveats and cautions ...

- 'lived experience' may be everywhere, but not everyone has or brings Lived Experience expertise.
- Context is everything!
- 'Consumers' and 'Carers' are not the same.
- Service users, advocates/representatives and lived experience (peer) workers are different.
- Designated roles are necessary.
- Intersectional lived experience visibility and action is critical.
- Leader with lived experience  Lived Experience Leader.

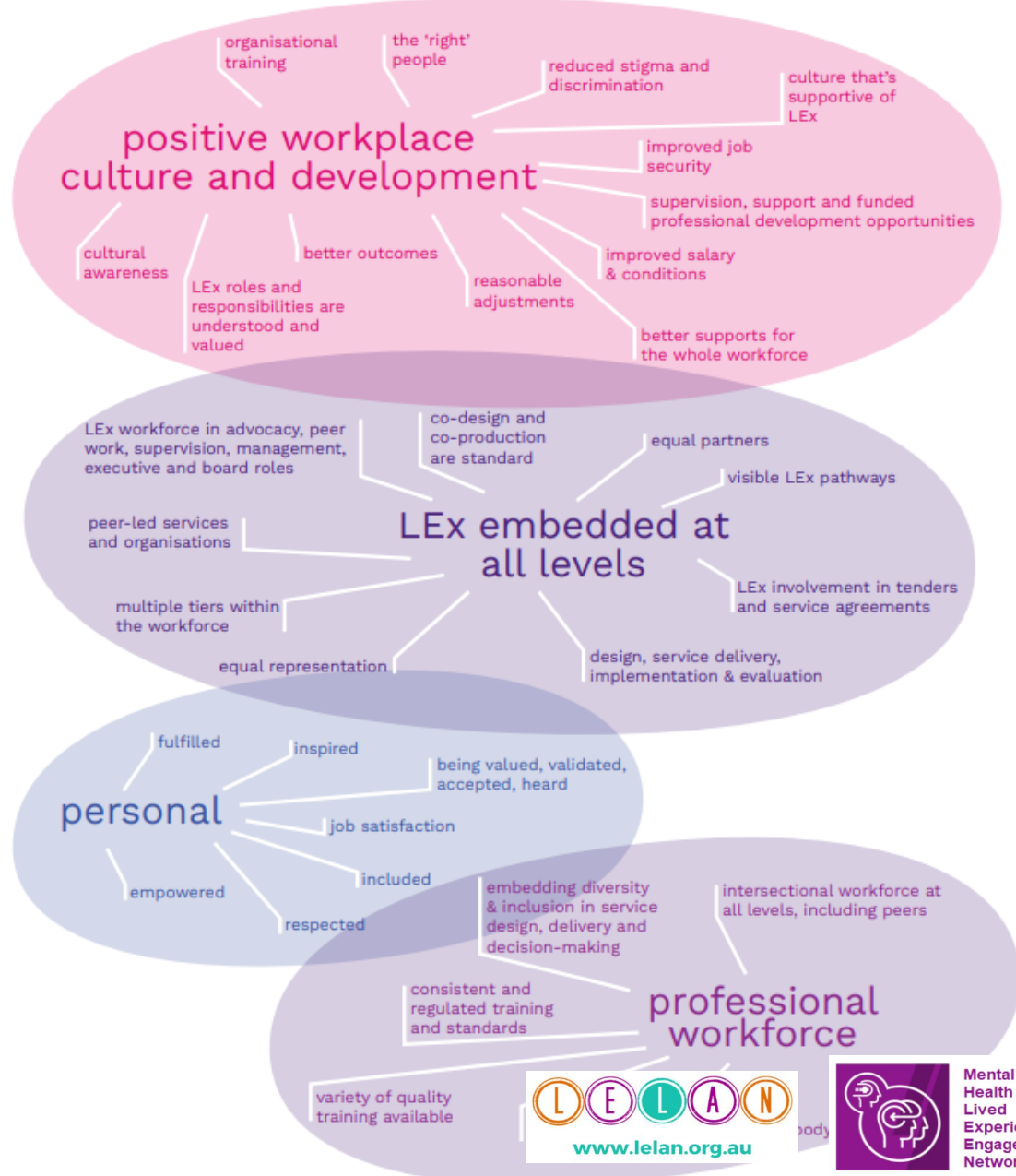
what will be  
experienced and  
seen in  
governance  
systems and  
processes

- [Domain 4] **Transformative Workforces & Practices:**
  - Person-directed and –led.
  - Organisational Commitment to Adopt and Align.
  - Shared Understanding.
  - Shared Responsibility.
  - Role Clarity.
  - Self-determining.
  - Allyship.

# Current experiences of people in the lived experience (peer) workforces



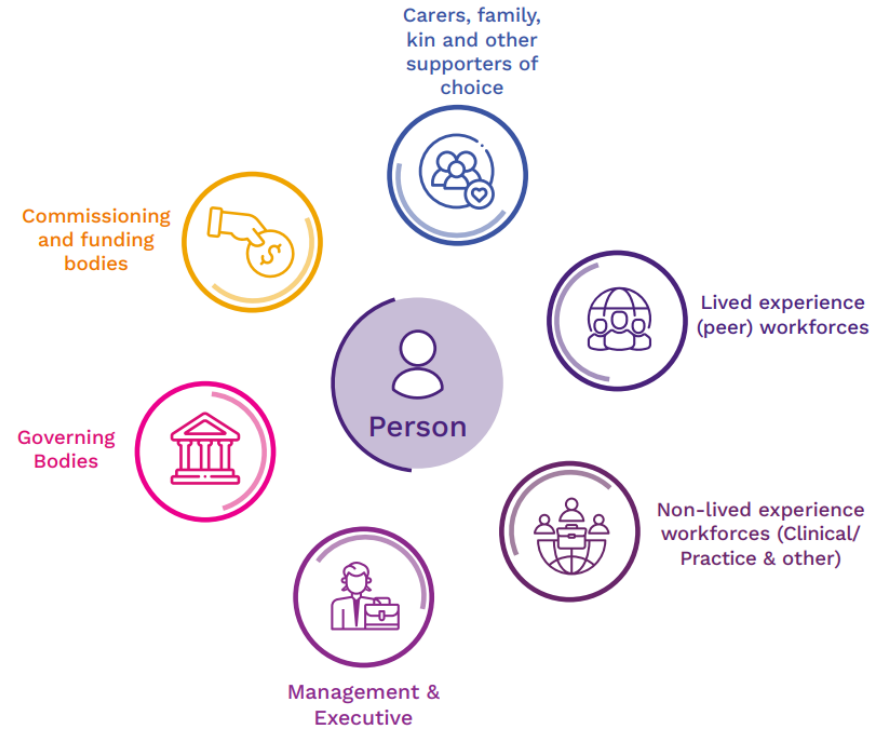
# Hoped for ideal experiences of people in the lived experience (peer) workforces



what will be  
experienced and  
seen in  
governance  
systems and  
processes

- [Domain 5] **Innovation & Continuous Improvement:**
  - Rights-Based.
  - Person-centred Decision-making.
  - Lived Experience-led Change.
  - Evidence-Informed Improvement.
  - Best Practice Development.
  - Sustained Investment.
  - Ongoing Innovation and Improvement.

# roles and responsibilities for Lived Experience Governance



*It's everybody's responsibility, it's not just the people in the lived experience roles. That everyone else plays a systematic role in embedding lived experience leadership, even though they're not employed as a lived experience leader, that's two different things. That's how I see it is enveloping at all, in a sense that, with your clinician or a CEO that isn't in a lived experience, you still have... you arguably have the most responsibility in upholding those principles and values.*

ThinkTank Participant

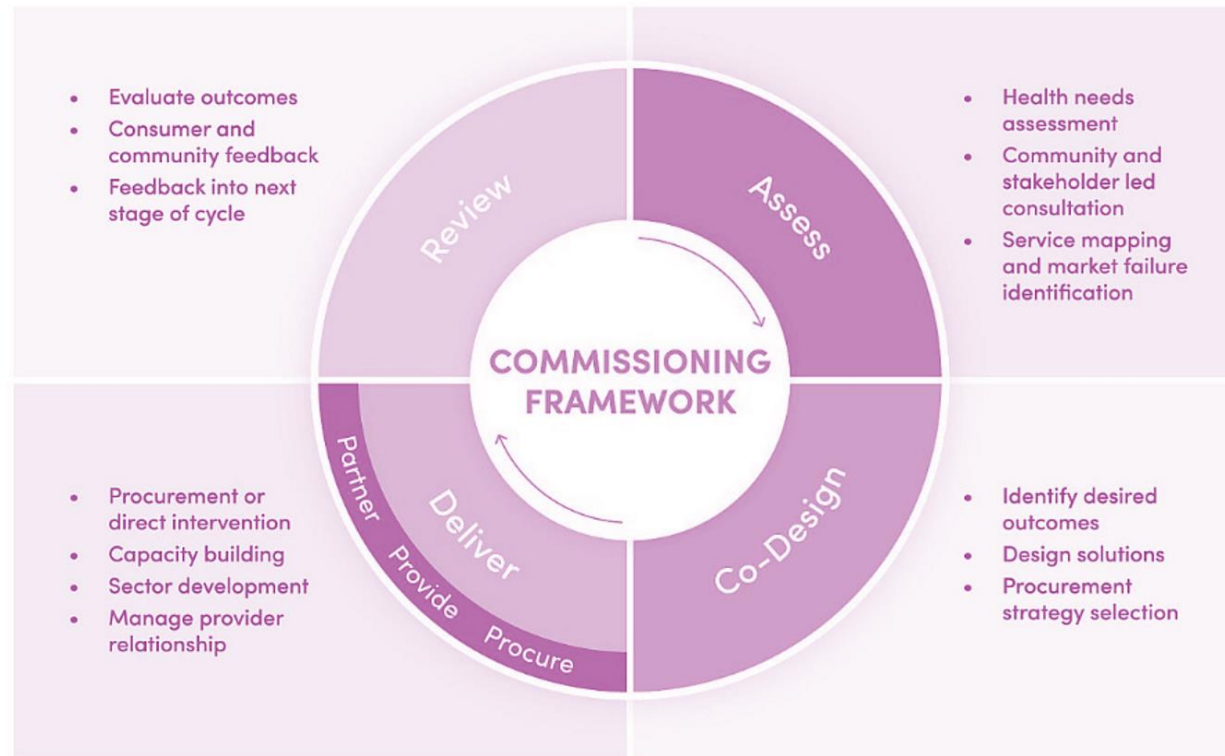
# the PHN context

## What does it involve?

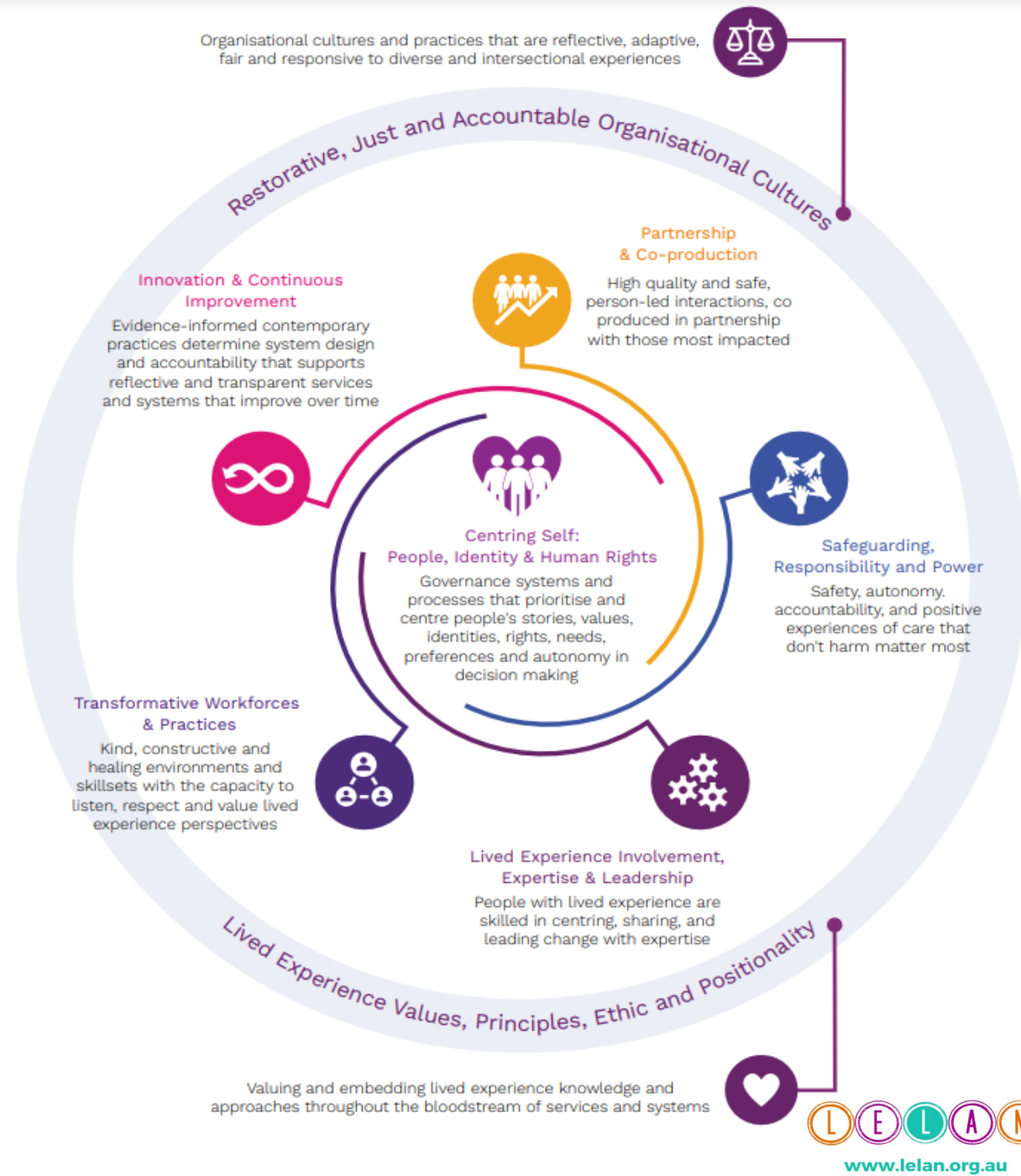
Commissioning is an ongoing process. We assess our community's needs by consulting with community members, then designing solutions with stakeholders.

Our transparent processes promote implementing these solutions, and this includes the way we identify potential service providers.

These solutions are then evaluated, and the outcomes are used to inform further assessment and planning.



# what success looks like





# enablers and accountability for Lived Experience Governance to be meaningfully embedded

## Enablers

### Resourcing

Budgets and timeframes support lived experience involvement and leadership.

People with lived experience are appropriately remunerated and provided with the resources and supports they need to participate.

### Business Processes

Business systems support the representation and leadership of people with lived experience.

Requirements for lived experience representation and leadership are built into contracts.

People with lived experience are involved in commissioning processes.

Priority is given to lived experience-led contractors and agencies.

### Capability Building

The organisation and non-lived experience workforce understand their readiness, willingness and capability for embedding lived experience.

The service has a clear purpose and rationale to underpin lived experience governance.

People with lived experience are supported to contribute to and lead governance approaches.

### Partnerships

The service develops reciprocal partnerships with lived experience communities.

Partnerships are resourced adequately.

## Accountability

### Organisational-level Accountability

Rights-based policies and procedures informed by people with lived experience, that are regularly reviewed and improved.

Regular, easy to understand communications.

It is easy to contact the right person within the service in a timely manner.

Organisations discuss their strengths and weaknesses openly and provide clear steps for involving people with lived experience in improving what they do.

Monitoring, evaluation and learning from a lived experience lens.

### System-level Accountability

Open and transparent communication about organisations' own accountability efforts, what they are doing and the opportunities for improvement.

Organisations build partnerships with the community and sector, based on mutual listening.

Key relationships with sector stakeholders are developed, collaboratively sharing what works, and pushing each other to improve.

Advocacy for lived experience leadership and involvement in system-level change.





*You've got to weigh out the benefit of being able to provide a service that is peer-led, where people feel comfortable and trusting to come, to a service that is so clinically-led that people are not going to be wanting to be there. ... All the way through we've been able to show good decision-making around the decisions that we've made. Things will go wrong, there is no doubt, touch wood it won't be any time soon. There is no doubt at some point something will happen. It's just a fact of life in the services that we're operating, at some point there will be some kind of adverse event. ... And all we can do is show that we have made considered informed decisions around what we've done, and I think we can show that all the way along the process. We have to have a bit of risk appetite, because otherwise we will never move forward. If we're not prepared to have a bit of risk appetite, we're going to sit in the 1950s forever.*

Thinktank  
Participant

# Closing Out

resonant points,  
and the  
questions that  
remain

1. What has **stood out** to you today?
2. What do you and your colleagues **need to keep talking about** and **grappling with**?
3. What **excites or energises you** about this work?
4. What **questions and/or concerns** are you left with?
5. Any **additional comments** you would like to add?

# THE most important thing

- With everything that we have explored and talked about today [and with everything else that you have ever read, observed, thought or been curious about] ... what is THE most important consideration for how Lived Experience Governance can inform your work in the PHN context?

**Pathways For Supporting The 'Not Negotiable' Lived Experience (Peer) Workforces To Thrive**

A scoping paper for formal lived experience expertise training programs and supports

PRESENTED BY

**The Lived Experience Governance Framework**

Centering People, Identity and Human Rights for the Benefit of All

PRESENTED BY

**A Toolkit to Authentically Embed Lived Experience Governance**

Centering People, Identity and Human Rights for the Benefit of All

PRESENTED BY

**SA Health A co-created Philosophy of Care**

Version Two DECEMBER 2022

**SA Health A co-created Philosophy of Care**

July 2020

**Enabling Lived Experience Involvement to Thrive and Have Impact**

Right conditions for enabling lived experience involvement and leadership to thrive and have impact within organisations are highlighted in this guide. Each condition contributes to an overall right to better outcomes of staff opportunity for inclusion of people with lived experience, the greater benefit to all people because teams that do right conditions are enhanced.

This work was facilitated by LEARN's Executive Director, Ella Hedges in 2021. It emerged after extensive review of national literature and lived experience in a lived experience representative of staff and national level in both personal and professional roles held at the time.

LEARN | SA Lived Experience Leadership & Advocacy Network | www.lelan.org.au

**A Roadmap for Strengthening Lived Experience Leadership for Transformative Systems Change in South Australia**

Activating Lived Experience Leadership (ALEL) Project

**The Model of Lived Experience Leadership**

The model of lived experience leadership was developed to guide living with lived experience leaders and other stakeholders across a range of settings to engage in collaborative work. We recognise your health and well-being is central to the work of lived experience leadership and that your experience is the starting point for all work.

Centered on the individual lived experience leader, the model is built on four pillars: **Authenticity, Mutuality, Intentionality, and Peer Support**. These pillars are supported by a range of strategies and practices that are detailed in the accompanying toolkit.

**Authenticity**

- Centered on the individual lived experience leader
- Authenticity is a core value and practice
- Authenticity is a core value and practice
- Authenticity is a core value and practice

**Mutuality**

- Centered on the individual lived experience leader
- Mutuality is a core value and practice
- Mutuality is a core value and practice
- Mutuality is a core value and practice

**Intentionality**

- Centered on the individual lived experience leader
- Intentionality is a core value and practice
- Intentionality is a core value and practice
- Intentionality is a core value and practice

**Peer Support**

- Centered on the individual lived experience leader
- Peer support is a core value and practice
- Peer support is a core value and practice
- Peer support is a core value and practice

**Strengthening Lived Experience Leadership for Transformative Systems Change: A South Australian Consensus Statement**

**Our Vision**

We believe passionately that now is the time for lived experience leadership to be developed and embedded in our systems. The need is visible and the conditions for change are right. The vision for lived experience leadership and care services is where humanity and connection are central and where people with lived experience meaningfully and equitably contribute at all levels. It is the goal that inspires the work.

Through taking action together a more holistic approach will guide change, and ensure that our language, power, and resources shift beyond biomedical and linear, dominant narratives. Community rights, giving control to people to determine that over time and subject to ongoing essential foundations of the change we seek, services where people are valued, compassionate care is abundant and accountability exists, after people working support a better experience of care and better outcomes for their lives. Systems are strengthened when discrimination and bias are removed and where people's dignity is prioritised.

Leadership across the system, including by and with people with lived experience, is core to the vision being realised and is itself a key driver of the broader systems change that the mental health and social services sectors require.

**Our Actions**

As a collective we believe that the following actions will contribute to fundamental change, and we are committed to bringing them to fruition.

1. Increase the presence of lived experience leaders in governance. Ensure more lived experience designated director positions with boards, advisory councils and coordinating groups.
2. Learning and cultural change programs of lived experience leadership, supports, preferences and working through stigma and change.
3. Strengthen learning pathways and leadership skills development for people with lived experience and enable and encourage opportunities for them to lead and guide others. Create open access to professional development and formal qualifications.
4. Fund leading lived experience organisations to develop and deliver networking activities, including coordination of information, activities and events that support local lived experience leadership, community resilience and voice across diverse population groups. Focus on intentionality.
5. Enable resource flows for meaningful co-production of all services and programs. This should include training of organisations, leaders and staff, and funding opportunities at the state for lived experience advisors.
6. Promote lived experience leadership and accountability measures through service agreements, KPIs and, where appropriate, regulatory frameworks and legislative provisions.
7. Ensure models of care include equal recognition of lived experience workforce and peer support.
8. Create range of organisational and sector infrastructure for the effective recognition, valuing and embedding of the lived experience workforce.

**REFLECTIVE RESOURCE**

**How ready, willing and able are you to embark on an authentic co-design process?**

This reflective resource is designed to support both individuals and teams to understand how ready, willing and able you are to embark on an authentic co-design process.

The Co-Design Network

**getting OUR Rights right Right?**

by the SA Lived Experience Leadership & Advocacy Network | LEARN

[www.lelan.org.au/shared-resources](http://www.lelan.org.au/shared-resources)



THANK YOU!

[ellie@lelan.org.au](mailto:ellie@lelan.org.au) if anything comes to mind later

