Mental Health *Safety and* **Quality** Engagement Guide

Australian Government

National Mental Health Commission

Contents

A word from the National Mental Health Commission's Chief Executive Officer

The *Mental Health Safety and Quality Engagement Guide* is a welcome and practical addition to Australia's investment in consumer and carer engagement and participation in the development and delivery of mental health services.
It is a priority action under the *Fifth National Mental Health and Suicide Prevention Plan*.

The role of consumers and carers in the design, delivery and evaluation of mental health services is critical. There must be dynamic and viable partnerships between service users, service providers and service leaders. The *Mental Health Safety and Quality Engagement Guide* is a practical tool aimed at empowering mental health consumers and carers, health service leaders and service providers to engage in meaningful partnerships to improve the safety and quality of mental health services.

The Guide focuses on participation by consumers and carers at a governance level recognising the importance of lived experience influencing strategic decision-making and systemic change.

The Guide provides practical information about how consumers and carers can navigate the process, how health service leaders can ensure a culturally appropriate, welcoming space for a diverse range of consumer and carer representatives, and how to develop and foster a positive partnering environment.
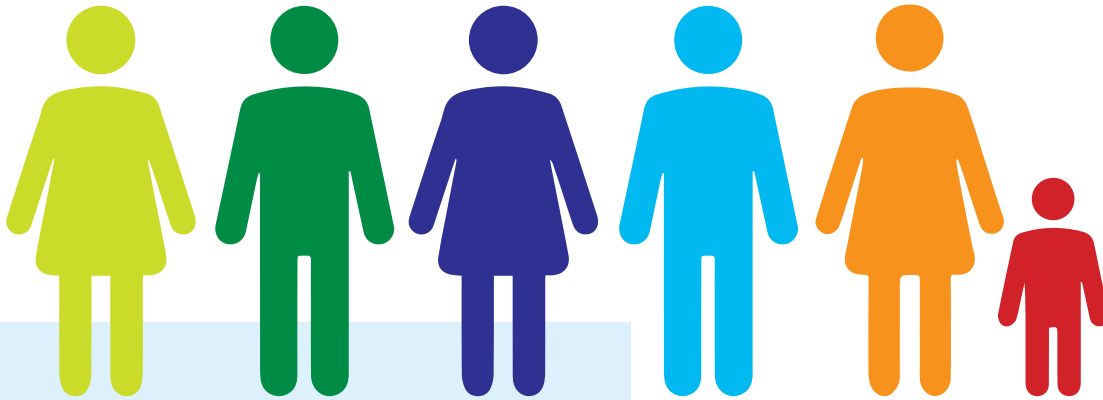
For consumers and carers the Guide includes information on how to get engaged, understand your role, build a network, establish a mentor and manage self-care. For health service leaders and providers, the Guide provides information on supporting diversity, creating a safe environment and the role of leaders.

The development, delivery and evaluation of mental health services that put individuals first requires strong partnership between consumers and carers, health service providers and health service leaders. As we continue to encourage and support positive partnerships and collaborative efforts we will be working to ensure significant improvements for all.

Christine Morgan
CEO, National Mental Health Commission

Our thanks

We acknowledge and thank everyone who has contributed to the development of this guide through sharing their experiences as part of the national consultation, and those who agreed to have their words included throughout the guide.

The Commission was pleased to lead the collaboration on this document with the National Mental Health Consumer and Carer Forum, and the National Safety and Quality Partnership Standing Committee.

We acknowledge the support and guidance of the members of the Advisory Committee: Lynette Anderson, Chris Gibbs, Bill Gye, Kerry Hawkins (co-chair), Darren Jiggins, Eileen McDonald, Naomi Poole, Hayley Solich, Carol Turnbull, Kylie Wake and Terri Warner.

We also acknowledge and thank Kirsty Baker, Dr Monika Ferguson, Dr Mark Loughhead and Professor Nicholas Procter from the Mental Health and Suicide Prevention Research Group, University of South Australia for assisting in the production of this guide. The team ran a national consultation process to inform the Guide and drafted most of the written content.

1 Overview
of the guide

About the *Mental Health Safety and Quality Engagement Guide*

The *Mental Health Safety and Quality Engagement Guide* aims to empower and support mental health consumers and carers who would like to participate and engage in improving safety and quality in mental health services. The guide provides practical guidance and information to help you contribute to, and partner with, services to promote positive change.

The area of lived experience engagement includes many diverse terms and phrases that refer to people, roles and processes. This guide recognises that your preferred terminology in mental health may vary from both the terms in policy documents and the terms other people prefer.

Lived experience is used in this guide as a broad term referring to the personal perspectives on, and experiences of, being a consumer or carer, and how this becomes awareness and knowledge that can be communicated to others. The term covers people's core experiences around mental health challenges and service use that may have occurred in the past or may be ongoing (sometimes called living experience).

*See **Appendix 1** for more detail on the language used in this guide.*

The guide also provides useful information for service providers and planners who would like to improve their processes for engaging with mental health consumers and carers on safety and quality issues. Although consumers and carers can engage with services on safety and quality issues in many ways, this guide focuses on strategies for engaging at a governance level. This means encouraging people with lived experience to partner in planning and decision-making to ensure high-quality, person-centred and family-centred care.

We chose this focus to complement existing consumer and carer guides, and to support consumers and carers to promote systemic change in all aspects of mental health services.

> *Safety for me is being able to talk about risks and things that scare me, but knowing I will have the power to decide what to do.*
>
> Lived experience perspective

> *I see quality as a sense of community, being well connected with staff, and feeling important and wanted.*
>
> Lived experience perspective

A focus on safety and quality

Safety means the absence of preventable harm to people during the process of health care, and reduction of unnecessary harm associated with health care to an acceptable minimum. Safety includes adhering to clinical and work standards for health and safety, and ensuring that people don't get hurt. It also includes emotional safety: creating a welcoming environment free from stigma and judgement, and ensuring that people feel comfortable, validated and respected. For Aboriginal and Torres Strait Islander people, services need to be culturally safe. Ensuring sexual safety within services is also essential.

*See **Section 3** for cultural safety principles.*

Quality means providing the best possible services for a person's individual needs and circumstances, with the goal of supporting personal recovery in a culture that feels safe, comfortable and respectful. Quality includes providing services that are evidence based and cost effective—but also providing care that is tailored to a person's individual needs and ensures that the people who use a service have a positive experience. Quality is underpinned by the principles of human rights.

Diverse perspectives

Different people have different perspectives about what is most important for safety and quality. If you've used mental health services, you have probably developed your own ideas about safety and quality.

Many consumers see safety in terms of what they will go through when using services. They may have concerns about the legal issues regarding inpatient treatment orders, or they may worry about medicines and their own power to make choices about treatment. They may wonder about the safety of other people on the ward. Feeling safe might include being listened to by doctors, nurses and other health professionals.

Many carers see safety in similar ways, or they might think quality concerns the timely availability of care and the ways in which treatment, support and discharge occur. They might want to be involved in care decisions and receive follow-up phone calls from services. The nature and quality of engagement are vital.

It's important to understand that carers cannot speak on behalf of consumers, and vice versa. Even if a carer also has lived experience as a consumer, they must be clear about what hat they are wearing when speaking up or speaking out.

Consumers, carers, family and kinship groups may all experience frustrating and traumatising gaps in services, or have concerns about how mental health services relate to general practitioners and other community services and supports. They may experience situations where cultural identity and preferences are not taken into account. And the experience of crisis and police involvement is often difficult.

Quality is when we take our young people to hospital, they will be cared for, and not just filled with medicine and sent back.

Aboriginal and Torres Strait Islander community perspective

Mental health professionals are aware of the range of experiences that consumers and carers regularly face when seeking services. They also observe how services operate, and see both positive and negative patterns in the availability of mental health care and how it is provided. Health professionals also have professional, organisational and clinical perspectives that affect their safety and quality priorities. Concerns about risk and security can dominate how professionals relate to consumers and carers. Perspectives of people with lived experience of mental ill-health acknowledge the importance of safe and high-quality health care from the conventional perspective. However, they stress that the process of determining what is safe and high-quality care must be informed by, and meaningful for, their lived experience.

This process goes beyond valuing subjective points of view: it's about recognising life context, culture, identity, risks and opportunities—it's about working together in partnership to identify what's appropriate for consumers, carers, families and kinship groups, and then acting on this. Safe, quality care that acknowledges lived experience perspectives requires structural competency, conceptual competency and relational recovery. This is embodied in the principles of recovery, dignity of risk, trauma-informed care, cultural safety and co-production.

Safety and quality is about mental health providers who listen and respond to my experience and what I need for recovery and to get through my distress.

Lived experience perspective

My experience of safety and quality begins when I walk into the reception at the community health service.

Lived experience perspective

Person-centred care and personal recovery

The definitions of safety and quality used in this guide are underpinned by the recognition that our right to health is a fundamental part of our human rights, and is informed by the concepts of person-centred care and personal recovery. Participating in governance is an opportunity to ensure that the human rights of individuals are protected—respect for human rights is fundamental to supporting the recovery of people living with mental health problems.

Person-centred care is about providing the services and support that are right for each person, taking into account their unique needs, circumstances, preferences and recovery goals. Person-centred care focuses on what each person needs and what works for them. It requires service providers to work in partnership with consumers to understand their personal preferences, establish trust and mutual respect, and plan and make decisions about care.[1] We encourage all services to employ a person-centred and family-centred approach. This approach involves working with the consumer and their family or kinship group, as appropriate.

Person-centred care is related to the concept of personal recovery, which focuses on achieving the goals and outcomes that a person considers important and meaningful for their recovery. Personal recovery is guided by each person's goals and priorities, rather than relying only on diagnostic criteria or what a clinician or service provider thinks is a 'good' outcome.

Person-centred care and personal recovery play an essential role in ensuring safety and quality in mental health care. According to the Australian Commission on Safety and Quality in Health Care, person-centred care is "widely recognised as a foundation to safe, high-quality health care".[2]

Safety and dignity of risk

Recovery and steps in personal growth can occur outside a person's comfort zone. The principle of 'dignity of risk' is also important. Service environments and interactions between consumers, carers and health professionals need to provide opportunities for positive risk-taking. The balance between risk and safety and the tensions around this should be discussed and worked through with mutual respect and personal integrity.

Trauma-informed care

This approach recognises that many people accessing mental health care have experienced significant adverse life events, particularly during their childhood. These events include experiencing or witnessing such things as war, violence, natural disasters, accidents and loss. In addition, the approach recognises that many people experience traumatic events while receiving mental health care. Others have experienced trauma in the context of cultural, gender or sexual discrimination and marginalisation.

National standards

This guide introduces the two sets of national standards that apply to a framework for providing mental health services. The standards guide healthcare systems to deliver safe care and continually improve the quality of their services.

The first set is the National Safety and Quality Health Service (NSQHS) Standards. The eight NSQHS Standards were developed by the Australian Commission on Safety and Quality in Health Care, and are designed to provide a nationally consistent statement about the level of care that people can expect from health services. All public and private hospitals, day-procedure services and public dental practices in Australia must be accredited for the eight NSQHS Standards.

The second set is the National Standards for Mental Health Services. These standards are managed by the Australian Government Department of Health to guide continual quality improvement throughout all mental health services across Australia, from general practice to community mental health services to acute hospital-based services. They also apply across all sectors—public, private and non-government.

See **Appendix 2** for further details on these standards.

A partnership approach

This guide supports a partnership approach for improving safety and quality in mental health services. In a partnership approach, the people who provide services and the people who use services come together as equals to help make mental health services the best they can be.

A partnership approach recognises that people who have lived experience of mental health challenges and personal recovery, or who have been a carer or family member of someone with lived experience, have unique knowledge and expertise that is essential to the delivery of safe and high-quality mental health services. Planning and producing services together at the local level helps to ensure that services are relevant and meaningful for the recovery needs and wishes of consumers, carers, families and kinship groups.

This is a key reason why the NSQHS Standards encourage all public and private health services to develop and maintain local partnerships and activities. Genuine person-centred care and recovery cannot be achieved through top-down, bureaucratic activities; they must involve relationship-based activities generated by local meetings and interactions between service providers, consumers, carers, families and kinship groups. Discussions and planning are thus grounded in the context of local lives, aspirations and opportunities.[3]

2 Getting engaged

There are many ways in which consumers, carers, families and kinship groups can become involved in, and contribute to, conversations about safety and quality that lead to improved services.

Through your own lived experience, you are likely to know about a range of key issues and areas of service that could be improved. You may have talked to clinicians and service leaders about how your own care could be improved—for example, with better communication and coordination. You may have suggested changes to medicines, reported issues, complimented the service or made a complaint without fear of retribution. You may have written to the service or used a feedback form for voicing your thoughts.

Some services already take responsibility for actively promoting and recruiting consumers and carers to participate in service planning and governance structures.

Getting involved in service planning or governance

Many consumers, carers, families and kinship groups become active in assisting others. This can occur in inpatient units, through support groups or organisations, and through groups of consumers, carers, families and kinship groups. Getting involved in the decision-making in public mental health services is an extension of this helping role.

Many people talk about wanting to improve services for others and make sure others don't have to go through difficult experiences. You can share what you have learned so that others may benefit.

To become active in decision-making in your local mental health services, you can take one (or more) of these steps:

- Talk to your clinician or peer worker about ways of becoming involved—ask about the 'partnering with consumer and carer activities' of the service.

- Talk to the consumer adviser or complaints manager at the hospital or health service. How to contact these people should be advertised throughout the service.

- Ask to speak to a member of the quality improvement team. Members of this team should be aware of activities for partnering with consumers and carers.

- Ask any of these people how you can communicate your suggestions for improving the service to decision makers, or how to become involved in decision-making.

- Ask if you can complete a Your Experience of Service (YES) survey and a Care Experience of Services (CES) survey.[4] These surveys should be available Australia-wide in public services, and offered to consumers and carers using a service.

- Ask if any local mental health services, health networks, health departments or national organisations provide information or newsletters you can subscribe to.

- Ask if you can be put on a contact database or membership register that distributes information about reforms in mental health care, and sends invitations to consultation meetings and forums.

We're all in this together; we're all here to improve care for people and to prevent bad things from happening. We're all here to optimise outcomes, and we need everyone's perspective for this to work.

Lived experience perspective

There are other ways you can learn about what is happening locally:

- Talk with other people with lived experience about issues you share, common concerns, and ways of communicating your concerns to service leaders. You could do this at a service, in a support group or over a coffee.
- Talk with Elders or health leaders in your family and kinship groups, or with health leaders in an Aboriginal Community Controlled Health Service.
- Identify your state's peak consumer or carer organisation, and contact this organisation.

Through these contacts, you can get information about a range of events and projects that may interest you. Subscribing to newsletters or being on membership registers will help you learn about consultation meetings. At these public meetings, the service will ask people to share their thoughts and perspectives about change. Consumer and carer organisations also hold these meetings. You usually need to RSVP to these events through email or by phone.

Many health services have consumer, carer and community advisory groups that play an important part in improving safety and quality. Local health networks and health departments advertise for these consumer or carer adviser positions. These are positions or roles for being a part of project groups or committees that work on service improvement. Usually, positions require you to write an application or an expression of interest.

Examples of partnership

Here are some examples of the ways in which consumers, carers, families, kinship groups and service providers can work together.

- A health service establishes an overview committee for mental health safety and quality to monitor the outcomes of the regional mental health services. It creates adviser positions on the committee for two consumers and two carers with lived experience. The committee reviews critical incidents, the Your Experience of Service surveys and other data about trends to identify issues. It makes recommendations to executive leaders.

- A statewide consumer organisation runs a series of consultation meetings before writing a submission to the state government's review of mental health legislation and consumer rights. Several multicultural welfare groups, disability advocates, and many consumers and carers are invited to the meeting.
- A Local Health Network has a Consumer and Community Council that reports to the senior executive of the health service. Two council members are leaders in mental health lived experience. Two members are Aboriginal and Torres Strait Islander representatives who connect the council activity to local networks. The council also has members with lived experience from other health areas.
- A Primary Health Network invites local people with lived experience to be part of the 6-month co-production process for developing ideas about how to commission primary mental health services for the regional population. It also invites community advisers from Aboriginal and Torres Strait Islander groups and LGBTIQ+ networks to partner in the process. These members work with service providers to formulate the quality standards and consumer engagement expected of the organisations that apply for funding to provide the services.

Want to be involved?

Here are some key contacts:

- leaders of local mental health teams
- consumer or carer consultants in your service
- consumer or carer peak bodies in your state
- Aboriginal and Torres Strait Islander health workers
- advocacy and complaints services
- statutory organisations that monitor health services.

*See **Appendix 3** for details in your state.*

The broader aims of engagement: partnerships and co-production

The above examples are taken from projects occurring in various cities and regions around Australia. They are part of a commitment to the fundamental belief that mental health services must be designed, planned, monitored and evaluated via partnerships between consumers and carers using the service, the clinicians and peer workers who directly provide the services, and the service leaders.

Lived experience leaders and advisers play vital roles in communicating aspects of experience that can be overlooked or assumed by services providers. This experience might relate to community concerns or issues, accessibility, barriers, perspectives about medicines and treatment, preferred staff behaviours and standards, gaps in services, and wider impacts of the service on consumers and families. Lived experience leaders provide a non-institutional perspective that reflects information and experience within community networks about the value of the service in people's lives.

The expectations of partnership are built into the National Safety and Quality Health Service (NSQHS) Standards, and are best reflected in the Clinical Governance Standard and the Partnering with Consumers Standard. Table 1 provides a summary of the actions that public and private health services need to demonstrate regarding partnership under the NSQHS Standards. Similar expectations are reflected in the National Mental Health Service Standards and various workforce standards.

To achieve the aim of partnership, leaders in lived experience must be engaged in all decision-making forums within the mental health service. This process must be supported and systematic, and recognise the value of lived experience perspectives alongside clinical and financial perspectives and the perspectives of leaders in other health sectors. Many local health services have frameworks for consumer, carer and community engagement to oversee actions that the service commits to.

Co-production is a valuable approach for bringing people together in ways that ensure that lived experience perspectives are heard, valued and incorporated into planning, implementation and evaluation. The focus is on setting agendas for change together and identifying ways in which diverse voices can be involved in decision-making processes. Co-production deliberately sets out to create a culture that values all expertise and knowledge, particularly the expertise and knowledge of the people who are most affected by the problem and the solution. Lived experience leaders often co-chair or co-facilitate meetings. The approach aims to equal basis of power sharing and influence, which often means that consumers take a leadership role in the process with clinicians and other leaders being contributors and learners.

*See more examples in **Section 4** Working together.*

Table 1: *Actions relating to partnership in the Clinical Governance Standard and Partnering with Consumers Standard of the National Safety and Quality Health Service Standards*

Action	Summary of required actions by the health service
Clinical Governance Standard	
1.1	Provide leadership to establish culture of safety and quality and a culture of partnership with consumers and carers
1.2	Ensure that the safety and quality priorities address specific health needs of Aboriginal and Torres Strait Islander people
1.4	Implement and monitor strategies to meet the health service's safety and quality priorities for Aboriginal and Torres Strait Islander people
1.8	Involve consumers and the workforce in the review of safety and quality performance and systems
1.13	Use processes to encourage regular feedback from consumers, carers and families about their experiences and outcomes of care, and use this information to improve safety and quality
1.33	Provide a welcoming environment that recognises the significance of cultural beliefs and practices of Aboriginal and Torres Strait Islander people
Partnering with Consumers Standard	
2.2	Implement strategies that improve partnerships with consumers and carers
Monitor and report on these strategies	
2.9	Involve consumers and carers in developing and reviewing the organisation's health literacy products (e.g. health and services brochures, posters)
2.11	Involve consumers and carers in partnerships within governance, and in the design and review of health service programs and health care
Seek to engage a range of consumers and carers that reflects the diversity of health service users and the local community	
2.12	Provide orientation, support and education to consumers and carers who are partnering in governance, design and review of health service programs
2.13	Work in partnership with Aboriginal and Torres Strait Islander communities to meet healthcare needs
2.14	Work in partnership with consumers and carers to bring their perspectives and experiences into workforce training and education

Information you will need from service providers

If you are interested in being involved, attending a meeting, or becoming an adviser or representative, a range of information is available to help with your planning *(see Table 2)*. Service leaders and managers must provide this information to help you prepare; the information must be available in printed form. There should also be a contact person to talk with.

Table 2: *Information that service providers need to provide to help you engage*

Role	A clear statement about the role of people with lived experience. What is the nature of input and contributions to the group?
Purpose	A clear statement of the purpose of the group or event. What is being worked on and what is hoped for? What is the scope, or focus, of change? What information is shared? What is the time frame of the group?
Contact point	A contact person to talk to about the position. Often you need to talk through the purpose and consumer/carer roles in the group. Also, details should be provided on how the group functions and makes decisions.
Who's involved	Information about other roles in the group or project. Who else is involved?
Distribution of papers	How will papers be handled? Information should be provided on hard copy availability, distribution, timelines for reading and preparation, printing support.
Supports available	Information about accessibility and inclusion, and available supports. A contact person should be listed.
Inclusive values	Is the group informed by lived experience values? Are other members aware of, and skilled in, working with lived experience perspectives? Is there a culture of inclusion?
History and handover	A handover about the history and current business of the group. For example, how long has it been running?
Meeting dates and venues	Information about meeting dates, times and venues; the length of your involvement; and access and any supports available to help you travel to the meeting.
Payment and reimbursement	Are there sitting fees? Is there recognition of, and reimbursement for, travel and prereading? How are payments organised and delivered to you? A contact person should be available to discuss these aspects.
Decision-making	Information about the organisational structure of the group—how it links and reports to other decision makers in the health service.
Clearances	Whether any clearances are required (e.g. national police check or confidentiality agreement).

Identifying your knowledge and skill set

If you have received the above information and you are interested in exploring further, one thing to consider is how your knowledge and skills align with the purpose of the event or group.

It's good to explore the issues you feel are most important from both your perspective and your network's perspective. For example, you might be interested in joining a committee looking at mental health medicines. So you could consider the issues around consumer experience of medicines in terms of your own views and experience, and those you know are common among consumer circles. Issues might include choice, control, access to information, experience of side effects, adverse events, communication with clinicians, and involvement in treatment planning.

Before joining a group, also consider your experience and the level at which you want to be involved. Committees and consultations occur at different levels: some focus on the local service area, whereas others are connected to the state departments of health. It's good to talk with an experienced lived experience leader about your interests and your expertise, which can help you decide whether you are comfortable in applying.

Local services and peak consumer groups should offer training to help you understand the skills and knowledge involved in becoming active. There should also be pathways for people who want to offer their views and experience without needing experience or training in being a representative. *See **Section 8** for more on training.*

Cultural considerations for consultation and partnerships

Many people from Aboriginal and Torres Strait Islander communities, and culturally and linguistically diverse communities are aware of existing community leaders and services that play a role in representing key health issues in the community. There are often cultural protocols about who can speak about key issues or can consult within kinship groups. If you are interested in being a lived experience adviser in Aboriginal and Torres Strait Islander mental health, ensure that service providers are aware that you may need to speak with Elders and leaders in the community first. Service providers should also approach the local Aboriginal Community Controlled Health Service to discuss the various ways to make and strengthen partnerships, and who to approach regarding lived experience roles.

Creating advisory and representative positions for Aboriginal and Torres Strait Islander people on committees: *for service providers*

Before creating positions and recruiting members, services should:

- build relationships with local Aboriginal Controlled Community Health Services, family service organisations and Elders groups

- talk to these services about the best methods of engagement and partnership in decision-making. Explore what the service says about preferred ways of engagement that work culturally and practically

- identify leadership and employment opportunities within the health services, so that relationships are strengthened through commitments to build the health workforce of Aboriginal and Torres Strait Islander people

- identify the links between improving the services and programs offered to families and kinship groups and an improved Aboriginal and Torres Strait Islander health workforce, and how this opens opportunities for safety and quality discussions.

For further reading

The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute, 2017, *National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health*, ACSQHC, Sydney.

Use of information and data: privacy and informed consent

The information used in safety and quality discussions often comes from within the service. Numerous privacy and consent issues are involved. Public health services have information systems into which clinicians and managers enter data. This data includes information about critical incidents and both complaints and compliments. The information often refers to specific consumers of the service and the clinicians involved.

Sometimes critical incidents are examined by safety and quality committees. Therefore, both clinical and lived experience committee members need to understand the confidentiality of this information.

In addition, confidential information about a consumer's experience is often shared during inpatient inspections or when 'listening posts' are set up to hear from consumers and carers using a service. In this case, the lived experience adviser needs to understand that consumers reporting their experience must consent to sharing of the information within the service for the purpose of improving quality.

On many occasions, safety and quality work involves looking at generalised data about service trends. An example would be the numbers of complaints and the categories of complaints, and whether these are being resolved. Another might be looking at the rates of seclusion and restrictive practices in the service and making recommendations about how to reduce and eliminate these.

Good practice in reimbursement and payments for lived experience partners

- Recognise that engaging in health service planning and decision-making has costs for people in terms of reading, preparation and travel time. Confirm the payment in writing before the engagement takes place.

- Recognise the value of lived experience perspectives regarding the purpose of the event, forum or meeting.

- Have information about the Centrelink and tax implications of how both sitting-fee payments and reimbursement effect on income assessment.

- People on low incomes may not have the resources to cover costs and wait for reimbursement. Work on ways to create access and remove barriers (e.g. consider the cost and accessibility of public transport, and providing taxi vouchers or Visa gift cards).

- If possible, state health departments and local health services should have consistent policies and provisions for lived experience representatives who are active at local and statewide levels.

*We're all in this together;
we're all here to improve care
for people and to prevent
bad things from happening.
We're all here to optimise outcomes,
and we need everyone's perspective
for this to work.*

Lived experience perspective
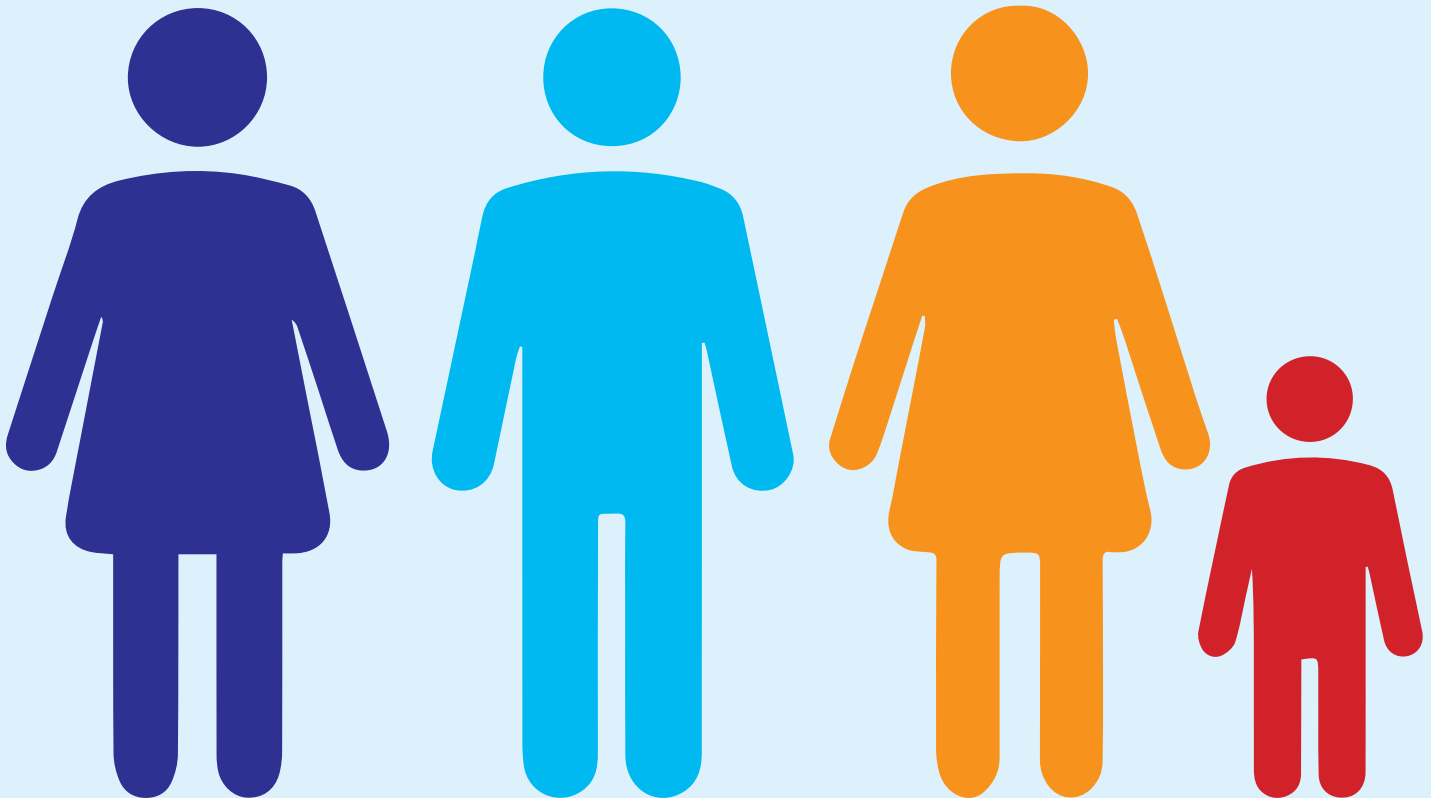
3 *Enabling* diverse participation

When working to improve the safety and quality of services, we need to think and act in ways that are inclusive and consider diversity. Traditionally, mental health services have been designed along the model of the medical ward or community clinic. Services can make assumptions about the culture, language, gender, age, abilities and identity preferences of people accessing the service.

For example, mis-gendering occurs when a person is spoken to or described using words and phrases that do not accord with their gender identity. These assumptions can negatively affect a person's current and future engagement with the service or service provider and may result in distress and shame.[5]

Assumptions around culture and family decision-making can occur when treatment teams work only with the individual consumer or their partner. Often, important family or kin perspectives are not included in decision-making, which affects the family's understanding of, and commitment to, engaging with treatment processes. And conversely, someone from a culturally diverse background may not necessarily choose for their family to be involved.

> *Our services have got to be well connected to the grassroots; to be about our communities. And do their job properly and look after people.*
>
> Aboriginal and Torres Strait Islander community perspective

> *There is a challenge as often you are relating to the lived experience of the articulate. Consider the most vulnerable who don't have opportunities. Do we hear those who are quiet such as homeless people, those in child protection, or prison? Or are only the bigger voices heard?*
>
> Lived experience perspective

Here are three key ideas for lived experience representatives and service providers that enable and support diversity

Recognition
- Are we recognising the needs, wishes and preferences of diverse consumers, carers, family and kinship groups in the community? Are we aware of these factors in the way we generally talk about mental health?
- Does the service recognise that people and families may live with multiple and overlapping forms of discrimination and disadvantage?
- Does the service recognise that some people may have been marginalised and experienced trauma in previous use of services?

Engagement
- Does the service have productive connections and partnerships with members or representatives of diverse groups in planning and decision-making committees, and in its workforce?
- Are there strategies for strengthening and supporting these partnerships, and for designing engagement that supports culture and identity?

Voice
- Does the service enable diverse voices to be heard regarding lived experience, accessing the service, and ways of improving safety and quality? Can the most vulnerable and disadvantaged be heard?

From a diversity perspective, services must be alert to the barriers to good safety and quality of services for everyone; they must develop effective responses to these barriers. This can genuinely happen only by ensuring that various community groups are central in service design and planning.

Diverse age groups

Key issues affect consumers, families and kinship groups in all age groups. For children and young people and their families, timely access to services is critical for families coping with the early onset of mental distress and symptoms. Engaging with children and their families is an important but often neglected part of engagement policies for safety and quality. Particular issues and specific approaches are required. Medicine use, continuity of care, and supported timely transition into adult services are important safety and quality issues. Appropriate responses and follow-up for young people and families experiencing a suicide crisis are a priority. Service access and quality issues are also important for young people who have experienced early childhood trauma, and for young people in contact with the youth justice system. There are numerous strategies for engaging children and young people in organisational decision-making.[6] However, another layer of complexity is added because permission is required from a parent or guardian for children and young people under 18 years—particularly when discussing topics such as suicide or trauma.

Older people can experience similar issues in terms of transition to Older People's Mental Health services for people living with long-term illness. Older people experiencing depression related to ageing and chronic illness, or those experiencing dementia, may need to access services for the first time in their lives. Often older people have complex mental and physical health needs, and care may occur across the health and aged care sectors. Issues also arise regarding medicine use, information about treatment, access to treatment, and exposure to experiences that lack dignity and respect. These are all key safety and quality issues.[7]

Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people have their own ways of understanding mental health lived experience. Aspects of cultural identity, collective experience and lived experience of trauma and distress and service use inform how the experience is understood and expressed.[8]

Also, the framework of social and emotional wellbeing developed from Aboriginal and Torres Strait Islander perspectives differs from the concept of mental health in Western culture, which means many people have a unique service context. For example, you may be getting help from traditional and contemporary healing, wellbeing services from an Aboriginal Community Controlled Health Service, and primary care and public mental health services.

The setting of consumer or carer leadership in service decision-making also overlaps with other areas of health and community leadership. There may be cultural protocols and kinship preferences that affect whether you can take on the role of consumer adviser, representative or peer worker within a service.

High-quality services and actions to prevent suicide are a priority for Australia. This guide integrates many of the ideas and practices relevant to our national priorities for improvement. These key concepts and policy documents have informed the guide:

- The social and emotional wellbeing framework.[9]
- Trauma-competent and healing-focused practice.[10]
- The Gayaa Dhuwi (Proud Spirit) Declaration.[11]
- Cultural safety principles and practices.[12]
- The framework of cultural respect.[13]
- Aboriginal and Torres Strait Islander health leadership and workforce development.
- Culturally responsive assessment and treatment. practices.
- Frameworks for respectful community engagement.
- Integration of National Safety and Quality Health Standards.[14]

Cultural safety principles

Cultural safety principles originated in New Zealand and have been widely adopted in Australia. They are particularly prominent in Aboriginal and Torres Strait Islander health and in nursing. There are five key principles[15] that are focused on health professional values, practices and organisations:

1. Reflect on practice
- Reflect on assumptions of your own identity, health, illness and people.
- Include your own and other's definitions of health.

2. Seek to minimise power differentials
- Focus on power differentials between self and consumers and kinship groups.
- Understand how biomedical dominance may be experienced as unsafe care by consumer, carers, family and kinship groups.
- Reflect on colonial histories and the power invested in healthcare professions.

3. Talk, ask, engage in dialogue with people
- Understand unique needs, beliefs, understandings and preferences.
- Understand that safety and comfort are defined by the person.
- Engage, listen and grow awareness of Aboriginal health systems.

4. Undertake decolonisation processes
- Create spaces that recognise and enable expression of culture and identity.
- Avoid reinforcing practices that work from unexplored assumptions and values.

5. Do not diminish, demean or disempower people
- Reflect on the outcomes of your actions for others.
- Ask: what are the person's or group's experiences of the interactions?

Culturally and linguistically diverse communities

Many people from culturally and linguistically diverse communities experience difficulties in accessing mental health care. Key safety and quality issues relate to the nature of communication and shared understanding among consumers, families and clinicians. Language barriers and cultural misunderstandings can cause issues in diagnosis, understanding treatment and involvement in care. Education to reduce stigma and improve access to care remain important areas for development.[16] Recognition is required of the significant legal-, settlement- and trauma-related stresses facing asylum seekers and refugees. These issues compound distress and influence the experience of mental health problems.

Engagement and partnership strategies must be suitable and comfortable for people, and connect with bilingual workers. Effective strategies include visiting established groups and networks within communities, planning specific events with community groups, and linking with welfare or culturally representative organisations. Developing a mental health workforce with bilingual skills is also a key goal.[17]

Lesbian, gay, bisexual, transgender, intersex, queer + communities

Members of LGBTIQ+ groups experience higher rates of mental health challenges, including psychological distress, depression and suicide-related crisis. Recognition, acceptance and inclusion are vital experiences that enable people to access services with a sense of safety and trust, and are key actions and areas of development.

The general mental health sector does not yet have the effective awareness and partnerships that exist in the LGBTIQ+ and youth health areas. Services should engage with and support LGBTIQ+ community, advocacy and service networks.[18] These partnerships should enable shared learning and organisational development on policies and commitments to safe, non-discriminatory care for LGBTIQ+ people, which includes the use of inclusive language in services' forms and practices.[19, 20] Policies should also promote service partnerships and referral networks with specific programs for LGBTIQ+ youth, adults and older people, including those in rural, regional and remote communities.

Rural and remote communities

As in many communities, for rural, regional and remote consumers and carers, issues around mental health safety and quality relate to accessing help, as well as the quality of help people receive once they are in the service. Quality of care can depend on the knowledge and skills regarding mental health of local general practitioners and hospitals. Generally, rural Australians lack choice in their preferred mental health professionals and services.

Community mental health teams play a critical role in providing advice and coordination of care for consumers, families and kinship networks. Aboriginal Community Controlled Health Services also provide local clinical care, and support people to attend wellbeing services and traditional healers. Where telecommunication infrastructure permits, telemedicine and video conferencing may enable people to access medical treatment. In addition, peer networks and peer workers are becoming available in regional cities. Suicide prevention networks are working to develop referral pathways and improve community awareness and supports for people experiencing crisis.

Rural Primary Health Networks (PHNs) play a key role in bringing people together to discuss mental health needs and create service networks. The commissioning role of PHNs means that consumers and community leaders can partner to identify the types of services that are required, and the criteria to evaluate the services. Consumers, family and kinship groups can also participate in consultation and decision-making forums within public health services operating across regional areas.[21]

Challenges facing consumer and carer engagement in rural areas include transport and distance, telecommunication limitations, funding to support engagement and travel of people with lived experience, and consumers' and carers' of loss of privacy and stigmatisation, and that complaints may influence future care.

Very few carers want to be involved – they are too busy and don't want to rock the boat. As a small community there is no choice in services as there is only one hospital.

Lived experience perspective

People with disability

Many people using public mental health services live with other forms of disability. This includes people with intellectual disability, neuro-diverse people and people with sensory impairments. Successful communication and access to care depends on the skills, knowledge and awareness of clinicians, so that care can be informed by, and respond to, preferences and needs. Services need to prioritise accessibility and inclusive language. In addition, public services for mental health and disability support must be well coordinated to ensure good communication and easy transition between services.

On the governance level, engagement practices and strategies must focus on access and recognition—ways of empowering diverse voices and supporting people to enter the peer and clinical workforces. Many advocacy organisations and groups promote awareness of preferred practices.[22-24]
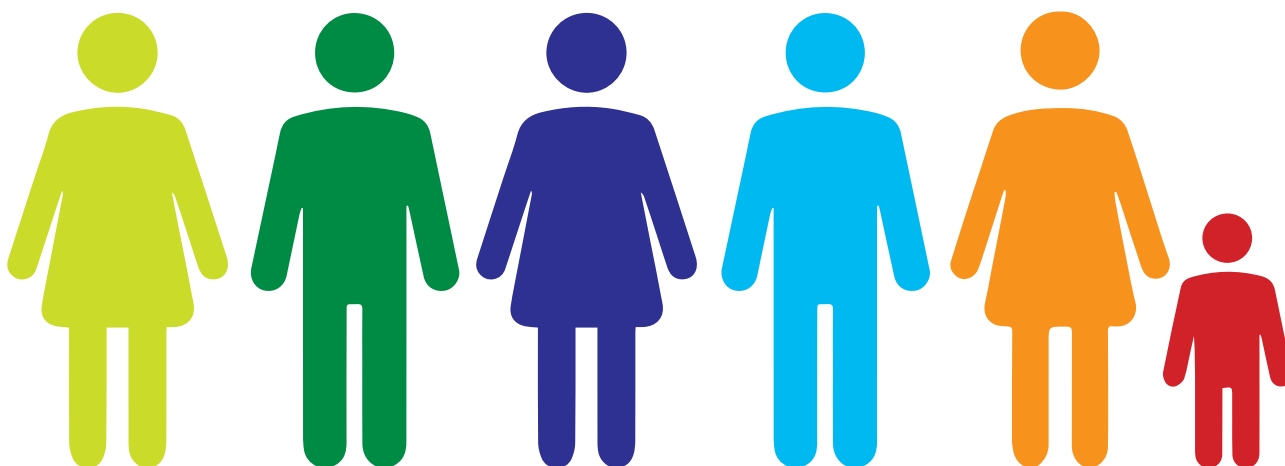
4 *Working* together

In this section, we describe several aspects of effective partnerships within safety and quality groups. The discussion covers the importance of expectations about lived experience roles and the roles of other group members, and the leadership skills required by chairs and group leaders.

Orientation and preparation

What is orientation?

All new group members within a team receive an orientation about the group within the health service. This should include an orientation pack presented either online or as a hard copy. The pack will provide you with information related to the organisation's core values, and the policies and procedures that guide the group's functions. Common inclusions are the organisation's framework for consumer engagement, and their commitments to person-centred and family-centred care. Information about the Partnering with Consumers Standard and about partnering with consumers and carers is often provided too. A sample 'terms of reference' might be included to outline the membership of the group, and its functions, and key reporting relationships.

Questions to ask during induction

- What is expected of me in this group?
- How do the lived experience members and others contribute to the group?
- How do members inform and support one another?

Where the group fits within the wider service should be described so all members understand the structures of the service they are in, and how decision-making works.

Clarity of expectations in the lived experience role

What is your purpose for being in the group?

It is important to have an understanding about a group's expectation for lived experience partnerships and what the group is seeking from people in advisory or representative roles. All members have a purpose for being at the table and providing their perspective. It is important that the group leader lets you know about the purpose of the group and is clear about the role of lived experience leaders. This helps you to think about your own expectations too. When you understand the expectations of the role, this helps you to communicate clearly and with purpose. A similar process occurs for any tasks and project work that the group wants to complete.

What can you achieve in your role?

Everyone on a committee needs to know how much the group can achieve. This helps you to set goals that are realistic and achievable. You might ask yourself "What do I need to do to successfully engage and participate?" This information can be found by speaking to the committee chair as well as your mentors about the role and the ways you can make change. It may be helpful to send some written notes addressing key points to the chair prior to your discussion. What you can achieve will be influenced by the group's focus and ability to make decisions for change.

How much of my contribution will be included?

Some people enter a group with expectations above what is expected of them. They may wish to tell their story and have this formally recognised. When this is outside the context of the group, people can feel disillusioned because their experiences are not acknowledged as expected. You can clarify exactly what is expected of you and how your views will be recognised early in the process to ensure that you have a clear understanding of the group's workings.

What are the processes for change?

Expect things to change slowly.

Lived experience perspective

System processes can take a long time; it often takes months or even years to see any results. Find out about the processes for change in the system you are working within, and explore how long it may take to see outcomes from your contribution. Information should be provided about processes for feedback and communication to update you on progress. Health services need to fund people to ensure that communication and feedback are thoughtful, thorough and timely. Consumer engagement coordinators usually play a key role in this process. However, chairs of specific groups often do this too.

Co-production principles

Co-production is an approach for working together to set the agenda for changes to policy, planning, service design and evaluation. Co-production is about planning activities that value lived experience of services alongside professional knowledge, and works toward practical ways of sharing power in organisational decision-making. There are three key principles of co-production:[25]

1. Consumers and family/carers are partners from the outset

- Consumers and family/carers are involved in setting agendas from the beginning.
- Consumers and family/carers are engaged for their expertise and leadership.
- All parties have a clear and shared understanding of purpose and share relevant information.

2. Power differentials are acknowledged, explored and addressed

- Affirmative actions are taken to ensure that consumer voices are heard and influential, and to achieve an equal balance of power.
- More powerful parties share power to promote consumer voices and priorities.

3. Leadership and capacity of consumers and families/carers are developed

- Activities recognise and develop consumers as leaders.
- Resources and opportunities that build capacity and leadership are accessible and shared.

Role of the group leader

How does the group leader support lived experience members?

The chair needs to have a good understanding of the role of the lived experience member. Consumers and carers can have a different understanding of what engagement and partnership look like—if it is mismatched, people can get the wrong expectations and understandings.

Lived experience perspective

The group leader or chair requires a good understanding of the role of the lived experience members and provides ongoing support from the beginning of their involvement. Support is offered at regular intervals, and frequent checks ensure that the lived experience members feel engaged, safe and informed. This might be in the form of conversations—at the start of meetings to check in or at the end of meetings for debriefing. The group leader should be approachable and easy to contact before and after meetings.

The group leader can clarify key points from meetings and check everyone's understandings about what was discussed. Training and supervision might be offered to members; the chair should be experienced in identifying these needs.

The group leader should be inclusive and should support each member to contribute, identifying quiet members who may need encouragement or a different format through which to communicate their ideas or questions. Open and safe communication can occur when the lived experience member can talk to the chair about what they need to successfully engage with the group.

The group leader validates everybody's contribution to the discussion and acknowledges each person's unique experience and knowledge. They also support the value of both perspectives—lived experience and non-lived experience—and the need for respectful, inclusive communication. In a partnership context, the group leader acknowledges the need for shared knowledge, and that lived experience perspectives express valid points, as do learned experience perspectives.

At times, group leaders may need to manage the behaviour of individuals who behave inappropriately. Clear guidelines should be established for a mediation process within the group. This helps people understand what constitutes inappropriate behaviour, may be inappropriate and that there are mechanisms to support and encourage positive, healthy, safe engagement.

Inclusive and valuing of lived experience perspectives

The problem of stigma and discrimination is still experienced by lived experience leaders in the safety and quality area. This has been reported in the form of being questioned about your background, being seen as your diagnosis and not as a person, having your opinion ignored, feeling devalued, being patronised ("We know better"), seen as a lesser person, and being treated with suspicion: ("Why is this person looking at the service files?").

Power dynamics operate to shape decisions made in groups, with different members having different levels of influence and authority to their claims. In this guide, we have highlighted the need for understanding power dynamics through cultural safety and trauma-informed care. Both sets of principles encourage members of groups to examine their own assumptions and judgements about the values, knowledge and capacity of consumers, carers, families and kinship groups. They also encourage awareness and reflection on the power that is inherent in health professional roles, and how this power can be consciously shared to create opportunities for people with lived experience, rather than to reinforce traditional roles and privilege.

An example of shared power is to have groups that are co-chaired. These groups have a consumer or carer co-chair as well as a clinical co-chair. Agenda items and the progress of the group are led in partnership. This approach to supporting lived experience leadership empowers consumers and carers in the group and challenges stigma about capacity and knowledge. It also builds capacity and skills.

How do we become more inclusive and respectful of one another?

Stigma and discrimination hurts and is still painful every time it happens. Everyone in the mental health area needs to reflect on their limiting assumptions they hold about consumers. Validate our experience and our knowledge.

Lived experience perspective

This guide highlights qualities and practices for successful group partnerships:

- Ensure that lived experience advisers or leaders are involved from the beginning to end and not in an ad hoc manner.
- Communicate working documents in a timely way, including offering to print and courier them to members.
- Acknowledge and respect the unique expertise of lived experience leaders and their contributions to safety and quality.
- Listen to what is important to everyone and encourage mutual respect for all members.
- Acknowledge power imbalances, and support ways to enhance lived experience voice and leadership, and increase member numbers.
- Let people know they are being helpful—not everyone knows if their participation is valued.
- Be collegial and remember the person behind the role.
- Be committed to learning from consumers and carers, and working within the spirit of shared learning and partnership.
- Reflect on, and discuss, the benefits of partnerships as a group.
- Avoid using jargon and acronyms that exclude lived experience participants from understanding and thus contributing.

An example of effective group leadership

A Local Health Network sets up a project group to identify improvements for the mental health inpatient unit at the regional hospital. To provide a more welcoming environment, facilities and practices on the ward need reviewing, as do safety and quality. The review also aims to find ways of increasing comfort and reducing conflict between staff and consumers.

Eight members of the region's consumer and carer reference group are invited onto the project; six clinical leaders are also involved. At the first meeting, the group leader wants to establish an inclusive culture for the group and acknowledge lived experience leadership. She:

- gives an Acknowledgement of Country for traditional owners
- acknowledges the Aboriginal people present
- acknowledges the people with lived experience, and recognises how their experiences and insights inform the work of the group/organisation/sector
- conducts an introductory round of members
- raises the importance of lived experience contributions and leadership to the project
- acknowledges that inpatient units can be places of traumatic and difficult experience for consumers, and the significance of diverse consumer perspectives for defining safety in these contexts
- works with the group to identify everyone's values for working together. These values are written on coloured A4 sheets of paper and put on the wall for reference
- speaks to the values, noting that conversations may reflect different perspectives on power and safety, and that lived experience can and should challenge the thinking and routines of the health service. She emphasises mutual respect
- works to encourage voice, and how shared awareness and knowledge come from working together.

Language and communication

Language can be a learning curve—when you first go into the mental health system as a consumer/carer it takes a few years to understanding the language, diagnoses, etc. A similar learning curve is experienced when on a committee.

Lived experience perspective

Language and acronyms used by clinicians and service managers can be difficult to decipher by anyone who does not usually work in the health sector. Foreign terms and words are used to describe common diagnoses, treatments and interventions, as well as other aspects of the safety and quality area. There is 'assumed knowledge' among health professionals, which must be identified and discussed within the principles of conceptual competency and sharing power with lived experience members. Using conceptual competence is the ability to see the big picture goal and provide leadership and direction to work towards achieving it. Equally, lived experience members may use language from consumer and carer knowledge frameworks and projects that needs to be explained to health professionals. Developing health literacy happens over time with ongoing involvement, but often people need to know the meaning of common terms used in meetings. All members must have access to information and education about the topics being discussed, and their context. Services need to provide lived experience members with information to ensure that they are well informed about the context of the group and therefore can contribute meaningfully.

Use of acronyms and medical terminology should be minimised to ensure that everybody at the table understands what is being said.

Contact person

One person should be identified as the contact person for lived experience members. Members can ask the contact person questions about the content of the meeting and clarify points. The person could be another member of the group, or the chair. The contact is vital for encouraging members of vulnerable communities to connect and have a positive group experience. A contact person needs a strong commitment to ensuring that the voices of consumers, carers, families and kinship groups are supported and heard. Additionally, they should ensure that any payments for participation and reimbursement of expenses are progressed in a timely manner.

Contact details of all people on the committee should be distributed via email to provide a communication channel for all.

Collaborative and strategic approaches

Taking a solutions approach with positive communication promotes collaboration between service managers and lived experience leaders. Ideas in the form of positive suggestions and ways to improve safety and quality from a consumer or carer perspective are encouraged. This should be balanced with awareness about the best ways to achieve change, given the various interests affecting health services.

Consumers can find it hard to know if they're being helpful or not. Letting them know that they are helping and making a difference, and that their participation is valued, is important.

Lived experience perspective

Transparency and feedback about outcomes

Feedback loops are critical ways to let people know they have been heard and their ideas are taken seriously. Often people report not knowing what has happened to their contributions after engaging with a committee. Changes in system processes within the healthcare system often take months or years, and can leave people wondering whether anything has happened. People like to know if their contribution has been helpful or useful to the project. Providing feedback and updates to all members of a committee lets them know they are being listened to, and valued. Feedback is a central feature of accountability.

Pathways to communicate information and give feedback to members across the life of a project include email, phone, meeting minutes and face-to-face discussions. Groups should consciously plan how communication and feedback will happen across the life of the group or project, and then follow through on these commitments. This is an important part of accountability. Executive-level feedback and reflection help members to understand the impact of their contribution.

Reflecting on contributions

Health service leaders should provide a clear communication pathway for lived experience members to provide feedback to management about the partnership experience. This allows opportunities to discuss any barriers to engagement, or other aspects of group membership. Group leaders can check in with lived experience members in ways and on terms predetermined by the member—for example, at the start, during or after meetings. The check-in could occur in a one-to-one setting or with other members present. Either way, the lived experience member must be provided with appropriate support in a comfortable context to communicate any concerns about their role, the group environment and the outcomes of decisions.

This process also enables group leaders to offer feedback about your and others' contributions to the meeting, and the effects of the contributions. This is an important process.

Questions to ask yourself about barriers to engagement
- Did you feel safe, heard and listened to in committee meetings?
- Were you able to provide open contributions?
- Do other members understand lived experience leadership?
- What stopped you from speaking up?
- Do you have access to the resources you need?
- How can you be better supported to engage?

5 *Being heard* and having influence

When preparing this guide, we talked with people about being an effective lived experience leader. They gave many suggestions about ways of being heard and having influence, as well as tips for navigating the challenging aspects of being an adviser or leader.

This section covers the areas of preparing for meetings, building confidence, communicating key issues, interpersonal and professional boundaries, dealing with conflicts and power imbalances, talking with networks, and community organisations.

Preparing for meetings

Here are some practices that work for experienced lived experience leaders:

- Meeting papers are generally distributed well before the meeting date. Look at the agenda and minutes from last meeting—write a list of the things you would like to raise at the next meeting. You can request to add an issue to the agenda for the next meeting.

- Write down some considered and challenging questions that you can ask the group.

- Tell the chair about the things you want to raise at the next meeting, or what you wanted to say during the last meeting.

- Ask the chair or contact if they have any questions about consumer or carer perspectives on the area everyone is working on.

- Do your background homework—research ideas and experiences by reading about the topic and talking with members of your networks. Use the National Safety and Quality Health Service Standards and the Charter of Consumer Rights for context.

- Don't hesitate to ask questions about how things work in the service and the committee.

- Reflect on your role in the committee, in terms of its purpose as defined by the health service and your own interests as part of the lived experience movement. This will take some time, but it helps you to know what your contribution will be.

- Learn to recognise the experience of feeling silenced and what contributes to it; develop strategies for overcoming it.

When you have less experience academically and clinically than others in a group, how do you prove your worth? Explain who you are and realise that you don't have to be in their league; you're in your own league and you are here for a reason.

Lived experience perspective

Your values and communication skills

Being heard and having influence is about your values, your communication skills, learning about the health service context, and building relationships. Table 3 outlines important things to keep in mind.

Table 3: *Values and communication skills*

Your preferred values	Your communication skills
• Honesty and transparency • Respect for self and others • Contributing in goodwill • Challenging thinking in constructive ways • Being inclusive, and respecting diverse communities and experience • Being positive and helpful—seeking to improve health outcomes for consumers and families, and their experience of the service	• Greetings and general conversation • Asking relevant questions that expand thinking • Reminding others of common consumer experiences and ideas • Respecting your personal boundaries and those of others • Being assertive, and having confidence in your preparation and knowledge • Speaking from a consumer or carer perspective, not just your own story
Things to understand	**Building relationships**
• Background and history of the committee; how it fits with other parts of the service • Scope of the decision-making in the group; some things can be achieved in the group, whereas other issues must be approached in other forums • Change occurs in small steps as well as big ones	• Getting to know the people in the group and their roles and interests. Looking for supporters of the lived experience voice (allies) • Building a productive working relationship with the chair • Meeting other people with lived experience at events and groups • Meeting with the chair and other leaders individually

Confidence in your experience and role

You may feel that you are 'only a carer', or 'only a consumer'. You may feel you have lesser knowledge, a lesser voice. But you're there to communicate a perspective that's unique and different to the clinical voice, or to the management voice.

Lived experience perspective

Many consumers and carers are well aware of power imbalances when engaging with health services. You will probably engage with senior clinicians, service managers and leaders who have many years of experience, and formal qualifications. Some may even have been part of your own treatment and support team.

It's time to reflect again on why you're involved, and on the lived experience movement. You will recognise that you have been invited to bring a deep and rich understanding of the issues at hand. Your lived experience perspective is very different from the learned expertise of clinicians. You bring a consumer or carer perspective that's a mix of your own story, what you have learned from others, and the values of lived experience. You can contribute thoughts, views and ideas that are independent of the professional and financial interests of the service, and of the health sector as a whole. You can remind others about rights and community standards.

Confidence takes time to develop but comes with experience, preparation and the support of your peers.

Being prepared and informed helps your credibility with others. Do your homework.

Lived experience perspective

It's important to evaluate whether the group recognises and values lived experience leadership and expertise. Does the group leadership recognise and engage with lived experience values? Are opportunities for leadership shared with you and other lived experience members?

Speak to the right people to ensure they have the ability to make the changes you recommend; know who the people are who have the ability to do something to help you. We need to be mindful of this in advocacy— who is the person that can help us achieve what we want?

Lived experience perspective

The role of allies and supporters

People—such as clinicians—who work in non-designated lived experience roles can feel confronted as lived experience leaders and peer workers become more influential in decision-making. Reasons for this include increased accountability towards the lived experience perspective and the need to share power within decision-making. Much reflection is involved in considering issues of power, ethics and rights in service provision and decision-making. A key area of learning and development is to consider the role of allies for lived experience. Being an ally requires rethinking traditional professional–consumer relationships and taking a deliberate stance to support empowerment and social justice, as espoused in the principles throughout this guide.

Personal boundaries and recovery

It's important to be aware that you are going to make yourself vulnerable—you can share what you feel comfortable with. If it's still raw for you, you may not be ready to share that journey yet, but there might be some things that you are feeling quite comfortable with.

Lived experience perspective

Most people who become active in safety and quality are a fair way into their recovery journey. This helps because they have had time to reflect on their experience and distil key issues that need to be communicated to others.

Many lived experience leaders talk about the need for boundaries between your own experience and story and your work as a leader.

You may notice that mentors and experienced leaders do not always talk about their own stories during forums and meetings, or they might only use their story to reinforce a key point. This boundary achieves several things. It helps to focus their advocacy on the principles and issues being discussed, and to maintain privacy around their experiences and memories of mental health and distress. In addition, communicating through your story may require a lot of processing and time to settle, and may affect others in various ways. Repeatedly sharing your story as part of your advocacy and participation may also affect your recovery. Allow time for self-care checks.

Everyone has their own style. Choosing your boundaries is something all lived experience leaders need to do. An effective consumer leader is one who has integrated their experiences of mental distress into their lives, and gained value from their lived experience, and wisdom to share with others.

Building your networks

The lived experience movement is built on its membership and peer-support networks. It's important that any role you undertake empowers you to connect with and maintain your networks of local people. This helps to deepen your knowledge of the views of others, and your connections support your role. When you bring strong networks to an advisory role, you strengthen your credibility and reflect the shared knowledge of your community networks. When you communicate faithfully with your networks, you build and deepen trust with your peers over time; they trust they can depend on you to communicate their perspectives in your advice and advocacy.

Confidentiality, communication and networks

A key issue is the confidentiality of safety and quality information. Health services will probably want confidentiality agreements in place for lived experience advisers who access and discuss this material. If you sign a confidentiality agreement, does it mean that you can't talk with your networks about any aspects of this work?

Probably the best answer is that you can usually talk with others about the general areas of change that the health service is undertaking. You can also ask your network members questions about the topic without breaking confidentiality. For example, a health service is working on its discharge planning processes; you might share this with people and ask them about their best experiences around discharge planning.

Another key point is to check in with the chair about what you would like to communicate informally to your networks. Mostly, paperwork associated with a project is confidential and cannot be shared—it's best to check. However, this doesn't stop a service from preparing specific paperwork to assist external communication.

Partnerships with services

You need to know it's the health service's role to enable consultation with consumers, carers, families and kinship groups. It's unrealistic to expect this of a lived experience consumer adviser or leader. One consumer or carer cannot represent the views of all consumers and carers.

Health services should build connections and partnerships with formal representative organisations such as Aboriginal Controlled Community Health Services, Elders, infant or parent health groups, specific cultural organisations, LGBTIQ+ networks, and consumer and carer peak bodies.

Many lived experience leaders participate in safety and quality projects while also sitting on other committees or being members of other organisations. For example, an Aboriginal Elder may also be a board member of an Aboriginal health service. If you are in this position and work within several organisations, it's good to encourage providers of mental health services to connect directly with these organisations so you are not the only point of contact.

In some settings, you may feel it is difficult to voice quality-related concerns. Leaders based in regional and country areas have told us that it can be difficult to criticise local services—they worry about the impact on treatment relationships if there is only one mental health team and hospital in the area. In these instances, a useful strategy is to talk with state consumer and carer bodies for some guidance on the best way to proceed. Another is to talk with a mentor to find the best approach for discussing improvements that you or your group want to see.

6 Mentoring *and support*

> *Having a mentor helped me to keep going, helped to renew me.*
>
> Lived experience perspective

> *For those who are new to the carer role, they do have important perspectives to offer, but they need a lot of support and mentoring to understand their role. They need to understand how they might get hurt— and so, build up some skills around this.*
>
> Lived experience perspective

> *It is ideal to have someone who has been there before you and understands the landscape, can guide you and debrief in ways that are right for you at challenging times. Mentorship can also help you to get perspective, and help give you context to what is going on.*
>
> Lived experience perspective

In this section we discuss the importance of mentorship and support. One of the consistent messages we heard during the consultation process for this guide is that mentorship is a critical element of safe and supported engagement of people with lived experience in the safety and quality area. Mentorship can take many forms, and should be discussed and tailored to individual preferences. Here we discuss several aspects of mentorship and support.

The role of a mentor

Engaging in the area of safety and quality requires mentoring from someone with lived experience who has 'been there, done that' and can honestly discuss issues with you. You have important perspectives to offer, and a mentor can help you to better understand your role and potential. Mentorship is valuable at any stage of your lived experience journey; however, those newer to this role may find mentorship particularly beneficial.

Various people can act as mentors. Your mentor may be someone with lived experience who is also a member of the same committee or is involved in the same activity. This allows you to discuss confidential information with them.

Alternatively, your mentor might be someone from the service, but not necessarily from the group you are involved in. These mentors can help you understand the function and dynamics of the service. You should be able to talk openly without needing to explain all of the details because your mentor understands the context.

A mentor can also be someone who is not directly connected to the service or project that you are involved in. For example, they might be active in other areas but have considerable experience in the lived experience movement.

Identifying and engaging with a mentor

There are various ways to identify a mentor. For example, some services may have a formal mentorship program, with a list of available mentors and a process for connecting new lived experience advisers with them. Other services don't have a formal process. In other instances, you might identify a mentor yourself. It's important you have flexibility and choice about your mentor and what you want from the relationship. In addition, there should be regular opportunities for you to engage with your mentor— for example, arranging a monthly coffee meeting or a fortnightly phone call between meetings.

How can a mentor help you?

A good mentor can help you understand, navigate, explore and reflect on your role as a lived experience representative. Specifically, a mentor can help you:

- feel understood and validated in your role as a lived experience representative, because they have been in your shoes—for example, you might feel anxious or insecure about your involvement; a mentor can help you work through those feelings

- understand your role and your expectations—for example, if you are new to this role, your mentor may reassure you that you haven't been exposed to this environment or process before and so you can't be expected to know everything

- become familiar with the language and knowledge needed in a particular context

- see the links between potential distress triggers, being active and being on a recovery journey

- by providing honest feedback in the right format for you

- find further resources to assist with your role

- reflect on your involvement—for example, by asking "Are you ok?" "How do you think that meeting went?"

- understand other perspectives—for example, those expressed by clinicians

- feel motivated and renewed in your role—for example, by reminding you why you are doing this

- by discussing and facilitating future opportunities and directions—for example, developing networks.

Supervision by peers or allies

In addition to having a mentor, having access to some supervision may help to support you. This supervision works like clinical supervision for health workers; a peer can act as your supervisor. Unlike a mentor, however, a supervisor is not necessarily someone who has lived experience. Rather, a supervisor is someone who is a member of the group you are engaged with, and an ally in supporting lived experience.

Particularly in the safety and quality area, services invite you to be involved in discussions that may trigger distress for you. Peer supervision by someone who also has a lived experience can help support your self-care. They can provide opportunities for you to debrief or seek alternative ways of managing your lived experience role that work for you.

Building relationships across groups and organisations

In addition to formal mentorship and supervision, you will build many other important relationships across the groups and organisations you contribute to.

It's the responsibility of both lived experience leaders and other health service leaders to connect with each other. The service needs to ensure that lived experience is part of a broader network of people who sit at all levels of the service. For example, people with lived experience should participate in all management meetings, patient safety and quality meetings, inpatient meetings, service-management meetings, and working groups that govern strategic service improvement. Similarly, there should be pathways for people with lived experience to communicate with and transmit information to higher levels of the service (e.g. a monthly consumer advisory meeting).

7 Managing *your self-care*

In this section, we discuss some ideas for self-care. This is an important topic as many conversations that occur in the safety and quality area may be challenging emotionally for everyone involved. The conversations and subject areas may remind people with lived experience of difficult and traumatic personal memories. It is useful to know something about areas that may be challenging for you.

Trauma-informed support and self-care

This approach builds awareness and recognition of the impacts of trauma for consumers, particularly trauma that has been experienced during childhood.

The approach also recognises that many consumers have had traumatic experiences within mental health services. These experiences include service responses that are invalidating, detention, restraint, forced treatment and seclusion.

In addition, many people have experienced trauma in the context of cultural, gender or sexual identity. Colonisation has exposed Aboriginal and Torres Strait Islander people to the impacts of intergenerational trauma: disruptions to parenting and family culture, and experiences of trauma related to forced separation of children from families have had ongoing effects on generations. Many Aboriginal and Torres Strait Islander people have had difficult and challenging experiences when they have accessed health services, including racism, discrimination and adverse events.

Many people with insecure visa status—such as refugees, asylum seekers and culturally diverse people—have experienced trauma and insecurity in their home countries, and during life in refugee camps and immigration processing centres.

One of the key impacts of trauma is that it makes people hesitant and fearful about engaging with mental health services or child health services. A history of trauma can lead people to question themselves—for example, by asking "Is this situation safe or unsafe for me?" Surviving trauma can increase a person's vigilance and need for certainty and control. Entering or re-entering a mental health service can trigger feelings associated with past experiences, such as fear, danger and strong feelings of vulnerability.

Because lived experience of mental health challenges can be linked with using mental health services, as well as cultural, gender and sexual identity, service providers and engagement leaders must be trauma aware and offer supports for people.

Good self-care is critical— being made aware of sensitive information and managing that with good self-care as a routine activity. This should be established at the first meeting.
Lived experience perspective

An approach for trauma-informed care

A well-known approach to trauma-informed care was developed by the Substance Abuse and Mental Health Services Administration in the United States. This approach emphasises that services should be aware of the effects and prevalence of trauma, and that services should recognise the signs of trauma in people and populations requiring care. Services should also develop organisational policies, procedures and practices that integrate knowledge about effective trauma care and responses. And services should resist practices that re-traumatise people.[26]

Is this engagement practice trauma-informed?

The engagement opportunities in safety and quality that interest you should be informed by the principles of trauma-informed care:

- safety
- trustworthiness and transparency
- peer support
- collaboration and mutuality
- empowerment, voice and choice
- importance of culture, history and gender.

Challenging topics

When you see an opportunity, or receive an invitation, to be involved in safety and quality, it's likely that the organisers have considered the best way of involving consumers, carers, families and kinship groups.

Most services employ consumer consultants and Aboriginal and Torres Strait Islander advisers. These people should have guided earlier discussions about the best way to involve people, considering the nature of the proposed topics.

Emotionally sensitive topics can include detailed discussions about adverse events or self-harm when a person was injured or died in care, child safety issues, the experience of restraints and seclusion, and suicide prevention in the service setting. Another area of sensitivity arises when clinicians or specific services are named in complaints processes, which has legal implications. All these factors influence opportunities for involvement and partnership.

Service providers can be worried that the information can be triggering for consumers and/or carers and they don't always trust that they won't breach confidentiality. But people with lived experience tend to be more careful—"If this was me or my family, how would I want this information to be treated?"

Lived experience perspective

Evaluating potential triggers and self-care

Sometimes people with lived experience can experience the language used in safety and quality, and the ways of discussing sensitive topics, as technical, clinical, detached or unwittingly objectifying. However, consumers and carers may not realise all the things that can go wrong in health care, or the various pressures that services are under. They can experience these discussions in unexpected ways, which may be emotionally triggering and distressing.

When we were consulting about this guide, lived experience leaders and service leaders suggested that the questions in Table 4 are useful for evaluating triggers and deciding on ways of being involved and partnering.

General questions for lived experience advisers and service leaders

- What is the nature of discussions in this area?
- Are they about individual consumers' experience in care?
- Are consumers, carers, family or kinship groups identified?
- How will the information be packaged and presented for the discussions?
- How triggering would the discussions be?
- What behaviours are needed in the group environment to help people stay safe?
- Are there better opportunities for engagement? For example, working on future recommendations rather than reviewing the critical incident, or working on identifying trends and gathering statistics.
- What are the benefits and opportunities versus the possible costs of being 'at the table'?

Other questions for lived experience advisers

- Am I ready for this type of discussion? Is my experience still too recent?
- What topics are usually triggering for me?
- Am I in the right place emotionally for these discussions?
- What supports do I need and who would help me feel safe?

Questions for lived experience groups

- What would work best for lived experience leaders as a group? For example, being able to make an informed group decision.
- From a lived experience perspective, who could best contribute to these discussions?

Strategies for self-care from the lived experience perspective

There are many strategies for self-care when you are involved in safety and quality work:

- **Writing or creating a self-care plan.** A plan can help you prepare for your work and remind you when you need self-care. It's good to prepare your plan before you start working in the group.
- **Briefing.** Ask questions of the contact person or chair as you start getting involved. Find out what's going to be discussed in the next meeting, and how it will be discussed.
- **Debriefing.** Share your thoughts and responses after meetings with the contact person or chair.
- **Clarifying any confidentiality matters.** Get clear on these matters if you think they will affect your self-care.
- **Checking in.** Talk with other group members, including lived experience members, about how you are handling the subject matter.
- **Talking to your mentor and support person.** Talk about how you are going and your self-care strategies. What practices do they find helpful?
- **Working out boundaries for your involvement.** For example, create limits for your reading and preparation time at home so you have some free times during the day, night or week.
- **Opt-out strategies.** Let group members know that you might need to take a break for self-care during discussions.
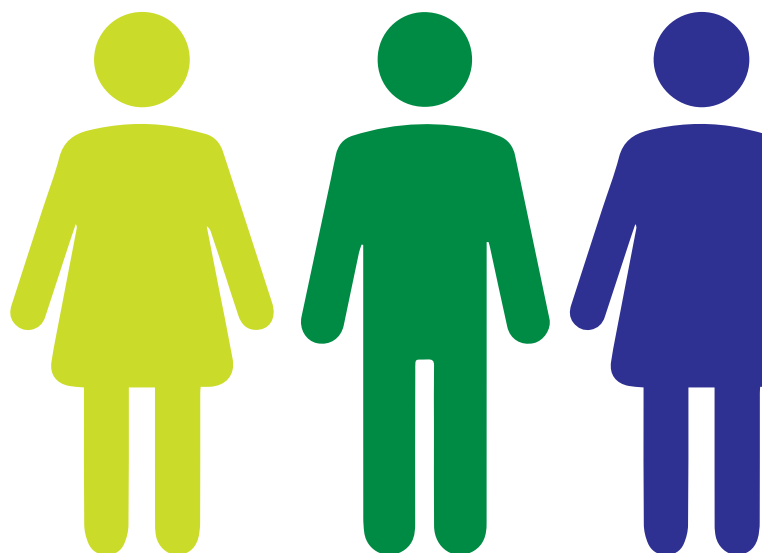
Strategies if you are experiencing significant distress

For various reasons, there may be times when you need to prioritise your own mental health over your participation in a safety and quality project; you may need to scale back your involvement for a time. Safety and quality leaders can offer organisational supports to assist you.

Organisational supports to assist self-care

Services should have a flexible support system in place to assist representatives and leaders. Ideally, services will:

- have a joint understanding with appropriate human resource staff about time for a person's healing and recovery (if the leader is being paid)

- be aware that a consumer may need time away from meeting processes, just like other members of the committee, to address personal or family issues

- ensure a variety of ways for all committee members to provide input (e.g. via video, telephone conferencing, email and in writing, as well as in person)

- engage in supportive conversations to hear and respond to the person's views about whether they are able to participate (e.g. the person may decide they are well enough to participate, which should be supported)

- ask the consumer to follow up with their doctor if medical clearance is an issue

- check in with the person to see if they need assistance to contact supports and services.

Safe engagement: important practices for chairs, and safety and quality leaders

- Work through the ethics of engaging people with lived experience with consumer consultants and advisers. Have more than one representative involved.

- Provide a range of supports to both lived experience members and non-lived experience members of committees and groups, remembering that employees usually have more supports in place, such as employee assistance programs and supervision. Connect lived experience representatives with others (e.g. a meeting buddy).

- Encourage all members of the group to have wellbeing strategies as a normal part of caring for themselves, each other and the group as a whole.

- Ensure that briefing and debriefing opportunities are available for lived experience representatives. Allow time to check in before and after meetings.

- Provide context on quality improvement during discussions, highlighting how specific local issues are related to general trends in safety and quality. Work together to identify the bigger picture of quality and safety improvement.

- Consider safety issues around culture, gender and age. How do these issues affect discussions and lived experience representatives?

- Clarify confidentiality boundaries to ensure that representatives can speak with mentors and support people.

- Plan meetings well: find ways to present difficult information that help protect and create boundaries for group members. Clarify the purpose and ways of working together.

- Use safe and respectful language. Model respectful language and behaviour for group members. This acknowledges the distress that people involved in discussions of particular topics may have experienced.

- Follow practices for a welcoming, inclusive culture, as detailed in *Section 4*.
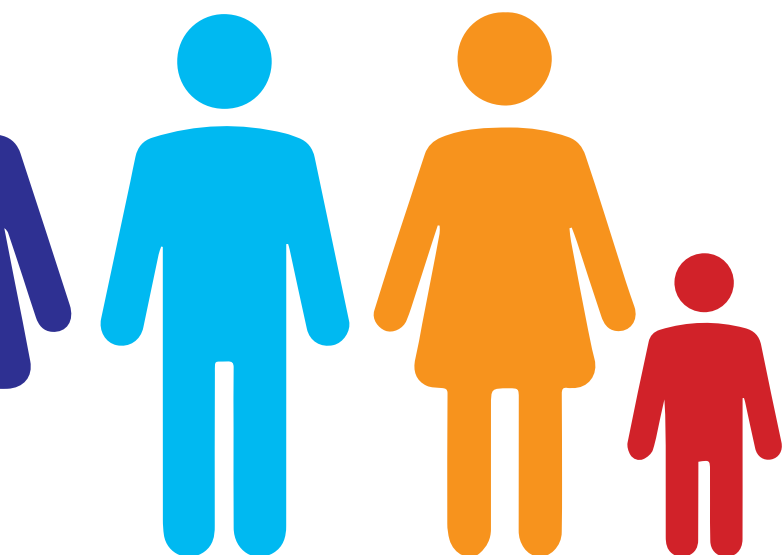
8 Training *and learning*

Becoming a part of a safety and quality group in the mental health sector can be a new and challenging experience. This section outlines some important facts about training and learning.

Service support for knowledge and skill development

Providing opportunities for developing consumer and carer leadership is one of the most important ways to recognise the value of lived experience perspectives. Services can demonstrate their support by funding people to engage in formal education related to the role. Some examples are completing a Certificate IV, work training with peers, and training in consumer advocacy and representation. Providing scholarships for members to attend conferences about safety and quality in the healthcare setting adds value to people's skill sets and promotes networking and building relationships. Programs for mental health leadership are another important pathway for learning.

Under the Partnering with Consumers Standard in the National Safety and Quality Health Service Standards, health services are expected to provide training opportunities for consumers and carers to assist engagement and partnerships. Part of accreditation for services is reporting on their progress in this area.

Training for non-lived experience managers

Partnerships between people with lived experience and clinical leaders are becoming commonplace but are still a new concept for some leaders and managers. Some people still question the role and purpose of lived experience leaders on committees. Everyone benefits if service managers can access training, and develop their awareness, knowledge and skills in this area. This includes training on standards, establishing partnerships, supporting the lived experience workforce, the values of the consumer movement, and co-leadership practices.

Examples

- Health Consumers Queensland,
  www.hcq.org.au/for-health-providers/training
- Mental Health Coalition of SA, Lived Experience Workforce,
  www.mhcsa.org.au/lived-experience/for-leaders

Public speaking and communication

Many education centres offer courses on public speaking. These courses help you develop confidence and skills around organising presentations and communicating key messages. Sometimes courses are offered across health services in which consumer groups are invited to participate.

Consumer advocacy and representation training

Most state peak consumer organisations provide introductory training days for you to become familiar with key policies and practices in consumer representation. If the training is in the general health area, 'consumer

Training can be more engaging when it's fun, humorous and interactive. I like role-plays and scenarios.

Lived experience perspective

representation' covers both consumer and carer experiences, because this term is generally used in national policy documents. If the training is specific to mental health, the training is directed toward lived experience advocacy or consumer and carer perspectives.

Examples

- ACT Mental Health Consumer Network, www.actmhcn.org.au/i-want-to-become-a-consumer-representative
- Health Consumers Council, WA, www.hconc.org.au/what-we-do/workshops

Sharing stories safely

Some organisations offer training to help you safely use your lived experience. This includes how to use your story in advocacy work, community education and work on suicide prevention. The training focuses on key messages and setting safe boundaries for yourself and audiences.

Examples

- Batyr, www.batyr.com.au/being-herd
- Roses in the Ocean, https://rosesintheocean.com.au/our-voice-in-action
- Lived Experience Leadership and Advocacy Network SA, www.lelan.org.au/workshops-sessions

Policies, standards and acts

Safety and quality are linked to specific policies and procedures for services that are bound by specific standards and acts in each state and territory. These documents should be reviewed by all members of a committee, including people more familiar with the service—the review can act as a refresher for them.

Common documents related to issues of safety and quality include:

- Australian Charter of Healthcare Rights 2019
- National Standards for Mental Health Services 2010
- *Carers Recognition Act 2010* (and various state acts)
- National Safety and Quality Health Service Standards
- National Mental Health Service Standards

- mental health acts in your state or territory
- guardianship legislation in your state
- codes of conduct and codes of ethics for mental health professions
- state health legislation and policies on mental health services
- *Privacy Act 1988.*

The references throughout this guide provide links to many resources.

How committees and groups work

You should understand the practices and skills that are used in committees, including typical committee functions, common duties of the chair and minute taker, how to use terms of reference and role statements, how to contribute ideas and proposals, decision-making styles, and voting. Specialist groups can provide training in these areas. Many state peak bodies for health consumers provide governance training specifically for health services regarding lived experience roles.

'Starting a consumer group' on Our Consumer Place provides information about committees of management, including detailed information about management groups and meetings (www.ourconsumerplace.com.au/consumer/starterkit).

Online training about safety and quality

All members should have access to free online training specifically related to safety and quality improvement to ensure that they are equipped with knowledge about safety and quality standards, common tools used in reviews, basic quality improvement processes, and audits.

Training in basic IT skills and online systems also benefits new committee members. Other helpful training areas for members with lived experience include occupational health, safety and welfare; approaches to trauma-informed care; and cultural awareness and safety.

Ask your local health service if you can access online training modules in these areas.

Appendix 1
Language used in the guide

The area of lived experience engagement includes many diverse terms and phrases that refer to people, roles and processes *(see **Appendix 5** for additional terms)*.

This guide recognises that your preferred terminology in mental health may vary from both the terms in policy documents and the terms other people prefer. We use the following terms throughout the document.

Consumers are people who identify as having a living or lived experience of mental illness, irrespective of whether they have a formal diagnosis, have accessed services and/or have received treatment. Consumers include people who describe themselves as a 'peer', 'survivor' or 'expert by experience'.[27]

Carers are people, often family members and/or families of choice (including children and young people), who have a lived experience of providing, or have provided in the past, ongoing personal care, support, advocacy and/or assistance for a person with mental illness. Carers include people in the consumer's extended family, or families of choice and support networks, who play a meaningful support role. This role differs from the role of a paid carer, who is a person employed to care for someone.

Co-production is an approach to developing, implementing and evaluating policy, programs and services in which consumers, carers and health professionals work together as equal participants and partners. The approach is guided by awareness of, and actions towards, shared power and leadership in decision-making, and an understanding that the products (policies, programs and services) must effectively respond to consumer and carer experience and interests.

Engagement has a similar meaning to involvement and participation. Engagement refers to the methods, practices and actions that enable people to become involved in organisational planning and decision-making. This includes consumers, carers and other community members.

Kinship group is a term that refers to the relationships, roles, responsibilities and obligations of many Aboriginal and Torres Strait Islander people. Kinship relations and culture need to be described by local Aboriginal and Torres Strait Islander people, and are not easily understood in terms of relationships in the Western definition of family.[28] An important aspect of kinship care and responsibility concerns which people can be involved in a person's care, and the people who can play leadership roles in the community.

Lived experience is a broad term that refers to the personal perspectives on, and experiences of, being a consumer or carer, and how this becomes awareness and knowledge that can be communicated to others. The term covers people's core experiences around mental health challenges and service use that may have occurred in the past or may be ongoing (sometimes called living experience).

Lived experience advisers are people who are active in the following roles:

Consumer adviser: A consumer with expertise in this area who participates in consultation or decision-making groups, and speaks and acts from a collective consumer perspective. A consumer adviser works to ensure that the rights, interests and needs of consumers are heard, recognised and responded to. A consumer adviser can be independent, or they can act on behalf of a consumer organisation. Sometimes they are called consumer advocates.

Carer adviser: A carer adviser plays a very similar role to that of a consumer adviser in contributing to decision-making groups, but speaks and acts from a carer perspective. Carer advisers work to ensure that the rights, interests and needs of carers are heard, recognised and responded to. Experienced carers understand the need to recognise consumer voices rather than speaking for them.

We acknowledge that lived experience roles are still developing in the health contexts of culturally and linguistically diverse communities, and Aboriginal and Torres Strait Islander peoples. The definition of lived experience is being considered in light of perspectives on cultural experience, preferences, and the social and emotional wellbeing framework.

Lived experience leader: This is an umbrella term that includes people with lived experience who are recognised as leaders within the consumer and carer community in actively promoting consumer or carer perspectives, sharing with others and seeking change.

These roles include people who are active as advisers, consultants, representatives, community and peer educators, peer workers, advocates and activists. Leaders can be volunteers (e.g. representatives, some peer educators and other educators, advocates) or they can hold paid positions (e.g. peer workers, researchers, consumer or carer consultants and representatives, educators, advocates).

Safety and quality is about having a carer consultant at the Emergency Dept, to help us to understand what is going on with our son's care.

Lived experience perspective

Recovery: Recovery is a personally defined process. A common definition is "being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues".[29] Values associated with recovery are hope, personal choice and self-determination, empowerment, transformation, discovery, connection, dignity and justice. Increasingly, recovery is seen not only as a psychological process but also as a social and relational process. This development recognises that change occurs through relationships and opportunities that consumers want, and that result in healing and empowering experiences. Recovery is about transforming relationships in community life, especially around employment, education and other areas of social participation. This requires action on the social determinants of mental health and upholding human rights to promote understanding, acceptance and inclusion.[30]
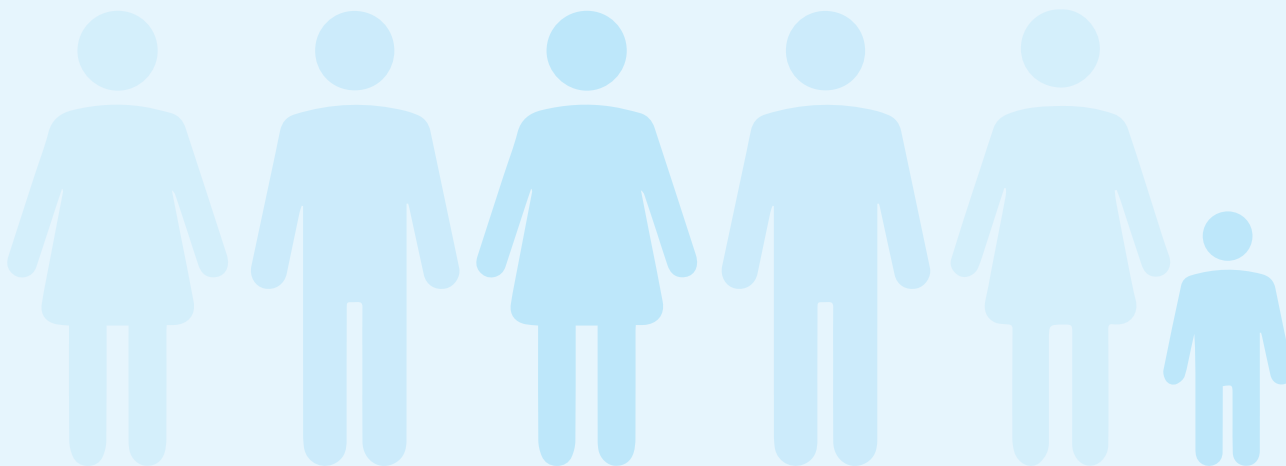
Appendix 2
Safety and quality standards

This section provides information about Australian formal standards for safety and quality, and how these standards set expectations about partnerships, continual quality improvement, and accountability. These standards are very important documents for consumers, carers, families and kinship groups because they 'set the standard' for what you should expect from your care, service experience and participation.

National standards

There are two key sets of national standards that relate to safety and quality in mental health care.

The first set is the National Safety and Quality Health Service (NSQHS) Standards. The eight NSQHS Standards were developed by the Australian Commission on Safety and Quality in Health Care, and are designed to provide a nationally consistent statement about the level of care that people can expect from health services. Each standard has key required actions for implementation. Table A1 lays out the six standards that are highly relevant to public mental health services and shows important areas for improvement.

All public and private hospitals, day-procedure services and public dental practices in Australia must be accredited to the NSQHS Standards. Because they cover a wide range of services, some of the NSQHS Standards are more relevant to physical health services than to mental health services (such as standards for infection control and blood management). However, the NSQHS Standards still provide important guidance on the delivery of safe and high-quality mental health care.

The NSQHS Standards include a specific Partnering with Consumers Standard. This standard requires health service organisations to include consumers as partners both in their own care and in the planning, design, delivery, measurement and evaluation of systems and services. The Partnering with Consumers Standard is considered particularly important because, along with the Clinical Governance Standard, it underpins all of the other NSQHS Standards. A summary table of actions that health services are required to achieve is found in **Section 2** *Getting engaged*.

The second set of standards is the National Standards for Mental Health Services (NSMHS).[31] The Australian Government Department of Health manages the NSMHS, which guide continual quality improvement in mental health services throughout Australia.

The NSMHS apply to a broad range of mental health services, from general practice to community mental health services and acute hospital-based services. They also apply to all sectors (public, private and non-government).

Table A1: *Actions with high relevance to mental health in the NSQHS Standards*

Standard	Criteria	Area of focus and action
Clinical Governance	Governance, leadership and culture	• Governance, leadership and culture • Organisational leadership • Clinical leadership
	Patient safety and quality systems	• Policies and procedures • Measurement and quality improvement • Risk management • Incident management systems and open disclosure • Feedback and complaints management • Diversity and high-risk groups
	Safe environments for delivery of care	• Safe environment
Partnering with Consumers	Partnering with patients in their own care	• Healthcare rights and informed consent • Sharing decisions and planning care
Medication Safety	Documentation of patient information	• Medication reconciliation • Adverse drug reactions
Comprehensive Care	Developing the comprehensive care plan	• Screening of risk • Clinical assessment • Developing the comprehensive care plan
	Delivering comprehensive care	• Using the comprehensive care plan
	Minimising patient harm	• Predicting, preventing and managing self-harm and suicide • Predicting, preventing and managing aggression and violence • Minimising restrictive practices: restraint • Minimising restrictive practices: seclusion
Communicating for Safety	Communication at clinical handover	• Clinical handover
	Communication of critical information	• Communicating critical information
Recognising and Responding to Acute Deterioration	Detecting and recognising acute deterioration, and escalating care	• Recognising acute deterioration • Escalating care
	Responding to acute deterioration	• Responding to deterioration

Reference: National Quality and Safety Health Service Standards: User Guide for Health Services Providing Care for People with Mental Health Issues, 2018. www.safetyandquality.gov.au/publications-and-resources/resource-library/nsqhs-standards-user-guide-health-services-providing-care-people-mental-health-issues

The NSMHS have a strong focus on promoting the rights, responsibilities and safety of people who use mental health services. The NSMHS also include specific consumer standards and carer standards that provide guidance on what consumers and carers can expect from mental health services.

The NSQHS Standards and the NSMHS set national benchmarks for safety and quality in mental health services. They are useful tools for ensuring accountability, identifying shortcomings in service provision, and encouraging improvements in the safety and quality of services.

Other standards

States and territories have a range of policies, guidelines and legislation that influence the way mental health services are provided. Some healthcare organisations also have their own service standards and guidelines.

These standards often cover issues related to safety and quality and, like the national standards, provide useful benchmarks for identifying shortcomings and encouraging improvements. Even if a particular state, territory or service has its own set of safety and quality standards, however, the NSQHS Standards and the NSMHS may still apply.

When engaging with mental health services, think about the different standards that may apply to a service and how these standards could be used to open a discussion about safety and quality. A good starting point is to ask services for information about the standards, policies and guidelines they use to ensure safety and quality.
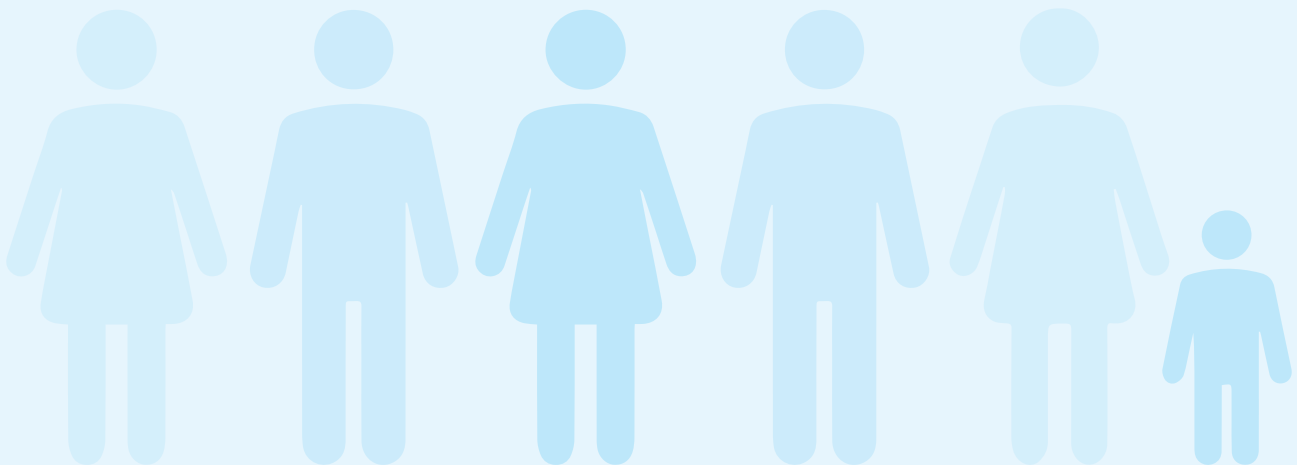
Appendix 3
Organisations and key contacts

National consumer and carer organisations

National Mental Health Consumer and Carer Forum (NMHCCF)
(02) 6285 3100
NMHCCF@mhaustralia.org
nmhccf.org.au

The NMHCCF is a combined national voice for mental health consumers and carers. NMHCCF members represent mental health consumers and carers on a range of national bodies, including government committees and advisory groups, professional bodies, and other consultative forums and events.

National Register of Mental Health Consumer and Carer Representatives
(02) 6285 3100
natreg@mhaustralia.org
mhaustralia.org/report/national-register-mental-health-consumers-and-carers

The National Register is a pool of trained mental health consumer and carer representatives from across Australia. They work at the national level to provide a strong consumer and carer voice in the mental health sector.

Lived Experience Australia
1300 620 042
www.livedexperienceaustralia.com.au

Formerly known as the Private Mental Health Consumer Carer Network.

Mental Health Carers Australia
contact.us@mentalhealthcarersaustralia.org.au
www.mentalhealthcarersaustralia.org.au

Mental Health Carers Australia is a national advocacy group focusing on the wellbeing of mental health carers, and promoting their needs.

State and territory consumer and carer organisation

Area	Consumer and carer organisation
ACT	**ACT Mental Health Consumer Network** (02) 6230 5796; actmhcn@actmhcn.org.au; www.actmhcn.org.au The ACT Mental Health Consumer Network is a consumer-led peak organisation representing the interests of mental health consumers in the Australian Capital Territory in policy and decision-making forums.
	Carers ACT (02) 6296 9900; carers@carersact.org.au; www.carersact.org.au Carers ACT is the peak body for carers in the Australian Capital Territory. It supports those who assist someone who has a disability, is ageing or has an ongoing mental or other illness.
NSW	**Being** 1300 234 640; info@being.org.au; being.org.au Being is an independent, state-wide peak organisation for people with a lived/living experience of mental health issues (consumers) in New South Wales.
	Mental Health Carers NSW (02) 9332 0777; MHCNadmin@mentalhealthcarersnsw.org; www.mentalhealthcarersnsw.org Mental Health Carers NSW provides systemic advocacy and support for families, relatives and friends of people who experience mental illness, living in New South Wales.
NT	**Helping Minds and Carers NT** (08) 9427 7100; helpingminds.org.au
Qld	**ARAFMI** (07) 3254 1881; www.arafmi.com.au ARAFMI provides support services for families and friends of people with mental illness and psychiatric disability in Queensland.
SA	**Lived Experience Leadership and Advocacy Network (LELAN)** info@lelan.org.au; www.lelan.org.au LELAN is an independent organisation that is run by, for and with people with personal lived experience of mental health issues (i.e. consumers) in South Australia. Its purpose is to amplify the voice, influence and leadership of people with lived experience to drive systemic change.

Area	Consumer and carer organisation
Tas	**Flourish Tasmania** (03) 6223 1952; admin@flourishtas.org.au; flourishtas.org.au Flourish aims to provide a strong voice for people with lived experience of mental ill-health in Tasmania. Its purpose is to offer input and expertise on lived experience to mental health policy and services, and to reduce discrimination and stigma surrounding mental health.
	Mental Health Families and Friends Tasmania (MHFFTas) (03) 6228 7448; mhfamiliesfriendstas.org.au MHFFTas (formerly Mental Health Carers Tasmania) provides support to families, friends and carers of people living with mental health issues and mental illness in Tasmania.
Vic	**Tandem** (03) 8803 5555; info@tandemcarers.org.au; www.tandemcarers.org.au Tandem is the Victorian peak body representing family and friends who support people living with mental health issues.
	Victorian Mental Illness Awareness Council (VMIAC) (03) 9380 3900; reception@vmiac.org.au; www.vmiac.org.au VMIAC is the peak Victorian organisation for people with lived experience of mental ill-health or emotional challenges.
WA	**Consumers of Mental Health WA (CoMHWA)** (08) 9258 8911; admin@comhwa.org.au; www.comhwa.org.au CoMHWA is Western Australia's mental health consumer association, providing education and training, peer support and systemic advocacy.

Aboriginal and Torres Strait Islander mental health organisations

Aboriginal and Torres Strait Islander Lived Experience Network

indigenouslec@blackdog.org.au
www.blackdoginstitute.org.au/education-services/aboriginal-and-torres-strait-islander-network

This newly established network within the Black Dog Institute is led by Aboriginal and Torres Strait Islander people. It aims to develop and support a 'workforce' of Aboriginal and Torres Strait Islander advocates to inform, influence and enhance culturally appropriate suicide prevention activities and mental health support programs for First Nations peoples.

Gayaa Dhuwi (Proud Spirit) Australia

www.gayaadhuwi.org.au

Gayaa Dhuwi is the national leadership group for Aboriginal and Torres Strait Islander social and emotional wellbeing, mental health and suicide prevention.

National Aboriginal Community Controlled Health Organisation (NACCHO)

(02) 6246 9300; www.naccho.org.au

NACCHO is the national peak body representing Aboriginal Community Controlled Health Services across Australia on Aboriginal health and wellbeing issues.

Mental health peak bodies

Area	Mental health peak bodies
National	**Community Mental Health Australia (CMHA)** (02) 9060 9629; cmha.org.au CMHA is a coalition of community mental health organisations from each state and territory of Australia. It was established to provide leadership and direction to promote the importance and benefits of community mental health and recovery services across Australia. **Mental Health Australia** (02) 6285 3100; mhaustralia.org Mental Health Australia is a peak national non-government organisation representing and promoting the interests of the Australian mental health sector.
ACT	**Mental Health Community Coalition ACT (MHCC ACT)** (02) 6249 7756; admin@mhccact.org.au; www.mhccact.org.au MHCC ACT is the peak body representing the community-managed mental health sector in the ACT.
NSW	**Mental Health Coordinating Council (MHCC)** (02) 9060 9627; info@mhcc.org.au; www.mhcc.org.au MHCC is the peak body for community-managed mental health organisations in New South Wales.
NT	**Northern Territory Mental Health Coalition (NTMHC)** (08) 8948 2246; eo@ntmhc.org.au; www.ntmhc.org.au The NTMHC is the peak body for community-managed mental health services across the Northern Territory.
Qld	**Queensland Alliance for Mental Health** (07) 3252 9411; www.qamh.org.au Queensland Alliance for Mental Health is the peak body for mental health service providers and the wider mental health community in Queensland.
SA	**Mental Health Coalition of South Australia** (08) 8212 8873; administration@mhcsa.org.au; www.mhcsa.org.au The Mental Health Coalition of South Australia is the peak body for the non-government mental health sector in South Australia.
Tas	**Mental Health Council of Tasmania** (03) 6224 9222; enquiries@mhct.org; mhct.org The Mental Health Council of Tasmania is the peak body for community-managed mental health services in Tasmania.
Vic	**Mental Health Victoria** (03) 9519 7000; mhvic@mhvic.org.au; www.mhvic.org.au Mental Health Victoria is the peak body for mental health service providers in Victoria.
WA	**Western Australian Association for Mental Health (WAAMH)** (08) 6246 3000; waamh.org.au WAAMH is the peak body for community mental health in Western Australia.

Chief psychiatrists

Chief psychiatrists are appointed by state and territory health departments to provide advice and leadership on mental health needs in their jurisdiction. Chief psychiatrists also respond to complaints about psychiatric practice and treatment provided by public mental health services. Contact details for the Office of the Chief Psychiatrist in each state and territory are listed below.

Area	Chief psychiatrist contact
ACT	(02) 6205 1313
NSW	c/o Mental Health Branch: (02) 9391 9000
NT	c/o Mental Health Alcohol and Other Drugs Branch: (08) 8999 2829
Qld	c/o Mental Health Alcohol and Other Drugs Branch: MHAODB-ED@health.qld.gov.au
SA	(08) 8226 1091 healthocp@sa.gov.au
Tas	(03) 6166 0778 chief.psychiatrist@health.tas.gov.au
Vic	(03) 9096 7571 ocp@dhhs.vic.gov.au
WA	(08) 6553 0000 reception@ocp.wa.gov.au

Mental health commissions

Mental health commissions are independent government agencies that monitor, and provide advice on, mental health policy and services in their jurisdiction.

Area	Mental health commission
National	National Mental Health Commission (02) 8229 7550 enquiries@mentalhealthcommission.gov.au www.mentalhealthcommission.gov.au
NSW	Mental Health Commission of New South Wales (02) 9859 5200 mhc@mhc.nsw.gov.au nswmentalhealthcommission.com.au
Qld	Queensland Mental Health Commission 1300 855 945 info@qmhc.qld.gov.au www.qmhc.qld.gov.au
SA	South Australian Mental Health Commission, Wellbeing SA 1300 293 220 samhc@sa.gov.au www.samentalhealthcommission.com.au
WA	Western Australian Mental Health Commission (08) 6553 0600 www.mhc.wa.gov.au

Handling bodies for oversight and complaints

Official visitors and community visitors are independent observers who monitor treatment and conditions in mental health facilities. Their role is to protect the rights and dignity of people in these facilities, particularly those receiving compulsory treatment.

Healthcare complaints commissions are independent government agencies that deal with complaints about health service providers.

	Visitors	Complaints
ACT	**ACT Official Visitor Scheme** 1800 150 036 www.ptg.act.gov.au/visitor-scheme	**ACT Human Rights Commission** (02) 6205 2222 human.rights@act.gov.au hrc.act.gov.au
NSW	**Official Community Visitors** (02) 9407 1831 OCV@adc.nsw.gov.au	**Health Care Complaints Commission** 1800 043 159 www.hccc.nsw.gov.au
NT	**NT Community Visitor Program** (08) 8999 1451 cvpprogramadc@nt.gov.au cvp.nt.gov.au	**Health and Community Services Complaints Commission** (08) 8999 1969 hcscc@nt.gov.au www.hcscc.nt.gov.au
Qld	**Community Visitors** c/o Office of the Public Guardian 1800 661 533	**Office of the Health Ombudsman** 133 646 info@oho.qld.gov.au www.oho.qld.gov.au
SA	**SA Community Visitor Scheme** 1800 606 302 cvs@sa.gov.au communityvisitorscheme.sa.gov.au	**Health and Community Services Complaints Commissioner** (08) 8226 8652 info@hcscc.sa.gov.au www.hcscc.sa.gov.au
Tas	**Mental Health Official Visitors** 1800 001 170 officialvisitors@ombudsman.tas.gov.au www.officialvisitors.tas.gov.au	**Health Complaints Commissioner** 1800 001 170 health.complaints@ombudsman.tas.gov.au www.healthcomplaints.tas.gov.au
Vic	**Community Visitors** c/o Office of the Public Advocate 1300 309 337	**Mental Health Complaints Commissioner** 1800 246 054 help@mhcc.vic.gov.au www.mhcc.vic.gov.au
WA	**Mental Health Advocacy Service** (08) 6234 6300 contactus@mhas.wa.gov.au mhas.wa.gov.au	**Health and Disability Services Complaints Office (HaDSCO)** (08) 6551 7600 mail@hadsco.wa.gov.au www.hadsco.wa.gov.au/home

Appendix 4
Further reading

- Aftab, A, Waterman, GS, Conceptual competence in psychiatry: Recommendations for education and training. *Acad Psychiatry*, 2020, https://doi.org/10.1007/s40596-020-01183-3.

- Australian Commission on Safety and Quality in Health Care, 2018, *National Safety and Quality Health Service Standards user guide for health services providing care for people with mental health issues*, ACSQHC, Sydney.

- Australian Commission on Safety and Quality in Health Care, 2018, *Review of the key attributes of high-performing person-centred healthcare organisations*, ACSQHC, Sydney.

- Australian Government, 2019, *Sit beside me, not above me: supporting safe and effective engagement and participation of people with lived experience*, National Mental Health Commission, Sydney, https://www.mentalhealthcommission.gov.au/getmedia/e1baaf32-27c2-4a14-992c-d7043df9f954/Sit-beside-me,-not-above-me.

- Byrne, L, Wang, L, Roennfeldt, H, Chapman, M, Darwin, L, 2013, *Queensland framework for the development of the mental health lived experience workforce*, Queensland Government, Brisbane.

- Connect Groups, 2018, *Foundational engagement*, Connect Groups, Booragoon, Western Australia, http://www.mentalhealthmatters2.com.au/wp-content/uploads/2018/10/Foundational-Engagement-report-2018.pdf.

- Consumers Health Forum, 2019, *Guidelines for consumer representatives*, CHF, Australian Capital Territory, https://chf.org.au/guidelines-consumer-representatives.

- Department of Health and Family Services, 1998, *The kit—a guide to the advocacy we choose to do: a resource kit for consumers of mental health services and family carers*, Commonwealth Department of Health and Family Services, Canberra, https://www.hcnsw.org.au/hcnsw_resource/the-kit-a-guide-to-the-advocacy-we-choose-to-do/.

- Dudgeon, P, Darwin, L, Hirvonen, T, Boe, M, Johnson, R, Cox, R, Gregory, L, McKenna, R, McKenna, V, Smith, D, Turner, J, Von Helle, S, Garrett, L, 2018, *We are not the problem, we are part of the solution: Indigenous Lived Experience Project report*, University of Western Australia and Black Dog Institute, https://www.blackdoginstitute.org.au/docs/default-source/lifespan/lived-experience-report--final-nov-2018.pdf?sfvrsn=2.

- Emerging Minds, 2020, Child and Family Partnerships Toolkit, https://emergingminds.com.au/resources/toolkits/child-and-family-partnerships-toolkit/.

- Happell, B, Scholz, B, 2018, Doing what we can, but knowing our place: Being an ally to promote consumer leadership in mental health. *International Journal of Mental Health Nursing*, 27(1):440–447.

- Hunt, J, 2013, *Engaging with Indigenous Australia—exploring the conditions for effective relationships with Aboriginal and Torres Strait Islander communities*, AIHW and AIFS, Canberra.

- Metzl, JM, Hansen, H, 2018, Structural competency and psychiatry *JAMA Psychiatry*, 75(2):115–116. https://jamanetwork.com/journals/jamapsychiatry/article-abstract/2665216.

- National Mental Health Commission, 2018, *The National Mental Health Commission's consumer and carer engagement: a practical guide*, National Mental Health Commission, Sydney, https://www.mentalhealthcommission.gov.au/getmedia/afef7eba-866f-4775-a386-57645bfb3453/NMHC-Consumer-and-Carer-engagement-a-practical-guide.

- Our Consumer Place, n.d., *Mad meetings: consumers and committees*, https://www.ourcommunity.com.au/files/OCP/MadMeetings.pdf.

- Our Consumer Place, n.d., *Networking and mentoring: how can it help?*, http://www.ourconsumerplace.com.au/consumer/helpsheet?id=3513.

- Our Consumer Place Resources, 2011, http://www.ourconsumerplace.com.au/consumer/resources.

- Price-Robertson, R, Morgan, B, Obradovic, A, 2016, Relational recovery: Beyond individualism in the recovery approach, *Advances in Mental Health*, 15(2):108–120 https://www.researchgate.net/publication/309127037_Relational_recovery_Beyond_individualism_in_the_recovery_approach.

- Roper, C, Grey, F, Cadogan, E, 2018, *Co-production: putting principles into practice in mental health contexts*, https://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0010/2659969/Co-production_putting-principles-into-practice.pdf.

- Substance Abuse and Mental Health Services Administration, 2014, *Trauma-informed care in behavioral health services. Treatment improvement protocol (TIP) Series 57*, HHS Publication, Rockville, MA.

- The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute, 2017, *National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health*, ACSQHC, Sydney.

- Victorian Government, 2018, *The right to be safe. Ensuring sexually safety in acute mental health inpatient units: sexual safety project report*, Mental Health Complaints Commission. https://www.mhcc.vic.gov.au/News-and-events/News/Mental%20health%20service%20responses%20to%20our%20sexual%20safety%20report.

- WA Mental Health Commission, 2019, *Consumer, family, carer and community paid partnership policy*, https://www.mhc.wa.gov.au/media/2649/consumer-family-and-community-paid-partnership-policy-april-2019.pdf.

- World Health Organization, 2019, *QualityRights materials for training, guidance and transformation*, https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools.

Appendix 5
Glossary

Below are some key clinical terms that are found throughout safety and quality standards and in health service settings.

Acute deterioration general/mental state
A physiological, psychological or cognitive change that may indicate a worsening of the patient's health status; this may occur across hours or days.[32]

Adverse event
An incident that results, or could have resulted, in harm to a patient or consumer. A 'near miss' is a type of adverse event.[33]

Clinical governance
Clinical governance is an integrated component of the corporate governance of health service organisations. It ensures that everyone—from frontline clinicians to managers and members of governing bodies such as boards—is accountable to patients and the community for assuring the delivery of safe, effective and high-quality services. Clinical governance systems provide confidence to the community and the healthcare organisation that systems are in place to deliver safe, high-quality health care.[34]

Clinical handover
Clinical handover is the transfer of professional responsibility and accountability for some or all aspects of care for a patient, or group of patients, to another person or professional group on a temporary or permanent basis.[35]

Complaint
An expression of dissatisfaction made to or about an organisation that is related to its products, services, staff or handling of a complaint, for which a response or resolution is explicitly or implicitly expected or legally required.[36]

Complaints management system
Encompasses all aspects of the policies, procedures, practices, staff, hardware and software used by the organisation to manage complaints.[37]

Critical incident
Any unintended event that occurs when a patient receives treatment in a hospital that (a) results in death, or serious disability, injury or harm to the patient, and (b) does not result primarily from the patient's underlying medical condition or from a known risk inherent in providing the treatment.[38]

De-escalation strategies
Psycho-social techniques that aim to reduce violent or disruptive behaviour. They are intended to reduce or eliminate the risk of violence during the escalation phase by using verbal and non-verbal communication skills. De-escalation is about establishing rapport to gain the patient's trust, minimising restriction to protect their self-esteem, appearing externally calm and self-aware in the face of aggressive behaviour, and intuitively identifying creative and flexible interventions that reduce the need for aggression.[39]

Escalation of care
An intervention whereby a patient or family member is assisted within a hospital setting to raise concerns with healthcare professionals to assess and respond to clinical deterioration that they are worried about.[40]

Health literacy
The Australian Commission on Safety and Quality in Health Care separates health literacy into two components: individual health literacy and the health literacy environment.

Individual health literacy is the skills, knowledge, motivation and capacity of a consumer to access, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action.

The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the healthcare system and affect the ways in which consumers access, understand, appraise and apply health-related information and services.[41]

Medication reconciliation

Medication reconciliation is the formal process of obtaining and verifying a complete and accurate list of a patient's current medicines, and matching the medicines the patient should be prescribed to those they are actually prescribed. Any discrepancies are discussed with the prescriber, and reasons for changes to therapy are documented and communicated when care is transferred. Medication review may form part of the medication reconciliation process.[42]

Open disclosure

Open disclosure involves an open discussion with a patient and their carer about an incident that resulted in harm to the patient while receiving health care. The criteria of open disclosure are an expression of regret, a factual explanation of what happened, the potential consequences, and the steps taken to manage the event and prevent recurrence.[43]

Quality improvement

Quality improvement involves the combined efforts of the workforce and others—including consumers, patients and their families, researchers, planners and educators—to make changes that will lead to better patient outcomes (health), better system performance (care) and better professional development. Quality improvement activities may be undertaken in sequence, intermittently or continually.[44]

Restrictive practices

Restrictive practices involve the use of interventions and practices that have the effect of restricting the rights or freedom of movement of a person. These primarily include restraint (chemical, mechanical, social or physical) and seclusion.[45]

Risk management system

Risk management system is the design and implementation of a program to identify and avoid or minimise risks to patients, employees, volunteers, visitors and the organisation.[46]

Risk screening

Risk screening is a short process to identify patients who may be at risk of, or already have, a disease or injury. It is not a diagnostic exercise, but rather a trigger for further assessment or action.[47]

Root cause analysis

A method or methodology used to investigate an incident in order to assist in the identification of health system failures that may not be immediately apparent at initial review. It is interdisciplinary in nature and uses a structured process that endeavours to answer three questions: What happened? Why did it happen? How can it be prevented from occurring again?[48]

Shared decision-making

Shared decision-making is a consultation process in which a clinician and a patient jointly participate in making a health decision, having discussed the options, and their benefits and harms, and having considered the patient's values, preferences and circumstances.[49]

Transitions of care

Situations when all or part of a patient's care is transferred between healthcare locations, providers, or levels of care within the same location, as the patient's conditions and care needs change.[50]

References

1. Procter, NG, Hamer, H, McGarry, D, Wilson, R, Froggatt, T, 2017, *Mental health: a person-centred approach* (2nd ed), Cambridge University Press, Melbourne.

2. Australian Commission on Safety and Quality in Health Care, 2019, *Person-centred care*, ACSQHC, Sydney, https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care.

3. Rock, D, Cross, SP, 2020, Regional planning for meaningful person-centred care in mental health: context is the signal not the noise. *Epidemiology and Psychiatric Sciences*, 29:e104.

4. Australian Mental Health Outcomes and Classification Network, 2020, Your Experience of Service surveys, https://www.amhocn.org/your-experience-service-surveys.

5. Dolan, IJ, Strauss, P, Winter, S, Lin, A, 2020, Misgendering and experiences of stigma within health care settings for transgender individuals, *The Medical Journal of Australia*, 212(4):150–151.

6. NSW Office of the Advocate for Children and Young People, 2019, *Engaging children and young people in your organisation*, NSW Advocate for Children and Young People, Strawberry Hill, https://www.acyp.nsw.gov.au/participation-guide.

7. Groves, A, Thomson, D, McKellar, D Procter, N, 2017, *The Oakden Report*, Department for Health and Ageing, Adelaide, https://www.sahealth.sa.gov.au/wps/wcm/connect/4ae57e8040d7d0d58d52af3ee9bece4b/Oakden+Report+Final+Email+Version.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-4ae57e8040d7d0d58d52af3ee9bece4b-n5hvsml.

8. Dudgeon, P, Darwin, L, Hirvonen, T, Boe, M, Johnson, R, Cox, R, Gregory, L, McKenna, R, McKenna, V, Smith, D, Turner, J, Von Helle, S, Garrett, L, 2018, *We are not the problem, we are part of the solution: Indigenous Lived Experience Project report*, University of Western Australia and Black Dog Institute, https://www.blackdoginstitute.org.au/wp-content/uploads/2020/04/lived-experience-report-final-nov-2018.pdf.

9. Commonwealth of Australia, 2017, *National strategic framework for Aboriginal and Torres Strait Islander peoples' mental health and social and emotional wellbeing*, Department of the Prime Minister and Cabinet, Canberra.

10. See, for example, The Healing Foundation, https://healingfoundation.org.au/community-healing.

11. National Aboriginal and Torres Strait Islander Leadership in Mental Health, 2015, *Gayaa Dhuwi (Proud Spirit) Declaration: a companion declaration to the Wharerātā Declaration for use by Aboriginal and Torres Strait Islander peoples*, https://natsilmh.org.au/sites/default/files/WEB_gayaa_dhuwi_declaration_A4-2.pdf.

12. Best, O. and Fredericks, B., 2017. *Yatdjuligin: Aboriginal and Torres Strait Islander nursing and midwifery care.* Cambridge University Press, pp. 59-61.

13. Australian Government, 2016, *Cultural respect framework 2016−2026 for Aboriginal and Torres Strait Islander health: a national approach for building a culturally respectful health system*, https://nacchocommunique.files.wordpress.com/2016/12/cultural_respect_framework_1december2016_1.pdf.

14. The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute, 2017, *National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health*, ACSQHC, Sydney.

15. Adapted from Best, O. and Fredericks, B., 2017. *Yatdjuligin: Aboriginal and Torres Strait Islander nursing and midwifery care.* Cambridge University Press, pp. 59-61.

16. Minas, H, Kakuma, R, San Too, L, Vayani, H, Orapeleng, S, Prasad-Ildes, R, Turner, G, Procter, N, Oehm, D, 2013, Mental health research and evaluation in multicultural Australia: developing a culture of inclusion, *International Journal of Mental Health Systems*, 7(23):1−25.

17. Embrace Multicultural Mental Health n.d., *Framework for mental health in multicultural Australia: towards culturally inclusive service delivery*, https://embracementalhealth.org.au/service-providers/framework.

18. ACON, NADA, n.d., AOD LGBTIQ inclusive guidelines for treatment providers, ACON and NADA, Sydney, https://www.nada.org.au/wp-content/uploads/2019/08/AOD-Inclusive-Practice-Guidelines-for-Treatment-Providers_A4_v11.pdf.

19. Victorian Department of Premier and Cabinet, 2020, *LGBTIQ inclusive language guide*, Government of Victoria, Melbourne, https://www.vic.gov.au/inclusive-language-guide.

20. Queensland Public Sector Commission, 2017, *Queensland public sector LGBTIQ+ inclusion strategy*, Queensland Government, Brisbane, https://www.forgov.qld.gov.au/file/49361/download?token=i9fUFfJY.

21. Western NSW Primary Health Network, 2018, *Western Health Alliance Limited commissioning framework*, Western NSW PHN, Dubbo, https://www.wnswphn.org.au/uploads/documents/corporate%20documents/Commissioning%20Framework_Approved_May2018_Web.docx.pdf.

22. People with Disability Australia, 2018, https://pwd.org.au.

23. Autism Aspergers Advocacy Australia, n.d., http://www.a4.org.au.

24. Australian Network on Disability, 2020, *Inclusive language*, https://www.and.org.au/pages/inclusive-language.html.

25. Roper, C, Grey, F, Cadogan, E, 2018, *Co-production: putting principles into practice in mental health contexts*, https://recoverylibrary.unimelb.edu.au/__data/assets/pdf_file/0010/2659969/Co-production_putting-principles-into-practice.pdf. The authors frame the principles in the consumer context. The principles can be applied to co-production, which works with consumers, carers, families and kinship groups.

26. Substance Abuse and Mental Health Services Administration, 2014, *Trauma-informed care in behavioral health services. Treatment improvement protocol (TIP) Series 57*, HHS Publication, Rockville, MA.

27. National Mental Health Commission , 2018, *The National Mental Health Commission's consumer and carer engagement: a practical guide*, National Mental Health Commission, Sydney, https://www.mentalhealthcommission.gov.au/getmedia/afef7eba-866f-4775-a386-57645bfb3453/NMHC-Consumer-and-Carer-engagement-a-practical-guide.

28. Lohoar, S, Butera, N, Kennedy, E, 2014, *Strengths of Australian Aboriginal cultural practices in family life and child rearing*, CFCA Paper No. 25, Australian Institute of Family Studies, Victoria, https://aifs.gov.au/cfca/publications/strengths-australian-aboriginal-cultural-practices-fam/introduction.

29. Australian Government Department of Health, 2013, *A national framework for recovery-oriented mental health services: guide for practitioners and providers*, Department of Health, Canberra, https://www1.health.gov.au/internet/main/publishing.nsf/Content/67D17065514CF8E8CA257C1D00017A90/$File/recovgde.pdf.

30. Patel, V, Saxena, S, Lund, C., Thornicroft, G, Baingana, F, Bolton, P, Chisholm, D, Collins, PY, Cooper, JL, Eaton, J, Herrman, H, 2018, The Lancet Commission on global mental health and sustainable development. *Lancet*, 392(10157):1553–1598.

31. Australian Government Department of Health, 2010, National standards for mental health services, Department of Health, Canberra, https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-servst10.

32. Australian Commission on Safety and Quality in Health Care, 2017, *National Safety and Quality Health Service Standards*, 2nd ed., Sydney, https://www.safetyandquality.gov.au/sites/default/files/2019-04/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf.

References

33. Ibid.

34. Ibid.

35. Ibid.

36. Standards Australia, 2014, AS/NZS 10002:2014, *Guidelines for complaint management in organizations*, Standards Australia, Sydney, https://shop.standards. govt.nz/catalog/10002:2014(AS%7CNZS)/scope.

37. Ibid.

38. Ministry of Health and Long-Term Care, 2010, *Excellent care for all: guidelines for critical incident reporting*, Government of Canada, http://www.health.gov.on.ca/ en/pro/programs/ecfa/docs/guidelines_cir.pdf.

39. Australian Commission on Safety and Quality in Health Care, 2017, *National Safety and Quality Health Service Standards*, 2nd ed., https://www.safetyandquality.gov. au/sites/default/files/2019-04/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf.

40. McKinney, A, Fitzsimons, D, Blackwood, B, McGaughey, J, 2019, Patient and family-initiated escalation of care: a qualitative systematic review protocol, *Systematic Reviews*, 8(1):91. https://pubmed. ncbi.nlm.nih.gov/32202339.

41. Ibid.

42. Ibid.

43. Ibid.

44. Ibid.

45. Australian Government 2014, *Equality, capacity and disability in Commonwealth Laws* (DP 81), Commonwealth of Australia, Sydney, https://www.alrc. gov.au/wp-content/uploads/2019/08/whole_dp81.pdf.

46. Australian Commission on Safety and Quality in Health Care, 2018, *Implementing the comprehensive care standard: approaches to person-centred risk screening.* Sydney, https://www.safetyandquality.gov.au/sites/ default/files/migrated/Implementing-Comprehensive-Care-Approaches-to-person-centred-risk-screening-Accessibility-PDF.pdf.

47. Ibid.

48. SA Health 2019, *Root cause analysis* (RCA), SA Health, Adelaide, https://www.sahealth.sa.gov.au/wps/ wcm/connect/public+content/sa+health+internet/ clinical+resources/safety+and+quality/ governance+for+safety+and+quality/ root+cause+analysis+rca.

49. Ibid.

50. Ibid.

www.mentalhealthcommission.gov.au