

Griffith Centre for Mental Health Lived Experiences Network

Terms of Reference

March 2023

V1.6

Contact Details:

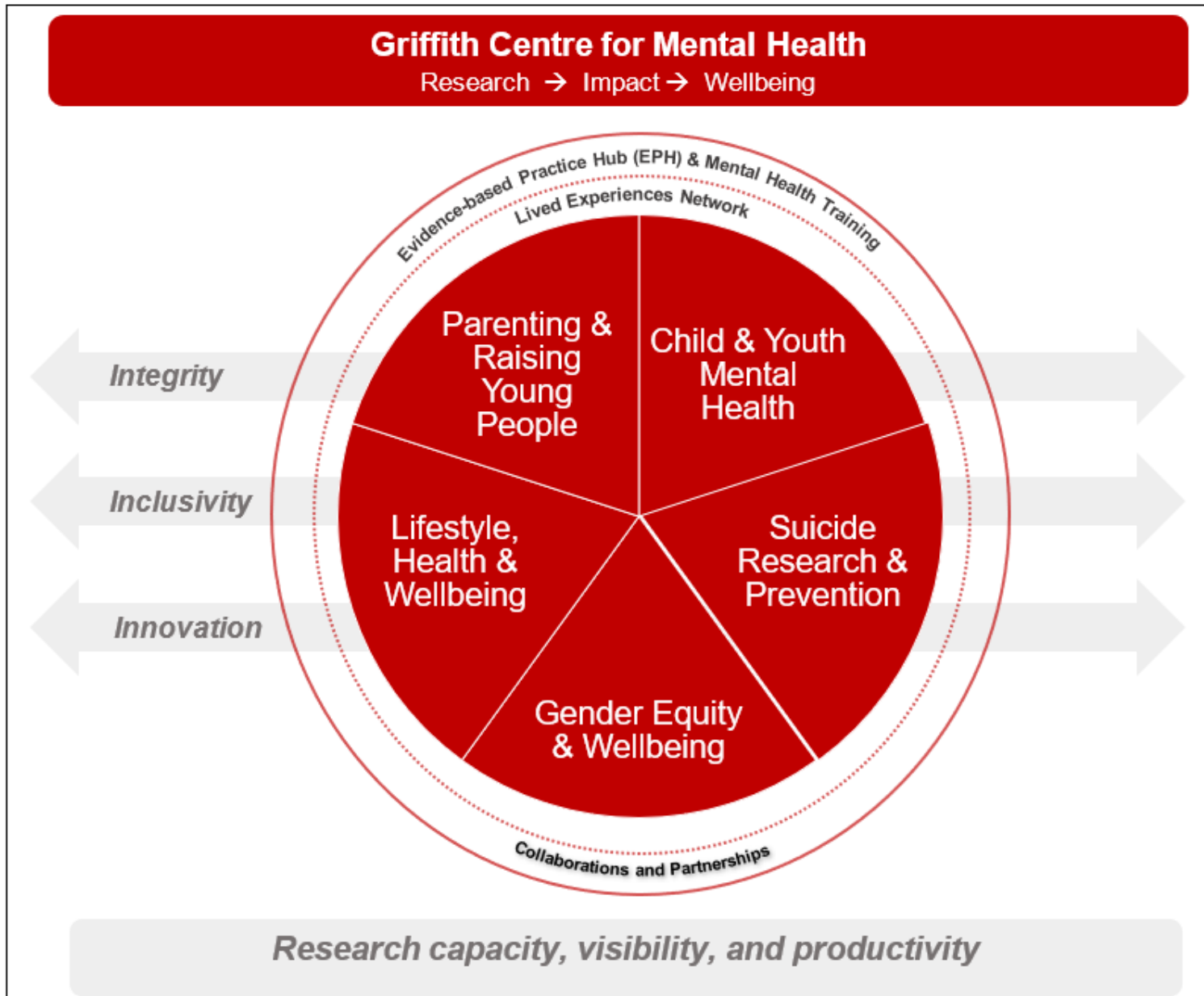
Professor Allison Waters (Director, Griffith Centre for Mental Health)

+61 7 3735 3434 | a.waters@griffith.edu.au | gcmh@griffith.edu.au

Acknowledgements:

Sharna Mathieu, Helena Roennfeldt, Ali Chauvenet, Elizabeth Asser, Amanda Wheeler, Jacinta Hawgood, Victoria Stewart & Allison Waters are acknowledged as the inaugural Network working group and were responsible for early drafts of this living document.

Figure 1: Conceptual model for Griffith Centre for Mental Health



Griffith Centre for Mental Health Lived Experiences Network

The Griffith Centre for Mental Health Lived Experiences Network (the Network) will build on the intent and foundations of the Griffith Centre for Mental Health (the Centre) to be an authentic collaborative network fostering shared knowledge between people with lived experiences (from within and outside the Centre) and Centre members to co-produce high quality research in the field of mental health and wellbeing across the lifespan. The Network embodies the Centre values of *integrity*, *innovation*, and *inclusivity* and encapsulates the main research streams of Centre members (Figure 1).

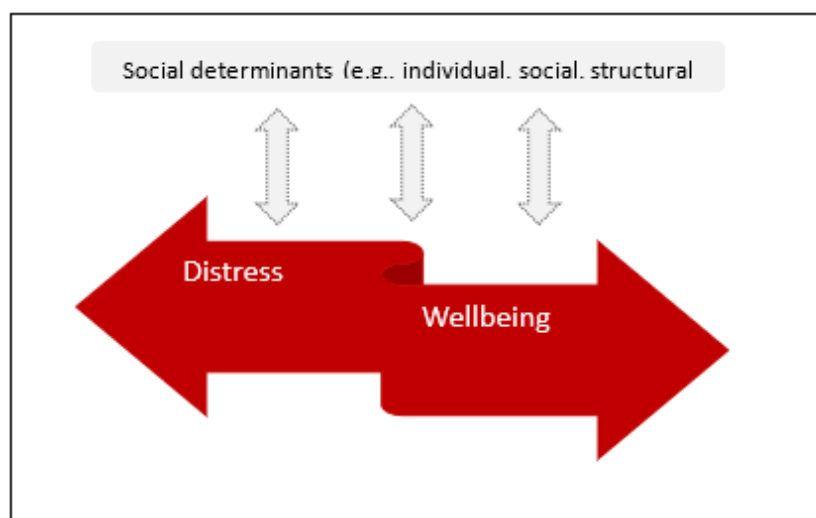
The purpose of this Terms of Reference is to outline the values and processes of working together to ensure optimal co-production or co-design is possible.

Definitions:

In the context of the network, a broad and overarching view of the following terms is assumed in an endeavour to be as inclusive as possible with the use of these terms. It is acknowledged that some individuals may not identify with them and so it is hoped that the following operationalisations serve to resolve any uncertainty or issues in clarity.

- 'Lived Experience' refers to lived/living experiences of mental ill health, psychological distress, or suicide/suicidality. The perspectives of families and/or carers who have supported a person with these experiences are also invited to participate in the Network.
- 'Mental health' is operationalised to incorporate the full spectrum of wellbeing. Mental health experiences vary from person to person, can change overtime, and where someone falls on this spectrum is influenced by a variety of determinants (Figure 2).¹ For current purposes, mental health experiences can include anyone who has received a mental health diagnosis or personally identifies as experiencing mental or emotional distress, crisis, trauma, substance use concerns, anxiety, depression, eating disorders, or psychosis. The Centre recognises that not everyone uses the language of mental health to describe their experience. Also, experiences of suicidality are acknowledged as overlapping but often considered distinct from experiences of mental health diagnosis.

Figure 2: Spectrum of mental health experiences



¹ <https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response> (last accessed 22nd November 2022)

- 'Co-production' refers to genuine collaborative partnerships developed to identify and evaluate the problem and find solutions together with consideration of the role of power, and intentionally including those most impacted in a context where they can influence decision making.

Vision:

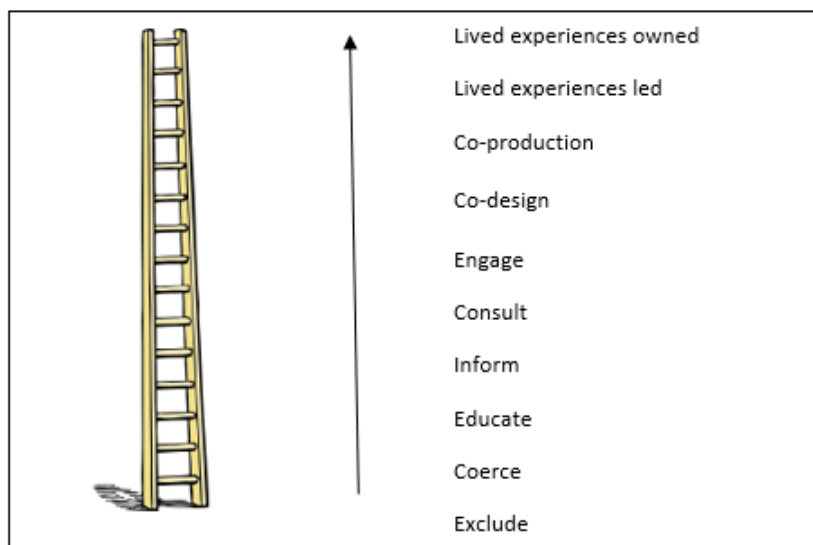
All research conducted within the Griffith Centre for Mental Health will meaningfully incorporate diverse voices of people with lived experiences of mental health across a range of individual, social, and cultural backgrounds. The intention of the network is to create a platform for authentic co-production or co-design where first-hand knowledge and expertise related to these lived experiences are privileged. The Network will work with the Centre to ensure that diverse voices of people with lived experiences of mental ill health, psychological distress, or suicide/suicidality are meaningfully incorporated in all areas of research.

Values:

The Centre has three core underlying values of Inclusivity, Integrity, Innovation. In relation to the Network, **inclusivity** refers to respect for the diversity and intersectionality of people and experiences, and being inclusive across different individuals, groups, and communities whose voices have been traditionally excluded from mental health research. Therefore, the Network is inclusive of diverse perspectives and experiences including different gender identities, sexualities, neurodiversity, ethnicities/language groups/cultures, and other intersectional lenses. across a range of individual, social, and cultural backgrounds. Inclusive partnerships with other lived experiences organisations and groups are also highly valued. **Integrity** refers to the value of conducting ethical research, and building authentic, honest, and collaborative relationships with people with lived experiences in the co-production of this research wherever possible. Finally, **innovation** refers to a commitment to striving for innovative research methods and partnerships, and mutual sharing of new knowledge. The Centre also uses a strengths-based approach, and it is acknowledged that people are more than their mental health experiences, are experts in their own experiences, and have important wisdom into recovery, resilience, and coping.

The Network aims to ensure that all partnerships and collaboration are underpinned by the principles of co-production (Figure 3)².

Figure 3. Ladder of participation with more desirable elements in the top rungs



² Roper, C., Grey, F., Cadogan, E. (2018) Co-production: Putting principles into practice in mental health contexts. Melbourne: Australia

The extent of involvement of people with lived experiences in research can vary and it is important for Centre members to be honest about this in any research output or funding applications. The Network also encompasses and seeks to apply lived experiences workforce values (Table 1)³ and strives to ensure mutual benefit to all parties. Members will acknowledge and actively seek to confront power imbalances so people with lived experiences are equal partners. The GCMH acknowledges it receives direct benefit from the Network through the strengthening of research funding applications and outputs by utilising elements of co-design or co-production, broadening potential recruitment for studies, and improving evidence-based treatments and workshops that contribute to the financial sustainability of the Evidence-based Practice Hub (EPH). The GCMH acknowledges and actively seeks to confront power imbalances so people with Lived Experiences of mental ill health, psychological distress or suicidality are equal partners.

Table 1: Core values of Lived Experience work

Core values	What does it mean?
Hope	Belief in people’s fundamental capacity to overcome challenges
Equality/Equity	Working from a place of common humanity and vulnerability. Actively working to minimise power imbalances
Mutuality	Being in a relationship with another person where both people learn, grow and are challenged through the relationship. Sharing responsibility in relationships
Empathy	Understanding another’s experience from a point of common experience and genuine connection
Choice	Acknowledging and respecting each person’s choices, dignity of risk and boundaries. Acknowledging that the person is the expert of their own experience
Respect	Honouring another’s view and experience without judgement or making assumptions
Authenticity	Integrity, being open, honest, trustworthy, and transparent in work practices and relationships. Valuing the use of lived experience and vulnerability in the service of others transforms these from what may have been perceived as weaknesses into strengths
Belonging/Inclusion	Respecting and understanding the value of inclusion and impact of exclusion. Recognising intersectionality and valuing diversity culture, spirituality, membership in chosen groups and community
Interdependence	Recognition that we exist in relationships and that the relationships with families and/or social networks are often impactful in our lives and important to healing
Justice/Human Rights	Understanding the impact of social justice/inequity on identity and opportunity e.g. race, culture, sexual orientation. Recognising that equal access to resources and support is an important factor in everyone’s recovery and healing. Recognising the consumer movement as a response to the history of social injustice and discrimination towards people with lived experience and that Lived Experience work is connected to the human rights movement and upholding the human rights of people with lived experience

³ Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. National Lived Experience Workforce Guidelines. 2021, National Mental Health Commission. (Tables 2; Pages 22-23)

Process:

The process for creating this Charter document was first establishing a small working group of people with lived experiences familiar with both Griffith University and lived experiences workforce development and Centre members. Centre members had varied levels of familiarity and experience in co-designing research. The initial document was drafted by a working group member, it was discussed in working group meetings, and circulated for review. Based upon feedback received the initial draft was revised. This feedback included perspectives of people with lived experiences. The document was also informed by relevant national and state-based guidelines, as well as other co-production resources (see bibliography).

This is a living document, and it is expected that this document will continue to be updated and refined as the Network evolves, knowledge expands, and partnerships grow. Changes will be reflexively documented in Appendix A, with formal reviews planned every 24-months. The next formal review will take place in November 2024.

Network Objectives:

- Build research partnerships between interested people with lived experiences, lived experiences organisations, community members, and Centre members – this may lead to enhanced capacity for research, training, and leadership for all parties
- Enhance the meaningful and authentic inclusion of diverse lived experiences perspectives in Centre research and activities
- Emphasise where possible the co-production of highly impactful research that aspires to increase shared understanding of mental health experiences across the lifespan and improve outcomes for individuals accessing care
- Promote the identification of research priorities by people with lived experiences for the Centre and the Network to collectively address in future research
- Encourage opportunities for research determined, and led, by people with lived experiences
- Provide opportunities to facilitate mentoring relationships between interested Network and Centre members (in both directions)
- Provide opportunities for Network members to collaborate in training, education, and Centre decision making

Structure:

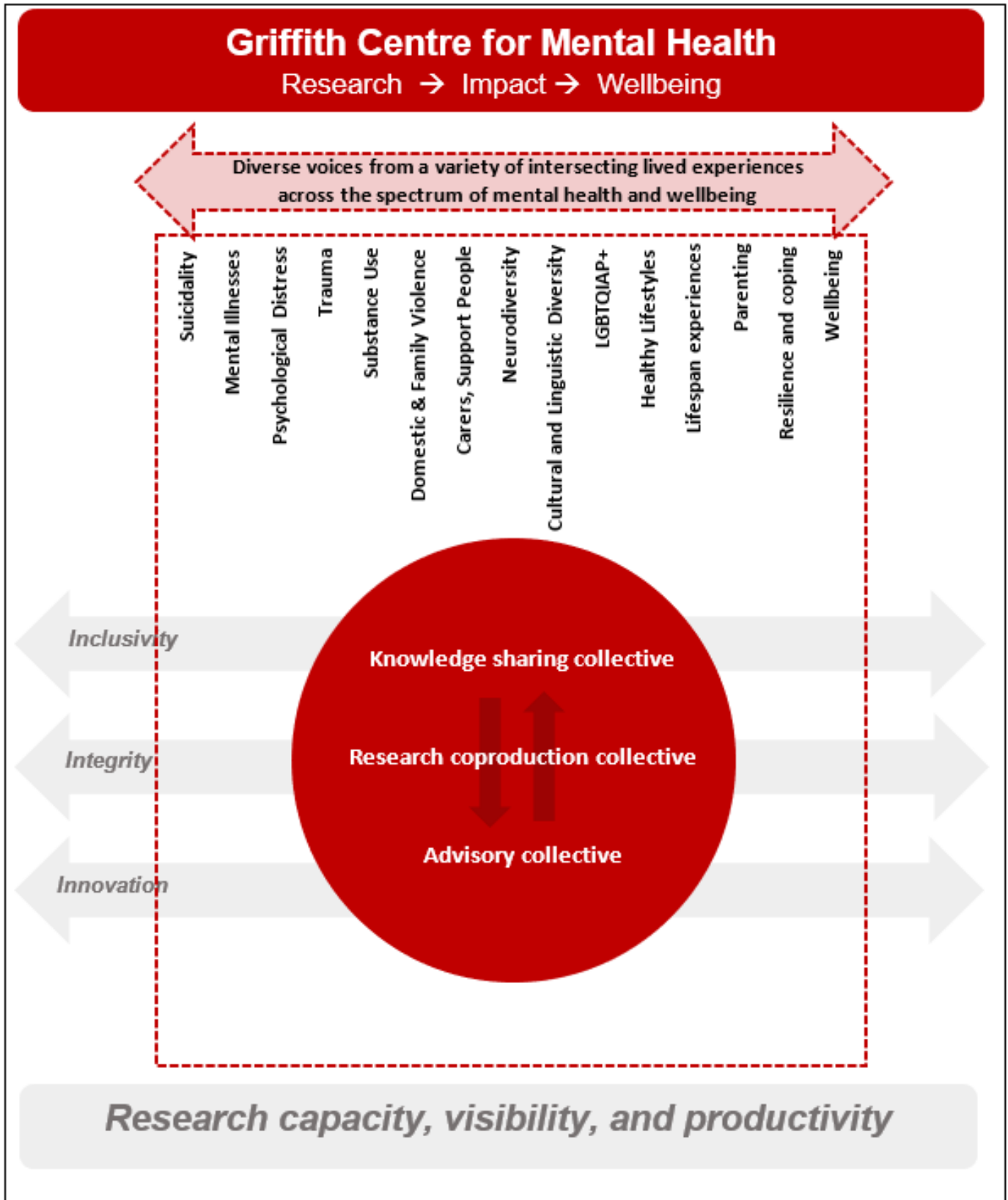
Membership in the Network will be completely voluntary, and members will have the opportunity to opt in/opt out of different Collectives of engagement and participation (Figure 4). These Collectives are not mutually exclusive and there will be multiple pathways that people may access Network membership. For example, past, current, and future research participants will be invited to participate by the associated research team(s) via an informed consent process. All Network members will be asked to provide their consent to have personal contact details stored confidentially on a secure Griffith server. When opting out contact details will be removed from the contact database permanently, unless the individual decides to re-join. The database will be maintained by the Network Coordinator.

The Knowledge Sharing Collective will be a communications channel to receive semi-regular updates on Centre/Network activities, events, workshops, and research findings. From time-to-time, members will also receive various 'expressions of interest' (EOI) calls for co-production opportunities, mentoring/support, chances to participate in research direction setting or grant review etc. In addition, study recruitment for participation may also be disseminated via the Network. In each communication piece there will be regular calls for feedback, ideas, or updates from Network members to facilitate reciprocal communication.

The Research Coproduction Collective will be comprised of those who decide to participate in co-production opportunities, work on research projects, engage in grant review, co-facilitate training workshops or events, and participate in mentoring etc. This will be largely project-to-project and may be time limited. Various calls for EOIs may try to centralise particular voices as relevant to the project or task at hand. All Network members in this collective will be paid for their time. In situations where someone is too young to be employed this may be through gift vouchers.

The Advisory Collective will be those who are involved in the Network 'working group' and Centre 'Advisory Council'. The working group will be a small group of both Network and Centre representatives involved in the initial stages of development and direction setting for the Network. The advisory council will be comprised of various stakeholders and lived experiences representatives (school executive, Griffith Centre for Mental Health leadership team, Griffith Health Clinics Director and clinic managers, Student Placement Coordinators, Student representatives, and Network members). The advisory council will work closely with the 'steering committee' of the Evidence-based Practice Hub (EPH). Again, all working group or advisory members will be paid for their time.

Figure 4. Lived Experiences Network Engagement Collectives, underlying values, and example groups of lived experiences relevant to Centre research streams



Network Conditions and Agreed Expectations:

The Network strives to provide mutual benefit to all members.

Network members can expect

- To be treated with courtesy, acceptance, and respect
- To feel valued and an important part of the Network, research team(s) and/or Centre
- To receive information via email on Centre activities, events, workshops, funding applications to review, or co-production opportunities
- To receive and/or promote opportunities for providing or receiving mentoring and support to build research capacity in co-production teams
- To be able to opt in and out of the network and associated communications without any undue consequences or pressure
- To have complete autonomy on whether to engage in any further co-production, mentoring, or other involvement in research
- To receive timely feedback on how contributions were used and the outcomes from participation in different activities
- To have the expectations, risks, and benefits of their engagement explained in an honest, open, and easy to understand way
- To have power differentials acknowledged, made transparent, and actively addressed
- To be fairly compensated for hours actively worked in research, training, or decision-making
- To be made reasonably aware of how to achieve any role objectives and receive capacity building opportunities where needed
- To be made reasonably aware of how any contributions are relevant to the matter at hand and will be included
- To participate in regular debriefing on each project to discuss challenges and experiences in a safe manner
- To have opportunities to provide feedback, ask questions, or raise concerns in a safe manner (either to direct collaborators) or the Lived Experiences Network Coordinator
- To withdraw from engagement obligations at any time without consequence or providing reason
- To receive timely feedback on how contributions were used and what difference(s) they made or will contribute to (if any)
- To have any contact information stored securely and confidentially
- To have any complaints addressed in a timely and professional manner

Griffith Centre for Mental Health members can expect

- To be treated with courtesy, acceptance, and respect
- To feel valued and an important part of the team and Centre
- To promote meaningful and authentic opportunities for co-production of research that adheres to the principals of co-production, and in the event true co-production is not possible that this will be acknowledged in all expressions of interest opportunities, grant applications, and research outputs
- To promote opportunities for providing or receiving mentoring and support to build research capacity in co-production teams
- To promote a research culture within the Centre that values and is respectful of the diverse perspectives of people with lived experiences across the research streams
- To provide a reasonable amount of time for co-production
- To have clearly articulated roles and expectations for lived experiences colleagues
- To be transparent in acknowledging and actively address power differentials

A note on safety and self-care for Network and Centre members:

Given the long-standing systems in place within academic/research and healthcare environments it is anticipated that both Network and Centre members may experience some discomfort and uncertainty at times, particularly as new ways of doing things together are navigated and when establishing new projects. By being respectful, authentic, transparent, and allowing thoughtful questions or feedback from all members it is hoped that this will be traversed respectfully and collaboratively and contribute to higher quality innovative research that is underpinned by integrity and inclusion.

Everyone's wellbeing is important and any negative impacts from being a member of the Network and/or Centre should be addressed or minimised. Therefore, it is important that everyone has access to the supports they feel they need. Everyone is the expert of their own experiences and in knowing what is right for them. It may be helpful at times to have access to additional supports or to speak to someone outside the Centre or Network about personal thoughts, feelings, or experiences.

Various help sources are provided in Appendix B. Network and Centre members are encouraged to practice safe collaboration, encourage opportunities to regularly debrief, or access supports where needed.

Bibliography

- Arnstein S. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35(4),216-224. Doi: 10.1080/01944366908977225
- Byrne L, Wang L, Roennfeldt H, Chapman M, Darwin L, Castles C, Craze L, Saunders M. (2021) National Lived Experience Workforce Guidelines. National Mental Health Commission. [https://www.mentalhealthcommission.gov.au/lived-experience/lived-experience-workforces/peer-experience-workforce-guidelines/national-lived-experience-\(peer\)-workforce-develop](https://www.mentalhealthcommission.gov.au/lived-experience/lived-experience-workforces/peer-experience-workforce-guidelines/national-lived-experience-(peer)-workforce-develop)
- Daya I. The Participation Ladder: A consumer/survivor lens (a working draft). <http://www.indigodaya.com/resources/> (last accessed 22nd November 2022)
- Mental Health Coordinating Council. (2022). Recovery oriented language guide: Third Edition. Sydney: Australia. <https://mhcc.org.au/wp-content/uploads/2022/10/Recovery-Oriented-Language-Guide-3rd-edition.pdf>
- Pearce, T., Maple, M., Shakeshaft, A., Wayland, S., McKay, K. (2020) What is the co-creation of new knowledge? A content analysis and proposed definition for health interventions. *International Journal of Environmental Research and Public Health*, 17, 2229. Doi: 10.3390/ijerph17072229
- Queensland Mental Health Commission. (2019). Queensland Framework for the development of the mental health lived experience workforce. Brisbane: Australia
- Roper, C., Grey, F., Cadogan, E. (2018) Co-production: Putting principles into practice in mental health contexts. Melbourne: Australia
- Roses in the Ocean. (2022). Building a lived experience informed and inclusive culture: A practical guide for organisations. Brisbane: Australia
- World Health Organization. (2022). Mental health: strengthening our response. <https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response> (last accessed 22nd November 2022)

Appendix A – Version History

Date	Record of Changes
November 2022	Initial draft created and review by Lived Experiences Network working group
March 2023	Updated to include Lived Experience Values

Appendix B – Supports

Everyone is the expert of their own experiences and in knowing what is right for them. In the event you wish to seek support outside the Centre, Lived Experiences Network, Griffith University Psychology Clinics or Evidence-based Practice Hub you may wish to access peer supports or contact one or more of the following:

Lifeline (All)	24/7	13 11 14	lifeline.org.au
Beyond Blue (All)	24/7	1300 224 636	beyondblue.org.au
13 YARN (First Peoples)	24/7	13 92 76	13yarn.org.au
QLD Crisis Line (All)	24/7	1300 642 255	N/A
eheadspace (Youth)	9AM-1AM	1800 650 890	eheadspace.org.au
1800 RESPECT (Domestic Violence)	24/7	1800 737 732	1800respect.org.au
MensLine (Men)	24/7	1300 78 99 78	mensline.org.au
Open Arms (Service, Veterans & Family)	24/7	1800 011 046	openarms.gov.au
Care Leavers Network (Child welfare)	Weekdays	1800 008 774	clan.org.au
Carers Australia (Carers)	Weekdays	1800 422 737	carersaustralia.com.au
GriefLine (Bereaved)	6AM-12AM	1300 845 745	griefline.org.au
QLife (LGBTQ+)	3PM-12AM	1800 184 527	qlife.org.au
SANE Australia (Mental Health)	Weekdays	1800 187 263	sane.org
Wellways Helpline (Mental Health)	Weekdays	1300 111 400	wellways.org
Alcohol and Drug Support	24/7	1800 177 833	adis.health.qld.gov.au/
Alcohol and Drug Foundation	Weekdays	1300 85 85 84	adf.org.au
Suicide Call Back Service (Suicidality)	24/7	1300 659 467	suicidecallbackservice.org.au
StandBy (Suicide postvention)	24/7	1300 727 247	standbysupport.com.au
Kids Helpline (Youth)	24/7	1800 55 1800	kidshelpline.com.au
ReachOut (All)	24/7	N/A	au.reachout.com

Alternatively, you can contact your GP to receive a mental health care plan to receive Medicare rebated sessions with a psychologist of your choosing in consultation with your doctor.