The co-development of the Eating Disorders Peer Workforce Guidelines

A reflective piece

Acknowledgment of Lived Experience:

As an organisation which works with people affected by eating disorders, including families and carers, we recognise the value of lived experience as a form of knowledge and as a force for positive change. We would like to acknowledge and thank all people with lived experience who participated in the lived experience survey, consultations, focus groups and co-design group to contribute to the Guidelines.

This reflective article provides insight into the process of how Butterfly partnered with people with lived experience through a staged engagement approach to develop the guidelines. The article may help peer work services, community organisations, and stakeholders within the eating disorder sector, to co-ideate, co-plan, co-develop, and co-evaluate peer work services and guidelines, alongside people with lived experience.

Why are the perspectives of people with lived experience essential to the development of the peer workforce?

Lived experience is at the core of eating disorders peer work. People with lived experience of an eating disorder have told Butterfly that accessing peer work was transformative in supporting them to navigate the complexities of managing an eating disorder and the process of recovery. Peer workers can provide a safe, empathetic, non-judgemental, hopeful, reflective, and connective space for individuals to share their experiences of living with an eating disorder or the experience of caring for someone with an eating disorder. Being heard by someone who has gone through a similar journey can offer a place of shared understanding.

"They have allowed me to discuss my recovery experiences/challenges in an open space without judgement. Being able to talk with someone who understands what I'm going through has been invaluable and has given me a greater sense of hope of what full recovery might look like when it's not something I've known for a large part of my life. Listening to their experiences of their eating disorder and recovery has reduced some of the shame I feel about my eating disorder and helped me to feel less alone during such a difficult time" – Survey respondent who has accessed peer work.

Peer workers who are supporting participants with an eating disorder shared how becoming a peer worker following their own recovery was rewarding and healing in nature. Peer workers felt empowered to be able to use elements of their lived expertise to give back and provide support to individuals who want to connect and hear from someone who has been through what they have been through.

"One of the most beautiful things is to see people come together over the similarities of the shared experience of an eating disorder despite those differences...I think such a core part of being a peer worker is providing hope of recovery of that journey and the fact that you are saying you have been through that and you've lived that for some people that's everything..." – Peer Worker focus group participant

Involving people with a lived experience of an eating disorder including carers and supporters of individuals living with an eating disorder, peer workers, and peer work supervisors was therefore integral to the co-development of Butterfly's Eating Disorder Peer Workforce Guidelines. Through various engagements, people with lived experience spoke to the nuances of eating disorder peer work, current challenges within the field, the value of eating disorder peer work, and best practices to enable and support eating disorder peer workers in their roles.

Peer workers currently practising and people with lived experience strongly agreed upon the need for greater guidance, development, and structure around the eating disorder peer workforce in Australia. People with lived experience voiced the significance of developing guidelines to:

- ensure that a uniform approach to peer work practice across Australia is being undertaken in the absence of a national accreditation process
- define the nature of a peer worker within a multidisciplinary team and to increase clarity around the role of an eating disorder peer worker for services embedding peer work.
- ensure that peer work is practised safely and to reduce 'peer drift' from occurring.

- ensure that peer work services and organisations are continuously improving to improve care and treatment outcomes for people engaging with peer support.
- ensure that peer work promotes inclusive practices, holding space for the diversity and intersectionality of eating disorder experiences.
- ensure that the perspectives of community members, people with lived experience, and peer workers are reflected within future peer work frameworks, policies, and governance.

"I believe that peer workforce guidelines are needed for the eating disorder sector as a lived experience peer is vital for eating disorder recovery. Peer support provides others with hope, a collective understanding of shared experiences, self-determination, empowerment and can be an important facilitator of behavioural change. For some people, their peer support person may be the thing they find most helpful in their recovery journey. Therefore, having some guidelines would be important to ensure the highest quality care and best practice services are given". – Person who had accessed peer work.

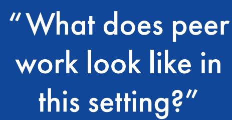
The process of co-developing the guidelines with people with lived experience

127 people with lived experience including carers, people who had accessed peer work, people who were unable to access peer work, eating disorder and mental health peer workers, recovery coaches, peer mentors, and peer supervisors were involved in a multistage lived experience engagement process. From the beginning to the end of the process, an eating disorder peer worker with lived experience and a carer who had accessed carer peer work were involved in an Expert Advisory Group alongside other experts within the eating disorder sector.

Ideation

In the first stages of developing the guidelines, several ideation consultations were run with Butterfly's Lived Experience Community Insights Group, a 14-member group developed to contribute to systemic change within the eating disorder sector. In small groups, members examined what makes peer work effective, reflected on potential guiding principles, and provided ideas as to how people with lived experience should be involved in the process of developing the guidelines.

In the second consultation, members engaged in a journey-mapping activity to explore the role of eating disorder peer workers across a range of settings including eating disorder treatment-specific community programs, inpatient treatment settings, individual private peer coaching, and outpatient programs. Journey mapping is a collaborative design method that allows individuals to visualise a persona and explore an experience of engaging with a service from the beginning to the end, including emotions, learnings, and frustrations experienced along the journey. Members used various resources alongside their own lived expertise to examine the expectations of peer workers, challenges within the setting, and guidance for peer workers to best overcome these challenges. This journey mapping activity helped members to explore embedded assumptions held about the role of peer workers and allowed participants to ask, "What if?" about current peer work practices, to allow for creative ideas around improvements to the workforce. These first consultations helped to shape concepts and questions that would be asked more broadly through the latter survey, focus group consultations, and co-development working groups.



"What are the challenges a peer worker might come across in this context? What resources, structures, and supports are needed?"

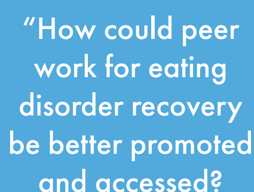
"What guidance could address these challenges?"

Survey

In the second stage, a tiered survey –dependent on an individual's most recent experience with peer work (including whether they had accessed peer work) – was shared with Butterfly's community, lived experience networks, eating disorder services, health networks, and other not-for-profit organisations. The survey aimed to understand the current landscape of the eating disorder peer workforce including current best practices that support a safe, effective, and coordinated eating disorder peer workforce. The results helped to identify current challenges, limitations, and gaps within the eating disorder peer workforce and support, structures, and principles that are needed to underpin eating disorder peer work. From these results, common threads of information across the stakeholder groups were identified.

Focus groups

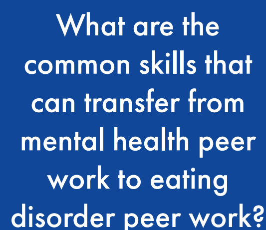
From the survey, two focus groups were formed, one involving peer workers and supervisors, and one involving people who have accessed a peer worker or peer work service for support with an eating disorder. This stage of engagement aimed to explore some of the concepts highlighted in the survey in more depth and increase clarity on areas of contention around peer work that had been debated upon by the working group. These groups were co-facilitated by a peer mentor and a person who had accessed peer work during their recovery and the discussions were tailored to the experiences of being a peer worker or accessing peer work. Both groups discussed the training and educational requirements of peer workers, to compare perspectives. Those with lived experience and carers who had accessed peer work shared their expertise as to what it was like to access peer work, and identified at what stages, guidance was needed to improve the quality of care received.



What needs to be agreed upon between a peer worker and consumer at the beginning of the support journey?

What does accountable and safe peer work look like? What possible triggers might a peer work participant face and what does a peer worker need to be aware of when providing support?

Peer workers within their focus group examined the question: "What does accountable and safe peer work within the eating disorder sector look like?" This discussion canvassed training and education requirements, supervision requirements, and the scope of peer work.



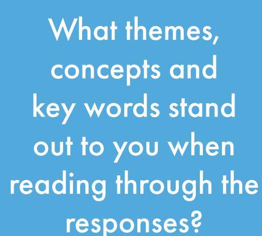
What is the scope of ED peer work practice? What is out of scope?

What unique support can clinical supervision of peer workers provide? What unique support can supervision from a senior peer worker bring? Are there other forms of supervision that could be helpful?

While some of the above questions may have assumed responses, it is important to remove presumptions and expectations around current knowledge of peer work to embark on exploring new perspectives. For example, in response to the question "Is it a requirement that eating disorder peer workers should have their own lived experience of an eating disorder?" it would be assumed that the response would be "Yes". However, peer workers, and those who had accessed peer work in regional and remote Australia, with an understanding of service access issues, said that lived experience of an eating disorder was not essential. They shared that they were able to connect with peer workers through relative lived experiences, such as addiction, or other intersectional experiences such as system navigation with mental ill-health.

Analysis and affinity mapping

At the fourth stage of the guideline development, people who had accessed peer work, people who were unable to access peer work, peer workers, peer supervisors/coordinators, carers, and Butterfly staff collaborated to participate in an analysis and affinity mapping exercise to identify recurring themes that stemmed from the previous engagements and to co-develop guiding principles from the themes that had been highlighted. As with most collaborative lived experience engagements, the activity required patience, adaptability, and spaces for reflection, as the group learned to work with one another and hear others' ideas. This was a learning process for Butterfly staff, who entered the collaboration activity with a structured plan, and then learned to adopt a design mindset of curiosity and 'being in the grey area' as the group navigated the complexities of peer work practice together. Participants reviewed de-identified raw data from previous engagements, analysed the responses, and created concept headings. Responses were then mapped and themed by the group and the group discussed the connections between concepts and microconcepts.



Do these themes relate to your experiences?

Are there relationships between the main concepts?

What are the relationships between lived experience and intersectionality within peer work?

These questions led to further discussion about 'recovery' in peer work, lived experience of a peer worker, and matching peer workers' experiences with peer work consumers. Values, qualities, and competencies of peer work from the concepts were prioritised to develop into guiding principles.

Review of draft Guidelines – consultation group and written feedback

In the final stage, a review consultation focus group was facilitated to receive feedback on the first draft of the guidelines. Survey respondents, focus group participants, and other stakeholders who had not yet engaged with the process were invited to provide written and verbal feedback.

Reflections on the process

People with lived experience and peer workers enthusiastically co-developed the guidelines through an exchange of experiences and ideas. A space was provided for them to share their experiences of peer work in connection with others, and to engage in important conversation around the peer workforce, including an evaluation of how the current system is working. People with lived experience have not previously had the opportunities to share their lived expertise on peer work and voiced the significance of needing more opportunities to co-ideate, co-design, co-implement, co-evaluate and lead the development of peer work training, frameworks, guidelines, services, and systems.

On reflection, there were opportunities to improve this multistage process including:

- Reduce the complexity of the tiered survey to strengthen data findings and common experiences.
- Involve people with lived experience in developing the engagement strategy and overseeing the strategy to give feedback at each stage.
- Provide more time and resources to participants at stage four of the engagement process to support further in-depth exploration of topics including recovery, intersectionality, and trauma-informed approaches to peer work. This includes giving more space for participants to articulate guiding principles.
- Increase the diversity of those who we engaged with including increasing engagement with carers, individuals in rural and regional areas in Australia, male peer workers, and consumers of peer work.

These and other lessons learned during the co-development process will be incorporated into future projects of this type.

Appendix A

Questions that were explored with people with lived experience in the development of the peer workforce guidelines.

Eating Disorder Peer Work Training and Education:

1. What formal qualifications and/or training should a peer worker have? Should this require a Cert 4 in Mental Health Peer Work? Should this be the standard for peer workers supporting those experiencing eating disorders?
2. What additional or specific eating disorder training should a peer worker have?
3. Is it a requirement that eating disorder peer workers should have their own lived experience of an eating disorder? Could a mental health peer worker with training in eating disorders still be able to deliver support?
4. Were there personal attributes of peer work and what was helpful?
5. If an eating disorder peer worker has no qualification beforehand, what could on-the-job training look like?
6. What should the training requirements be for peer workers providing support in a group setting versus one-on-one support?
7. What are the common skills that can transfer from mental health peer work to eating disorder peer work? What is teachable and what is not teachable?
8. With long waitlists to access support, would it be better to have general mental health peer workers with eating disorder training provide support rather than having no access to peer work at all?

Supervision of peer workers/working in a multidisciplinary team:

1. Should peer workers be supervised by someone who also has lived experience? Why or why not?
2. What supervision is required for peer workers?
3. What unique support can clinical supervision of peer workers provide? What unique support can supervision from a senior peer worker bring? Are there other forms of supervision that could be helpful?
4. How should peer workers work within a multidisciplinary team?
5. How can peer workers educate their team to clarify the role and value of lived experience and peer work?

Accountable and safe peer work practice:

1. What is the scope of ED peer work practice? What is out of scope?
2. What does accountable and safe practice look like? What boundaries should be set at the start of supporting a consumer?
3. How can carers and families be more involved in the recovery process with the peer worker and consumer?
4. How can peer workers provide safe and effective service while receiving on-the-job training?
5. Are there opportunities for peer workers to be matched with consumers based on diagnostic criteria and lived experiences?
6. How much autonomy should a consumer have in the process of choosing a peer worker?
7. Confidentiality: What information should a peer worker have access to on a peer work participant and consumer?

The journey of receiving Eating Disorder Peer Work Support:

1. How could peer work for eating disorder recovery be better promoted and accessed?
2. At what stages of recovery should peer work be available to support someone who is experiencing an eating disorder?
3. What needs to be agreed upon between a peer worker and consumer at the beginning of the support journey?
4. What boundaries need to be set? How can rapport and trust be formed at the beginning?
5. How long should a consumer have access to a peer worker?
6. What considerations should be made when a peer worker is ending the provision of support to a consumer?
7. What activities should a peer worker and consumer engage in throughout the recovery process?
8. How can family members, carers, and supporters be included in the recovery process with a peer worker and consumer? How can they be supported?
9. What does accountable and safe peer work look like? What possible triggers might a peer work participant face and what does a peer worker need to be aware of when providing support?

Questions about Guiding Principles in the Guidelines:

1. Thinking about the diverse experiences of people recovering from eating disorders and their loved ones, what sort of risks does peer work present? How might these be best managed?
2. Thinking broadly, what might we consider as foundational principles to guide the way eating disorder peer work is practiced in Australia?
3. From the Guiding Principles thought of, what principles should be a priority to ensure that peer work is a safe practice for both the consumer and the peer worker?