LifeSpan Lived Experience Framework

A systematic, evidence-based framework for the engagement of people with lived experience of suicide. For use in the LifeSpan integrated systems approach to suicide prevention and beyond.

The Lived Experience Framework was developed alongside the evidence for individual strategies and recommended programs within LifeSpan, The Black Dog Institute’s model for an evidence-based systems-approach to suicide prevention. A separate literature review was commissioned to inform LifeSpan trial regions on how to strategically and purposefully involve people who had a lived experience of suicidality and suicide bereavement in their implementation and apply the principle of ‘Nothing about us, without us’.

Based on the findings of the literature review, the Lived Experience Framework provides recommendations for engagement in all stages of a project, from design to governance & management, delivery and evaluation.

To ensure accountability mechanisms were built into the Framework, a focus was given to specific, practical and measurable actions for meaningful engagement that could be applied across various LifeSpan.

The Framework was developed in response to the finding that ‘No single, comprehensive framework for engagement of people with lived experience of suicide was identified and measures of the effectiveness of engagement strategies tended to focus on “experiential knowledge” rather than traditional evidence’.

The Framework can be used by people with lived experience and the organisations they are working with (e.g. Primary Health Networks, suicide prevention organisations) to expand the scope of activities they are actively involved in. Using the measures suggested, the impact of lived experience contribution can be assessed, helping us learn what types of engagement are working well and where we need to focus efforts on improvement.

Guiding Principles for Effective Engagement

- Engagement needs to be appropriate – don’t set people up to fail
- Build in plenty of time and resources for engagement – these should be central to program and research design, not an afterthought
- Shared expectations are crucial to a good experience for all parties
- Be prepared to negotiate and ensure you are in a position to use the feedback provided

Additional details for each of the 14 evidence-based activities are available in a report prepared by the ANU research team. A link can be found on the Resources page of the LifeSpan website: www.lifespan.org.au

See overleaf for a high-level summary of the Framework.

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1 Dr Aino Suomi, Mr Ben Freeman & Dr Michelle Banfield, Framework for the engagement of people with a lived experience in program implementation and research: Review and report prepared for the LifeSpan suicide prevention project (the Australian National University), p.8.
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<table>
<thead>
<tr>
<th>Design</th>
<th>Governance and Management</th>
<th>Delivery</th>
<th>Evaluation</th>
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<tbody>
<tr>
<td><strong>Individual Level</strong></td>
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<td><strong>Organisational Level</strong></td>
<td><strong>Policy or Strategy Level</strong></td>
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<tr>
<td>Individuals are empowered to make decisions about their own care and are active participants in evaluating the care they received; provided information resources and groups to support personal care preferences.</td>
<td>Individuals help design services, training programs, campaigns, physical spaces; serve on service advisory councils; participate in the execution of treatments, services, quality improvement, assist with staff hiring, training and development.</td>
<td>Individuals are engaged early, meaningfully and systematically at each level of the organisation (not token or single representatives) e.g. participate as decision-making members in quality teams, assist with hiring, develop and deliver training.</td>
<td>Individuals or representatives of consumer organisations (speaking for a constituency) are engaged in developing, implementing and evaluating policy / strategy to help ensure these are reflective and responsive to perspectives of people with lived experience.</td>
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</tbody>
</table>

**[1]** Shared decision-making  
**[2]** Treatment preferences  
**[3]** Self-help-programs and tools  
**[4]** Satisfaction surveys  
**[5]** Co-design of services and programs  
**[6]** Reference Groups and representatives or committees  
**[7]** Peer workers and peer-led programs  
**[8]** Lived experience feedback and co-evaluation  
**[9]** Advisory Group and representatives on working groups  
**[10]** Lived experience-led committees and equal representation in all decision-making bodies  
**[11]** Lived experience-led training for staff  
**[12]** Interviews with lived experience representatives; regular audit of engagement activities  
**[13]** Co-design of policy and strategy  
**[14]** Regular reviews of policy and its implementation by lived experience representatives