National Mental Health Commission

National Lived Experience (Peer) Workforce Development Guidelines

Summary of Consultations

Informing the development of the National Guidelines
Summary of Consultations

About this report
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This publication is the second in a series of annual consumer and carer perspectives reports. A complete list of the Commission’s publications is available from our website.

ISBN: 978-0-6452319-3-9 (Online)

Acknowledgement
The Commission has worked closely with mental health stakeholders to develop the Lived Experience (Peer) Workforce Development National Guidelines.

The Commission would like to thank all of the people who gave their time and expertise to the development of National Development Guidelines including the Steering Committee:

- Margaret Doherty (Carer Peer Worker; Deputy Co-Chair)
- Tim Heffernan (Consumer Peer Worker; Deputy Co-Chair)
- Darren Jiggins, Lived Experience Australia
- Sandi Taylor, Indigenous Sector Perspective
- Heather Nowak, Consumer Peer Worker
- Jessica English, Consumer Peer Worker
- Max Simensen, Consumer Peer Worker
- Ruth O’Sullivan, Carer Peer Worker
- Susan Adam, Lived Experience Australia
- Emma Cadogan, Government Perspective
- Megan Still, Employer/ Service Perspective

We would also like to thank Lesley Cook for her contribution to development of the National Guidelines.

Suggested citation

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Introduction

The Lived Experience (Peer) Workforce Development Guidelines (the National Development Guidelines) are the result of extensive consultation and a co-production process to ensure that national standards for Lived Experience workforce development are grounded in the expertise of lived experience.

This report provides details of the findings from consultations conducted as part of the development of the National Development Guidelines. Consultations included focus groups, a series of targeted interviews, consultations with Aboriginal and Torres Strait Islander Peoples within Indigenous-specific organisations in Victoria and Queensland, and an online survey.
Focus groups and interviews

The *National Development Guidelines* are the result of extensive consultation and a co-production process to ensure that national standards for Lived Experience workforce development are grounded in the expertise of lived experience. Stakeholders included people with personal or direct lived experience (consumers), families/carers, designated Lived Experience workers, people working for government departments, mental health commissions, managers/employers, and non-designated colleagues. Across the engagement activities 787 people participated. All engagement activities sought diverse perspectives to ensure a broad range of views, experiences, identifications and cultural perspectives were included.

Overview

The first focus group was specific to consumer and carer peak agencies and networks, the second group identified key government and clinical stakeholders, while the interviews were targeted at ensuring the consultations included a broad range of perspectives and experiences. All consultations aimed to represent stakeholders spanning national and state jurisdictions. A total of 78 people have participated in consultations.

Approach

Each interview began with a description of the background to the *National Development Guidelines*, an overview and discussion of the aims of the research. The overarching elements of the *National Development Guidelines* were outlined as:

1. Guiding principles/values of peer/Lived Experience work, including role delineation/ definitions and what uniquely informs the work for peers, organisations/management/ non-peer colleagues and funders/policy makers.
2. Organisational supports and strategies needed to support the Lived Experience workforce.
3. Recommendations.

The core theme identified through the national consultation process was the need to develop flexible, recovery-oriented workplaces where Lived Experience workers are enabled to achieve in their professional roles with flow-on benefits for the whole workforce and for service users and their families.
**Focus groups and interviews**

### Demographics of participants

The self-identified demographics of these participants are listed below:

**Table 1.** Demographics of participants in focus groups and interviews

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<td>participants</td>
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<td>25</td>
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<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>78</strong>*</td>
</tr>
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</table>

*The total included people who identified as belonging to more than one group.*
Overall, the National Development Guidelines were considered timely and an opportunity to unite the workforce and provide consistent understanding of Lived Experience work across organisations, contexts and jurisdictions, including common principles/values/skill set of the Lived Experience workforce.

The National Development Guidelines were further viewed as an opportunity to ensure lived experience language and concepts were centred and an opportunity to explore alternate terms and understandings of distress and role identity – beyond deficit, medical and individual models of understanding.

In response to presenting the background and context of the National Development Guidelines, several points were raised by participants. These are grouped under the areas of values and understanding, applicability and aim.

### Values and understanding
- Participants raised the importance of an understanding of the common values of Lived Experience work and for values to underpin the National Development Guidelines. This was reinforced as the first stage in the development and foundational to the National Development Guidelines.
- Lack of unified understandings of Lived Experience work was raised as an issue along with the need for consistent understanding of what the Lived Experience workforce is.
- Importance of language and frameworks. The National Development Guidelines were viewed as an opportunity to use alternate terms and understandings of distress – beyond current deficit and individual models of understanding.
- Need to include the skill set of the Lived Experience workforce and how this differs from non-Lived Experience roles.
- Need for relational recovery perspective in relation to families and diverse cultures – the individual paradigm will not meet the needs of diverse communities.

### Process of developing the National Development Guidelines
- Participants appreciated the consultation process and the desire for meaningful inclusion of diverse voices.
- Desire to acknowledge existing examples of best practice and reference Lived Experience operated (managed/run) organisations – “it is happening in niche pockets. Duplicate. Others have done the work. Use it”. This was echoed by other participants who reinforced the need to ‘not reinvent the wheel’ and to ‘use best practice examples’.
- Buy-in from Human Resources (HR) departments, management and funding bodies was viewed as critical in making implementation a priority.
- Include link to existing resources and those under construction. Participants wanted supporting resources and tools that can support guidelines implementation.
- Link the National Development Guidelines to Mental Health Standards and Quality Standards and Frameworks.
Applicability of the National Development Guidelines

- Guidelines need to be relevant across different levels of and types of Lived Experience roles.
- Look beyond mental health. The Lived Experience workforce can be in any workforce, although at present it is almost entirely in mental health organisations.
- Carer and consumer workforce: desire to understand how the National Development Guidelines might be able to include and appropriately recognise the differences and commonalities between these workforces.
- ‘Systemic’ issues within mental health service delivery need to be recognised and steps taken to address these as a barrier to Lived Experience Workforce.
- Need to embed diversity and the requirement for Lived Experience workforce as policy recommendations within the National Development Guidelines to make sure it happens. Example used was the mandatory use of Lived Experience Workers in the Department of Social Services: Personal Helpers and Mentors Program (PHaMS).
- Accessible in plain English, culturally adapted and use of examples, stories, scenarios to increase relevance.

Aims of the National Development Guidelines

- Incorporate systemic as well as practice level responses and recommendations.
- The National Development Guidelines need to acknowledge Lived Experience work as transformative practice and influencing system change.
- Highlight practical and implementation needs for organisation regarding the value and delineation of roles.
- Ideas for future development. For example, resources to assist with designing roles.
- Desire to meaningfully incorporate recommendations.
- The National Development Guidelines will be flexible and able to be adapted to different contexts. Recognition that several resources are already in use. For example, self-assessment tool in South Australia.
- Needs to include the overarching shared vision for the Lived Experience workforce.
- The National Development Guidelines promote transparency. Organisational self-assessments on operational readiness should be available for peer workforce applicants to assess environment they are applying for employment that they ‘include the self-assessment and star ratings for organisations’.
Lived Experience was preferred by the majority of participants as the overarching term for the workforce. This was based on the following reasons:

1. Peer work workforce carried an implication of direct support work.
2. Many participants in Lived Experience roles described the term ‘peer work workforce’ as limiting and raised concerns that it may not be seen to represent the whole workforce. For example, policy, strategic, non-human facing roles.
3. Lived experience or consumer lens described the perspective that they were bringing to roles in consultancy, education etc. “Peer work doesn’t reflect my role.”

Several participants described the Peer Workforce as part of the Lived Experience workforce with Lived Experience the broad umbrella term. However, it is noted that while some participants did prefer peer workforce, and consumer and carer workforce, this was the minority of participants.

Role titles

Language was also raised in relation to the job titles of consumer and carer. Many participants described a preference for job titles as direct experience and family experience. It was also noted that many participants prefer to discuss emotional and mental wellbeing rather than mental illness/health.

The following considerations were raised in relation to role titles:

- The word ‘carer’ was a barrier for many people and did not adequately reflect many people’s perceptions of the role in supporting others.
- The term consumer was not a term that many participants were comfortable using in relation to their identity. It had a negative connotation for many participants who also described it in terms of associations with ‘marketing’. Interestingly participants acknowledged the history of the consumer movement and the origins of the term but stated that the gains of empowerment and human rights need to be discussed and that this wasn’t contingent on using the term consumer. Some participants also proposed using lived expertise rather than lived experience in reflecting the skill set and work role as opposed to personal experience.

Cultural considerations in relation to terminology

Specific cultural considerations are also included in relation to job titles and terminology:

- Social and emotional wellbeing was the preferred umbrella term for Aboriginal and Torres Strait Islander people.
- Healing or journey was preferred to recovery.
- Family or support person was preferred to carer.
- People accessing services or participant was preferred to consumer.

Lived expertise means that I have expertise that comes from lived experience, but I am also drawing on theory and literature that is developed and written in this field – many people have lived experience that they don’t use in their work.

We think the job title identifies what we do but it doesn’t. We need to get better at articulating how and why we work.
Values and beliefs underpinning all roles were discussed by participants and several values were shared across many of the participants. While Lived Experience work was considered broad and variable in scope, most participants distinguished Lived Experience work as non-clinical and oriented or informed by personal and collective lived experience/expertise. It was important for many participants that peer work was different from the status quo or traditional service delivery and presented an alternative approach that was often described as political. Other frequent descriptions included the importance of the human connection as notably different from the perception of clinical service delivery. The common values were:

- Equality/reducing power difference/shared power,
- Self-determination/empowerment/dignity of risk,
- Genuineness/honesty/transparency/authentic,
- Meeting people where they are at/non-judgemental,
- Mutuality/reciprocity,
- Respect,
- Hope/belief in the inherent capacity of the other,
- Compassion/self-compassion/empathy,
- Learning,
- Human rights/advocacy/social justice/responsibility to self and others, and
- Focus on relationship/story applied in the service of others.

**Knowledge**

Lived Experience work was also based on theoretical foundations or knowledge that differentiated the Lived Experience role. The following areas of knowledge were significant:

- Understanding of structural and social influences/determinants of distress.
- Understanding of intersectionality, culture and complexity in relation to layers of oppression and marginalisation (structural, multi-generational).
- Role of power and issues related to accessing and equity of support.
- Understanding of social exclusion, and importance of community and meaningful connection to social networks and activities in communities of the person’s choosing.
- Understanding of the role of trauma and impact on mental emotional wellbeing and mental health/symptoms/diagnosis.
- Knowledge of Human Rights, Mental Health Laws and the rights of people who are receiving treatment and how to advocate and support others to advocate for these rights.
- Understanding of the mental health system. How to navigate the system. Understanding of the roles of other disciplines.
- Understanding of community/alternative services and how to link to these supports outside of traditional mental health services.

It is about values that are transferred to practice – values about another human being, belief in another human being.

The inherent belief is that someone will be able to join the dots, maybe with support, but it is not interrupting that, but our mental health system is taught to interrupt and wrap it up.
Skills

- Relevant and judicious use/intentional use of personal experience.
- Role modelling skills, self-care and self-compassion.
- Communication and working collaboratively both with the person receiving support but also as part of a multi-disciplinary team.
- Conflict resolution/responding to situations of ‘crisis’.
- Community linking.

"Only as a peer can you be there for someone in a crisis if you are comfortable to sit with that distress and value it within yourself, so if you have not worked through your own stuff and have not had someone sit with you and have not understood the value of that personally then I can only come from a theoretical position."

"We have a right and responsibility to ask about trauma."

"Ability to translate our own story into the context of another."

"Rights based work, but it is more than that. It is relational and heart work. We need to stop describing peer work in relation or relative to clinical work and use our own frame of reference."

"We sell ourselves short. It is about standing in my own profession and skill base. Competency and capability base are how we convert experience. We need to be more robust in how we articulate this, and we continue to downplay expertise."
Goals
The goals of Lived Experience work were described by some participants as a way of describing the way Lived Experience work was different and unique from traditional services. These differences included:
• Flexible – not driven by a prescribed agenda.
• Meaning making is foregrounded.
• Outcomes must be related to the values that you work from in the first place.

Practice framework
The practice framework underpinning Lived Experience work was articulated as:
• Strengths-based.
• Recovery/recovery-oriented practice.
• Community development.
• Trauma informed practice.
• Social justice.
• Broader mental and emotional wellbeing or holistic frameworks.
• Non-clinical.
• Systems change.
• Coaching frameworks.

Lived experience spaces are significant beyond the relationship.

The outcome focus of Peer Work is a surprise; it is not about the destination.
Consumer/carer roles – similarities and differences

The consumer and carer workforces were considered by most participants as distinct workforces. Participants described and visually presented a point of overlap between the workforces within a Venn diagram. The point of connection was important, however there was a risk expressed by participants, that by focusing on the point of connection we would lose the distinction and uniqueness of both workforces. Both consumer and carer workforces highlighted the need for mutual respect and understanding for each workforce and many of the values were considered as essential across both workforces. Appreciably, there were hesitations expressed by some participants in not wanting to offend or upset the other workforce, rather than having an open conversation about roles and differences.

Some participants emphasised the commonality and not wanting to segregate/box-in the workforces – described as ‘same bus, different passengers’. Whereas other participants were clear that the workforces should not be considered together. Further, barriers were identified in the current structures of service delivery and that services are individualised with a focus on the person of concern rather than having structures to support a whole family unit, even though it was acknowledged that people do not exist in isolation, and recovery and support for families and networks is needed. The consumer and carer workforce were seen as an opportunity to work collaboratively with the whole family. Both are non-clinical and meet people ‘at that human level’.

Overall, the majority of participants held that the National Development Guidelines consider the consumer and carer workforces as distinct workforces with distinct specialties, with distinct scopes of practice. This is captured well in this quote from one of the participants:

"If you break down the pedagogy – you have clinical and learnt or lived experience. And then underneath that, lived experience of a family member and direct experience."

Some of these key concerns or challenges with including the workforces under one umbrella, without a clear delineation between the workforces, are summarised here:

- The carer workforce is not well understood, and the carer Lived Experience workforce is smaller. Poor role delineation may be due to job availability.
- Fewer carer specific services so Lived Experience workers gravitate to what already exists because they don’t want to lose opportunities.
- Need evidence and position descriptions that are tailored for the carer workforce.
- There is parallel work between the consumer and carer workforce, but we don’t know enough about what makes carer work effective and it is too soon to join these two workforces.
- Consumer Lived Experience had to do the work of defining itself in order to prove its effectiveness and to get funding. Carer Lived Experience needs to do the same.
- Scope of practice – who can you speak for and on behalf of when you speak about lived experience?
- Practice challenges – documentation and outcomes around carer support when services focus on individual support. Where do you record notes? How do referrals happen? How do you ensure confidentiality and privacy?
Consumer/carer roles – similarities and differences

Discussions regarding the consumer and carer workforce raised issues regarding the wider social context. Some of these concerns were:

• Caring is gendered and many carer Lived Experience workers are female.
• Domestic and family violence needs to be considered in the context of carer roles who are in contact with consumers.
• The struggle in combining the workforces was also considered as part of the structural and systemic constraints and focus on individuals rather than families.

Informed by Lived Experience

The lived experience that informs the role considered essential in shaping the knowledge and values that the worker draws from. Personal and direct lived experience was considered different to family experience and the lived experience that informed the paid role as a consumer or carer is significant in ways that shape and make these two positions different and unique areas of practice.

Although the experience as a consumer and carer was considered as distinct from the experience of a consumer or carer Lived Experience worker, the experience was still considered by most as significant in shaping the values, knowledge and skill set of workers in these roles. It was considered important that Lived Experience workers could articulate their role as a consumer/carer worker and align this to their position description based on whether they were employed in a consumer or carer position.

Although it was highlighted that someone could be both a consumer and carer, participants were clear that someone could not work from both and suggested that the role is shaped by what ‘leaves the biggest imprint’ on your life.

Role clarity was also essential to guide practice and, for people with dual identity, the position description needs to be clear about how you work and what experience you are drawing from, and for workers to use transparency and intentionality when drawing from experiences that are not part of their primary role, for example a carer Lived Experience worker may draw from personal or direct experience to share with other carers when this is purposeful and transparent.

I wouldn’t call family work Lived Experience. There is direct experience and family experience.

Carers want to be included within consumer workforce and have the same explanation of their role but it has been a disservice to the carer peer workforce and suspect it has diminished differences that may have helped the carer workforce to grow.

When we see the distinction, we see representation and increased diversity of voice and we see both workforces prosper.

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Similarities between workforces

Commonalities between the workforces were described in focus groups and interviews in terms of the values and skills of the workforces. Shared values across consultations included connection, advocacy, support, navigation, skill development, safety, social change, mutuality and learning together. For both workforces, authenticity was stressed by participants and a need to be self-aware of our own history, experiences and bias. Working and being informed by trauma was considered essential for both workforces.

Differences between the carer and consumer workforces

Differences were noted with participants emphasising the values of diversity, autonomy, dignity of risk, power and confidentiality as more pronounced within consumer roles. Consumer roles were also seen as having more emphasis on rights-based or ‘change work’, defined as shaping or changing the system. Similarly, the consumer movement was considered an essential part of the identity of many consumer workers and this was compared to carers with questions regarding whether the emphasis on the consumer movement was significant to carer Lived Experience workers. There was a significant difference for consumers in direct personal experience of oppression as opposed to supporting someone in this experience. Experiences of power and stigma were also considered as points of difference with consumers often subjected to higher incidence of stigma and disempowerment.

Although participants identified that many values and skills could run across both the consumer and carer workforce, some participants posed that these skills may look the same on the surface, but how they are applied to practice and what they look like on the ground, is very different. Some examples discussed included: values/principles of human rights, dignity of risk, autonomy, self-determination and safety. Some of the content and learning objectives may also be different, for example, self-determination may be different for carers who may need to work through ‘carer anxiety’ and develop healthy boundaries.

These participants concluded that although the skill set may be the same and the workforces may share some values, a distinction still needs to be made between workforces.

Summary of Consultations
Carer roles recognised the need for a relational understanding of recovery rather than seeing recovery as strictly individual in focus. A point of tension was noted with confidentiality and ‘nothing about us without us’ as potentially being different in the work for consumer and carer workers.

In addition, work practices may be different based on the setting and operational factors, such as referral process and initial contact may be different for carers. For example, carers working in an acute setting do not directly approach consumers but wait until the consumer’s family are identified as needing support.

Throughout the consultations, participants described the need to respect both perspectives and hear the wisdom of both. Participants stated that they did not want to limit either workforce but wanted to acknowledge that experiences of power and privilege within these roles may be different. Some of these points were articulated as:

- Carers do not usually have their competence questioned whereas consumers often have their reality and competence questioned.
- The current structure of service delivery is that the consumer is the focus of attention and services. This results in complications for referrals, documentation and outcomes. The goal of carer worker needs to be supporting family/carer wellbeing, not supporting carers so that there are better outcomes for the consumer.
- Risk of being stuck in caring dynamic for families. Sometimes the caring dynamic and caring roles have not been helpful for consumers and can be challenging when translated to interacting with the carer workforce.
- Some participants raised concerns in the applicability of a consumer framework to the carer workforce when frameworks such as Intentional Peer Support (IPS) training have been developed for consumers and scenarios are based on working with consumers.
- The carer workforce needs to struggle to find their own identity as a workforce or they will get lost completely.
- Competencies as a workforce may be similar but their competencies of something different – meaning making, advocacy and capacity building is the same. However, competency for a carer worker would be about meaning making for the family. The advocacy is also different and may oppose the advocacy needs of consumer. Capacity building is for the family not focused on the consumer.
- For family workers, identity is tied up in relationship. This shapes the role and focus for family/carer workers.
- It was also proposed that consumers may be able to provide a consumer perspective to carers.

Summary of Consultations
But we can’t jump and hold the same perspective. It needs to match your lived experience and what can be empathised with.

Consumer and carer better positioned as sections under the lived experience workforce. Risk diluting the workforce. Just combining because … without being meaningful, strategic, intentional in including both workforces.

Carers bring a skill set in advocating for their loved one. Carers may not have experience in working alongside other carers. Skills as a carer may not translate to skills working with carers.

As a general rule the work is very different and reasons for lived experience and family experience work is different.

Family agenda is about care and protect. The lived experience agenda is about thrive and live, take risks and challenges. That’s where they butt heads. Family perspective is still around a cocoon of safety.

There is a different kind of thinking around the reasons that they are in peoples lives. Some of the values are the same but some are very different for example maybe a loved one needs care and support, advocacy to get into hospital and that is different from a lived experience perspective.

Compared to beliefs that they have about people in distress, it is very different. Care and protect is closer to a professional paradigm.
What is Lived Experience in relation to Lived Experience roles?

Participants described their understanding of lived experience as required for designated roles. Overarching themes included the importance of identity and context. Context was mentioned repeatedly as a consideration of relevance of lived experience. The position description and purpose of the role was significant for participants in identifying the relevance/purposeful use of lived experience in relation to connection to people within different settings or different experiences, and the use of lived experience to benefit others.

Many participants considered self-identity as key. Others questioned identity in relation to the specific experiences of others. This concern was salient in regard to considerations of culture, LGBTIQA+, specific lived experiences of hearing voices, perinatal mental health, veterans, eating disorders and suicidality. Conversely, some participants suggested that it is important to ask people what they want and not assume they want someone with a similar experience. Generally, diversity within the workforce was important, and having a range of perspectives and representation in the workforce.

Identity
Identity was important in deciding how much lived experience was important. Identity was also considered as self-identification, and that it changes over time, is not based on diagnosis and the importance of intersectionality, especially in relation to culture.

Purposeful use of lived experience
The experience was considered as being centre of the work and the source of expertise. Further, it was the use of lived experience to benefit others/achieve system change and improve service delivery that was significant. This was described as lived experience being the connection point rather than the content.

Context of roles is important
Context for the roles may be an advantage in understanding the setting and having greater empathy and providing a role model for peers.

Lived experience was also considered in terms of an understanding of receiving peer work and participants described the need to have experienced and received peer work to be able to have an appreciation of what is needed in providing support to others. This related to the need for managers to have experience in providing peer support before moving into roles within management or leadership. A few participants described an apprenticeship model in developing skills and progressing their career. The apprenticeship model gave a pathway for generalist skills as foundational and then the option to specialise in different areas. An analogy used was becoming a chef and then having the option to specialise in a specific area.

However, some participants struggled with generalising about what is enough lived experience and were concerned that debates about lived experience marginalise and separate people.

Do not want people to reach the lows to gain the magical thing that is enough.
Summary of key points in relation to understanding what lived experience is required for Lived Experience roles are:

- Lived Experience needs to speak to the context and capabilities of the roles, to support connection.
- Expertise gained is more important than the lived experience itself.
- People need to have accessed peer support for themselves. It can also be an advantage to have had experiences of being in a specific setting or having a particular experience e.g. acute settings or hearing voices.
- Carer role – it is an advantage being a carer of someone who has experience in the context described above.
- Lived Experience workforce needs to have a range of cultures and experiences.
- It is about relatability, but also our strength is a commonality within difference.
- Complex – sometimes people find it helpful to have support from someone who hasn’t had the same experience.
- Some participants said level of recovery was important, but this was not a prominent finding.
- Other factors and life experiences are important e.g. age, being a student or migrant.
- Perception of lived experience seems to be public mental health services. This equals more significant Lived Experience at the ‘pointy end’ and considered by some as more ‘right’ to be a Lived Experience worker. However, this was disputed by others as limiting.
- Cultural considerations are important – some cultures do not readily access services but identify as having mental health/emotional challenges.
- Intersectionality is an important consideration in terms of experiences, culture and trauma.
- Trauma experiences may be more significant in being a thread of connection.
Participants were asked to identify existing interventions and strategies that organisations use to support the peer workforce. Strategies were identified that are currently in place and working well, along with ideas for what is needed and specific interventions. Repeated topics included supervision, opportunities for networking, flexibility, an inclusive workplace culture and policies that support lived experience. Many participants identified the need for greater Lived Experience supervision and for more choice and flexibility for supervision i.e. group, individual or external supervision. Supervision was described as needing to be ‘ongoing and supportive’. For Aboriginal and Torres Strait Islander people, the need for Elder supervision was essential. Some Lived Experience participants described challenges in being operationally managed by clinical staff, while others described supervision as being ad hoc and consisting of group-based supervision only or informal ‘catch ups’.

Opportunities for networking and communities of practice was mentioned by several participants. Participants further identified the importance of formalising values into vision statements, policy and position statements, stating the importance of supporting and developing the consumer and carer identified workforce.

Recruitment and design of role descriptions need to be developed by people with lived experience of these roles and in the absence of senior Lived Experience roles, this needs to include either external Lived Experience consultants or be guided by entry level roles that develop Lived Experience based on the specific needs of the service.

Summary of strategies needed to better support the Lived Experience workforce

Table 2: Summary of organisational strategies

<table>
<thead>
<tr>
<th>Strategy needed</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td>Preparation, training and planning</td>
<td>- Whole of workplace training, open discussions with the whole workplace, opportunity to share concerns and share together safely</td>
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<tr>
<td></td>
<td>- Access and opportunities for training in person or online, developed by Lived Experience champions</td>
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<tr>
<td></td>
<td>- More educators are needed</td>
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<tr>
<td>Training, professional development and career pathways for the Lived Experience workforce</td>
<td>- More professional development training</td>
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<tr>
<td></td>
<td>- Identification of training needs and gaps</td>
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<td></td>
<td>- Long term strategy for building the workforce and capacity</td>
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<td></td>
<td>- Career pathways and recognition of success and effectiveness</td>
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<tr>
<td></td>
<td>- Lived Experience academics play an important role in developing the evidence base to give the workforce greater strength</td>
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### Strategy needed

**The embedding of the Lived Experience workforce – a strong philosophical approach**

- Lived Experience roles still need to be across all levels of the organisation
- Valuing and understanding of Lived Experience workforce
- The Lived Experience workforce should be considered an asset. ‘Lived experience should not be optional’
- Lived Experience leadership roles at all levels and on the Board
- Development of a workforce strategy and Lived Experience workforce model of practice training for managers developed and delivered by Lived Experience workers in working with and developing the Lived Experience workforce
- Whole of staff training around the value of Lived Experience workers, supporting and valuing the experience and contribution of all staff with lived experience
- Lived Experience input into position descriptions, recruitment, orientation, policies and procedures relating to practice
- Lived Experience specific orientation
- Robust, comprehensive recruitment process
- Organisational readiness training
- Training for the Board about the consumer movement and perspectives

**Role clarity**

- Need to first define what the role is, and what skills are required
- Position descriptions developed with Lived Experience workers
- Strategic development and understanding of consumer and carer roles

**Supervision**

- Lived Experience supervision is essential. Greater opportunities for supervision are needed. Options for external supervision
- Co-reflection should also be available across organisations using structured and unstructured formats. Supervision by line manager (operations/management) and practice supervisor (strategic oversight and support) to work together
- The inclusion of Lived Experience supervision at these levels is needed and should be valued and formalised by the organisation. Need someone in these roles who can escalate concerns
- Carer specific and consumer specific supervision is needed to support role clarity
- Clinical supervision in some settings raised concern that this impacted role clarity for Lived Experience workers
- Differences in supervision were also noted as distinct for government and non-government workers
- Additional support and supervision available through the Employee Assistance Program (EAP)

**Workplace culture**

- In meetings, team days, support one another. Create a vibrant, diverse and inclusive community at work and a culture that supports all people in designated roles and the lived experience of all workers. Support to challenge non-Lived Experience friendly practices
- Culture and practice supervisor designated position

**Standards**

- Minimum best practice standards for Lived Experience workers
- Implementation of Key Performance Indicators (KPIs) and for these to be visible and a high standard

### Summary of Consultations
<table>
<thead>
<tr>
<th>Strategy needed</th>
<th>Details</th>
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<tbody>
<tr>
<td>Supervision for supervisors</td>
<td>• Formalised support and training for Lived Experience supervisors</td>
</tr>
</tbody>
</table>
| Policy and practice                    | • Policies and practices that are specific to Lived Experience work e.g. documentation/progress notes  
• Policies and practice that support whole of workplace wellbeing, including greater opportunities for using mental health as a credible reason for taking leave  
• Lived experience needs to be embedded within policies and practices  
• Organisational policies against stigma and discrimination |
| Reasonable accommodations              | • For all staff. When you do things that support peer workers, you support the whole workforce and change the organisational culture  
• Some participants also advocated that for people using their lived experience within their roles, that additional support needs to be available |
| Flexibility                            | • Flexible support and working arrangements                                                                                                                                                           |
| Peaks and leadership                   | • Need Peak workforce body, at state and national levels                                                                                                                                               |
| Anti-stigma                            | • Stigma is still prevalent – e.g. staff debriefing about consumers and carers in the lunchroom, even with the Lived Experience worker in place. Need commitment to call out language – culturally this is also an issue  
• Advocacy and educating public and politicians e.g. highly visible, public positioning at events, festivals, public statements around mental health rights and LGBTIQ+ rights  
• Change anti-stigma to inclusive workplace culture. Sometimes stigma is really discrimination and poor practice and there needs mechanisms to hold organisations accountable  
• A major concern for Lived Experience workers is the requirement to complete Wellness Plans when other workers are not required to do so. The Plans were held by their line manager. Wellness Plans as a whole of workplace initiative was suggested as a way to address this discrimination  
• Organisations and peaks have an advocacy role and aim to educate the public and breakdown stigma |
| Disparity between Lived Experience and traditional workers | • Appropriate remuneration for Lived Experience workers is needed                                                                                                                                       |
| Networking                             | • Many participants recognised the value of connection and wanted more opportunities for networking. This was needed at all levels including for leaders, for example a leadership network for coordinators and managers of organisations working together to develop strategies  
• Opportunities for collaborative working with other Lived Experience workers. More communities of practice with online formats. Local forums and conferences |
| Beyond mental health                   | • Consider investing and supporting other industries developing Lived Experience workforce                                                                                                              |
Strategies/interventions to support the Lived Experience workforce

<table>
<thead>
<tr>
<th>Strategy needed</th>
<th>Details</th>
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| Cultural considerations         | • Creating cultural safety within organisation and recognition of cultural practice and significant days  
• In Aboriginal and Torres Strait Islander consultations a number of specific considerations were raised e.g. the need for Elder supervision  
• Cultural considerations need to recognise the importance of spirituality, trust, identity, connection to country, trauma, impacts of colonisation  
• Consistency and time are significant and a holistic approach that recognises the impact of trauma  
• Cultural obligation within the agency  |
| Ratios of Lived Experience workers | • Needs to be more than one. Need to develop minimum number of peer workers needed to support an effective Lived Experience workforce  |
| Collaborations between organisations | • Develop Memoranda of Understanding (MOUs) and increase and use networks to provide administrative support to support professional development  
• Mentoring and support for organisations to employ Lived Experience Sharing resources, training and support/staff exchange for regional and rural services  |
| Lived Experience representation | • Memberships with advisory groups, academic groups, clinical boards. Work with local politicians  |

Challenges in implementing supportive strategies

• The decommissioning of the mental health sector and the move towards National Disability Insurance Scheme (NDIS).  
• Reasonable adjustments don’t take into account the uniqueness of working from lived experience perspective, either as a consumer or carer. Some participants described having to fight for reasonable adjustments and that there were no formal structures that currently existed in their workplace.  
• Leave entitlements are not flexible or tailored to mental health and wellbeing needs of workers and their role in supporting families.  
• Lack of adequate expert/experienced Lived Experience supervisors and lack of training to support the development of supervisors. Lived Experience supervision is confused with line management.  
• ‘Anti-stigma’ and ‘anti-discrimination’ should be called out as such not using ‘weasel’ words to describe it. “There is no stigma – only discrimination.”  
• Current KPIs and what is valued by organisations is not congruent with what is significant to a Lived Experience worker “half of my job is challenging culture – I wish this was a KPI”.  
• Casualised workforce, short shifts. Seen as a cheap workforce. Workforce is further marginalised without job security and no room to speak up and often one person to represent a discipline.  
• Physical environment of settings – space, noise, lighting.  
• Need respect and increased valued status for the Lived Experience role. Seen as a lesser role and as a homogeneous group “I am seen as the same as consumers who receives services”.  
• Mental health services need an understanding of social issues and their impact. For example, domestic violence, homelessness, physical health, disability, autism.
What strategies are in place and working well?

- **Development of state and organisational guidelines and frameworks:** Recent work by some participants include co-designed Lived Experience workforce standards and guidelines for the Non-Government Organisation (NGO) mental health sector, which can be adapted for government or clinical services. Working on designing Lived Experience-led supervision framework.

- **Supervision:** Mentorship model – designated Lived Experience mentor role. Options for external supervision, paid monthly external supervision of your choice. Reflective breakfasts. Mentoring. Frequent de-briefing opportunities. Lived Experience huddle after meetings.

- **Reasonable adjustments:** Flourish Australia have a policy called ‘embracing inclusion’ that outlines best practice policy in this area. All staff may fill out a personal plan to allow for adjustments to work and leave.

- **Peaks and leadership:** Consumer and carer peak bodies have been or are being developed e.g. Lived Experience Leadership and Advocacy Network (LELAN), Queensland Lived Experience Workforce Network (QLEWN).

- **Networking:** Community of practice e.g. WA leader’s network.

- **Flexibility:** Family friendly workplace policy with flexible work conditions for children and families. “If we don’t do that, we are not supporting enough.” Flexible work hours.

- **Workplace culture:** Team meetings and open communication. Regular team meetings to discuss what is a healthy workplace and how to address conflict – team comes up with ideas how we want to run as an organisation, strong emphasis on self-care, ensuring all staff are keeping that balance.

- **Reflective practice:** Check in regularly on how the team is upholding the values of Lived Experience work.

- **Organisational preparation/organisational capacity:** Professional development delivered by a Lived Experience champion. Training includes understanding the value of lived experience.

- **Policy and practice:** Supervision practice that includes both one on one and group sessions.

- **Professional development:** Co-design and run regular professional development for Lived Experience workers and their supervisors.

- **Anti-stigma:** Human rights working group with strong lived experience involvement.

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**Allyship**

Participants were also asked about what made a good ally. Here participants generally identified the value of people who acknowledge the value of lived experience and having the skills to respectfully listen and hold space, share power and step aside for lived experience voices. The need for mutual respect for both Lived Experience workers and allies and being willing to shift, change and challenge language, was similarly identified. Effective allyship was described as requiring an openness on both sides and an understanding of lived experience principles and roles. Allies were also significant in advocating and being in authoritative positions where they could actively support and allocate funds for Lived Experience roles.

Allyship was described as an active role that intentionally created spaces for Lived Experience work and found ways to open doors. Allies were able to identify alignments for Lived Experience work within the work setting and find ways to educate and advocate for Lived Experience work. Allies were also needed at all levels to have someone to communicate with and for marginalised workers to feel supported. There is a need for layers of representation within an organisation. A good champion further influences and grows champions within the workplace.

Allies were considered an essential part of the process of organisational acceptance and workplace culture. Participants used the change model in understanding the impact of allies where there were early adopters who readily accepted the value of peer/Lived Experience work and others who initially experienced some challenges but through exposure became supportive and recognised the value of Lived Experience work.

Moreover, the need for allies needs to be formalised to ensure that these roles are implemented, and that the role is recognised within the organisation. Also, the requirement for succession planning so that when champions leave the work is not lost.
Emerging issues and gaps in relation to the Lived Experience workforce

Diversity

Diversity was valued by participants. Attaining diversity within workplaces needed to be proactive and this needed to be stated in recruitment, to ensure that diversity was represented. There was also a need to address systemic issues within mental health systems and barriers to diversity which included attitudes, policy and practices that did not facilitate diverse recruitment or support diverse communities and experiences.

Resources needed to be adapted to be accessible to different cultural groups with an emphasis on easily accessible language for all. Community development and flexible approaches were also significant in reaching and valuing the perspectives of marginalised communities.

Key points included:
- Local Lived Experience workforce should reflect the culture and demographics of the local community.
- In some cultures, family has a more significant role than in Caucasian culture.
- Need to look at defining Lived Experience workers differently in Aboriginal communities. They may be doing Lived Experience work but not identify as such e.g. as a liaison person.
- A rainbow specific policy that sets clear guidelines and goals for the organisation.
- Cultural safety training required for all mental health providers.
- Understanding of trauma for all workers. Trauma was often seen as the common thread regardless of culture or background.
- Intersectionality is important in consideration of the needs of people and in considerations of what makes someone a peer.
- Additional considerations need to be in place when working with people from refugee backgrounds e.g. trauma, language, mindfulness of triggers in relation to oppressors, gender preferences for workers.
- Lived Experience workers recruited from within refugee communities need to be mindful of appropriate cultural mix and cross-cultural understanding. Flexibility in what constitutes lived experience considering many people will not have accessed mental health services but still experience trauma and mental health challenges.

Specialisations

Specialisations overall were seen to have value. However, there was a risk expressed by some participants that by seeing specialisation as separate, this could silo the workforce. Participants identified that there are common and core skills within Lived Experience workforce, but there are also specialised skills e.g. perinatal mental health, suicide prevention. Specialisation was one way of respecting the specialised knowledge that the lived experience brings. Specialisations were more important in some areas e.g. hearing voices, eating disorders, involuntary treatment, forensic settings, Alcohol and other Drugs, veterans, disability, perinatal and young people. This was also seen to mirror specialisations in other health and community service disciplines, where workers can be a generalist or specialist. Yet, a number of challenges exist. Currently, structures and systems do not make specialisations easy to implement and we do not have the numbers or maturity as a workforce to do this effectively.

By specialisations you create opportunities to fund and proportion roles; this was considered significant in growing the Lived Experience workforce. Specialisations were also acknowledged in appreciating intersectionality and the need for diversity to adequately support marginalised experiences.

Summary of Consultations

It doesn't work to have all Caucasian or straight people supporting all individuals.

Advertising commonality is important to join together and to have a common voice. We need both commonality and diversity.
A summary of the key points raised in relation to specialisation are included below:

- Specialisations have value. But seeing specialisations as separate would silo the workforce.
- There are common and core skills, but there are specialised skills. It’s about using fundamentals of lived experience as a strong foundation for then branching into specialised areas.
- The Lived Experience worker has to have a lived experience in that speciality e.g. ‘mental health challenge must have occurred in youth to work as a youth worker.’
- Lived Experience academics play an important role in developing the evidence base to give the workforce power.
- Risk – the field still emerging, which puts us in a vulnerable situation if we diversify and lack unity.
- A participant offered the analogy of a mosaic: “diversity within a whole and each shining in our own ways”.

**Rural and remote**

There were additional challenges in rural and remote areas. These were related to stigma, limited career opportunities, isolation and safety. Participants described being defined within the community and not being able to get away from the label. The small numbers of peer workers added an additional risk of lack of support and burn out. However, some participants also described the strength in being known and being able to raise awareness within local community as a living example, where you become an access point for everybody in the community.

Participants highlighted the need to be very creative in connecting with peers and services, and to use technology; however, technology was not seen as ideal. Training for Lived Experience work was a barrier in regional areas. Suggestions to address barriers included peer exchange programs and greater opportunities for Lived Experience networking.

A summary of the points raised in regard to rural and remote considerations:

- Finding an organisation to be located in is difficult.
- Isolation as a Lived Experience worker.
- NDIS may offer the solution of setting up as your own business.
- Could be positioned in General Practice (GP) but risk that you could be co-opted into a medical model.
- Need to be very creative as not many services, but potential for more flexibility in rural areas.
- Teleconferencing is not ideal – although preference for linking people in different rural areas (not rural to city).
- Education for Lived Experience worker is a barrier and difficulty to access in regional areas.
- Peer exchange idea. Have more people come out into the community for ‘train the trainer’.
- Lived Experience networking is needed in regional areas.
- Travel requirements of regional workers and being considerate in not over burdening people.
- Additional intersectionality with cultural considerations and government policy to resettle refugees in rural areas.

**National Disability Insurance Service (NDIS)**

NDIS was acknowledged as being ‘where the money is’ and this offered potential for more Lived Experience workers to be employed and more Lived Experience workers are working in private enterprise. However, training was needed, and supervision was a potential issue. Other challenges included concerns regarding low pay and a need to recommend that Lived Experience workers be embedded within the National Disability Insurance Agency (NDIA) to advocate for Lived Experience roles and the value of Lived Experience workers within support plans. Points of interest included:

- The reality that it is where the money is.
- Potential for more Lived Experience workers to be employed and more Lived Experience work in private enterprise.
- Higher rate of pay in recognition of training, skills and experience – additional training is required for managers, supervisors.
- Peer should be embedded in NDIA; strong training to change the medical perspective.

Solo work in this area is tough, it is not safe.
Coercive practice

Most Lived Experience workers were adamant that these practices shouldn’t be happening at all and need to be eliminated. However, other Lived Experience workers discussed that it would be naive to think they could be eliminated, and the Lived Experience workers need to be there to provide a different narrative. Generally, participants queried the role of Lived Experience workers within contexts of coercive or restrictive practices, whether actively supporting the person (e.g. providing information about what is happening or in de-escalation) or as witnesses to restrictive practices. They thought the role for Lived Experience workers needed to be clarified and formalised. There was also acknowledgement that the environment of acute settings is challenging and creates, tension and impact for both consumers receiving services in these settings and the Lived Experience worker.

Points of consideration are:

- Exposure to seclusion/coercion as a Lived Experience worker contradicts values, triggers own trauma and/or vicarious trauma.
- Lived Experience workers can have a positive effect in de-escalation, diversion, education and influence staff to avoid restrictive practices and use alternatives.
- Solo voice within a clinical workforce – difficult to be taken seriously and huge responsibility. Lived Experience workers cannot be the only voice advocating for system change.
- Lived Experience role needs to be well defined. This is what we do and don’t do. Currently there is no clear understanding within team of the role of lived experience in this space.
- Need regular supervision, debriefing, pre-briefing, compassion-based leave. Need to give the level of support so that people can be sustainable in these spaces.
- Education, training and awareness is needed to be aware of what is coercive.
- Education and training is also needed on Human Rights and what mechanisms are in place to uphold Human Rights in these spaces.
- Training needs to be role specific. Generic behavioural/aggression training is not appropriate.
- Lived Experience workers need to be in these places as people don’t have a voice. However, this is a skilled role to advocate and needs allies to provide leadership to support and empower people to escalate concerns if necessary.

Summary of Consultations
Cultural considerations

Cultural considerations need to recognise the importance of spirituality, trust, identity, connection to country, trauma and, impacts of colonisation. Consistency and time are significant and a holistic approach that recognises the impact of trauma is also important.

Some overarching considerations were raised during the Indigenous specific consultations:

• The choice to have people from Aboriginal and Torres Strait Islander culture as Lived Experience workers is important and can be very significant in the healing journey.
• Employers also need to be accountable in how they assist Aboriginal and Torres Strait Islander Lived Experience workers and not assume that every Aboriginal and Torres Strait Islander person is the same.
• Cultural obligation within the agency covers both the person and family, but the carer experience is different.
• People from Aboriginal and Torres Strait Islander cultures do not need to identify as having a mental health experience – it can be assumed that through experiences of trauma and marginalisation that they have been impacted and have lived experience.
• Culture often trumps a mental health diagnosis in making someone a Lived Experience worker.

Language and terminology

• Social and emotional wellbeing is the preferred umbrella term.
• Healing or journey was preferred to recovery.
• Family or support person was preferred to carer.
• People accessing services or participant was preferred to consumer.
• Depends on the person, depends on the experience. Ask.
• Language matters.

A Lived Experience worker needs to have these qualities

• Empathy.
• No assumptions or judgement.
• Resilience and being emotionally robust.
• Patient.
• Self-reflective and self-aware.
• Recognise your limits.

Organisational support

• Elder support is very important.
• Supervision within an organisation is challenging. It needs to be personalised, timely, customised and someone who can be an advocate.
• Aboriginal and Torres Strait Islander population can be called on to be a part of services in a way that makes them vulnerable. Need support before you can step into the role. Reality is there isn’t support in organisations.
• Organisations can’t be kind or supportive when their resources are stretched. “The work can be brutal”.

Knowing and understanding the extra layer a person may require with recognising that there are additional barriers and additional rights.

Family/carer workforce

• Family perspective is useful to show a different perspective – not individualised in focus.
• It should be inclusive of whoever is seen to be family, and whoever the person wants to be included.

Supervision

• Cultural/Elder supervision.
• Support/guidance and mentoring.
Participants anticipated that the National Development Guidelines would provide a collective voice for the Lived Experience workforce and a platform for organisational and system change; alongside practical and implementation needs for organisations regarding the value and delineation of roles. The National Development Guidelines needed to address issues that currently exist for Lived Experience workers, including non-existent or lack of appropriate policies (including cultural safety and diversity policies) and procedures, poor or insufficient planning, no evaluation mechanism/process and poor, untimely and/or insufficient collaboration with traditional staff.

There was a strong interest in the National Development Guidelines providing formal recommendations and a vision for the Lived Experience workforce. Recommendations included:

- National and state peak bodies/professional body for Lived Experience workers separate to consumers/carer peak bodies.
- Resources for allies to provide information on how to be an effective ally.
- Clear workplace standards and mechanisms to hold organisations to account – suggestion for Lived Experience auditors to assess or star rating for organisations. Some participants suggested aligning the National Development Guidelines to the National Mental Health Standards, Accreditation and Quality Assurance tools.
- More Lived Experience-led/run organisations.
- An advocacy body or union for Lived Experience workers. Existing unions need to have an understanding of the needs of Lived Experience workers.
- Fair and adequate remuneration for Lived Experience.
- Uniformity in relation to values and principles of Lived Experience work across national and state/territories.
- Lived Experience leadership and mechanisms or pathways to grow lived experience leadership. Lived Experience workers part of decision-making and leadership within organisations. There was a need to change the perception or change the narrative, so not just using or seeing Lived Experience workers as people with lived experience who have strong support and relationship skills, but seeing Lived Experience workers as having expertise in developing policy and guiding practice.
- Stress the need for professional development and networking for Lived Experience workers.

- Reasonable ratios for consumer/carer reps and peer workers. At least one in every team, at least one on every shift, enough so there is representation all the time, not just 9–5.
- PHaMs made a significant contribution to the peer workforce and a historical change within the NGO services. Need policy and structures in place to support the growth of the carer peer workforce. Need at least one in each district. Opportunities within family and carer programs for family/carer workers but may need to have family/carer Lived Experience workers mandated to make this happen.
- Formalised ally role who is accountable to provide support and advocate. Needs to be a position of authority and power. Needs to have control of budget.
- A registry of more senior Lived Experience workers and their specialisations for organisations or workers wanting external supervisors and consultants.
- Relatable, clean, simple language. Use stories, scenarios to make the National Development Guidelines come ‘alive’.
- The National Development Guidelines can be used as a stigma reducing mechanism if they are easily understood and available in accessible formats e.g. videos.
- Include examples of best practice, templates and resources.
- Support organisation to adopt co-designed approaches and co-production. However, the ideal would be lived experience designed.
- The National Development Guidelines are adaptable and flexible – not a homogeneous approach for all. National Development Guidelines will be flexible and able to be adapted to different contexts. Recognition that several resources are already in use e.g. self-assessment tool in South Australia.
- Welcome diversity and the ‘mosaic’ analogy of embracing the value of difference within a whole.
- Register of consumer and carers workforces in each jurisdiction.
- The National Development Guidelines need to be reviewed regularly and this needs to be done by Lived Experience workers researchers/leaders.
Culturally specific recommendations

- Need to tailor for Aboriginal and Torres Strait Islander Peoples and adapt for other cultures. Easy to understand language, culturally appropriate language and translated where possible.
- Aboriginal staff supporting cultural safety and doing cultural safety training in organisations.
- Proactive recruiting to attract more diverse workforce.
- Thinking carefully about what is acceptable? The way people are talked about needs to be called out.
- Need to include responsibility and expectations to be culturally inclusive.
- Aboriginal Specific Framework – organisations will support this to happen.
- More considered and developed slowly – it takes time.

Funding

Many participants named funding as critical to grow the Lived Experience workforce. Some additional considerations included:

- Need diversity of representation.
- Employment of needs to be tied to KPIs, accreditation and National Standards.
- PhaMs was significant in growing the Lived Experience roles may need to be mandated.
- Primary care funding streams are currently too restrictive. Lived Experience workers could be employed in primary health settings.
- Where our funding comes from can impact the effectiveness of Lived Experience roles. In the case of PHN, it is not necessarily attached to funding streams. Some PHNs are looking at consumer/carer strategy as a KPI.
- Discrepancy and variability in paying consumer/carer in different states. It varies from states to states – some have scholarships for Cert IV, some have additional training, others have non-nationally accredited pathway.
- Paying peer workers appropriately.
- Majority of funding still goes towards the use of the medical model.
Proposed resources for development

Participants in the focus groups were asked to vote and comment on proposed new resources. Although there was confusion regarding the order for voting in the first focus group, the results from the second focus group are more conclusive and are provided below. However, these results may indicate the level of development and maturity of the lived experience among this group of participants. Participants who were interviewed and participants in the first focus group, similarly, supported the need to develop these resources and wanted self-assessment tools and resources to maintain the fidelity of lived experience and to support its effective implementation within organisations. The voting for resources from the second focus group gave the following results in order of preference. The list below is ranked from highest (1) to lowest (4) in order of preference:

1. Roles and titles document describing roles and functions of Lived Experience work that can be utilised to create position descriptions. Comments included: the inclusion of specialisation would be helpful.
2. Role fidelity or role clarity measure for Lived Experience workers/organisations defining what is and is not Lived Experience work.
3. Ongoing development, self-assessment tool to assist organisations already employing peers to assess stage of current Lived Experience workforce and plan further development.
4. Organisational self-assessment tool for organisational readiness (for organisations that do not currently employ peer workers to prepare for effective employment of peer workers).

Resources – other resources that are needed and not already identified

Participants were also asked to identify resources that were needed to support effective Lived Experience work based on their experience:

- Unified, authoritative body of knowledge – agreed upon theories/philosophies for all Lived Experience work.
- Formal code of conduct developed for an Australian context – includes performance indicators.
- Supervisory model that works (clinical supervisory model doesn’t apply to peer work).
- Online Continuous Professional Development (CPD) to incentivise participation. Also need to be a guide for Lived Experience workers about communication, understanding your rights and responsibilities as well as your employers.
- Accreditation (like a rainbow tick) with standards set nationally.
- Resource specifically for Aboriginal peer workers with language and concepts developed by Aboriginal and Torres Strait Islander Lived Experience workers.
- Quantitative performance indicators tools to assess Lived Experience workers – outcome measures related to peer workers (Brook RED has a scale they are trialling).
- Measure for co-workers as to how Lived Experience is changing workplace culture. Maybe also external parties can rate it on measures of system change or recovery? (Make it tailored to different organisational context).
- Resource for allies – what is useful and why and what isn’t?
- Something in writing that clearly differentiates Lived Experience and community support roles in the community sector. These roles were seen as potential areas of blurring between responsibilities and practice.
- Family model that includes ways for consumers and carers to work collaboratively with family or social networks.
- Ideas for organisation to develop and grow the workforce e.g. resource to assist with designing roles at different levels.
- Need for audit and self-assessment tools from the perspective of both the organisation and Lived Experience workers.
- Development of a toolkit for boards, advisory groups and other bodies that invite people with lived experience to be members, including training for other members such as confidentiality, ethics, self-care, best practice model for implementing peer support engagement and inclusion.
- Development of risk register that identifies and incorporates risk, minimisation/mitigation for issues such as attitudes, vulnerabilities, unconscious bias, stigma, working in isolation, being viewed as different or misunderstood.
Survey results

Approach
There was a total of 1,053 survey starts, with 556 (52.9%) surveys being completed, 326 (30.9%) partially completed and 171 (16.2%) which did not proceed beyond early questions.

Of the completions 386 (69.4%) were Lived Experience participants and 170 (30.6%) were non-Lived Experience participants. Of those that were partially completed, 172 (52.8%) were Lived Experience participants and 154 (47.2%) were non-Lived Experience participants.

The following results are calculated based on the number of participants that answered each of the discussed questions.

Individual and role demographics
Results showed that the majority of participants were female (n = 606, 69%) and about a quarter of the participants were male (n = 225, 26%).

Most participants were of European heritage (n = 625, 68%). The remaining participants identified as Aboriginal (n = 24, 3%), Asian (n = 27, 3%), Multiracial (n = 31, 3%) or Torres Strait Islander, African, Hispanic/Latina, Maori, Middle Eastern or Pacific Islander (each category making up less than 1% of the sample).

Participants indicated they worked primarily in a metropolitan district (n = 459, 52%), followed by regional districts (n = 225, 25.5%), mixed districts (n = 147, 16.7%) and rural/remote districts (n = 51, 5.8%).

Of those participants who were working in Lived Experience roles, the majority of participants (66%, n=358) were working in direct support Lived Experience roles and/or were in management or supervisory roles (17%, n=94).

Of all participants not in Lived Experience-designated roles only 11% (n = 25) indicated that they did not identify as having any personal or caring experiences of emotional and wellbeing challenges.

Results: Terminology
Participants were asked to indicate the level of appropriateness for current terminology for supporting another, personal lived experience, the workforce title, as well as the appropriateness for the terminology for a ‘mental health’ experience. All answers were given on a five-point Likert scale of:
1 – not appropriate
2 – slightly appropriate
3 – moderately appropriate
4 – quite appropriate
5 – highly appropriate.

For the family/carer workforce, participants indicated that the current terms used were moderately to highly appropriate, although ‘Family/carer’ was identified as the most appropriate term for those who have experience supporting another through a mental health challenge. This result was consistent across both Lived Experience and non-Lived Experience roles.

Appropriateness of terms for supporting another, by role

<table>
<thead>
<tr>
<th>Term</th>
<th>Lived Experience</th>
<th>Non-Lived Experience</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver/family</td>
<td>High</td>
<td>Low</td>
<td>Medium</td>
</tr>
<tr>
<td>Carer</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
</tr>
<tr>
<td>Family</td>
<td>Medium</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Supporter</td>
<td>Medium</td>
<td>High</td>
<td>Average</td>
</tr>
<tr>
<td>Support experience</td>
<td>Low</td>
<td>Medium</td>
<td>High</td>
</tr>
</tbody>
</table>

Summary of Consultations
Survey results

For terminology used to describe a ‘personal lived experience’, participants indicated that most terminology was ‘moderately’ to ‘highly appropriate’, with the exception of ‘first person’, which was identified as only slightly appropriate to moderately appropriate. There was a consensus across Lived Experience and non-Lived Experience roles that the term ‘Lived Experience’ is the most appropriate term to describe those working in Lived Experience roles with a personal lived experience.

For the workforce as a whole, participants indicated that the term ‘Lived Experience Workforce’ was the most appropriate, with ‘Peer Workforce’ also being rated only slightly less appropriate (both rated as between quite and highly appropriate).

### Appropriateness of terms for personal Lived Experience, by role

<table>
<thead>
<tr>
<th>Term</th>
<th>Lived Experience</th>
<th>Non-Lived Experience</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lived Experience</td>
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<tr>
<td>Personal experience</td>
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<tr>
<td>Living experience</td>
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<tr>
<td>Direct experience</td>
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<td></td>
<td></td>
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<tr>
<td>Lived expertise</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Living expertise</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumer</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>First person</td>
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<td></td>
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<tr>
<td>Survivor</td>
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<td></td>
</tr>
</tbody>
</table>

### Appropriateness of workforce title, by role

<table>
<thead>
<tr>
<th>Workforce Title</th>
<th>Lived Experience</th>
<th>Non-Lived Experience</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lived Experience workforce</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Peer workforce</td>
<td></td>
<td></td>
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<tr>
<td>Living experience workforce</td>
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<td></td>
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<tr>
<td>Lived expertise workforce</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Living expertise workforce</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consumer and carer/family workforce</td>
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<tr>
<td>Expert by experience workforce</td>
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<td></td>
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<tr>
<td>Living expertise workforce</td>
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</tr>
</tbody>
</table>

### Summary of Consultations

For terminology used to describe a ‘personal lived experience’, participants indicated that most terminology was ‘moderately’ to ‘highly appropriate’, with the exception of ‘first person’, which was identified as only slightly appropriate to moderately appropriate. There was a consensus across Lived Experience and non-Lived Experience roles that the term ‘Lived Experience’ is the most appropriate term to describe those working in Lived Experience roles with a personal lived experience.

For the workforce as a whole, participants indicated that the term ‘Lived Experience Workforce’ was the most appropriate, with ‘Peer Workforce’ also being rated only slightly less appropriate (both rated as between quite and highly appropriate).
Survey results

For terminology to describe a ‘mental health experience’, ‘social and emotional wellbeing’ was identified as the most appropriate terminology by both Lived Experience and non-Lived Experience roles (rated as quite to highly appropriate by Lived Experience participants and moderately to quite appropriate by non-Lived Experience participants).

The majority of participants, both Lived Experience and non-Lived Experience indicated that the titles and terms provided in the above questions adequately described Lived Experience work and experiences (92% of Lived Experience and 89.2% of non-Lived Experience) and most agreed that they were culturally inclusive (77.7% of Lived Experience and 74% of non-Lived Experience). However, when asked if it would be useful to have a specific exploration into cultural and diversity issues within Lived Experience work, including language and terminology, most agreed it would (91.8% of Lived Experience and 90.7% of non-Lived Experience).
Survey results

Results: *Differences between carer and consumer workforces*

Participants were asked to indicate the importance of experiences for both Lived Experience and family/carer roles on a 5-point Likert scale of:

1 – not at all important
2 – slightly important
3 – moderately important
4 – quite important
5 – highly important.

Results showed that there was reasonable alignment in the views of Lived Experience and non-Lived Experience participants, with the experiences of loss and regaining of hope, shared humanity identifying as experiencing significant mental health issues and stigma all being rated between ‘quite’ and ‘highly important’ for consumer roles. All other options were rated as being between ‘moderately’ and ‘quite’ important.

### Importance of experience for consumer roles, by role

<table>
<thead>
<tr>
<th>Experience</th>
<th>Lived Experience</th>
<th>Non-Lived Experience</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss and regaining of hope</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Shared humanity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifies as experiencing significant mental health issues</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Stigma</td>
<td></td>
<td></td>
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<tr>
<td>Redefinition of self</td>
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<tr>
<td>Service use</td>
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<tr>
<td>Loss of rights</td>
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<td></td>
<td></td>
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<tr>
<td>Powerlessness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis of a significant mental health challenge of a loved one</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Hospitalisation of a loved one</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Marginalisation</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Involuntary treatment of a loved one</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Oppression</td>
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</tbody>
</table>

Results for experiences that were important for the family/carer workforce showed that, again, there was reasonable alignment in the views of Lived Experience and non-Lived Experience participants, with the experiences of shared humanity, loss and regaining of hope and service use by a loved one, all being rated between ‘quite’ and ‘highly important’ for family/carer roles. All other options were rated as being between ‘moderately’ and ‘quite’ important.
Survey results

Lived Experience participants were further asked to indicate how similar they thought the values, goals and work practices were between family/carer workers and Lived Experience workers on a 5-point Likert scale of:

1 – completely different
2 – somewhat different
3 – neutral
4 – somewhat similar
5 – very similar.

Participants indicated neutrality regarding the similarity or difference of the values and goals between the two workforces and also indicated close to neutrality regarding the differences and similarities of work practices between the two roles. However, the rating regarding the work practices, was slightly lower indicating the two workforces be somewhat different in their work practices.

When participants were asked whether it was appropriate for organisations to design roles that combine consumer and carer perspectives, data indicated some level of ambiguity, with 45.8% of Lived Experience participants indicating that, yes, it was appropriate. However, 37% said it was not appropriate and 17.1% said they were unsure. Results for non-Lived Experience participants were similar with slightly more participants indicating they were uncertain about the answer.

Results: Funding for the Lived Experience workforce

Participants were asked to indicate their level of agreement with three statements regarding funders on a five-point Likert scale of:

1 – strongly disagree
2 – disagree
3 – neither agree nor disagree
4 – agree
5 – strongly agree.

Overall, there was strong agreement that it is important for funding bodies to understand Lived Experience work and principles. But participants did not think funding bodies currently understand these things, and did not think current levels of funding were adequate.
Survey results

Results: Resources
Participants were asked to indicate from a range of resources, which they thought would be most important in terms of being needed and/or should be considered for use with the National Development Guidelines. The data showed reasonable alignment between Lived Experience and non-Lived Experience responses and highlighted the need for a range of resources, with all resources being rated as ‘quite’ to ‘highly’ important.

1 = Not at all important
2 = Slightly important
3 = Moderately important
4 = Quite important
5 = Highly important

Importance of resource type, by role

<table>
<thead>
<tr>
<th>Lived Experience</th>
<th>Non-Lived Experience</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>A self-assessment tool to assist organisations already employing peers to assess stage of current peer workforce and plan further development</td>
<td></td>
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</tr>
<tr>
<td>A role fidelity or role clarity measure for peer/Lived Experience workers/organisations employing peer workers defining what is and is not Lived Experience informed work</td>
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<tr>
<td>A fidelity measure for co-production to guide the development and implementation of co-production within organisations</td>
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<tr>
<td>An organisational readiness self-assessment tool, for organisations that do not currently employ peers to prepare for effective employment of peer workers</td>
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</tr>
<tr>
<td>A comprehensive guide to alternate terms and language that are culturally inclusive</td>
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<td></td>
</tr>
<tr>
<td>Video/s and other plain English versions of the guidelines for accessibility</td>
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</tr>
</tbody>
</table>
Lived Experience resources

Focus group and interview participants have provided numerous resources for consideration within the National Development Guidelines. A selection of these are included here:

Guides/frameworks related to peer work practice

- Lived Experience workforce Community of Practice – terms of reference; meeting report template; agenda template etc... Available at: www.mhcsa.org.au
- Lived Experience Workforce Strategies – AOD; Consumer, Carer provided through the Centre for Mental Health Learning Resource Hub: www.cmhl.org.au resources.
- Tasmanian Peer Workforce Strategy: www.mhct.org
- Centre for Excellence in Peer Support: https://www.peersupportvic.org/
  Publications and position descriptions.
- Scottish Recovery Self-Assessment Tool for Recovery Oriented Practice: https://www.scottishrecovery.net/resources/
- Peer Work Hub: https://www.nswmentalhealthcommission.com.au/content/peer-work-hub

Culturally specific approaches

- Indigenous Peer Mentoring VET training: An Aboriginal controlled RTO in Central Australia called CARHDS has co-designed a 3-day Indigenous Mentoring course for non-indigenous people who employ aboriginal health workers. A link to the program is included below: https://www.carhds.org.au/training-courses
- Miwatj Rapirri Rom Wellbeing Program: Miwatj is an ACCO Aboriginal Medical Service in East Arnhem of the Northern Territory. They have been extremely innovative in developing a program that through a model of two-way learning supports community mental health and wellbeing. https://healthinfonet.ecu.edu.au/key-resources/programs-and-projects/2344/?title=Rapirri%20Rom%20Wellbeing%20Program
- Sunrise Health Psychosocial Recovery Program: Sunrise is another ACCHO that runs a commonwealth funded psychosocial recovery program in the Roper Gulf remote region of the NT and using an Aboriginal peer workforce.

Different approaches

- Open Dialogue.
- Intentional Peer Support.
- Power Threat Meaning Framework.
- Emotional CPR.
- Hearing Voices Approach.

Summary of Consultations
Lived Experience resources

Books/articles

- Investigating the mobility of the peer specialist workforce in the US – findings from a National Survey – Jones et al.
- Peer Work in Australia, (2018). A New Future for Mental Health by: Tim Fong, Anthony Stratford (Editor), Janet Meagher (Editor), Fay Jackson (Editor), Erandathie Jayakody (Editor).

Hubs or centralised repositories of resources

- Lived Experience Workforce Strategies – Alcohol and other drugs; Consumer, Carer provided through the Centre for Mental Health Learning Resource Hub: www.cmhl.org.au/resources.
- Tasmanian Peer Workforce Strategy: www.mhct.org
- Centre for Excellence in Peer Support: https://www.peersupportvic.org/
- Publications and position descriptions: https://nmhcfc.org.au/resources/publications
- Scottish Recovery Self-Assessment Tool for Recovery Oriented Practice: https://www.scottishrecovery.net/resources/

Networks

- Peer Participation in Mental Health Services Network PPIMS Brisbane North PHN.

Assessment tools

- Peer Work Hub Readiness Kit: www.peerworkhub.com.au
- Peer Work Competencies: https://www.tepou.co.nz/resources/competencies-for-the-mental-health-and-addiction-service-user-consumer-and-peer-workforce

Diversity/inclusion resources

- MHA article: https://mhaustralia.org/media-releases/miwatj-mental-health-program-leading-way-remote-australia