

Levels of Lived Experience Engagement in Suicide Prevention Projects

Introduction:

Insights from individuals with lived experience can contribute to positive messaging, enriched programming, enhanced safety, and the destigmatization of an array of issues that impact individuals' lives and wellbeing. This document is intended to serve as a guide for organizations that engage, or plan to engage, people with lived experience in prevention projects in a variety of fields. We describe characteristics of projects that incorporate high, medium, and low levels of lived experience engagement to help organizations make informed decisions about meaningfully incorporating lived experience in their own projects.

Lived experience: Personal knowledge about the world gained through direct, firsthand involvement in everyday events rather than through representations constructed by other people. It may also refer to knowledge of people gained from direct face-to-face interaction rather than through a technological medium.¹

Projects: Efforts or initiatives an organization undertakes to advance prevention work.

Engagement: Engaging individuals with lived experience means listening to their advice and expertise and incorporating their suggestions to create more effective projects.

High Engagement (Lived-Led or Co-Designed)

Lived-led: Projects that are conceptualized and run by individuals with lived experience with support from organizational staff.

Co-designed: Projects that are co-conceptualized and implemented by individuals with lived experience and organizational staff. In co-designed projects, staff collaborate with individuals with lived experience at every phase of project development.

High engagement (lived-led or co-designed) projects are defined by constant collaboration between an organization's staff and their lived experience (LE) advisors. When an organization cares about and prioritizes the perspectives of individuals with lived experience, they may hire an external lived experience advisory group to provide guidance or even run projects. In high engagement projects, LE advisors don't just lend their perspectives, they work with staff to co-create the project, making real decisions based on their lived experience expertise.

High engagement projects embed lived experience expertise in every phase of the project's lifespan. They are marked by open, ongoing, and transparent communication between staff and LE advisors to ensure that all involved are informed and included equitably. LE advisors have a say in establishing project processes, scope, and outcomes.

In high engagement projects:

- LE advisors are brought in during the initial idea generation phase to work alongside organizational staff to co-design every aspect of the project.
- In the planning phase, staff work alongside LE advisors to determine project deliverables and expected outcomes.
- LE advisors may make decisions about the scope of the project.
- In research-related projects, LE advisors are involved in data collection and interpretation.
- LE advisors work side-by-side with staff to iterate the project's development.
- Project implementation involves joint decision-making between staff and LE advisors. The input of LE advisors is valued and integrated into the implementation strategy.
- LE advisors help determine the metrics for monitoring the project and they are involved in any project adaptations that may result from this monitoring.
- LE advisors collaborate with staff in the assessment process. They use their lived experience expertise to make significant contributions to determining evaluation criteria and methods. They also share accountability for project outcomes—as well as recognition and successes—with staff.
- LE advisors may be included in a project's promotional or marketing phase. This might include LE advisors using their social networks to inform the public of the project and their involvement with the work.

In high engagement projects, LE advisors have the freedom and flexibility to make decisions and drive the project forward. At every stage, LE advisors are involved in conversations around potential project challenges or limitations. They are also involved in making decisions about ways to address these issues.

Barriers to ongoing involvement by LE advisors are addressed thoughtfully and collaboratively. This can be done at the onset of a project or as soon as issues that affect participation arise. If LE advisors cannot participate in each project phase and co-share decision-making, a project is not a high-engagement collaboration.

Medium Engagement

Medium engagement projects incorporate LE advisors' insight and feedback in more than half of the project phases. LE advisors and staff collaborate throughout the project, while organizational staff maintain final decision-making power. LE advisors may or may not be included in final decision-making processes but are informed at the project's onset about the level of final input they will have and why.

Medium engagement projects incorporate two-way feedback processes. Conversations about communication needs, response expectations, and availability are held at the beginning of the project to ensure open and timely dialogue during critical points in the process. A comprehensive, transparent, and intentional expectation setting phase ensures LE advisors can make informed decisions from the start of their engagement with a project.

Organizational staff and LE advisors work collaboratively on project planning and staff make decisions about next steps, logistics, and other elements of the overall process. LE advisors are informed of project limitations, scope, and processes before they agree to participate. LE advisors can provide feedback but do not make final decisions about the scope of the project.

In medium engagement projects:

- LE advisors may be involved in the ideation/generation phase of project development. They may provide input and perspectives about project outcomes, approaches, potential barriers the project may encounter, and more. This input could be captured through formal or informal communication methods.
- LE advisors may be consulted during project implementation, and their feedback may be considered in decision-making processes. LE advisors' feedback is incorporated as often as possible. Feedback may not be included if it does not align with intended project outcomes or could change the project scope.
- LE advisors may be involved in monitoring the progress of the project and can provide feedback on shaping strategies.
- During the review and evaluation phase, LE advisors may provide insight into improvements that can be made. LE advisors are not accountable for outcomes.
- LE advisors may be included in a project's promotional or marketing phase. This might include LE advisors using their social networks to inform the public of the project and their involvement with the work.

Low Engagement

Low engagement projects incorporate LE advisors' input in fewer than half of the stages of the project. LE advisors typically only provide feedback at the beginning and/or end.

In low engagement projects, there are often significant power imbalances between organizational staff and LE advisors, which can limit trust, openness, and the overall quality of LE advisors' input.

Low engagement projects incorporate one-way feedback processes. LE advisors provide feedback, but often do not receive responses, explanations, or follow-up from staff.

In low engagement projects, there are few or no procedures to actualize LE advisors' input and feedback. LE advisors do not hold decision making power and cannot affect the project process, scope, or outcomes. Staff may or may not include LE advisors' feedback in project decisions and often do not communicate the reason for these decisions to LE advisors. Low engagement projects do not include opportunities for LE advisors to provide significant input or be included in a meaningful way. This may limit the quality of LE feedback, inhibiting opportunities for stronger engagement and more productive outcomes.

In low engagement projects:

- LE advisors may be brought on at the beginning of a project to generate ideas or “sign off” on a project’s overall purpose or mission.
- LE advisors may be brought on at the end of a project to review content, ensure an accurate representation of LE perspectives, or be informed a project is complete and ready for the promotional phase.
- LE advisors may be included in a project's promotional or marketing phase. Organizational staff may ask LE advisors to help them understand the needs of priority populations and they may rely on LE advisors to act as champions for the work. Staff may leverage LE advisors’ social capital to further the work, which can negatively impact trust, relationships, and future opportunities for collaboration with LE individuals.

Reference:

1. Chandler, D., & Munday, R. (2011). *A dictionary of media and communication* (1st edition). Oxford University Press.

Additional Resources:

Roses in the Ocean

Lived Experience of Suicide Engagement, Partnership and Integration Decision & Evaluation Tools:

<https://rosesintheocean.com.au/wp-content/uploads/2022/09/LESEPI-Decision-Evaluation-Tools-V1.2.pdf>

Partnerships Online

The Guide to Effective Prevention:

<https://www.partnerships.org.uk/guide/index.htm>