



Reflected Experience: Co-evaluation of the Lived Experience Engagement Project Group

June 2023



Acknowledgments

This document was prepared by seven members of the Lived Experience Engagement Project Group and the Project Coordinator from Neami National's Engagement team.

Many thanks to everyone who contributed their time and insights.

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About this document

Neami's Engagement team is responsible for communication and engagement initiatives that enable the organisation and teams to engage with consumers, staff, partners, funders and the community more broadly. In 2022, the team formed the Lived Experience Engagement Project Group of 11 Neami consumers and carers, who were consulted on several key Engagement projects over a period of five months. This co-evaluation of the group's processes highlights the importance of creating experiences of mutual benefit and meaningfulness to support the sharing of lived experience insights.

Seven group members and the Project Coordinator worked together on this co-evaluation. Each contributed their unique perspective on what worked well and what could have been done differently. At the outset, the group met online to discuss the project and were given a set of reflective evaluation questions. The questions prompted thinking on what they noticed during the consultation period, what was contrary to their expectations, and what, if anything, they found puzzling about the experience.

The reflective evaluation questions were presented as an optional tool, as participants were encouraged to create a reflective evaluation piece in a way that felt authentic and meaningful to them. From these contributions, common themes emerged highlighting what was important to participants and the project's success factors, which are presented in this document. The group met online to review the resulting themes and the overall document, ensuring everyone's views were represented.

The hope of all involved is that Neami teams and others working in the mental health sector will benefit from what was learned throughout this project and gain insights into how lived experience perspectives can meaningfully be given influence as an essential component of their work.



Background

When the Lived Experience Engagement Project Group was formed, the Engagement team were in the planning stages of several key projects. The team recognised it was important to seek input from Neami consumers and carers to help shape the direction of their work from these early stages.

The Lived Experience Engagement Project Group was made up of 11 Neami consumers and carers from around Australia. They had accessed a diverse range of Neami services, including community and clinical mental health, step-up step-down, Head to Health, and housing and homelessness supports.

The group met online with Engagement team members eight times between August and December 2022, providing input and feedback on:

- Redevelopment of the Neami website
- Advocacy Strategy
- Refreshing the Neami brand
- Community Engagement Framework
- Engagement Strategy
- Updating language in Neami’s Strategic Plan

Feedback on the Neami website redevelopment was provided through individual consultations, and for all other projects through group consultations. In the case that any group member could not attend a session, an individual consultation was offered so that they were able to participate in the entire series.

Approach

The Engagement team’s approach was one of creating mutual benefit, with project leads sharing knowledge about their roles, responsibilities and projects during the consultations. This opportunity for participants to learn about the strategic thinking and processes an Engagement team undertakes within a national mental health organisation was factored into the consultation design.

Staff consultation, including with Lived Experience staff members, and other research and data sources also informed several of the Engagement projects.

Level of participation

Participation was at the Consult level of the Spectrum of Participation, more detail of which can be found in the *Neami Consumer Participation Framework* and *Consumer Participation Practice Guide*. The decision to consult was made factoring in project timelines, complexity of stakeholder landscapes, resourcing, and seeking diverse Neami service user perspectives.

It was made clear during the recruitment process that applicants needed no prior knowledge about Engagement work. Nor was any understanding of Neami head office functions presumed. Participants' contributions from service user/carer and lived experience perspectives were of high value to each project.

The commitment of the Engagement team to consumer participation and bringing Lived Experience perspectives into their work continues beyond this project. Should future projects increase the depth of influence of Lived Experience in decision-making, for example at the Involve or Collaborate level of the Spectrum of Participation, further resourcing would be required. Recruitment of participants with some prior knowledge, experience, or particular interest in Engagement work would also be advantageous.

Project Coordinator

A Project Coordinator role was established, providing a consistent point of contact for group members and supporting participation through relationship.

The Project Coordinator liaised with the group members about meeting details, supported accessibility needs including technical support to use the online platform and closed captioning functionality for the hearing impaired, advised Engagement team facilitators on consultation design, prepared pre-reading and consultation summary documents, facilitated the opening and closing sections of each consultation, sought feedback about the group's experience, and was available to participants who required support during the meetings. The Project Coordinator also provided constancy through the weeks of consultations, as sessions were led by various project leads from the Engagement team.

Nurturing relationship and trust between the Project Coordinator and group members was prioritised as the foundation of this work, from which meaningful processes and ways of working

emerged and were refined. The result was a foundation of respect and mutuality that underpinned the Engagement team and group's work together.

The Project Coordinator's experience in community engagement and group facilitation in a service delivery context informed this work. Should the Engagement team embark on a similar project in the future, ensuring a Project Coordinator with relevant facilitation skills and understanding of trauma-informed practice would be an important factor in ensuring successful outcomes.

Furthermore, the time commitment to liaise with and support 11 group members required a prioritisation of this work over other projects. Where this is impracticable for future projects, the role could be shared by two staff members.

Project Coordinator's reflection

It was a privilege to work with this group of thoughtful, caring and insightful individuals. Their generous sharing has added great value to each of our Engagement projects.

Relationship was at the heart of this work, and I was guided by the principles of Neami's Collaborative Relational Practice (CRP), including developing processes with the group that fostered mutuality and understanding and that our team needed to 'move at the speed of trust'.

Some principles guiding our team's approach were:

- **Consulting early:** bringing lived experience perspectives into the early stages of project planning gave the group significant influence on our outcomes.
- **Valuing diversity:** we brought together a diverse group in terms of geographical location, age, gender, sexuality, and lived experience. While some of our participants had been involved in Lived Experience forums within the mental health sector for several years, we also made sure there was space at the table for voices that hadn't yet been heard.
- **Prioritising relationships:** I made time to get to know our group members and what was important to them. This allowed us to work from a place of mutuality and helped me learn about their communication preferences and accessibility needs so I could support them to participate meaningfully. I was able to share learnings and group perspectives within the Engagement team, which informed our consultation design and ways of working.
- **Shifting the balance of power:** our team were sensitive to the power imbalance that commonly exists between mental health service providers and consumers, and we worked to redress this.

We communicated that we wanted to listen, learn and grow. We also did our best to avoid jargon, explain all engagement concepts and terminology, and think through different ways of sharing information.

- **Culture of safety:** I made sure participants knew we cared about their wellbeing and that their feedback would always be welcome and listened to. As a group, we also established a ‘ways of working’ agreement in our first meeting, which included sensitivity around lived experience sharing.

The input of this group has been incredibly valuable to our work. The Neami Engagement team offer our sincere gratitude to all group members and hope you will enjoy and learn from their reflections on our time together.

- Narissa Doumani, Stakeholder and Community Engagement Officer



The group's reflections

Contributors: Branko Strehar, Catriona Matheson, Joy Wells, Lucas Kedda, Maree Santamaria, Stephanie Ramshaw & Steve Giles

Overview

The themes presented here highlight the project's success factors and those elements of the group process that supported meaningful and rewarding participation. Relational aspects feature strongly, both between group members and in their relationship with the Project Coordinator and Engagement team facilitators. So too do meeting structures and clear processes, and a culture of safety and care. The overall experience reported by the group was one of being involved in meaningful work together with respect, understanding and opportunity for personal growth.

Why we joined, what we gained

Group members shared varied reasons for joining, which included the opportunity to use their lived experience positively to improve aspects of Neami. For some, it was an opportunity to develop their lived experience skill set and practise sharing personal stories in a positive progressive way.

A sense of importance and meaningfulness of the work together was reported, as well as feelings of personal benefit

“the experience I had was overwhelmingly positive”

‘Overall, the experience I had was overwhelmingly positive and something that I looked forward to being a part of, even when I had some stressful things happening in my life at the time.’ – Steve

‘The work we were doing felt important.’ – Lucas

‘The prospect of this involvement was a breath of fresh air, something I looked forward to.’ – Maree

'The reflections and learnings gained from participating in the Neami Lived Experience Project Group have helped me to further develop the valuable skills I have from my lived experience to further progress me in my recovery journey and aid me in my career pathway plan as a trauma-informed LE Peer Support Educator/Coach.' – Joy

'I've been involved in consumer work for several years now and always appreciate it when organisations are genuine and thoughtful regarding lived experience engagement.' – Steve

What worked well

Meeting structure

The group were consulted on several different projects. In each case, they met with different Project Leads from the Neami Engagement team who shared details of their work and facilitated group discussions. Across the sessions, certain elements of the meeting structure remained consistent and were valued by the group. These included beginning with a check in, using breakout rooms for small group discussions, and an optional guided relaxation exercise to finish.

Checking in

The first ten minutes or so of each session was dedicated to a check in, to hear what everyone had been up to between meetings. Over the weeks, as the participants and facilitators got to know one another, there was often a candid sharing of what had been challenging over the past week along with details of daily life and any causes for celebration.

'The check ins gave us little glimpses of each person's day. Seeing everyone for those weeks was a refreshing welcome time of connection.' – Maree

Breakout groups

The group meetings were held online, and breakout rooms were used so that participants had a chance to speak in a small group setting before participating in large group discussions.

Participants commented that in each room, people willingly contributed to the discussion. Breakout rooms also provided a less intimidating way for people to share without having the entire group as

an audience. This alleviated anxious feelings and gave them the space to become comfortable with other group members.

The breakout room discussions were also seen as a valuable part of discussion, allowing topics to be narrowed down and elaborated on.

'I noticed that our group discussions really fostered ideas growth, while the breakout rooms gave us time to narrow down these ideas into meaningful and more elaborate concepts.' – Stephanie



“our group discussions really fostered ideas growth”

Relaxation Practices

A short, guided relaxation exercise was offered at the end of the sessions. It was an optional addition to the end of each meeting, for anyone needing to settle and feel grounded before leaving the space.

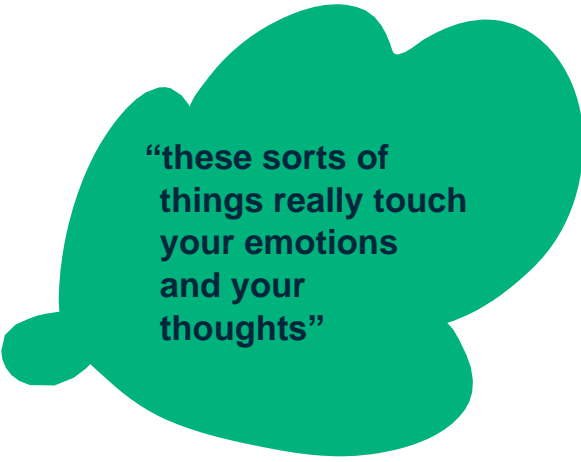
'While nothing traumatic or inappropriate was shared, I very much appreciated Narissa doing a short relaxation exercise, for those who wanted it, to de-stress and finish the group in a gentle way.' – Steve

Connection, humanity and common experience

Feedback from the group indicated that the experience was one of shared caring and mutual respect, interest and support with other people with lived experience, and 'gleaning the gems of our common humanity' (Maree). Group members also found it affirming to hear their experiences and beliefs about mental health echoed by other participants.

A feeling of being in someone's lounge room, sharing candidly and helpfully was reported, as was a sense of having Neami in common, as well as 'disability and issues we have, difficulties to get good service' (Branko).

Other noted commonalities were that most group members had little to no knowledge of Neami before they were referred or self-referred, and that most expressed positive experiences of the support they received. This was even though the group's function did not include evaluating their experience of Neami services.



“these sorts of things really touch your emotions and your thoughts”

It was also reported that the contributions of others provided motivation to contribute oneself, and that the group experience was valued for the learning opportunity it provided and for when it prompted self-reflection.

‘If there was a table with all of us sitting around...you would think, how amazing, how rich each of us are’ – Branko

‘I personally learnt a lot from everyone in the group, having several experiences where someone had managed to communicate something I had been thinking but couldn’t put into words, or giving a completely different perspective to me.’ – Steve

‘Given the opportunity, in something when you need to expand, help, really makes you think about what situation you’re in now. I’d think, how did I get to here? What brought me here? ...These sorts of things really touch your emotions and your thoughts.’ – Branko

While the group largely felt that their discussions were focused, feedback was also provided that at times some may have gone ‘off topic’. However, it was felt that when this happened, each individual’s contribution was met with acceptance and validation, which was not always the case when people with lived experience voiced their opinions in other contexts.

The experience of mutuality and understanding was a defining characteristic that featured within group members’ reflections, with one commenting:

‘It was a great group that affirmed my journey. But really, in a nutshell, when we give each other time, full attention and understanding, we give our undivided assent to a great gift hidden and unhidden in the human condition: that we are each here for each other.’ – Maree

A diverse group

Group members resided in various parts of Australia (VIC, NSW, QLD, WA and SA), and brought a diversity of perspectives and lived and living experience. This diversity was highly valued among the group, including for the opportunity to think differently and open oneself up more to the perspectives of others.

'The diversity of the group allowed lots of different perspectives, each from their own experience.' – Lucas

'It was lovely to be working alongside a group of diverse individuals... I also found it very interesting to hear other people's experiences that were very different to my own.' – Stephanie



'Well-chosen participants – a good range of age, sexuality, gender, life experience – willing to speak about Neami National – to make a good thing better.' – Catriona

Safe and supportive space

It was important that discussions and lived experience were held in a supportive space, and one that was reported to be 'safe and friendly.' In their first meeting, the group created a ways-of-working agreement, which included principles of respect and safety, listening without judgement, confidentiality, and giving everyone a chance to talk. It also included an agreed approach to sharing lived experience – that there was no expectation to do so, that the impact on others should be considered (i.e. avoiding details that could be triggering), and that it was important not to identify others who may be spoken about.

Participants were encouraged to take care of their wellbeing through the sessions and take breaks as needed. The Project Coordinator attended all group meetings and was available for support via private message in the chat or phone call.

'I felt allowed to speak openly and honestly, with a receptive audience'

– Lucas

'The project was very well planned through from start to finish and I was really pleasantly surprised that all the core principles of trauma informed care were used and applied throughout the whole project.' – Joy

'Everyone careful of feelings and possible triggers – feeling cared for via the chat facility and participants, also via Narissa's (Project Coordinator) words of encouragement and enlightenment.' – Catriona

'No one member dominated the group or did most of the talking, and I felt that I was given every opportunity to contribute.' – Steve

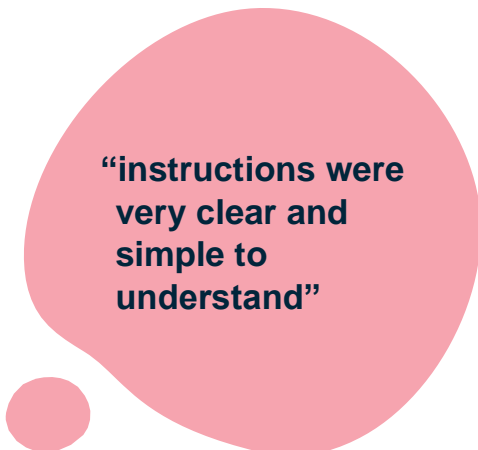
Clear processes

From week to week, having clearly defined processes and achievable, goal-oriented tasks supported meaningful participation. Feedback was received that there was a feeling of accountability, however expectations of the group members were never 'too intense or grandiose'.

'My experience of Neami Lived Experience Project Group... Building people up by the process, in the process, through the process.' – Catriona

'Narissa always went out of her way to ensure we were all on the same page, whether it be reminders about upcoming meetings, sending through summaries of what we spoke about, or pausing conversations to clarify terms.' – Stephanie

'The instructions were very clear and simple to understand, making all tasks stress-free. The follow-up communication was really amazing.' – Joy



“instructions were very clear and simple to understand”

Role of the Project Coordinator & facilitators

The Project Coordinator's role, along with other Neami facilitators, was an important part of the group's experience. Group members emphasised the importance of good facilitation, and their relationship with the Project Coordinator being characterised by empathy and compassion. These were key to establishing a respectful, inclusive and positive culture, within which feelings of being heard and genuinely valued were reported.

'(The Project Coordinator) guided us through each session, made it very easy and (was) very calming.' – Branko

'The facilitators were always very patient and helpful and nothing was too much trouble. My questions were always answered thoughtfully.' – Lucas

'I think as a group we will all leave the better having experienced Narissa modelling kindness as a group mediator. Her approach has certainly given me a lot of food for thought, and shown me just how much of a difference compassion can make in a setting where individuals may feel vulnerable and intimidated.' – Stephanie

'Excellent facilitator in Narissa – brought out the best in us – reflected back our thoughts, encouraged us to expand on our answers.' – Catriona

Things that surprised us

Things group members expected to see, but didn't:

- There wasn't a cold, clinical approach to the group.
- They didn't have to do a lot of paperwork.
- There wasn't uncomfortable oversharing about personal experiences.

What group members didn't expect to see, but did see:

- A strong bond and an encouraging atmosphere were developed in a short amount of time.

What could be improved

There is room for improvement in every group process. Group members have provided the following feedback and recommendations, although it was not felt they represented the experience of all group members.

Breakout room time and group size

Breakout room discussions were usually held between three to four participants. On occasion participants were put into groups of two, and it was reported that the smaller group size was found to be difficult.

Within the breakout rooms, participants were typically asked to discuss two questions within 10-15 minutes. After this time, groups would be invited to summarise their discussion points within a broader group discussion. While it was reported that a longer time in the breakout rooms may have been preferable, it was also acknowledged that this may have resulted in the meetings being too long.

Breakout room moderator

It was proposed that in the future, one of the group members be nominated as a moderator of the small group discussions. This would help keep discussions focused and ensure conversation abided by the group agreement, particularly where lived experience sharing was involved.

Should this strategy be implemented, a recommended consideration is the potential impact on participants' sense of mutuality. This could have been explored at the outset of the project when creating the group agreement, by asking participants how they wished to respond to one another, or have Neami staff respond, should anyone be adversely impacted by another's lived experience sharing. Although it was established at the outset that participants always had the option to leave a breakout room if they were uncomfortable or needed time out, it is also recommended that this option be reiterated at the beginning of each small group discussion.

Facilitation

A perspective was shared that Engagement team facilitators could have created a greater sense of excitement about their projects, increased their interactivity, and more clearly indicated how the group's contributions would be incorporated into their work.

However, feedback was also provided that the Engagement team facilitators were good at their respective jobs and contributed to a group dynamic where everyone had the opportunity to contribute.

Strengthening the feedback loop

Participants were consulted within the early stages of project planning to ensure maximum influence over outcomes. It was found to be rewarding when tangible results could be seen, such as when the group's input had shaped design concepts for the Brand Refresh project.

However, internal strategies or documents incorporating the group's feedback were not always as tangible. Within each consultation, planned implementation of the group's feedback was discussed. The Project Coordinator also provided participants with a summary document after the first five consultations, outlining the group's key feedback and recommendations and how these would be implemented within the next steps in each project.

Nonetheless, a perspective was shared that at times it felt as though the Engagement team were 'walking away' with the group's valuable contributions without having provided a clear enough understanding of how they would be used.

The feedback highlights the importance of all facilitators involved in consultations developing trust with the group and the importance of ensuring all group members have a clear understanding of how their contributions will be implemented. In future, more regular updates could be provided to the group as projects progress, and consultation summaries and project updates could also be presented to the group in a forum that provides opportunity for Q&A.

An update on project implementation and timelines was subsequently presented to the group by the Project Coordinator during the co-evaluation process.




Final thoughts

'Whatever our experience, each is so important for our journey onward. The heard sharings somehow give a strengthened courage to follow our hopes and dreams.' – Maree

Involvement in this group has been equally meaningful and rewarding for members of the Lived Experience Engagement Project Group and the Neami Engagement team.

Participation has helped some group members develop skills they are using in the Lived Experience workforce, and others found it rewarding to see their contributions come to life in a tangible way.

The work done together felt important. The group and Neami's Engagement team believe equally in the value of lived experience insights and the importance of giving these prominence to influence the mental health sector. In the words of group member Branko, 'there's nothing like lived experience, there really isn't.'



"the heard sharings somehow give a strengthened courage"

More information

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We acknowledge Aboriginal and/or Torres Strait Islander peoples and communities as the Traditional Custodians of the land we work on and pay our respects to Elders past, present and emerging. We recognise that their sovereignty was never ceded.

Neami celebrates, values and includes people of all backgrounds, genders, sexualities, cultures, bodies and abilities.