

Engaging people with a lived experience: Renewed priorities



Renewing Queensland's priorities for meaningful, well supported engagement of people with a lived experience as valued, equal partners.

Purpose

This discussion paper seeks feedback on ways to increase and improve engagement of people with lived experience, their families, carers and support people to influence policies, programs and services. It focuses on engagement in the mental health, alcohol and other drug and suicide prevention sectors.

Views shared in response to the discussion paper will inform the review of the *Queensland Mental Health, Drug and Alcohol Strategic Plan 2014–2019* (the Strategic Plan).

About the review

The Strategic Plan was released in October 2014 and sets a platform for change over three to five years. Significant reform has occurred in many areas both at the state and national levels since the Strategic Plan's release. These reforms include the increased roles of Primary Health Networks (PHNs), the roll out of the National Disability Insurance Scheme and the release of the *Connecting care to recovery 2016–2021: A plan for Queensland's State-funded mental health, alcohol and other drug services* (Connecting Care to Recovery).

To ensure reform continues and progress is made towards achieving better outcomes for Queenslanders, the Commission is undertaking a review of the Strategic Plan. The review particularly focuses on identifying ways to increase and improve engagement of people with a lived experience to influence policies, programs and service delivery.

The review will take into account:

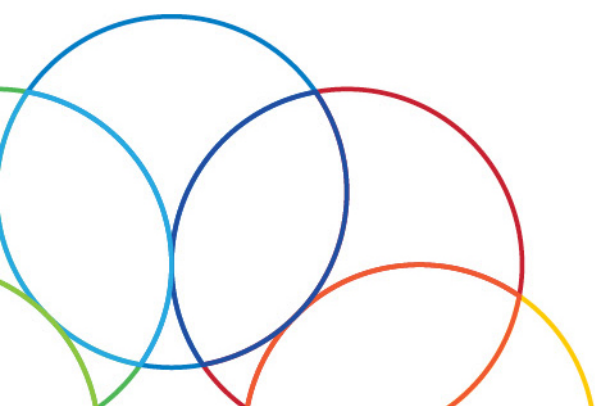
- progress made towards implementation to date
- reforms at the national and state levels
- new evidence about what works
- the views and experiences of stakeholders, including people with a lived experience, their families, carers and support people.

About this paper

Two discussion papers have been released by the Commission as part of its consultation process. This discussion paper focuses on lived experience engagement and is complemented by the discussion paper *A renewed plan for Queensland: Reviewing the Queensland Mental Health, Drug and Alcohol Strategic Plan 2014–2019* which has a broader focus on systemic issues.

Drawing on well-established evidence, policy and practice, and new research, this discussion paper seeks to identify the extent of engagement in Queensland and opportunities to further improve meaningful engagement. This discussion paper also draws on research and forums undertaken on behalf of the Commission, including:

- the Engagement Mapping Project² undertaken by Urbis
- Stretch2Engage: Service Engagement Framework for Mental Health and Alcohol and Other Drug Services³ (Stretch2Engage) undertaken by the Queensland Alliance for Mental Health Inc., Queensland Network of Alcohol and other Drug Agencies and Enlightened Consultants
- *Promoting Lived Experience Perspective* Discussion Paper⁴ authored by Dr Louise Byrne, Central Queensland University
- *Report of Promoting Lived Experience in Mental Health Forum*⁵ held on 29 July 2016.



What we mean by lived experience

Many different terms are used by the mental health, alcohol and other drug and suicide prevention sectors to describe people with a lived experience.

This discussion paper refers to people with a lived experience as those who **have a direct personal experience of mental illness and/or problematic alcohol and other drug use**.

It also notes the definition of a lived experience of suicide as used by Suicide Prevention Australia as a person who has **experienced suicidal thoughts, survived a suicide attempt, cared for someone who has attempted suicide, been bereaved by suicide, or been touched by suicide in another way⁶**.

Different terms are also used to describe family members, carers, and friends and support people by different sectors. This discussion paper uses the unique terms used by each of mental health, alcohol and other drug and suicide prevention sectors to describe people who play a vital role in the lives of people with a lived experience.

Share your views and experiences

To inform the review of the Strategic Plan and to increase engagement of people with a lived experience, their families, carers and support people, the Commission is seeking feedback regarding:

1. opportunities to increase meaningful engagement of people with a lived experience, their families, carers and support people from all backgrounds, to influence the mental health, alcohol and other drug and suicide prevention policies, programs and service delivery
2. opportunities to increase peer work and peer networks across the mental health, alcohol and other drug and suicide prevention sectors
3. future priorities for lived experience engagement and leadership across Queensland
4. examples of good practice, including those that target people from diverse backgrounds.

How you can provide your feedback

Respond to this discussion paper

Send a written response to this discussion paper by emailing strategicplanreview@qmhc.qld.gov.au.

Responses are due by 5pm Friday, 12 May 2017.

The Commission may share your submission with government agencies and may publish reports and other documents referring to your feedback. Please let us know if you do not wish your feedback to be publicly released or if your feedback is being provided anonymously.

Participate in a forum

Participate in a forum hosted by the Commission, held at locations across Queensland. Forums include:

- **Lived experience forums** to hear the views and experiences of people with a lived experience of mental illness, problematic alcohol and other drug use and people affected by suicide including their families, carers and support people
- **Community forums** to hear the views and experiences of government and non-government service providers and community members.

Strategic Plan forum locations and dates

Location	Lived experience forum	Community forum
Rockhampton	13 March	14 March
Mount Isa	23 March	24 March
Ipswich	28 March	29 March
Logan	4 April	5 April
Brisbane	10 April	11 April
Townsville	8 May	9 May
Cairns	10 May	11 May
Toowoomba	1 June	2 June

To get more information about the forums, including times and venues, and to register your attendance please go to www.qmhc.qld.gov.au.

Keep reform on track by getting involved and staying informed. Speak up and voice your views.

Background

People with a lived experience and their families, carers and support people interact with government and non-government agencies to develop and evaluate policies, programs and services in a wide variety of ways. This includes being provided with information, being consulted, and providing support to others receiving services.

These ways of interacting, when used appropriately, are important to enable people with a lived experience, families, carers and support people to be well informed and ensure their voices are heard and considered when making decisions.

However, there has been a continuing call for a higher level of interaction through engagement which involves people with a lived experience, their families, carers and support people being actively involved in decision-making as valued, equal partners.

What we mean by engagement and leadership

Engagement is very different from other forms of interactions and go beyond therapeutic relationships, participation, being informed or consulted.

In 2016, as part of work to support the Strategic Plan, a consortium of sector partners (Queensland Alliance for Mental Health Inc., Queensland Network of Alcohol and other Drug Agencies and Enlightened Consultants) through the Stretch2Engage project defined engagement as:

encompassing the processes or techniques that services employ to involve people using services and their families, carers and friends in the design or redesign of their services³.

This type of interaction is active and intentional. It requires government departments, agencies and services to think about engagement differently: from one that invites people with a lived experience to engage, to one where organisations actively change their approaches to enable engagement. Importantly this includes adapting engagement strategies to ensure that the voices of people from diverse backgrounds are heard including those who may be considered 'hard to reach' such as people who are homeless, have poor literacy or from diverse cultural backgrounds.³

Lived experience leadership takes many forms and includes peer operated and managed organisations and services.

Why engagement and leadership is important

Engagement of people with a lived experience has evolved differently and at a different pace in the mental health, alcohol and other drug and suicide prevention sectors³. Due to a range of historical and present day factors, the nature and extent of engagement and leadership opportunities varies between sectors⁷.

While these differences are important and should be recognised, there is an increasing acknowledgement across all sectors that engagement with people with lived experience is seen as a human right with people having the right to have a say in decisions which affect their lives⁴.

It is also widely accepted that engagement with people with a lived experience, their families, carers and support people contributes to reduced stigma and better outcomes^{4,7,8}.

The Strategic Plan

There is a continuing need to increase opportunities for engagement and leadership which are meaningful, well supported and embedded as a fundamental part of good practice.

Recognising the importance of drawing on their wisdom, the Strategic Plan's implementation is guided by a principle requiring engagement which values people with a lived experience as partners in guiding reform and in service development, planning, delivery and evaluation¹.

It commits to identify and implement actions (Shared Commitment to Action 1) to enhance engagement and leadership as an area for reform by:

- providing meaningful opportunities for individuals, families and carers to participate as equal partners in all levels of policy development, and the co-design, planning, monitoring and evaluation of mental health, alcohol and other drug services
- ensuring individuals, families and carers are informed, equipped and empowered to voice their perspectives, particularly in relation to their rights¹.

These actions are specifically focused on the ability of people with a lived experience, their families, carers and support people to:

- influence the system
- provide peer work and peer networks.

Influencing the system

Engagement and leadership to influence the system takes many forms across the mental health, alcohol and other drug and suicide prevention sectors. The most empowering form of engagement occurs within organisations and services which are managed and operated by people with a lived experience, their families, carers and support people³. Other engagement strategies include involving people with a lived experience, families and carers in governance and management groups, advisory groups, or membership of recruitment panels².

The Engagement Mapping Project undertaken by Urbis on behalf of the Commission indicated that engagement of people with a lived experience, their families, carers and friends in the mental health and alcohol and other drug sectors is largely in its developmental stage. However, some examples of good practice identified by the project included cross-sector working groups, involvement in system-level management, advisory council and board subcommittees².

The project strongly suggested a need for a renewed focus on engagement into the future, building on existing good practice as well as the need to share strategies and innovative approaches to effective engagement². Part of the renewed focus includes the development of the draft Best Practice Principles as part of the Stretch2Engage project³.

Mental health sector

Australian mental health policy has called for the engagement of people with a lived experience of mental illness, their families and carers in the design and delivery of services since the 1990s. This call has been informed and advocated by the consumer movement which focuses on engagement as a human right and citizenship issue which is embedded in a recovery-oriented approach to mental health treatment and care⁴.

Over many years, numerous guidelines and policies have provided guidance and have set standards requiring engagement with people with a lived experience, their families, carers and support people, including the *National Framework for Recovery-Oriented Mental Health Services*⁸ and the *National Standards for Mental Health Services*⁹ (the National Standards).

The National Standards are implemented in Hospital and Health Service mental health services through the 2010 *Queensland Health Consumer, Carer and Family Participation Framework*¹⁰ (the Queensland Health

Framework), which provides guidance on engagement in service planning, delivery and evaluation.

The Queensland Health Framework does not apply to non-government mental health services¹⁰. This sector engages with people, including through a number of organisations run by people with a lived experience, their families, carers and support people including Brook RED, FSG Australia's PEARL program, Peer Operated Service managed by Richmond PRA, Queensland Voice and Mental Health Carers Arafmi Queensland⁴.

Queenslanders with lived experience of mental illness and carers are also represented on the Mental Health Australia's National Mental Health Consumer and Carer Forum which provides an avenue for influencing policy and programs at the national level^{11,12}.

However, the Engagement Mapping Project indicated the most common form of engagement in the public and non-government sector involved seeking feedback on service delivery. While some organisations indicated they included people with a lived experience on management committees and advisory groups, this approach cannot be considered to be part of a systemic approach across the public or the non-government sectors².

The Engagement Mapping Project identified a lack of financial and human resources as the main barriers to meaningful engagement, particularly in the non-government sector². In some cases, and as indicated in research, a lack of organisational structures also plays a key role in supporting engagement and leadership opportunities within the mental health sector¹³.

Opportunities to strengthen the mental health system's approach to engagement exist with the review of the Queensland Health Framework, planned as part of the Connecting Care to Recovery¹⁴. Supporting cultural change and adopting a more effective approach to engagement will also be supported through the piloting and finalisation of draft Best Practice Principles, developed as part of the Stretch2Engage project³.

Alcohol and other drug sector

The call for clients of alcohol and other drug services to have a greater voice in the delivery of services is gaining momentum, with steps taken to define and support better engagement. It is important to acknowledge that peer operated organisations have been at the forefront of this momentum, providing effective harm-minimisation support and improving the ability to work with 'hard to reach clients'¹⁵.

Supported by evidence which demonstrates the clear benefits of engagement and leadership in the alcohol and other drug sector, much of the momentum for change is driven by national policy^{2,7}. For example, the *National Safety and Quality Health Service Standards* require client engagement in the organisation and strategic processes that guide the planning, design and evaluation of health services, including alcohol and other drug services¹⁶.

The *Draft National Drug Strategy 2016–2025* also includes a priority to increase engagement with people using alcohol and other drug services and peer organisations in alcohol and other drug strategies¹⁷.

The scope of engagement and leadership within the alcohol and other drug sector is influenced by factors unique to that sector. These factors include people with a lived experience of alcohol and other drug use fearing repercussions due to, in part, the illegality of possessing some substances, as well as high levels of stigma. Engagement is also impacted by a lack of resources and funding of alcohol and other drug services⁷.

In Queensland, a number of organisations are operated by or include people with a lived experience of problematic alcohol and other drug use, including the Queensland Injectors Health Network (QIHN), and play an advocacy role in policy development.

At the service delivery level, the Mapping Engagement Project indicated that the alcohol and other drug services surveyed placed a greater focus on engagement as part of everyday operations and on assisting people through treatment and support².

To address the factors unique to the alcohol and other drug sectors, Project Gauge released by Queensland Health provides a client engagement and participation toolkit, to enable public health alcohol and other drug services to create partnerships with their clients and improve the safety and quality of care⁷.

Opportunities to strengthen approaches to lived experience engagement, as well as engagement with their families and friends in alcohol and other drug services include piloting and finalisation of draft Best Practice Principles developed as part of the Stretch2Engage project³.

Suicide prevention

The importance of including the voices of people affected by suicide in decisions regarding government policy and actions to prevent suicide is well accepted^{6,18}. A number of organisations engage with people with a lived experience through advisory

committees and other ways within the suicide prevention sector^{6,19}.

Promoted through a variety of organisations, including Suicide Prevention Australia⁶ and in Queensland by Roses in the Ocean¹⁸, people who have attempted suicide and families and carers of people who have died by suicide are represented on a number of significant bodies, including the Queensland Suicide Prevention Health Taskforce and the Queensland Mental Health and Drug Advisory Council²⁰.

In Queensland, Roses in the Ocean supports a Lived Experience Advisory Committee and provides support to local groups to establish Lived Experience Reference Group to contribute to suicide prevention activities across Queensland¹⁸.

Peer work and networks

People with a lived experience, their families, carers and support people play a wide variety of roles in supporting others in their recovery journey. These roles include peer workers and being members of support networks⁴.

There are many perspectives on what a peer worker is and the role they play. In broad terms they are people who identify as having a direct lived experience of mental illness and/or problematic alcohol and other drug use who are employed in designated roles to draw on their experiences²¹.

While many people who work in the system have a lived experience or support others, these workers are not usually considered to be peer workers as they are not required to draw on their lived experiences as part of their role and are not required to be open about these experiences^{22,23}.

Peer networks are described in different ways by each sector and can include speaker bureaus and peer education provided to the community. They often involve people with a lived experience sharing their personal experiences with others to increase social connections and provide support. People with a lived experience may also share their experiences with the broader community to raise awareness and reduce stigma and discrimination^{4,15,22}.

Mental health sector

The increasing focus on recovery-oriented treatment and care within the mental health sector has seen the emergence and growth of the peer workforce. A peer workforce is now considered to be a fundamental feature of a contemporary evidence-based person-centered, recovery-oriented service system²⁴.

Peer workers are most commonly employed in the mental health sector in various roles, including providing peer support, consumer advocates, consumer consultants, carer representatives and consumer educators. These roles may involve people with a lived experience of mental illness, providing support, information and advice to others experiencing mental illness, their families and carers. They may also act as an important liaison point between a consumer and their treatment team.

In a direct service delivery role they 'walk with others on their recovery journey, one-on-one or in groups'⁴. Evidence suggests that peer workers in the mental health sector can contribute to recovery-oriented practice, reduce stigma and lead to more positive outcomes²⁵. As noted in *Connecting Care to Recovery*, the benefits of a peer workforce also include reduced hospital admission rates, social inclusion, reduced stigma, and a sense of hope among people receiving treatment and care¹⁴. It may also support better outcomes for particular groups, including Aboriginal peoples and Torres Strait Islanders and people from culturally and linguistically diverse backgrounds⁵.

As well as peer workers, peer support networks seek to reduce stigma and support social inclusion and recovery. They play an important role in sharing their personal stories and experiences of recovery⁴.

It is difficult to assess the number of people with a lived experience providing peer support in Queensland due, in part, to the different types of roles across the mental health sector. However, there are numerous examples of good practice. For example, in 2016, a partnership between people with a lived experience, non-government organisations, and Far North Queensland Partners in Recovery developed the *Far North Queensland Peer Workforce Framework*²⁶. The Framework provides an overview of the role of peer workers and guidance on supporting the workforce.

An opportunity to further support the mental health peer workforce in Queensland will occur through the commitment made in *Connecting Care to Recovery* to review current practices, protocols and scope of practice of the existing peer workforce to develop a peer workforce development plan¹⁴.

As well as people with a lived experience working in the mental health sector to provide support, a number of speaker bureaus and peer networks operate in Queensland. These networks have an increasing presence in Queensland, including through beyondblue Speakers Bureau²⁷ and the Brook RED Voices for Change program²⁸.

Alcohol and other drug sector

Peer support within the alcohol and other drug sector involves people with a lived experience providing mutual support and information to a person who is having, or who has had difficulties associated with their alcohol and other drug use. It is based on values of reciprocity and experiential knowledge and can either be provided alongside treatment or as a stand-alone activity²⁹. They may be described in a wide range of ways, including as peer mentors or recovery champions³⁰.

Peer education in the alcohol and other drug sector focuses on and is considered to be effective in reducing alcohol and other drug-related harm. As noted in the *Draft National Drug Strategy 2016–2025* it is particularly effective in service access and reaching hard to get to groups¹⁷.

The importance of peer support is recognised in the *Queensland Alcohol and other Drug Treatment Service Delivery Framework*³¹ developed by a consortium of public and non-government partners. The Framework notes the important role played by peers in prevention and early intervention (when harm has not yet occurred), intervention (when harm is occurring) and in aftercare (to mitigate future harm).

A number of peer-based services operate in Queensland including through the Queensland Injectors Health Network, peer support groups and peer support provided as part of residential rehabilitation programs.

Suicide prevention

Peer networks play a significant role in the suicide prevention sector. Work has mostly focused on the establishment of speaker bureaus, in which people who have been affected by suicide get support and training to share their experience and raise awareness in the broader community about suicide prevention^{6,19,27}.

In Queensland, Roses in the Ocean supports and operates the Voices of In-Sight lived experience speakers hub providing training and support to volunteers who have a lived experience of suicide¹⁹.

In 2015, as part of an action under the *Queensland Suicide Prevention Action Plan 2015–17*³², the Commission funded the Train the Trainer Speakers Bureau program. The program was delivered to 10 participants from regional and rural Queensland with funding provided by the Commission. The Train the Trainer program was created to expand the reach of the Speakers Bureau and develop a network of lived experience speakers in regional, rural and remote areas across Queensland³³.

Participants in the training program have acquired the knowledge and skills to host local Speakers Bureau workshops to train additional people with a lived experience of suicide to become active in suicide prevention roles in their communities³³.

References

1. Queensland Mental Health Commission. *Queensland mental health, drug and alcohol strategic plan 2014–2019*. Brisbane: Queensland Government; 2014.
2. Urbis. *Mapping of engagement project: summary of findings from the state-wide survey May 2016*. Brisbane: Queensland Mental Health Commission; 2017.
3. Queensland Alliance for Mental Health, Queensland Network of Alcohol and other Drug Agencies, & Enlightened Consultants. *Stretch2Engage: best practice principles for service engagement*. Brisbane: Queensland Mental Health Commission; 2017.
4. Byrne, L. *Promoting lived experience perspective: discussion paper*. Brisbane: Queensland Mental Health Commission; 2017.
5. Queensland Mental Health Commission. *Report of promoting lived experience in mental health forum (29 July 2016)*. Brisbane: Queensland Government; 2017.
6. Suicide Prevention Australia. *What is lived experience?* [Internet]. Suicide Prevention Australia; 2016. Available from: www.suicidepreventionaust.org/projects/learning-lived-experience/what-lived-experience.
7. Brandon, L. & Popovich, S. *It's not a one way street: Project Gauge alcohol and other drug client engagement and participation discussion paper*. Brisbane: Queensland Government (Metro North Hospital and Health Service); 2016.
8. Australian Health Ministers' Advisory Council. *A national framework for recovery-oriented mental health services: policy and theory*. Canberra: Australian Government; 2013.
9. Australian Government. *National standards for mental health services 2010* Canberra: Australian Government; 2010.
10. Queensland Health. *Consumer, carer and family participation framework*. Brisbane: Queensland Government; 2010.
11. National Mental Health Consumer and Carer Forum. *Consumer and carer participation – key issues and benefits*. Deakin West: Mental Health Australia; 2010.
12. Mental Health Australia. *National mental health consumer & carer forum* [Internet]. Mental Health

- Australia; 2016. Available from: <https://nmhccf.org.au/>.
13. Grey, F. & O'Hagan, M. *Evidence check: the effectiveness of services led or run by consumers in mental health*. Sydney: Sax Institute for the Mental Health Commission of New South Wales; 2015.
 14. Queensland Health. *Connecting care to recovery 2016–2021: A plan for Queensland's State-funded mental health, alcohol and other drug services*. Brisbane: Queensland Government; 2016.
 15. Jogens, R. "Nothing about us without us." *Greater, meaningful involvement of people who use illegal drugs: a public health, ethical, and human rights imperative (international edition)*. Toronto: Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance and Open Society Institute; 2008.
 16. Australian Commission on Safety and Quality in Health Care. *National safety and quality health service standards*. Sydney: Australian Commission on Safety and Quality in Health Care; 2012.
 17. Intergovernmental Committee on Drugs. *National drug strategy 2016–2025: draft for public consultation*. Canberra: Australian Government 2015.
 18. Roses in the Ocean. *Lived experience collective* [Internet]. Enfold Child WordPress Theme; 2016. Available from: <http://rosesintheocean.com.au/lived-experience-collective/>.
 19. Roses in the Ocean. *Voices of in-sight* [Internet]. Enfold Child WordPress Theme; 2016. Available from: <http://rosesintheocean.com.au/speakers-hub/>.
 20. Queensland Mental Health Commission. *Queensland mental health and drug advisory council* [Internet]. Queensland Mental Health Commission; 2016. Available from: www.qmhc.qld.gov.au/qmhdac/.
 21. Gallagher, C. & Halpin, M. *The lived experience workforce in South Australian public mental health services*. Adelaide: Central Adelaide Local Health Network; 2014.
 22. Peer Work Hub. *Employer's guide to implementing a peer workforce: a case for your organisation*. Sydney: New South Wales Government; 2016.
 23. Intergovernmental Committee on Drugs. *National alcohol and other drug workforce development strategy 2015–2018: a sub-strategy of the national drug strategy 2010–15*. Canberra: Australian Government; 2014.
 24. Health Workforce Australia. *Mental health peer workforce study*. Adelaide: Health Workforce Australia; 2014.
 25. Queensland Mental Health Commission. *Options for reform: moving towards a more recovery-oriented, least restrictive approach in acute mental health wards including locked wards*. Brisbane: Queensland Mental Health Commission; 2014.
 26. Far North Queensland Partners in Recovery. *FNQ peer workforce framework: valuing lived experience*. Cairns: Far North Queensland Partners in Recovery; 2016.
 27. Beyond Blue. *blueVoices* [Internet]. Beyond Blue Ltd; 2016. Available from: www.beyondblue.org.au/get-involved/bluevoices.
 28. Brook RED. *Voices for change: stories of mental health recovery* [Internet]. Brook RED; 2016. Available from: www.brookred.org.au/voices-for-change.
 29. Self Help Addiction Resource Centre. *Peer support: peer support capacity building project* [Internet]. Self Help Addiction Resource Centre; 2017. Available from: <http://sharc.org.au/peer-support/>.
 30. Substance Misuse Skills Consortium. *Peer support toolkit*. London: Adfam; 2015.
 31. MacBean, R., Buckley, J., Podevin, K., et al. *Queensland alcohol and other drug treatment service delivery framework, March 2015*. Brisbane: Queensland Government; 2015.
 32. Queensland Mental Health Commission. *Queensland suicide prevention action plan 2015–17*. Brisbane: Queensland Government; 2015.
 33. Queensland Mental Health Commission. *Queensland Mental Health Commission annual report 2015–16*. Brisbane: Queensland Government; 2016.