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Engage and Participate in Mental Health

Summary Report

June 2018

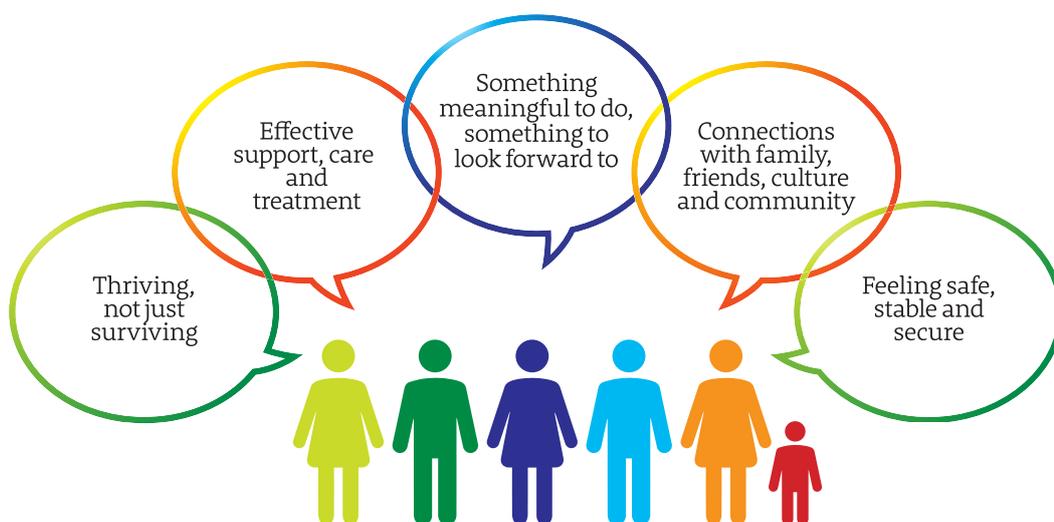


Australian Government
National Mental Health Commission

Preface

The National Mental Health Commission (the Commission) was established in 2012 to provide insight, advice and evidence on ways to continuously improve Australia's mental health and suicide prevention systems and to act as a catalyst for change to achieve those improvements. This includes increasing accountability and transparency in mental health through the provision of independent reports and advice to the Australian Government and the community.

We believe it is essential that people with lived experience of mental ill-health, families and support people are included and involved in decisions that impact them to lead a contributing life. A contributing life is one in which people can expect the same rights, opportunities, and health as the wider community. It is a life enriched with close connections to family and friends, supported by good health, wellbeing and health care. It means having a safe stable and secure home and having something to do each day that provides meaning and purpose, whether this is a job, supporting others, or volunteering.



Contributing Life

Five domains underpinning a contributing life

In 2017, we worked with a Lived Experience Steering Group and Craze Lateral Solutions to better understand and develop a national view of consumer and carer engagement and participation in relation to mental health and suicide prevention. The project: *Engage and Participate in Mental Health*, sought to inform, support and enhance opportunities for engagement and participation of people with a lived experience of mental ill-health and/or suicidality in decisions that impact them.

This summary report describes the range and extent of engagement and participation across the mental health sector in Australia.

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Acknowledgements

We would like to thank everyone who provided us with their ideas and insights and especially thank people with lived experience of mental ill-health and/or suicidality, their families and support people.

We also acknowledge the support and guidance from the Lived Experience Steering Group members: Margaret Springgay, Lynette Pearce, Julie Anderson, Phil Dempster, Margaret Farrell, Rebecca Randall, Peri O'Shea, Helen Glover, Louise Howe, Vicki Katsifis, Leilani Darwin, Samuel Hockey, Tracy McCown, Lyn English, Eileen McDonald, Janne McMahon, Patrick Hardwick, Kylie Wake (observer) and Jackie Crowe (Chair).

We thank Dr Leanne Craze, Ross Craze, Bè Aadam and Sandi Taylor the consulting team who worked tirelessly to maximise the opportunities for people to participate and who integrated the findings from a diverse range of stakeholders.

We sincerely thank all those who provided creative contributions to this project.



Lived Experience Steering Group Members

Front cover image

Kardi Lenoy is a young Aboriginal woman with ancestral links to the Kalkadoon, Yirandali, and Ngawun Nations of north-west Queensland and the Jittabul Nation of North Queensland. She is described as a contemporary artist with a lived experience and is passionate about caring and managing Country and wildlife in a sustainable way.

The artwork depicts the land and sea mass of Australia. The outer etchings describe the swirling oceans and tidal waves of Aboriginal and Torres Strait Islander Sea Country. These sea countries reflect the vast ebb and flow of First Nations moods and emotions as waves when they crash onto the beach or coastline. Often our people from different countries travel and gather at many meeting places. They share common beliefs when they yarn about similar issues and concerns. When they deep yarn and listen, the earth grounds them into one belonging to mob and each other, which in turn strengthens harmony and wellbeing on Country.

Dedication

by Leanne Craze, Principal Consultant Craze Lateral Solutions

This report is dedicated to Jackie Crowe, a National Mental Health Commissioner who passed away in October 2017. A friend, leader, and colleague who touched so many lives and left many people enriched for having known her. Jackie dreamed big dreams whilst being convinced they were not dreams but were reality taking shape.

“It’s going to happen, it’s happening, we can do this. We will together make this happen. Come on, let’s do this together.”

As Commissioner, Jackie initiated and led the Engage and Participate in Mental Health Project. Jackie led by example, insisting that all people with lived experience of mental ill-health and families, friends, and support people have an equal voice, and that their views be equally heard.

“Everyone is equal around this table.”

Jackie also led by example by demonstrating respect, kindness and compassion – which she was convinced are the cornerstones of inclusive engagement and participation.

Jackie asked us to be open to each other and to take the time to talk and listen to each other. She didn’t want us to stop there, rather, to keep going until we understand each other.

May her work live on through our work together to fulfil Jackie’s vision of inclusive engagement.



*What the world needs now, is respect and kindness, they’re the only things,
there is just too little of... (Apologies to Jackie DeShannon) © Pauline Miles 2017*

About the project

Engage and Participate in Mental Health gathered and reviewed information on existing policy frameworks and mechanisms for consumer and carer engagement and participation across key parts of the mental health system, from the individual treatment level to regional and national service and system levels.

A project website and an accompanying social media campaign publicised the project and informed people about opportunities to contribute. This included online surveys, stakeholder interviews, community conversations, yarnning circles, and web-consultations.

This report summarises the key findings from the project. The policies and frameworks for consumer and carer engagement and participation identified through this project are available separately in a resource database available on the Commission's website.

Objectives

The key objectives were to review and analyse the following across the mental health system:

1. The key principles underpinning consumer and carer engagement and participation and existing engagement and participation policy, strategies or frameworks
2. Mechanisms of engagement and participation
3. Challenges, barriers, and enablers to participation and engagement
4. Evaluation of consumer and carer engagement and participation and inclusion of capacity building

Key questions

The project invited people to discuss several key questions, including the following:

- What does engagement and participation in mental health mean to people with lived experience and their family and carers?
- What is considered genuine and effective engagement and participation in mental health?
- What do people want to achieve through engagement and participation in mental health?
- What is best practice?
- What are the key barriers?
- What enables participation?
- What should the next generation of engagement and participation look like?

What is Engagement and Participation?

The following definitions were proposed as starting points for shared understanding:

Participation is a practice that involves people directly, as equal partners, and with safety and equity, in decision making about their lives and in the co-design of relevant policies and services.

Engagement refers to methods used to involve people more generally but also allows for decision making and co-design and co-production processes to be undertaken.

Engagement and participation are centred on a person's values, experiences, perspectives and what is personally important.

Effective engagement and participation requires acceptance, kindness, understanding and compassion. Engagement and participation are not possible unless people feel safe and are safe.

Key findings

A total of 1,148 people shared their knowledge and experience through one or more of the consultation methods and six submissions were received. The responses are summarised below.

1. Key principles underpinning consumer and carer engagement and participation and existing engagement and participation

- **There is an increasing focus on engagement and participation throughout mental health and related sectors in Australia.** Underpinning this development is increased awareness of the importance and benefits of valuing and learning from lived experience. The Fifth National Mental Health and Suicide Prevention Plan commits Australian governments to a process of co-design with people with lived experience and other stakeholders. The reform environment has led to greater diversity in lived experience voices including:
 - Employers, employees, workforces and workplaces
 - Serving defence force personnel, veterans and their families
 - Emergency services personnel
 - People having experienced trauma including complex childhood trauma
 - People having experienced past adoption practices or who were otherwise separated from their biological families and cultures
 - Women experiencing perinatal and post-natal depression
 - Children and families
 - Farming communities
 - People affected by disasters, climate change, industry-wide or economic downturn
 - People with physical illnesses
 - People with disability
- **A wide variety of frameworks, guidelines, models and policies exist or are in development.** People identified that implementation of these is generally ad-hoc rather than systemic. Frameworks seek to engage people in different ways and at different levels, including at: an individual level, in decisions about a person's care or support; a service or program level, in terms of the design or delivery of the services being provided to them; an organisational level, with the policies, processes and directions of the organisation they interact with; or a systems level, in reform processes, or the development of policies or legislation that affect their lives. Also, valued was when policies and frameworks encompass social, emotional and physical wellbeing and reflect the view that mental ill-health is a common experience for many people. See [resource database](#).
- **Engagement and participation is a citizen's right.** The principles of engagement and participation that support effective partnerships include:
 - Safety – providing cultural, physical, moral and emotional safety for everyone involved
 - Equality – treating people with equal worth and value and therefore sharing power, resources and knowledge
 - Respect for people's views and opinions and recognition of the value that their engagement and participation brings
 - Inclusivity – recognising that people have diverse needs, experiences and capabilities and all should be included
 - Reciprocity – supporting balanced and mutual exchanges between people
 - Authenticity – being reliable, trustworthy and motivated to work together
 - Accountability – being transparent, honest and responsible for decisions and actions

- Ethical – ensuring responsible practices, procedures and requirements
- Connection – building rapport and relationships
- Evidence-based – applying evidence to inform decisions and actions

Embedding these principles enables better co-design in transparent and accountable decision making, practice and service delivery.

2. Mechanisms of engagement and participation

- **There is a wide range of methods and strategies in place for engagement and participation.**

These include:

- Formal mechanisms that are one-off, such as focus groups, consultations surveys or ongoing advisory groups and consultative processes
- Informal mechanisms, such as casual discussions between people and workers, online and paper-based feedback tools, such as your experience of service and carer’s experience of service
- Brainstorming ideas or discussion around how to develop service or programs during other meetings
- Project-based, where people are involved in a working group, or participating to develop a specific project and making decisions around the project
- New and emerging technology enabled mechanisms, which include web-based engagement platforms, interactive forums, discussion boards or feedback channels
- Universal mechanisms, which seek to engage with a wide range of people or the whole community
- Targeted mechanisms, which seek to engage with specific groups of people to obtain their views and increase their involvement or participation’ information sharing, and volunteering opportunities

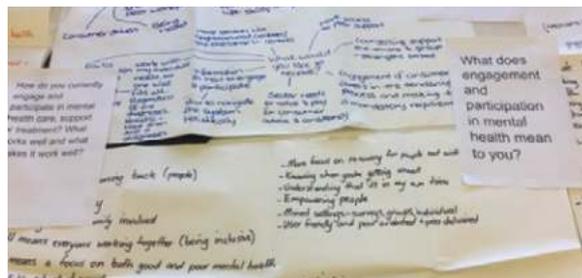
Some examples of mechanisms that support policy and strategic level participation and engagement, capacity building, peer networking and leadership include the National Mental Health Consumer and Carer Forum, the National Register of Mental Health Consumer and Carer Representatives, the Private Mental Health Consumer and Carer Network, Mental Health Carers Australia, state and territory-wide lived experience advisory groups, PHN community advisory/ consumer and carer advisory groups, and non-government community consumer and carer organisations.

- **Moving beyond traditional methods can increase opportunities for engagement and participation.** While representative, committee-based models have an important role to play, more dynamic models and strategic use of digital platforms including social media and new and emerging technologies would enable people to contribute when they feel a need to or when an issue or question is of interest to them. This would enable greater engagement and participation with wider groups of people to provide their views, ideas and expertise.

3. Challenges, barriers and enablers to engagement and participation

- **There is a growing understanding of the benefits of engagement and participation.**

Some of these benefits include a stronger sense of citizenship, personal benefits of involvement in own recovery, greater or new found sense of agency, i.e. being able to do things for oneself and to achieve new knowledge and life skills, new friendships and wider social connections and networks. Engagement and participation can also reduce isolation and mental health stigma.



Connections’ Community Conversation, Caboolture, QLD. Photo supplied Karen Thomas Goldsmith

- **People engage and participate in mental health for a variety of reasons.** People told us they engage at an individual level because to be able to do so reflects recognition of their dignity and respect for their right to make decisions about their treatment, care and support. Importantly, people engage because personal recovery cannot progress without it. People told us they engage and participate at the program, service and system level to make a difference and to achieve better outcomes for other people. People told us they engage at the wider community level to help create a society that is accepting of mental ill-health and values and respects people whose lives are so affected. They also engage at this level because they believe by doing so, they will contribute to a more inclusive and mentally healthy community.
- **Despite widespread support and commitment, genuine and inclusive engagement and participation remains challenging.** Some of the challenges identified included:
 - Lack of awareness of opportunities
 - Adequate resourcing
 - Availability in languages other than English
 - Insufficient/inappropriate timing
 - Geographical distance, such as not held where people live
 - Unequal standing or power imbalances
 - Access to cultural advice
 - Accessibility such as Auslan or captioning and the use of assistive technology and equipment for people with disabilities
 - A focus on adults
 - Technology dependent, which requires internet access and/or computing skills
 - Reliant on high literacy levels or using jargon or language people do not relate to, are afraid of, or shamed by
 - Restricted reach or only involving a small number of individuals
 - Varied skills and capabilities to support successful engagement and participation

- **Experience of exclusion was common.** Many groups reported lack of engagement and participation opportunity, being unable to engage with mental health services and unable to engage and participate in decision making about their lives. Many who experience exclusion reported they are unable to pass first base and access treatment, care and support that is safe and suited to their experience, age, culture, sexuality, sex or gender, capacity, abilities, language or the location where they live. A “one size fits all” approach is a barrier that arises when diverse communities and groups are viewed as homogenous and when diversity within and between groups is not recognised.



'Diversity is our normal' © Pauline Miles 2017

- **Essential enablers ensure engagement and participation is safe, secure and welcoming.** Some of the key enablers of engagement and participation that were identified included:

- A culture of respect, dignity, compassion and kindness
- Professionals who demonstrate engagement, participation and co-design skills
- Welcoming all equally
- Inclusive practice which values diversity as routine practice in engagement and participation
- Addressing power imbalances so that all people participate as equals
- Committed to ongoing relationships
- Focused on what is important to people
- Adequately resourced, in terms of time, resources, training and support
- Using communication assistance as standard routine
- Committing to making changes based on people's engagement and participation
- Incorporating immediate and ongoing feedback
- Tailored and made accessible to all
- Embedded in practice/clinical governance and evaluation



All welcome © Pauline Miles 2017

4. Evaluation and capacity building of consumer and carer engagement and participation

- **There is limited publicly available information about the outcomes or impacts of engagement and participation.** Despite evaluation and capacity building being gaps in current engagement, participation and co-design activities occurring around Australia, there was agreement about their importance. Some examples of capacity building strategies include: co-designed practice guidelines and training programs; providing scholarships for training; processes and structures developed for program development and career pathways, supervision and mentoring; skill development through recovery colleges; and scholarships to attend conferences and training initiatives.

Conclusion

This project demonstrates there is much enthusiasm and commitment to lived experience engagement and participation in Australia and improves our understanding of mental health and suicide prevention engagement and participation practices. The [resource database](#), a searchable tool, brings together frameworks, strategies and policies focused on mental health engagement and participation in this country.

This summary report emphasises the rights to participation and inclusion in decision making at all levels, from individual treatment to regional and national service and system, in its findings on key principles. There is a need to continue to address the obstacles this project identified, to help overcome barriers to engagement and participation as well the enablers that positively impact effective engagement and participation.

The Commission would like to see future approaches address resourcing, measurement, evaluation and capacity building among people with lived experience, policy makers and service providers so that engagement and participation becomes embedded as routine practice and considered core business. Additionally, we believe a greater focus on innovative and sophisticated engagement platforms that embrace new and emerging technology can increase opportunities for engagement and participation with a diverse range of people. We also support the call for a national mental health consumer peak organisation in Australia to provide a united national voice for mental health consumers.

Engagement and participation in practice, culture, and service delivery which places the voice of lived experience at the centre of decision making can drive and lead change in mental health and suicide prevention. We will continue to collaborate with others to achieve effective and meaningful engagement and participation at all levels.

We have listened to people's ideas and experiences, and to help translate the findings from this project into practice, the Commission is now developing a best practice guide. The best practice guide will take this information and showcase a range of issues to help policy makers, service providers, professionals, and people with lived experience achieve best practice in mental health engagement and participation at all levels of decision making.

Appendix

Participants

Lived experience ideas

People with lived experience of mental health issues, their families, friends and supporters were invited to give their ideas about engagement and participation:

- 162 online responses
- 11 responses received in writing from forensic patients in NSW
- A further 11 responses received by mail
- 6 responses by email
- 9 responses by text
- 3 responses by phone (a total of 205 responses)

Online stakeholder survey

An online survey with input from 652 people.

Community conversations

People with lived experience of mental ill-health, their families, friends and supporters were invited to hold a conversation about engagement and participation and to report back their views and ideas:

- 12 self-conducted conversations by community groups and organisations
- 1 conversation facilitated by the Project Team with 12 people at Thomas Embling Hospital (Secure Forensic Hospital, Melbourne)
- 1 conversation facilitated by the Project Team with 6 family members at Thomas Embling Hospital
- 1 conversation facilitated by the Project Team with 6 people who are deaf or hearing impaired at DeafVic, Melbourne (a total of 144 people)

Yarning circles

The Project Team facilitated yarn circles with Indigenous people experiencing mental health and social and emotional wellbeing issues at Cairns, Yarrabah Community, Brisbane and Ipswich, with a total of 59 people attending.

Web-consultations stakeholders

Discussions were conducted via web-based technology with representatives of stakeholder groups, with 88 people attending or contributing post webinar.

Strategic interviews were held by the consulting team with an additional 24 people.

Submissions were received from:

- Kimberley Aboriginal Law and Cultural Centre (KALACC)
- Commissioner for Children and Young People WA
- President, Ethnic Communities Council of Western Australia (ECCWA)
- National LGBTI Health Alliance
- Consumer of Mental Health Western Australia (CoMHWA)
- Post Adoption Advocates.

Glossary

Carer

A carer is someone who voluntarily provides ongoing care and assistance to another person who, because of mental ill health or psychosocial disability, requires support.

Consumer

A person with mental illness who has used a mental health service.

Contributing Life Framework

A term first used in the Commission's 2012 National Report Card on Mental Health and Suicide Prevention, which means: A fulfilling life where people with lived experience of mental ill-health can expect the same rights, opportunities and health as the wider community. It is a life enriched with close connections to family and friends, supported by good health, wellbeing and health care. It means having a safe stable and secure home and having something to do each day that provides meaning and purpose, whether this is a job, supporting others, or volunteering.

Lived experience

In this report, lived experience is used to refer to people who have experience of mental ill-health either as a consumer or a carer/family member/support person.