Evidence Brief

Enabler 2: Embedding lived experience decision-making and leadership.

Dr Karolina Krysinska[1], Dr Bridget Bassilios[1], Dr Lennart Reifels[1], Dr Bridget Kenny[2], Dr Angela Clapperton[1], Dr Jaelea Skehan OAM[3], Dr Karl Andriessen[1], Dr Danielle Newton[1], Dr Anna Ross[1], Prof Nicola Reavley[1], Prof Jo Robinson[2], A/Prof Dianne Currier[1].

[1] Centre for Mental Health, Melbourne School of Population and Global Health, University of Melbourne, [2] Orygen, Centre for Youth Mental Health, University of Melbourne, [3] Everymind.

Definition and scope of this enabler

Embedding lived experience of suicide into leadership structures and all levels of decision making to inform suicide prevention across governments and portfolios is one of the foundational areas of system reform in implementation of the National Suicide Prevention Strategy and broader suicide prevention efforts in Australia (1). People with lived experience of suicide provide invaluable personal insights about effective and appropriate suicide prevention responses that meet their needs. Lived experience leadership in suicide prevention was among the top achievements of the National Suicide Prevention Trial (2) and 'bringing in the collective voice of lived experience in the field' has been identified as one of the key successes in suicide prevention by key stakeholders in the sector (3). As such, it is critical that people with lived experience are increasingly involved in planning, implementation, and evaluation of suicide prevention activities and government agencies and service providers are equipped to partner effectively with people with lived experience.

What are the key issues?

Embedding lived experience in decision-making and leadership across relevant decision-making structures requires guidance and support for Governments to create settings in which people with lived experience of suicide are valued, empowered, and provided with support they need (1). To address this need, it is critical to strengthen meaningful inclusion of diverse lived experience perspectives to reflect both the diversity of experiences of suicide and diversity of the Australian population (1,4,). **Expert consultations** confirmed this need. The expertise of people with lived experience of suicide can be accessed through engagement on three levels: service/program-level through co-production, organisation-level through advisory group and working group representatives, and policy/strategy-level through co-production (5).

What is currently happening (in Australia)?

According to the National Suicide Prevention Strategy Scoping Paper (6), 'driving change to ensure systems and services are person-centred, compassionate, and developed in partnership with people with a lived experience of suicide' is one of the specific objectives of the Strategy. Further, the qualitative insights of people with lived experience of suicide have been included under the term 'evidence-informed' (7).

A recent environmental scan of suicide prevention activity in Australia found partial or mixed progress in regard to Principles and System Enablers (3). In regard to Principle 1, approximately half of the 34 policy documents in the scan referred either specifically to 'lived experience of suicide' or more generally 'lived experience in relation to mental health', and/or the process of co-design. In general, across the national-, and state/territory-level documents, people with lived experience have been recognised as key stakeholders in suicide prevention, who have to be involved at all levels of decision making, preferably through co-design/co-production. Principles of lived experience inclusion at every level and co-design/co-production are included in the *National Agreement* and state and territory level suicide prevention strategies, encompassing suicide prevention activities in First Nations peoples and the LGBTIQ+ community.

The environmental scan found partial or mixed progress in regard to System Enabler 2 (3). Around half of the 34 policy documents and one third of joint regional plans made a reference to people with lived experience and the process of co-design. According to the *Fifth National Mental Health and Suicide Prevention Plan,* consumers and carers need to be involved in the Suicide Prevention Subcommittee reporting to Mental Health Drug and Alcohol Principal Committee and evaluation of the Plan. There are local plans on state- and territory-level to involve people with lived experience through co-design in redesign of mental health services, and to employ and ensure membership of people with lived experience in suicide prevention policy and governance.

The environmental scan identified several projects funded under the National Suicide Prevention Leadership and Support Program (3). Under Activity 4 (National Support for Lived Experience of Suicide), there has been funding for Roses in the Ocean to provide national leadership in lived experience and the Black Dog Institute (BDI) to create a network of lived experience participants to support and contribute to the Regional Suicide Prevention Networks. Under Activity 6 (National Suicide Prevention Training), Roses in the Ocean was provided funding to deliver evidence-based training (Access and Equity Project) for people with lived experience living in regional areas and belonging to high-risk groups.

Further Government funding ($8.5 million) will be provided to support people with lived experience of mental health (8). This includes establishment and operation of two national mental health lived experience peak bodies to represent consumers, as well as carers, families, and kin. Continued funding will be provided to Lived Experience Australia to lead lived experience research and to build capacity of consumers and carers. A stakeholder forum will be established to increase transparency, accountability, and partnership within the sector.

What are the critical gaps (in Australia)?

Critical gaps remain in regard to lived experience participation and empowerment in suicide prevention in Australia (9). Although, people with lived experience are more often involved in decision-making process, not all groups (e.g., young people) are well-represented. Involvement of people with lived experience tends to be limited to design and delivery of specific suicide prevention programs or specific elements of the mental health system, and involvement in higher levels of decision making can address this gap. There is a need to extend lived experience participation from the levels of consultation and collaboration to empowerment (i.e., having final decision-making power) (9). Other critical gaps include lack of a standardised systematic approach, no 'peak' representation or lead agency driving

embedding lived experience into government, and lack of an agreed approach to demonstrate success or impact of embedding lived experience.

Where should efforts be focused (in Australia)?

The environmental scan of suicide prevention activity in Australia has produced a number of recommendations (3):

Principle 1: All suicide prevention efforts must be informed by people with a lived experience of suicide:

- Improve recognition of the value of lived experience in the suicide prevention sector. For example, routinely embed co-production including in policy, planning and program and service development; implementation; evaluation and monitoring; research and its translation; and workforce training. This could be achieved by making co-production a condition of funding and/or including people with lived experience in governance committees, procurement panels and other leadership roles.
- Ensure diversity and appropriateness of lived experience perspectives and inputs. For example, the type of lived experience (suicide attempt, ideation, bereavement, provision of care) should be matched to the needs of a particular project or initiative. Also, input should be sought from people with lived experience of suicide from hard-to-reach groups (e.g., due to socio-economic, cultural or circumstantial disadvantage).

Embedding lived experience decision-making and leadership:

- Provide ongoing opportunities for leadership development for people with lived experience of suicide. For instance, they should be provided with training and support opportunities for skill development to perform leadership roles (e.g., in governance committees, procurement panels etc.) within the suicide prevention sector.
- Provide ongoing funding for people with lived experience to be involved in leadership roles.

Further, there should be a greater focus on integration of lived experience into the service system and public narratives about suicide prevention (4) and a shift to consider the voice of lived experience as an essential input into suicide prevention design and delivery rather than 'anecdotal' evidence (4). Lived experience knowledge and expertise should be prioritised and integrated into the planning and delivery of whole of government suicide prevention activity and suicide prevention outcomes need to be focused on people with lived experience of suicide (4). Focus should be on engaging diverse lived experience groups, including Aboriginal and Torres Strait Islanders, young and older people, rural communities, LGBTIQ+ communities, people from culturally and linguistically diverse backgrounds, as well as veterans and their families (4).

ENABLER 2 ACTIONS

Action 1

Develop tailored guidance and provide support to government agencies to embed lived experience of suicide into relevant governance structures and decision-making processes.

Resources, training and guidance would:

a. Support decision making and prioritisation about areas of government for lived experience to be integrated and guidance on the best mechanisms to achieve this (this process will also inform approaches to actions 2 and 3)
b. include guidance on organisational and culture change including staff capacity building that may be required to ensure a safe and supportive work environment and productive partnerships with people with lived experience.
c. be developed through co-design with people with lived experience of suicide and government staff.
d. have the flexibility to be adapted to different contexts and functions across government.

Action 2

Related action in Enabler 4 regarding building capability of government to partner with people with lived experience of suicide.

Evidence for actions and possible sub-actions for Actions 1 and 2

A review of mental health and suicide prevention government policies in Australia showed an ongoing commitment by national and state/territory governments to include lived experience and co-design (10). Nonetheless, application of these concepts often fails to reflect the complexity of implementation and evaluation of suicide prevention programs and the full potential of co-creation of new knowledge remains to be reached. Despite the government policy recommendations on the engagement of lived experience in the design and development of suicide prevention research, people with lived experience of suicide to-date have not become lead stakeholders in this field (11).

Expert consultations confirmed that relevant training is necessary and should be provided to equip people with lived experience to participate in suicide prevention research design and interpretation, and development of public policy. Such training has become more widely available in Australia (12) and there is emerging evidence on the effectiveness of training programs for people with lived experience. A recent study evaluated Our voice in action (OVIA) foundation program developed by Roses in the Ocean, which aims to develop competency of people with lived experience around meaningful participation in suicide prevention activities (13). This study showed that the OVIA program generally increased participants' suicide literacy, knowledge of safe language, confidence in lived experience tasks, empowerment, and reduced psychological distress. There was no change in attitudes towards lived experience, which can be related to pre-existing positive attitudes among training participants.

Things we can build upon

To provide organisations with a systematic way to embed lived experience across suicide prevention activities Roses in the Ocean developed the Lived Experience of Suicide Engagement Framework (14). This Framework informs mapping engagement, employment, and partnership with people with lived experience across all stages of a project. Organisations can use the Framework when preparing to meet the Lived Experience of Suicide Accreditation Standard for the National Suicide Prevention Accreditation Program. The Lived Experience Resource Centre at the Black Dog Institute (15) supports best practice lived experience participation within the BDI Centre of Research Excellence in Suicide Prevention. The BDI developed a Lived Experience Framework (16) on strategic and purposeful lived experience involvement in implementation of BDI's suicide prevention systems-approach (LifeSpan).

The ALIVE Centre, funded by the National Health and Medical Research Council Special Initiative in Mental Health (2021-2026) has established an Implementation and Translation Network (17). This Network will provide its members access to implementation tools and techniques and will support development of research implementation guides, including co-design.

Action 3

Governments to develop and implement a strategic plan to integrate people with lived experience of suicide into relevant leadership and governance roles:

a. Building on the work in Action 1, the aim of this plan would be to support a consistent and strategic approach across departments to grow and build the capacity of people with lived experience for leadership and governance roles, to establish processes to increase the number of roles for people with lived experience of suicide across government and to guide ongoing support, mentoring and development mechanisms for people in these roles.

Evidence for the action and possible sub-actions

People with lived experience of suicide should be key stakeholders in implementation of suicide prevention programs and this process can be facilitated by adopting co-design principles in implementation research (18). A systematic review and meta-analysis of methods and effects of consumer engagement in health care policy, research and services found some evidence that people with lived experience can identify health care priorities and needs that complement professionals' perspectives and contribute to development of services (19). Nonetheless, despite a general consensus around the need for user involvement (i.e., involvement of people with lived experience) in health and community care policy and program development, including suicide prevention, evidence base around the key factors in this process, remains limited. A recent review highlighted that participatory methodologies are complex, require careful planning and management, sufficient resources, as well as the input of professionals with relevant experience (20).

Things we can build upon

Expert consultations considered that the leadership capacity of people with lived experience could be strengthened through opportunities for leadership skills development, placements and/or mentorship programs that build on skills and experience they already possess.

Action 4

Relevant government departments to establish standing lived experience of suicide advisory groups.

a. This action builds on the work in Action 1 and 2, which will identify and prioritise departments with the greatest impact on suicide prevention outcomes. Advisory groups will support the work of relevant departments through advising on strategy, planning and work with consideration of opportunities to build wellbeing and protective factors for suicide, to avoid or mitigate suicide risks that could occur through implementation of policy and programs, and providing lived experience insights to inform planning for program and service delivery and commissioning.
b. Advisory groups would have a role in supporting department planning and implementation of work covered in the National Suicide Prevention Strategy.

Things we can build upon

Organisations involved in suicide prevention in Australia, such as Beyond Blue, Suicide Prevention Australia, and the Black Dog Institute have developed guidelines and principles to ensure safe inclusion of people with lived experience of suicide in their activities and programs (12).

Action 5

In Primary Health Network contracts with the Department of Health, embed the requirement to increase the meaningful inclusion of a diversity of lived experience perspectives across governance and decision-making processes. This would include through staffing, involvement in regional suicide prevention planning, commissioning processes and membership of advisory groups.

Evidence for the action and possible sub-actions

A study on stakeholder insights around implementation of a systems-based suicide prevention program (LifeSpan) in regional and rural communities in Tasmania showed the key role of early community engagement and inclusion of people with lived experience and representatives of vulnerable populations in Working Groups (21). The operation of Working Groups was strongly influenced by experience, capacity, and knowledge of local needs, which were provided by community members, including people with lived experience, local services, and professionals. This study showed that community-based suicide prevention programs have a potential to equip communities with knowledge on implementation and monitoring of community-based programs, which can be tailored to meet community needs.

Things we can build upon

There is a need to ensure that lived experience is embedded within bodies making decisions relevant to suicide prevention. **Expert consultations** pointed out that the diversity of people's

lived experience must be considered, including the role for mental health and suicide professionals who also have lived experience in addition to community members with lived experience.

Action 6

Commissioning of suicide prevention related services by government departments and Primary Health Networks include requirements for services to demonstrate lived experience inclusion in governance and decision-making processes through applications for tenders and ongoing reporting arrangements. For example, through design and planning for services, recruitment panels for service staff, monitoring and evaluation of services and membership on advisory groups.

Evidence for the action and possible sub-actions

A systematic review on the role and effectiveness of co-produced community-based mental health interventions for adults found that stakeholder involvement in development of community-based suicide prevention interventions may improve engagement and create opportunities for people with lived experience of a suicidal crisis to provide input (22). The review also showed limited evidence base around evaluation of the long-term outcomes of co-produced suicide prevention interventions.

Things we can build upon

Expert consultations considered that it is not necessary to mandate the involvement of people with lived experience, rather, inclusivity should be promoted, including input from lived experience community members and from people with lived experience working in the suicide prevention and mental health sector.

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