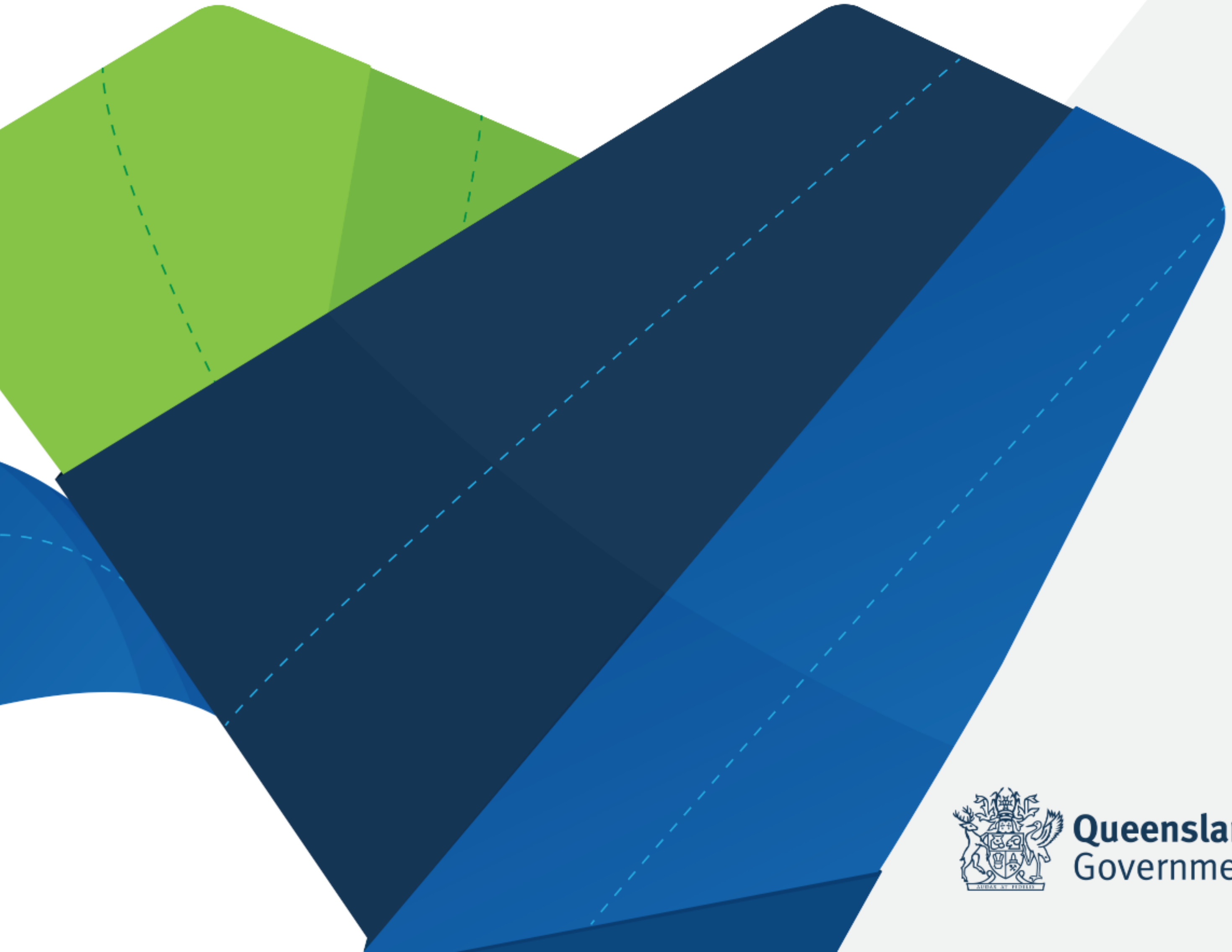
Queensland Health

Consumer and Carer Engagement Framework

Office of the Chief Psychiatrist



Queensland
Government

Consumer and Carer Engagement Framework
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An electronic version of this document is available at Office of the Chief Psychiatrist, Mental Health Alcohol and Other Drugs Branch.

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Acknowledgement of Country.

Queensland Health acknowledges the Traditional and Cultural custodians of the lands, waters and seas across Queensland, pays our respects to Elders past and present, and recognises the role of current and emerging leaders in shaping a better health system. We recognise the First Nations peoples in Queensland are both Aboriginal peoples and Torres Strait Islander peoples, and support the cultural knowledge, determination and commitment of Aboriginal and Torres Strait Islander communities in caring for the health and wellbeing of our people for millennia.

Recognition of lived experience.

Queensland Health recognises people with lived experience of mental illness, substance use disorders, mental health crisis and suicidality, their families, carers and support persons. Their contribution to driving and informing reforms to the mental health, alcohol and other drug service system is critical and valued.

A note on language.

Queensland Health (QH) acknowledges that language surrounding people with a lived experience of mental illness, substance use disorders, mental health crisis and suicidality can be emotive and at times, contested. People who experience substance use disorders and/ or mental illness often experience a high degree of stigma and discrimination, so using non stigmatising language is important. Not all these terms have commonly agreed definitions, and not all readers will identify with the use of labels in the same way as they are presented here. It is also recognised that these are not siloed concepts – for example, carers can also be consumers; people with a lived experience can also be consumers, etc. In the context of this publication, the following definitions will apply:

- **Carers** are people, often family members, who provide, or have provided in the past, ongoing personal care, support, advocacy and/or assistance to a person with mental illness, substance use disorders, mental health crisis and suicidality.
- **Co-design** recognises the equally valuable contributions of all stakeholders in identifying issues and problem solving in a way that reflects the needs, expectations and requirements of all those who participated in, and will be affected by the plan, initiative or service. Co-design processes should include people who are directly affected by an issue but can include other stakeholders and the general community.
- **Consumers** or **people with a lived experience** are people who identify as having a lived experience of mental illness[1], substance use disorders, mental health crisis and suicidality, irrespective of whether they have a formal diagnosis, have accessed services and/or received treatment.
- **Lived Experience workforce**[1] refers to people who are employed in their role based on using their lived experience and sharing these insights with others. They include peer support workers, lived experience researchers and executive lived experience roles.
- **Engagement** refers to methods and actions taken by organisations to involve the public, consumers and carers generally but also allows for decision-making and co-design and co-production processes to be undertaken.
- **Participation** in this document refers to the practice of involving people directly as partners with safety and equity.

For further information regarding language, the following resources are recommended:

- Communicating about mental illness (Everymind).
- Communicating about suicide (Mindframe).
- Communicating about alcohol and other drugs and the people who use them - NADA.

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[1] The term lived experience in this framework includes living experience.

Purpose of this framework.

The people who use and interact with QH services are in an ideal position to shape them. Participation by the people who use QH services is integral to ensuring we develop, implement and evaluate services and policies that best support Queenslanders. This document is both recognition of this and a guide to improving the way the Office of the Chief Psychiatrist (OCP) puts this approach into practice.

As we drive mental health, alcohol and other drug (MHAOD) and crisis reform across OCP work portfolios, we must engage effectively with consumers and carers, the MHAOD workforce, and the broader community. To do this, we recognise that engagement activities require more involvement and collaboration of the users of the services we provide including through co-design and co-production approaches when appropriate.

Through *HealthQ32: A vision for Queensland's health system*, the Queensland Government has committed to ensuring the healthcare system is flexible and innovative to improve health outcomes for Queenslanders.[5] *HealthQ32* includes a system priority to support consumer safety and quality through co-design. The healthcare system is stronger when consumers are at the heart of everything we do. Through a commitment to delivering better healthcare, QH sets out a priority to work with consumers as partners, not passengers. Consumers should consistently be influential at all levels of the health system – contributing ideas about practice, providing feedback on quality, and participating in design of new care models, monitoring and evaluation.

The Queensland Government is committed to improving the MHAOD services system. As part of this commitment, the Queensland Government released *Better Care Together: a plan for Queensland's state-funded mental health, alcohol, and other drug services to 2027 (Better Care Together)*.[7] A key approach to implementing actions from this strategic plan is to co-design solutions with people with a lived experience. It is important for all staff within the OCP to have shared knowledge and understanding about consumer and carer engagement. This framework serves as a foundation to build confidence and develop skills in consumer and carer engagement as well as outline key processes to assist and support staff to engage in participatory processes that include people with a lived experience and their carers.

The OCP is committed to engaging with consumers and carers to consider and include their thoughts, opinions, and ideas into all areas of OCP work. The insights of people with a lived experience and their carers are critical to inform policy development, quality improvement and safety initiatives and regulatory reform processes which aim to deliver safe and high-quality MHAOD services and responses to mental health crisis and suicidality in Queensland.

What is consumer and carer engagement?

Although there are a variety of meanings and understandings, in the context of this framework, consumer and carer engagement means incorporating the views and experiences of people with a lived experience of mental illness, substance use disorders, mental health crisis and suicidality, as well as carers in informing MHAOD services and initiatives.

Supporting effective consumer partnerships means offering multiple opportunities for and mechanisms of engagement across the spectrum. Meaningful methods of engagement range from representation on committees, working groups and boards, involvement in focus groups and consultations, and informal discussions.

The level of consumer partnership offered should be based on the consumer's preference, as well as the right fit for the project or piece of work. It is important to consider the time and resourcing available for the project as higher levels of consumer partnerships will require a greater amount of resourcing and possibly time. No single method for engaging with consumers is better than another as long as an authentic approach is adopted to including the views of those with lived experience.

For consumers and carers to participate meaningfully, the values of lived experience engagement need to be upheld by all those involved. ***Figure 1*** outlines these values.

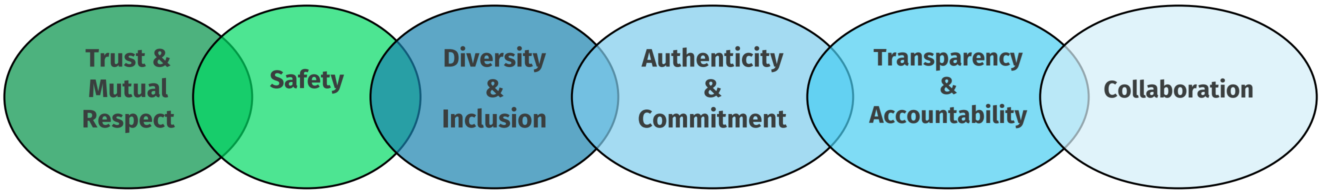


Figure 1: Values of consumer and carer engagement.

What are the benefits of engaging with consumers and carers?

> *"Lived experience engagement, participation and co-design supports a system and services that are better able to respond to the diverse needs of individuals and the broader community."* – Better Care Together: A plan for Queensland's state-funded mental health, alcohol and other drug services to 2027.

Consumers help shape the way health services and organisations operate to achieve mutually beneficial outcomes, and these consumers are reflective of the diversity of the people who use its services or, if relevant, the local community.

Figure 2 outlines some of the key benefits of consumer and carer engagement for health organisations, consumers and the system overall. [8]

Improve experiences of care which is known to be associated with improved health outcomes.	Produce health information that is understandable and meets the needs of consumers[9].	Ensure more accessible services[10].
Improve attitudes and cultures of health organisations being more open to involving consumers[11].	Increase quality of services.	Create more responsive services and better outcomes[12].

Figure 2: Benefits of consumer and carer engagement in health care.

OCP commitment to consumer and carer engagement.

Aligned with Queensland Health Strategic position, the OCP has a strong commitment to ensuring engagement with people with a lived experience and creating partnerships to achieve service improvement. The values outlined in ***Figure 1*** are upheld by senior officers, executive levels, and all staff across OCP and demonstrated in adherence to authentic engagement processes. OCP also commits to modelling and embedding social justice, human rights and a restorative just and learning culture across all our work.

This framework will support OCP to have standardised processes to continue to support meaningful lived experience engagement.

Steps to effectively lead consumer and carer engagement.

Please see **Appendix A: Planning for consumer and carer engagement** for key questions to consider during the planning phase of a project.

Step 1: Identify methods of engagement for consumers and carers.

Consumer and carer partnerships should be viewed as a spectrum of activity. Different types of consumer and carer partnerships exist within the MHAOD system and are not mutually exclusive. Consumers and carers need to be represented at all levels of governance for their input to have the greatest impact. Opportunities to provide feedback and input at the operational level are important to ensure a diversity of viewpoints and accessibility for all who wish to share information and knowledge.[13]

Table 1 is an adapted version of the International Association of Public Participation (IAP2)[14] spectrum which displays engagement across the spectrum and highlights activities which may be suitable at each level.

Co-design, a method increasingly used by governments, involves working alongside people with a lived experience in partnership. **Appendix B: Co-design explained** provides more information on the principles and conditions required to support a true co-design process.

All types of engagement are worthwhile and ensure quality outcomes are achieved. No matter the engagement type, it is important to be upfront and transparent about the limitations and the level of influence participants will have on the project and outcomes. This is important even if the project has ceased, or the evaluation/outcomes were unsuccessful. It is critical for people to know how their input was used and to continue to build trust with the people we engage with.

Type	Description	Type of activities
Inform	Consumers are informed about decisions	Factsheets Research and advocacy reports Website content Information sessions
Consult	Consumers are informed about the initiative; feedback is taken on and consumers are informed how feedback was incorporated into the decisions	Surveys Interviews Focus groups
Involve	Working with consumers to ensure their concerns and hopes are included in the final decision	Consumer and carer advisory groups Review and feedback processes
Collaborate	Consumers expertise is used to help create the final solution	Co-presenting at a conference Representation on steering committees Workshops and special projects
Empower	The project empowers consumer decision making and implements solutions based on these decisions.	Integration of stakeholders into governance
Co-design	Working together to discover unique perspectives through collaboration and to include user and stakeholder opinions in key decisions.	Designing solutions and improving outcomes as partners

Table 1: Consumer and Carer Engagement Spectrum.

Step 2: Identify with whom to engage.

Seeking relevant experiences.

As a general rule, consumers and/or carers recruited for a project should have lived experience closest to the quality improvement activity being undertaken. For example, if the project involves developing ICT solutions about a new digital healthcare platform, it would be beneficial having consumers who have experiences accessing the health system through digital solutions. When recruiting consumers or carers for a project, it is important to be clear about the experiences and strengths being sought.

When engaging with people with a lived experience, it can also be useful to engage with people who have a lived experience and work within our health system. ***Figure 3*** shows the types of experience and relationship between various roles lived experience workers perform.

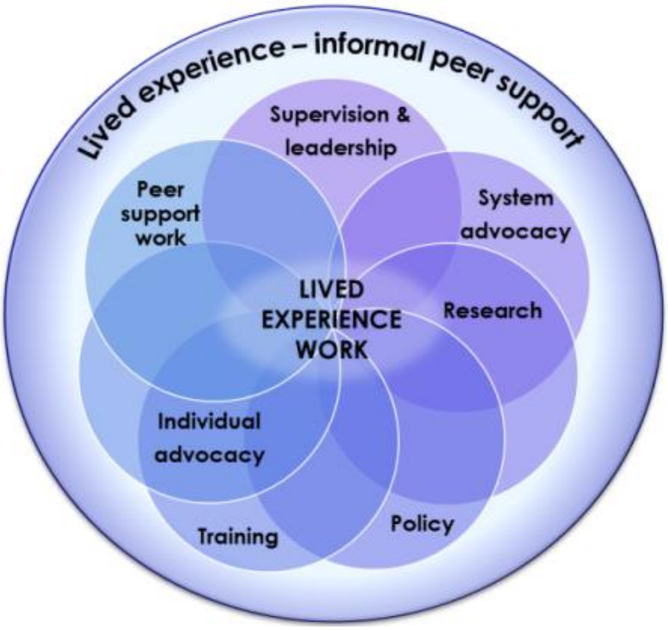


Figure 3: Lived experience work (Downes & Edan, 2017)[15]

For more information on including a wide diversity of viewpoints into all of your projects, please see Appendix C: Including diversity of viewpoints.

For more information about how to work with First Nations communities, please refer to Appendix D: Strategies for engagement with First Nations peoples.

Step 3: Consider best practice principles.

The OCP commits to the following guiding principles to support authentic and open consumer and carer engagement as outlined in ***Figure 4***.

Meaningful engagement:

- Engagement meets the needs of stakeholders, and they are armed with appropriate information to engage effectively.
- Decisions align to project's purpose and goals.

Safe and Supportive

- Fostering an environment for respectful discussions and balancing power differentials.
- Evidence-based information is used to challenge and test assumptions in a trauma informed and recovery focused manner.

Collaborative partnerships

- Partner with relevant government departments, non-government organisations, peak bodies, advocacy bodies as well as local community groups to develop broader system supports and drive a united agenda.

Dedicated resources

- Resourcing (time budget, remuneration) allows for adequate compensation in recognition of the value of the contribution of those with lived experience.

Figure 4: OCP guiding principles for authentic consumer and carer engagement.

One of the best practice principles for effective consumer and carer engagement is strategic partnering. **Appendix E: Organisations to support consumer and carer engagement and recruitment** outlines key organisations which can support engagement and recruitment processes for people with a lived experience of mental illness, substance use disorders, mental health crisis and suicidality, including their carers and families.

Supporting consumers and carers.

Safe and meaningful engagement.

As staff, we need to provide a safe environment that is mindful of further harms that may be experienced when discussing sensitive topics with consumers and carers such as hospitalisation, seclusion and restraint.

For key strategies for developing strategies for safety, including how to work with people who are in distress, please refer to **Appendix F: Approaches for creating consumer and carer safety**

Balancing power differentials.

Many consumers have experienced a significant loss of control in their treatment experiences at times when they have not been able to make decisions about their own treatment. For the OCP, who support the administration and operation of the *Mental Health Act 2016*, this is of particular relevance to considering power differentials arising in relation to engagement with consumers who have received involuntary treatment.

Power differentials can also come about because of a broad perception that professionals have greater knowledge, expertise, authority, and stability than a consumer, carer or member of the public.[13] It is important that engagement processes place an explicit value on the experience the person brings to the work (in this sense the 'expert' is qualified by virtue of implicit/tacit knowledge they have acquired through experience)[16] and works to establish a relationship of trust and mutual respect.

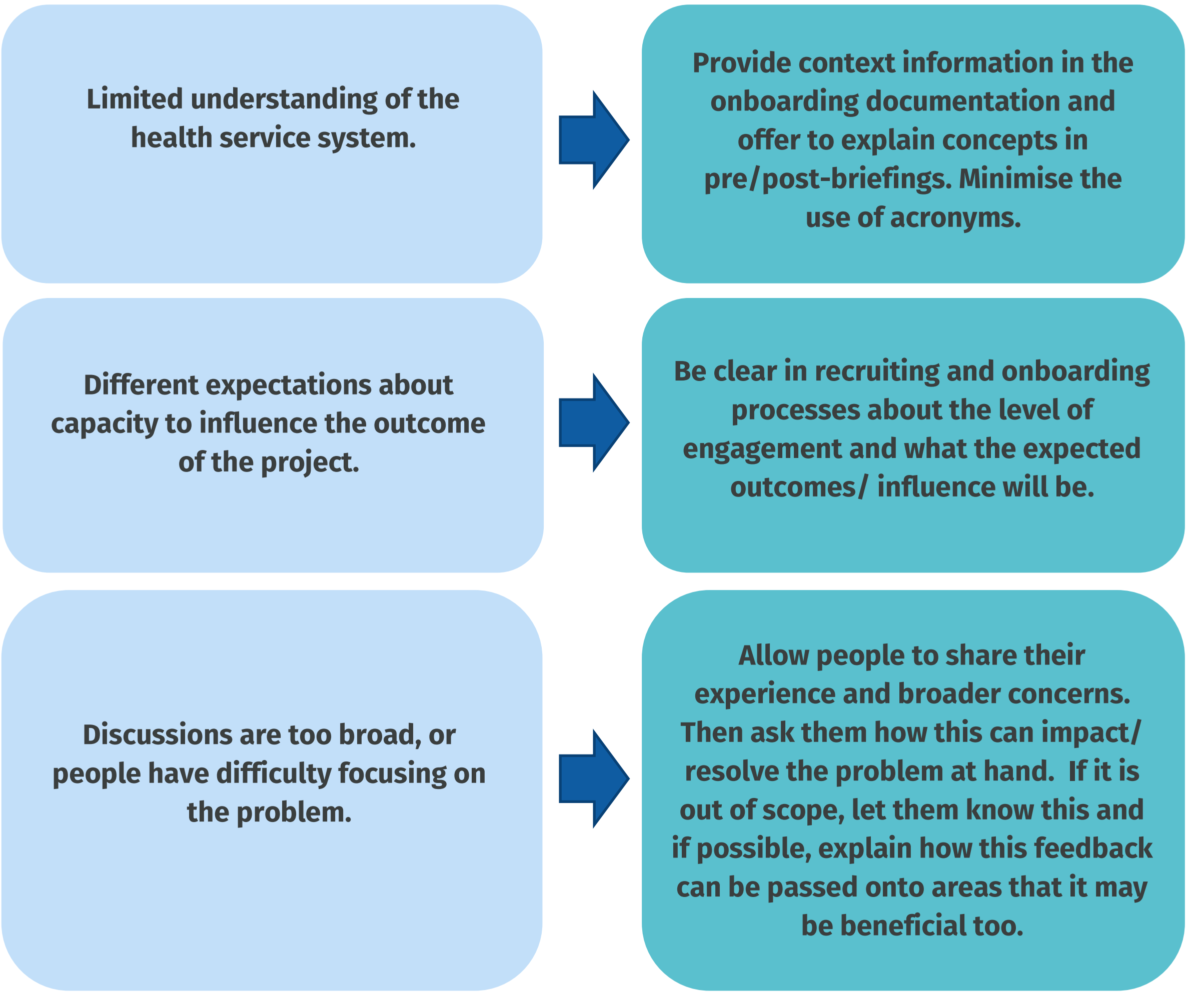
At times, consumer participation may involve the person sharing their experiences of clinical care. It is the responsibility of the OCP to ensure consumers have clinical information explained to them where it is necessary to be able to partner effectively.

Power imbalances can play out between policymakers, sector stakeholders and participants during engagement activities, especially in traditional committee settings where there may be many clinicians and service providers present but only one consumer and/or one carer. The culture of government (such as physical environment, language, and processes) may feel intimidating to people who are not used to these aspects of working with government. Power imbalance can also be reinforced through the use of jargon and knowledge assumptions.

There are simple ways in which staff can mindfully support people from the community to feel more welcome and able to participate fully.[17] Please see **Appendix G: Reducing power differentials** for a range of strategies that can support effective consumer engagement activities and assist consumers to feel more confident in their role in a project or piece of work where their expertise has been sought.

Challenges.

There may be challenges working with consumers and carers with lived experience. ***Figure 5*** provides some common examples and how to support consumers and carers.



Limited understanding of the health service system. → **Provide context information in the onboarding documentation and offer to explain concepts in pre/post-briefings. Minimise the use of acronyms.**

Different expectations about capacity to influence the outcome of the project. → **Be clear in recruiting and onboarding processes about the level of engagement and what the expected outcomes/ influence will be.**

Discussions are too broad, or people have difficulty focusing on the problem. → **Allow people to share their experience and broader concerns. Then ask them how this can impact/ resolve the problem at hand. If it is out of scope, let them know this and if possible, explain how this feedback can be passed onto areas that it may be beneficial too.**

Figure 5: Resolving common challenges when partnering with consumers and carers.

If you are having issues with consumer or carer partnerships or challenges that are difficult to resolve, please bring up these with your line manager so they can be managed appropriately.

Step 4: Remuneration and reimbursement.

Time commitments and other costs can be a barrier to community and consumer engagement. Remuneration aims to make it easier for people to contribute to engagement and improvement activities and recognises the valuable contributions they bring. However, funding may not always be available. It may also be appropriate to provide a gesture of thanks to a consumer, carer or community member, however this will depend on individual circumstances.

OCP currently refers to Health Consumers Queensland Remuneration and Reimbursement of consumers position statement for the payment rates for remuneration of health consumers in Queensland engaging with health services. Please note that a new position statement was published here in March 2024 with updated remuneration rates which are effective from 1 July 2024.

Whether the engagement is paid or voluntary, all gifts and or/benefits must align with the principles of accountability, integrity and transparency.[38] Individuals will only be paid for activities which they have been requested or approved to participate in by QH.

People who are eligible for remuneration as consumers and carers include:

- Any individual who identifies as a consumer, carer or representative of a vulnerable population group and is not already receiving payment for their participation in the activity from QH or by another organisation.
- Individuals who are employed by QH but are engaging in the QH activity as a consumer, carer or representative of a vulnerable population group in their own time, independent of their professional role.

People who are not eligible for remuneration as consumers and carers include:

- Consumers, carers and community members who are funded by another organisation to participate in the QH activity.
- Employees, contractors or consultants of QH who are already being remunerated for their participation in the activity by QH or another Queensland Government Department.
- A consumer, carer or community member who attends an event, seminar or conference as a matter of personal choice or interest and not at the request of QH.

Examples of activities eligible for remuneration (non-exhaustive):

- Membership and participation on QH consumer advisory councils, steering committees, clinical networks, subject matter expert groups, etc.
- Participation in a workshop or focus group to develop a new policy, guideline, strategic plan or resource.
- Review of policies, guidelines, patient-facing materials and other QH Publications.
- Participation in service design, redesign or improvement.

Example of activities not eligible for remuneration (non-exhaustive):

- Ad-hoc discussions or conversations between the individual and QH staff.

- Open invitations to attend seminars, lectures, conferences forums or other activities where the individual was not requested to attend and/or participate on behalf of QH.
- Any activity the individual has participated in without either request by, or approval from QH.
- Surveys and other collections of consumer and carer experiences and outcomes.
- Administrative activities to arrange their engagement.

Please see **Appendix H: Remuneration checklist** for more information.

Summary.

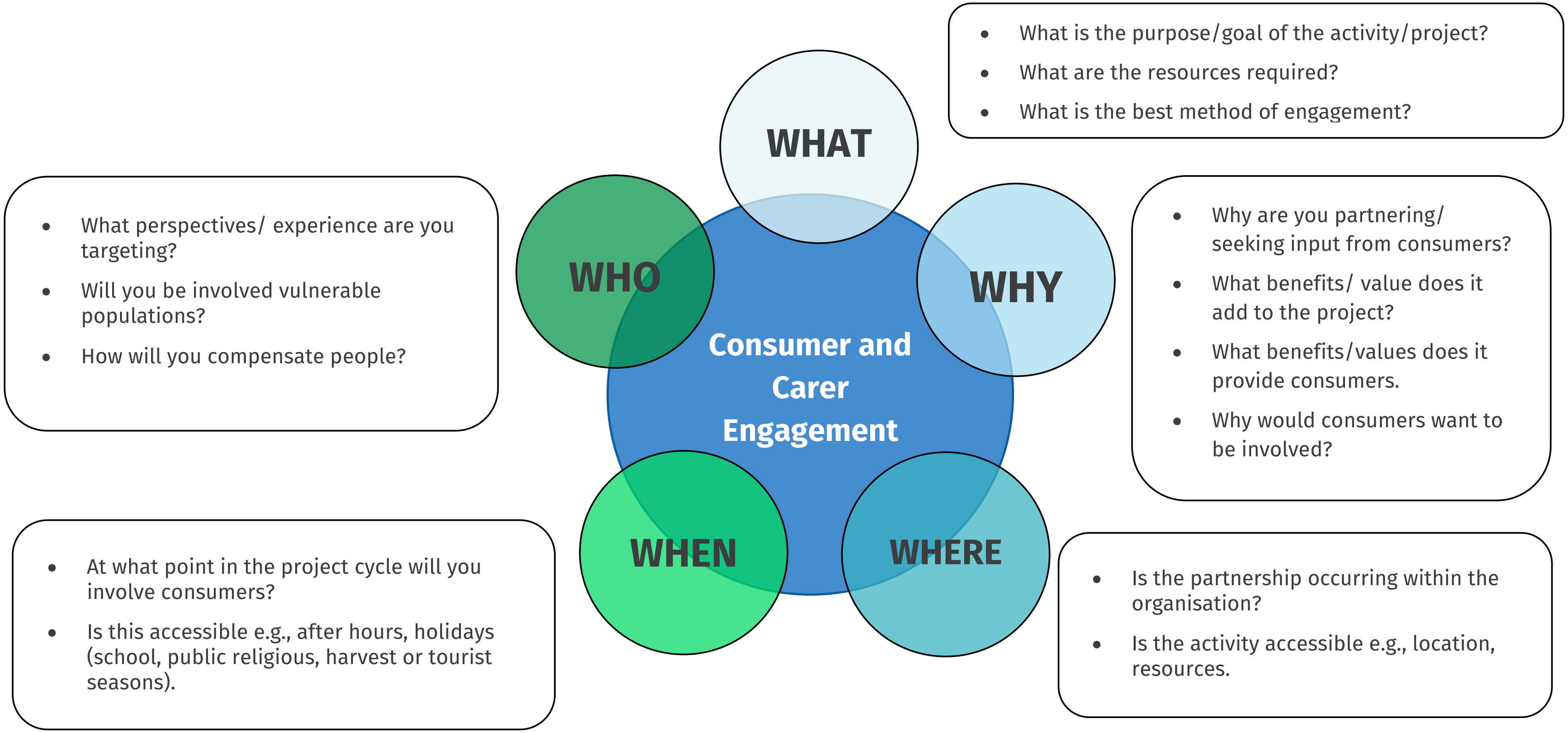
To ensure consumer and carer engagement is successful and continues to foster positive relationships it is important to plan out what level of engagement is suitable for the project and determine who may be involved and what viewpoints should be represented.

It is critical to always be open, honest, and transparent about the level of influence the lived experience representatives can have on the project and outcomes, as well as how they will or will not be remunerated for their involvement.

Partnering with consumers and carers is rewarding and can be very powerful. Consumers can often unlock doors and opportunities that staff may not be able to. To make the most of these mutually beneficial partnerships, time must be invested in the relationships and support provided to increase knowledge about the health system with consumers and carers regarding the specific areas they are working in. At the same time, consumers and carers will be increasing staff members' understanding of the issues and challenges faced by them and their communities, and how things may be improved.

Appendix A: Planning for consumer and carer engagement.

It is important when planning your project and before you determine which engagement strategy is most appropriate that you outline why consumers and carers should participate in the project, what role and level of influence they can bring to the project and outcome, and what perspectives and experience are you targeting.[18] ***Figure 6*** outlines key considerations when planning to engage with consumers and carers.



- What is the purpose/goal of the activity/project?
- What are the resources required?
- What is the best method of engagement?

- What perspectives/ experience are you targeting?
- Will you be involved vulnerable populations?
- How will you compensate people?

- Why are you partnering/ seeking input from consumers?
- What benefits/ value does it add to the project?
- What benefits/values does it provide consumers.
- Why would consumers want to be involved?

- At what point in the project cycle will you involve consumers?
- Is this accessible e.g., after hours, holidays (school, public religious, harvest or tourist seasons).

- Is the partnership occurring within the organisation?
- Is the activity accessible e.g., location, resources.

Figure 6: Considerations when planning consumer and carer engagement activities.

Appendix B: Co-Design explained.

What is co-design?

Co-design refers to an approach where consumers participate in designing solutions and are treated as collaborators with equally valuable contributions to the design process. This approach goes beyond just consulting with people and focuses on active and authentic collaboration between people affected by, or attempting to, resolve a particular challenge.[19]

Co-design is a term that is often misused and misunderstood. Co-design is a process, not an event. It is a participatory tool for problem solving that brings together those with technical or professional expertise in the chosen area along with people with a lived experience of the chosen area on shared ground to design solutions.[20] Co-design has the capacity to create innovative ideas to improve systems, services, and solve complex problems. Co-design, design research, and action-based research, rely heavily on generative techniques to host conversations and capture the thought processes of others.[21]

The MHAOD sector has adapted co-design to combine lived experience and professional expertise to identify and create an outcome or product. It builds on engagement processes such as social democracy and community development where all critical stakeholders, from service providers to end users are encouraged to participate and are respected as valued partners sharing expertise in the design of services and products.[22]

> *"If co-design means asking people with lived experience to help you achieve your strategic and operational priorities – you have started in the wrong place. Co-design is about what matters to people with lived experience and what matters to professionals – it is a negotiation, not a pre-determination."* – McKercher, K.A

What are the principles of co-design?

There are many different approaches and principles that can be applied when taking a co-design approach within a project or key initiative, however they often share key themes of all stakeholders finding space to learn from others, being comfortable in the grey areas and creating trusting and authentic relationships which develops a safe space for creativity and problem solving.

Figure 7 describes five principles of co-design, where were co-produced by a group of young people, stakeholders and staff of VicHealth and serves as an example of what is needed for true and authentic co-design.[23]

Principles of Co-design

1 **Experience**
Co-design is a process and a mindset not an event.

2 **Equality**
Co-design is about bringing those with lived experience and those technical expertise together, on equal footing.

3 **Empathy**
The more you connect with the problem, the more innovative and effective your solutions will be.

4 **Embrace ambiguity**
Get comfortable with the uncomfortable, unknown nature of co-design. Trust in the process.

5 **Experiment**
Approach your solutions like experiments, if you're not prepared to be wrong, you're not prepared to innovate. Test, learn and iterate.

Figure 7: Five Principles of co-design.

What conditions support co-design?

Not all projects are suitable to be co-designed, for example, if a decision has already been made about a solution to a problem and there is no chance to influence the outcome, this project cannot be co-designed. Projects like this are better suited to one of the other engagement strategies.

Support and Partnership

- People are needed to endorse and reinforce the approach we are taking and the outcomes we want to achieve.
- Sponsors and supporters help to build commitment, remove obstacles, and overcome resistance when it arises.

Time and Money

- Facilitation and convening
- Paying people with a lived experience for their time and any expenses
- Investing in solutions (after they have been co-designed)
- Supporting lived experience capability and leadership
- Prototyping, testing and learning (prior to implementation)
- Communicating the work throughout to build commitment and sustainability.
- Ensuring staff feel supported to take time to build relationships with stakeholders and partners to support active engagement processes.

Commitments

- Focusing on outcomes over outputs
- Remain aligned to the co-design values and principles
- Following through into implementation
- Staying committed to elevating the voice and contribution of lived experience
- Practising cultural intelligence and widening inclusion
- Sharing decision making, power and attribution
- Value and reciprocity with co-designers.[24]

Culture and Climate

- Authorising environments from formal and informal leaders
- Relationship building and authentic engagement
- A focus on learning and not control
- Permission to share learnings, failures, and successes
- Support to implement co-design mindsets such as curiosity, valuing many perspectives, hospitality, learning through doing, elevating lived experience and being okay with grey areas
- Accountability to the people we engage through co-design.

Figure

Figure 8: Conditions that support successful co-design initiatives.

What projects can be co-designed?

A co-design approach can be applied to any project which intends to make something better for those receiving or impacted by a health service, for example quality improvement projects, research projects, or when commissioning a new service. Examples of co-design opportunities:

- Patient information or educational resources.
- New/revised treatment pathways or models of care.
- New technology to support health care.

- Designing new health services (e.g., planning, infrastructure, physical design of building as well as the way the service operates).[25]

Appendix C: Including diversity of viewpoints.

Lived experience perspective versus lived experience workforce perspective.

Lived experience work includes a broad range of activities, which spans beyond peer support work alone. The lived experience workforce is diverse and comprised of advocates, policy makers, researchers, peer support workers and leaders in the sector.

Recruiting staff of health services who are also consumers of health care can bring valuable connections to community and an understanding of strategic priorities. These staff may have unique insights and understanding of MHAOD services compared to consumers who do not work in the sector, and both viewpoints should be considered and captured.

For more information on the Lived Experience workforce, please see The Queensland Health Lived Experience (Peer) Workforce 2023 which seeks to support Hospital and Health Services to further develop, strengthen and consolidate their Lived Experience (Peer) workforce.

Figure 9 showcases the different experiences across the consumer and carer workforce as well as overlaps between the consumer and family/carer experience.

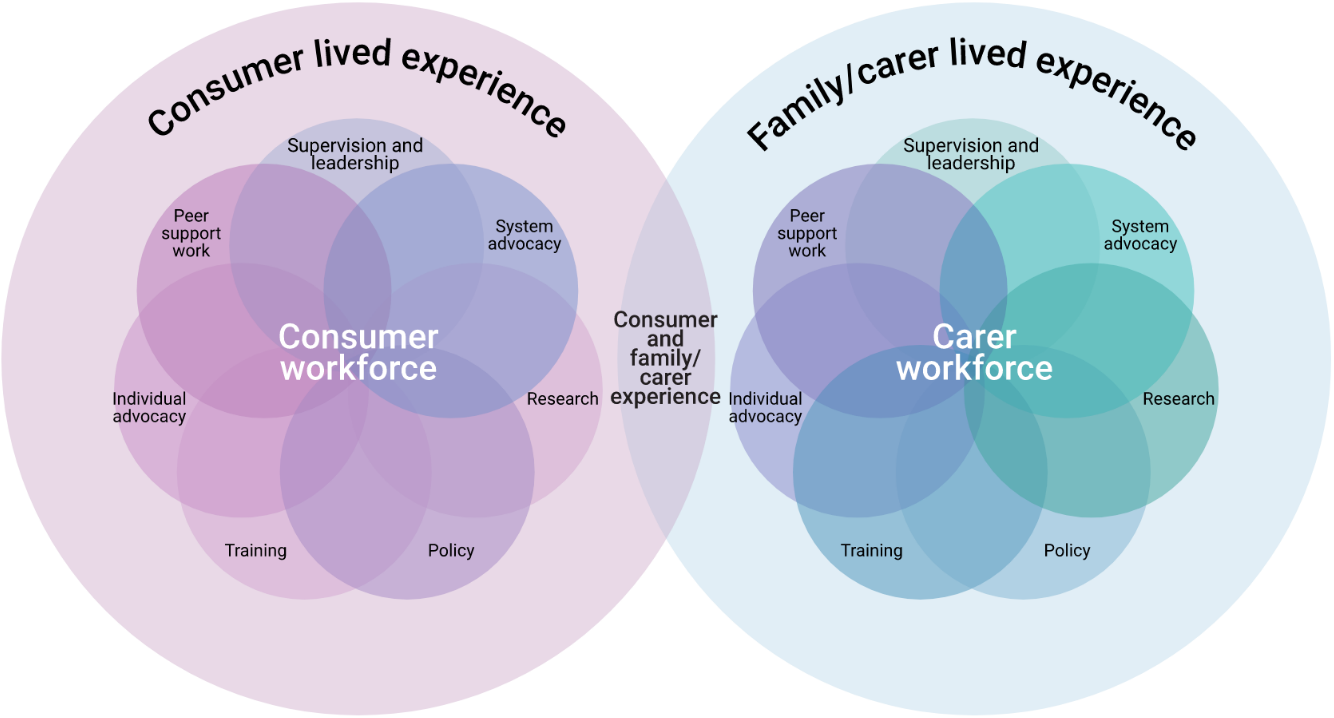


Figure 9: Consumer and family/carer lived experience workforce (Downes & Edan, 2017)[15].

Specific population groups.

Being aware of more difficult to reach and vulnerable populations and working to overcome barriers to participation by actively valuing diversity of views can strengthen trust and relationships with people with a lived experience. It is important to consider the inclusion of vulnerable population groups, including those listed below.

Children and young people.

Children and young people benefit from being involved and having a say on issues that affect them. When engaging with this population, consider that they may require informed consent from the child and their parent and/or carer to participate.

Project content should be age appropriate and engagement should take into consideration developmental stage and characteristics of children. This may include taking additional breaks and being considerate of other factors impacting them e.g., school, homework, exams and job responsibilities.

First Nations peoples.

Effective engagement with Aboriginal and Torres Strait Islander communities is a process that provides First Nations peoples with the opportunity to actively inform decision making. It requires a relationship built on trust and integrity and is undertaken with an understanding of the historical, cultural, and social complexity in specific local or regional contexts.

It is important to take the time to develop relationships with Aboriginal and Torres Strait Islander communities before beginning engagement activities and work with community partners to ensure that partnerships with people with a lived experience and communities result in more accessible and appropriate services.

For more information about how to work with First Nations communities, please refer to **Appendix C: Strategies for engagement with First Nations peoples.**

Culturally and Linguistically Diverse (CALD) groups.

Australia is a multicultural country with 22.7 per cent of the 2021 Queensland population born overseas and more than 19 per cent speaking a language other than English at home.[26]

Engagement can be understood differently across various cultural groups. Trauma, low health literacy and language barriers can all be challenges to engaging with CALD consumers.[27]

When engaging with people from CALD and refugee communities, developing relationships is central. Staff may wish to consider asking members of the community or a local cultural group to lead the project to develop partnerships for the future. The Queensland Transcultural Mental Health Centre can be a good place to start with education, training and resources to support culturally competent engagement with diverse communities. Staff should identify the need for interpreters and whether written, electronic and verbal information needs to be translated.

Rural, regional and remote communities.

Rural and remote communities experience challenges related to large geographic areas and dispersed populations, which means they bring a unique viewpoint to any project. There are widely differing needs between rural, regional and remote communities and challenges including isolation, harsh climate, job insecurity, geographic spread, low population density, limited infrastructure and a lack of social support. Multi-level approaches to consumer and carer engagement in rural communities are needed to maintain a local sense of place while considering policy, resourcing, and best practice at a regional level.[28]

People living with a disability.

Disability is very diverse term. It can encompass intellectual, cognitive, neurological, sensory, physical, or psychosocial impairments. People with disability are also diverse, with unique and individual needs and experiences.

Psychosocial disability is the term used to describe disabilities that may arise from persistent mental illness. Not everyone who has a mental health issue will experience psychosocial disability, but those who do can experience severe effects and social disadvantage. It is important to consider how someone's psychosocial disability may impact their ability to participate in engagement opportunities. It is helpful to discuss possible barriers to engagement before a participation activity so they can be adequately addressed.

When planning a project, it is important to consider how to make engagement opportunities as accessible as possible. For people living with a form of disability this may include; the use of communication devices, ensuring accessible locations/ covering the cost of wheelchair accessible taxis, having information available in alternative formats, such as plain text versions to suit screen readers, Braille, audio as well as including the consumer or carer's family members or support persons where needed.[30]

Furthermore, for those who may have issues with literacy, having all information written in plain English and free from jargon, including acronyms is very helpful and supports an equitable approach to engagement. Content should be written to a grade 7 or 8 level, which means that approximately 80 per cent of adult audiences can understand it. This aligns to the Queensland Health web publishing standards.

People who identify as Lesbian, Gay, Bisexual, Transgender, Intersex or Queer/Questioning (LGBTIQ+).

Through partnering with the LGBTIQ+ community, policies and programs can be designed to promote inclusion and prevent discrimination, vilification and harassment based on gender identity and sexual orientation. Including LGBTIQ+ representatives in engagement activities can support increased awareness of issues and needs within the community, increased community understanding of people who identify as LGBTIQ+ and the identification of barriers to health service delivery.[31]

Appendix D: Strategies for engagement with First Nations peoples.

The following considerations need to be reviewed when engaging with First Nations peoples.

- A Welcome to Country is a protocol where Aboriginal or Torres Strait Islander Traditional Owners welcome others to the land of their ancestors. This practice demonstrates respect for the Transitional Owners and Elders of the region. Staff should consider a welcome to country for significant events and formal functions (e.g. significant community and staff engagement forums).
- An Acknowledgment of Traditional Owners is a practice that demonstrates respect for Aboriginal and Torres Strait Islander cultures and recognises the importance of acknowledging Traditional Owners.
    - This acknowledgement should precede the commencement of formal meetings and committees.
    - Staff should consider whether a First Nations representative(s) would like to be responsible for this.
    - Acknowledgments should be tailored to the local land where the meeting is being held.
- When considering engaging with First Nations peoples, you will have to ensure that you are not catering to the mainstream/westernized processes and that you are responsive to culturally appropriate ways of engaging. For example, hosting virtual meetings for the entirety of the project may not be effective at engaging certain communities. Consideration of face-to-face meetings, yarning circles or other culturally appropriate strategies may be beneficial.[32]
- Effective engagement is undertaken with an understanding of the historical, cultural and social complexity of specific local or regional contexts.[33] For example, if there is only one representative on a project, they may not feel comfortable representing all First Nations peoples and may only represent their specific community. Consider engaging with the representatives about what perspectives they are bringing and where possible try to expand the engagement to include multiple First Nations voices.
- Consider partnering with other relevant agencies such as:
    - The Department of Treaty, Aboriginal and Torres Strait Islander Partnerships, Communities and the Arts (Aboriginal and Torres Strait Islander Partnerships and Local Thriving Communities).
    - The Office of First Nations (Previously known as the Aboriginal and Torres Strait Islander Health Division).
    - MHAOD Aboriginal and Torres Strait Islander Leadership Group.
- Indigenous Health Workers may be able to assist with engagement processes, as they have established relationships within the communities in which they work. OCP staff should, as far as is practicable, take the time to develop relationships with Aboriginal and Torres Strait Islander communities before beginning engagement activities.
- Ensure communication about the project clearly articulates how First Nations consumers will be impacted as a result and why their representation and engagement

on the project is important. Consideration should be given to how this work will further strengthen First Nations priorities.

The following avenues may be valuable to connect with during an engagement process with Aboriginal and Torres Strait Islander Communities:

- Local Elders.
- Regional councils/authorities.
- Community controlled organisations.
- Local churches.
- Community consultations with rural and remote communities.[34]

There are resources on QHEPS to support Aboriginal and Torres Strait Islander Cultural Capability. For more information contact the Aboriginal and Torres Strait Islander Cultural Capability Team here.

Please also refer to Making Tracks Together: Queensland's Aboriginal and Torres Strait Islander Healthy Equity Framework.

Appendix E: Organisations to support consumer and carer engagement and recruitment.

To assist with recruiting a broad range of consumers and carers from a variety of different backgrounds, skill sets and strengths, please consider engaging with the following organisations:

- Mental Health Lived Experience Peak Queensland (MHLEPQ) are the Queensland peak body for consumers with a lived experience of mental health and suicidality. They provide policy advice and systems advocacy for consumers of mental health services of all ages in Queensland.
  - If your project requires engagement from people with a lived experience of mental illness, the MHLEPQ can support engagement with their members. To request support from the MHLEPQ, complete an engagement request form through their engagement portal here.
  - More information can be found here on how the MHLEPQ can support lived experience engagement, including a better understanding of their processes.
- Health Consumers Queensland (HCQ).
  - HCQ can provide a full recruitment service of consumers from their state-wide consumer network. This includes promoting the opportunity, receiving Expressions of Interest, and shortlisting a final selection for OCP staff to choose from.
  - HCQ can assist with recruitment of consumers for healthcare generally. Please note HCQ no longer support recruitment for people with a lived experience of mental health and suicidality but work collaboratively with MHLEPQ.
- Roses in the Ocean is Australia's lived experience of suicide organisation. They collaborate with individuals and organisations across community, corporate, health and government sectors to engage lived experience of suicide expertise effectively and meaningfully with all aspects of suicide prevention.
- For First Nations engagement, utilising organisations such as First People Recruitment Solutions and advertising in places such as the Koori Mail to identify and tap into Aboriginal and Torres Strait Islander community consumer and carer voices is a useful strategy.
- Other organisations who can share consumer/carer opportunities but don't necessarily provide specific support with recruitment include:
  - Queensland Injectors Voice for Advocacy and Action (QuIVAA).
  - Queensland Aboriginal and Islander Health Council (QAIHC).
  - ARAFMI (supporting families and carers).

Appendix F: Approaches for creating consumer and carer safety.

Creating a safe environment.

Safe engagement and participation can ensure that everyone, not just consumers and carers, has the support they need for an activity. Talking about safety and what everyone needs as a safety response is part of building a strong culture of respect.

Practical safety supports may include:

- Co-developed ground rules about safe and acceptable disclosure.
- Formal documents to support the engagement and participation process, such as Terms of Reference that clearly state roles and responsibilities.
- Designated physical space for people to take a break if needed.
- Making known other available methods of support such as peer or professional debriefing and Employee Assistance Programs.

Safe disclosure.

Safe disclosure is about supporting people in groups to share their stories safely, in a way that minimises potential harm to others. Using trauma-informed communication strategies such as engaging body language, asking open-ended questions, and expressing kindness, patience and acceptance are useful techniques which consider people's history of adverse life experiences.[35]

Strategies for engaging with people in distress.

When designing a project, please ensure there are enough resources to support people should distress arise as part of an activity or meeting. People should be made aware of what supports are in place and what they need to do access them.

For example, the facilitator may:

- Have a separate chat (outside of the meeting chat) where representatives can ask questions which they may not be comfortable voicing aloud in the larger group.
- Offer the person the opportunity to step out and have a support person if they are feeling distressed during the meeting or activity.

Supporting people in heightened distress can be challenging. Strong expressions of emotions can feel uncomfortable to be around, but emotions and expressions of distress are common reactions to stressful and unexpected events, or when someone is feeling triggered by previous trauma. The way you respond can make a difference in assisting someone to feel less overwhelmed.

The following strategies may be useful when someone is in distress:

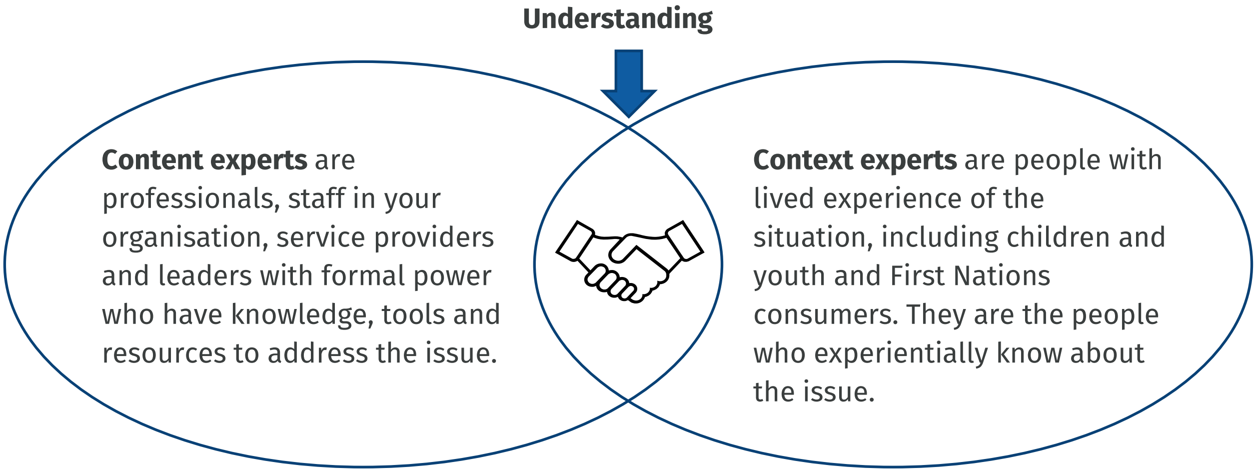
- Respond calmly, be warm and non-judgemental. Take concerns and feelings seriously without offering advice.
- Listen and acknowledge feelings. Show empathy. Do not try to rationalise, debate, try to fix the situation, make them see the bright side of things, or inadvertently shame them for feeling hopeless.

- Summarise what the person has said to show you are listening and understand their concerns.
- Help the person consider their most urgent needs, and how they could be met.
- Ask the person if there is anyone they might like to contact to support them, or if they would like you to contact that person on their behalf.
- Note that if the feelings continue and are impacting on everyday life, professional support is available, and recovery is possible and likely.
    - Offer for the person to use the QH Employee Assistance Program if they would like to access to professional support and do not already have existing mechanisms.
    - Offer for the person to contact the mental health telephone triage service on 1300 MH CALL (1300 34 22 55).

If you aren’t sure what to do when someone is in distress, please bring up these issues with your line manager so they can be managed appropriately.

Appendix G: Reducing power differentials.

Consumers and carers are more likely to trust our services and engage in partnerships when we build real understanding and have clear and open processes that don't rely on assumptions of perceived needs. To help reduce real or perceived power imbalances when engaging with consumers and carers, we need to recognise both the content expertise of our staff and professionals and the context expertise our consumers bring to the table (as illustrated in ***Figure 10***).



Content experts are professionals, staff in your organisation, service providers and leaders with formal power who have knowledge, tools and resources to address the issue.

Context experts are people with lived experience of the situation, including children and youth and First Nations consumers. They are the people who experientially know about the issue.

Figure 10: Bringing content and context expertise together to build understanding[36].

Some strategies that can help reduce power differentials and empower consumers include:

- **Provide consumers and carers with an orientation.**
    - Consumers and carers should be oriented to the specific activity they will be involved in, including the organisation, the project team and any key contacts that would be helpful for them to know.
    - Give consumers a key point of contact who can provide them with guidance and support during their involvement with the project or activity.
    - During the orientation, find out if the person needs any additional support to participate fully and allow time to answer their questions and concerns.
- **Provide consumers and carers with a pre-briefing session and post-briefing session.**
    - This is useful as it ensures there is dedicated time to any questions and can support reflective practice. Where appropriate the insights can later be shared with the larger group.
    - Tailor the modality of the session to the preferences of those you are engaging with (e.g., face-to-face vs online). Take into consideration geographical barriers, disability factors and cultural preferences.
- **Include more than one consumer/carer representative in any activity you are planning.**
    - This allows a peer support mechanism within the process.
    - It can also provide an opportunity for a diverse range of opinions. One lived experience may be very different to another, and it is important to recognise that no one journey is the same.

- **Employ communication skills such as reflective and active listening.**
    - This can help to validate consumer perspectives, create a safe environment for an open and honest discussion, and help elicit feedback.
    - Ensure people understand that their lived experience provides unique insights and expertise that may help improve the system for everyone.
- **Utilise peer support or peer-to-peer engagement activities.**
    - This can include small group discussions or interviews with a number of community members or consumers can help reduce power imbalances and create a supportive environment.[37]
- **Empower consumers and carers to feel confident in their advice and using their voice.**
    - Reiterate the importance of the consumer and/or carer sharing their experiences, knowledge and expertise with the group.
    - Ensure they understand the relevant topic areas being discussed.
    - Ensure all voices are heard, not just the loudest in the room.
    - Offer various forms of feedback and input such as tactile, written, visual, electronic and face-to-face.

Appendix H: Remuneration checklist.

The following is a checklist of forms and steps to complete to set up a consumer or carer representative up as a vendor in the QH finance system to enable them to be paid remuneration.

- ☐ The Consumer or Carer representative must complete the Statement by Supplier Form.
- ☐ The Consumer or Carer representative must complete the EFT Vendor Setup Form.
  - This form needs to be completed and witnessed so the consumer/vendor can be created in s4/HANA.
- ☐ Once you have the Statement by Supplier and EFT Vendor Setup Form completed together, send both forms through to the appropriate e-mail below:
  - LU staff – MHAODB-LU@health.qld.gov.au.
  - LP/CGU staff - mhaodb-ocp@health.qld.gov.au.
  - You will receive a vendor number once this form is processed, make a note of it for the Consumer Expense Claim Form.
  - It is useful to let the consumer know their vendor number for next time and for any other future activities they do with OCP.
  - If you have any issues, please contact your local Program Support Officer.
  - This process can take time to be finalised, so please complete these forms as soon as practicable to ensure it is set up prior to commencing your engagement activity.
  - ☐ Once the consumer or carer engagement activity is completed, the consumer or carer is required to complete as much information as they can on the Consumer Expense Claim Form.
    - Other minor details may need to be completed by the OCP staff member assisting with the consumer engagement activity.
    - Please ensure the cost centre used is correct depending on your unit and the activity undertaken.
  - ☐ Once the Consumer Expense Claim Form is completed, please send to the relevant address below for processing along with any receipts if applicable:
    - LU staff – MHAODB-LU@health.qld.gov.au.
    - LP/CGU staff - mhaodb-ocp@health.qld.gov.au.
    - It is the OCP staff member's responsibility to follow up with the person to make sure their forms are submitted so they are paid in a timely manner.
    - The consumer reimbursement rates currently used by QH are set by HCQ and can be found on their website here. The reimbursement rates should be decided upon prior to the engagement activity with the consumer or carer.
- ☐ It is important for consumer/carer engagement to be verified, so you can remunerate the consumer. You may wish to confirm the consumer's attendance via minutes of a meeting they are attending or reviewing their feedback or involvement in the selected activity.

Appendix I: Further info, resources, and training.

Consumer and Carer Engagement.

- Australian Commission on Safety and Quality in Health Care. (2023) – Partnering with Consumers: A guide for consumers.
- Safer Care Victoria – Partnering with Consumers: A guide for Government.
- QHEPS - partnering-with-consumers | Queensland Health Intranet.
- Health Consumers Queensland have a variety of resources and guides to support consumer engagement activities and processes.
    - Consumer and Community Engagement Framework (2017).
    - Guide for Health Staff Partnering with Consumers (2022).
    - Training available for Qld Health staff - Training and Skills Building.
- National Mental Health Consumer and Carer Forum and National Primary Health Network Mental Health Lived Experience Engagement Network. (2023) - Lived Experience Governance Framework: Centring People, Identity and Human Rights for the Benefit of All.

Lived Experience (Peer Workforce).

- Queensland Health (2023) - The Queensland Health Lived Experience (Peer) Workforce 2023

Co-design.

Resources.

- Beyond Sticky Notes (website and book).
- Metro North Health Co-design Framework (online tool).
- Point of Care Experience Based Co-design Toolkit.
- Agency for Clinical Innovation | NSW Health Co-design Toolkit (online library).
- Western Australian Council of Social Service (WACOSS) co-design toolkit (PDF).

Training.

- Design Thinking for Healthcare – 4 hours self-directed learning comprised of videos, quizzes, and simple practice exercises. Certificate of completion provided. This course was developed by CEQ BridgeLabs – Healthcare Excellence Accelerator (HEAL). *Get started >* (FREE).

- Beyond Sticky Notes Training (Kelly Ann McKercher) offers the following courses:
    - Understanding Co-design.
    - Using the Model of Care for co-design.
    - Introduction to co-design.
    - Design Foundations.
    - Prototyping Fundamentals.

- Immersive Introduction to Co-design; Co-design in Complex Systems; Co-design Practitioners (Emma Blomkamp).

- The Australian Centre for Social Innovation Co-design Training Course.

Blogs, podcasts, and videos.

- Beyond Sticky Notes – Co-design (podcast).
- Power and Co-design (video).
- What is co-design exactly? (blog).
- This is HCD (Human Centred Design) (podcast).
- Co-design or Faux Design (video).
- Shifting the power play in co-design (blog post).

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