

Lived Experience of Suicide
Engagement Principles
(LESEP) Guidance Document



DIVERSITY
INCLUSION

RESPECT &
COMPASSION

COLLABORATION

& POWER SHARING

TRANSPARENCY

ACCOUNTABILITY

What do
Lived Experience of Suicide
Engagement Principles
look like?

RESPECT &

COMPASSION

DIVERSITY

& INCLUSION

TRUST

& SAFETY

TRANSPARENCY

ACCOUNTABILITY

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CONTENTS

Purpose of this guide	3
Why we need specific guidelines for lived experience of suicide engagement	4
Roses in the Ocean's Lived Experience of Suicide Engagement Principles	5
■ TRUST & SAFETY	6
■ RESPECT & COMPASSION	7
■ COLLABORATION & POWER SHARING	8
■ TRANSPARENCY & ACCOUNTABILITY	9
■ DIVERSITY & INCLUSION	10
References	11

Roses in the Ocean defines a lived experience of suicide as ... having experienced suicidal thoughts, survived a suicide attempt, cared for someone through suicidal crisis, or been bereaved by suicide.

Aboriginal and Torres Strait Islander Lived Experience as defined by the Aboriginal and Torres Strait Islander Lived Experience Centre:

A lived experience recognises the effects of ongoing negative historical impacts and or specific events on the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples. It encompasses the cultural, spiritual, physical, emotional and mental wellbeing of the individual, family or community. People with lived or living experience of suicide are those who have experienced suicidal thoughts, survived a suicide attempt, cared for someone through a suicidal crisis, been bereaved by suicide or having a loved one who has died by suicide, acknowledging that this experience is significantly different and takes into consideration Aboriginal and Torres Strait Islander peoples ways of understanding social and emotional wellbeing.

PURPOSE OF THIS GUIDE

This document has been produced to guide staff and organisations intending to, or already, engaging and partnering with people with lived experience of suicide in suicide prevention related activity.

It sets out the foundational principles of safe, effective, and sustainable engagement and partnership, and has been specifically developed to be used in conjunction with six other key Roses in the Ocean guidance documents which collectively support lived experience informed culture change:

- Lived Experience of Suicide Engagement Partnership and Integration (LESEPI) Framework
- Lived Experience of Suicide Engagement Partnership and Integration (LESEPI) Framework: Implementation Toolkit
- Lived Experience of Suicide Engagement Partnership and Integration (LESEPI) Decision & Evaluation Tools
- Building a lived experience informed and inclusive culture: a practical guide for organisations
- Co-designing with people with a lived experience of suicide: planning guide
- Lived Experience of Suicide Language and Imagery Guide

It is important to note that authentic engagement with people with lived experience of suicide requires more than just compliance with the lived experience of suicide engagement principles set out in this guide. It involves a genuine commitment to living the principles which are articulated in this publication as Statements of Commitment.

It is also vital that a shared understanding and appreciation of the meaning and value of lived experience is developed across organisations and within internal project teams. The core concepts articulated in this guidance document can be summarised as a set of key messages:

- Lived experience of suicide is unique, complex, and multi-layered
- Approximately half the people who die by suicide have not been diagnosed with a mental illness
- Suicide does not discriminate – it impacts people of all walks of life
- Humility is a powerful bridge to greater understanding and more effective solutions
- It is imperative that we match the nature of lived experience of suicide to the purpose of an individual initiative
- Lived experience expertise is more than just sharing a story - it is grounded in a sophisticated ability to utilise insights with meaning and purpose
- To enable the full breadth and diversity of lived experiences to be represented, it is necessary to adequately resource individually tailored, culturally appropriate mechanisms for engagement and partnership
- Power imbalances are real and must be named and acknowledged before they can be rebalanced
- People with lived experience are profoundly resilient and thrive in cultures of respect, compassion and collaboration
- It is important to consider and understand the benefits of both internal and external lived experience expertise



WHY WE NEED SPECIFIC GUIDELINES FOR LIVED EXPERIENCE OF SUICIDE ENGAGEMENT

The Australian mental health consumer movement has played a vital role in advocating for the human rights of people with mental health challenges and the reduction of the stigma, discrimination, injustice, and inequality associated with experiences of psychiatric diagnosis and treatment.

Consumer and carer activists raised community and political awareness of the limitations of the mental health system and gave a public face and voice to people living with a diagnosis of mental illness and those who support them. After decades of systemic advocacy, mental health consumers and carers began to be formally consulted by government agencies and mental health organisations in system improvement processes. Consumer Advisory Groups were established as a permanent resource and paid advisory roles were eventually created within the government, non-government, and corporate sectors, including representation in state and national peak mental health bodies.

There has also been a significant increase in policy, program and research co-design and co-production activity that involve mental health consumers and carers - a mainstream recognition of the fact that consumers and carers are experts by experience of what works and what needs to improve. As a result of this significant activity at regional, state and national levels, there have been several guidelines and frameworks produced by government agencies, organisations and lived experience experts that aim to articulate best-practice principles and approaches for engaging people with lived experience.

While there is a significant overlap between mental ill-health and suicide, approximately half the people who die by suicide in Australia do not have a diagnosed mental illness and a large proportion of these people have had no contact with the mental health system in the year prior to their deaths. While the increased awareness of, and commitment to, the engagement and partnership of mental health consumers and carers has been vital for mental health reform, the tendency to conflate lived experience of suicide with

consumer/carer perspectives has limited genuine engagement with people whose experiences of suicide are not reducible to mental health. It is important that reform focuses on wellbeing as a whole. This is inclusive of all views including lived experience of suicide, mental health consumers and carers, people with lived and living experience of alcohol and other drugs, trauma and other intersectional experiences and life circumstances..

Conceptualising suicidality as exclusively a mental health issue fails to appreciate the situational and social distress that often leads people to ending their lives or attempting to do so. Poor living circumstances, relationship breakdown, loss of a loved one, drug and alcohol use, bullying, a lack of social support, the onset of disability, chronic pain, economic and legal problems, and a history of trauma have all been shown to contribute to an increased risk of suicide. Furthermore, people who are bereaved by suicide also sit under the umbrella of lived experience of suicide and as bereavement from suicide is not a mental illness, these people are not captured through traditional mental health consumer and carer perspectives.

It is essential that the unique features of someone's lived experience of suicide are recognised if we are to meaningfully harness their unique insights and wisdom in efforts to improve suicide prevention. The need for the distinct voices and expertise of people with lived experience of suicide to be included in suicide prevention activity has been formally recognised in several key national reports. The recommendations from *Shifting the Focus: A national whole-of-government approach to suicide prevention in Australia* - a report developed by the National Suicide Prevention Taskforce as part of the Prime Minister's Adviser on Suicide Prevention's Final Advice - as well as recommendations from the Productivity Commission Inquiry Report on Mental Health point squarely to the need for a Whole of Australian Government (WOAG) approach to suicide that is informed by, integrated with, and implemented through the critical voices of people with lived experiences of suicide.



ROSES IN THE OCEAN'S LIVED EXPERIENCE OF SUICIDE ENGAGEMENT PRINCIPLES

Roses in the Ocean is Australia's leading exponent of lived experience of suicide which exists to save lives and reduce emotional distress and pain. Over the last decade Roses in the Ocean has focused on building the capacity of people with a lived experience of suicide to find their voice, be heard and become a strong, sophisticated presence. A presence that has proved to be a driving force for change in suicide prevention in Australia. We have harnessed the perspectives of all we represent, along with our own lived experience of suicide expertise to innovate and transform suicide prevention, and drive and deliver system reform. Our work also extends to supporting organisations, service providers and government to meaningfully engage and integrate people with a lived experience of suicide.

Roses in the Ocean recognises that people with a lived experience of suicide bring unique insights, wisdom, and perspectives critical to informing and shaping the development of best practice approaches to reducing emotional distress and pain and saving lives. To make the most of their uniquely valuable expertise, it is necessary to systematically and sustainably support people with lived experience to build their capacity to utilise their voices with meaning and purpose.

In recognition of this, Roses in the Ocean has developed a specific set of Lived Experience of Suicide Engagement Principles (LESEP) that should underpin and guide an organisation's approach when engaging, or seeking to engage, people with lived experience in their suicide prevention activity. These are:

- TRUST & SAFETY
- RESPECT & COMPASSION
- COLLABORATION & POWER SHARING
- TRANSPARENCY & ACCOUNTABILITY
- DIVERSITY & INCLUSION

These engagement principles (and associated implementation toolkit) are informed by, and build on, the guiding principles articulated in a range of best-practice engagement and partnership guidelines frameworks, and other guidance documents which are listed at the end of this guide.

Roses in the Ocean's LESEP are also informed by the original set of guiding principles for lived experience inclusion in suicide prevention developed by Suicide Prevention Australia (SPA) through its lived experience symposium in 2014 which involved 35 lived experience participants who played a significant role in shaping these principles.

The LESEP are also informed by a decade of experience working with, walking alongside, and deeply listening to people with a lived experience of suicide. We have also drawn on expertise from our organisation's internal and external networks, including our Lived Experience Advisory Group, National Lived Experience Collective, and an extended team of staff, facilitators, and mentors (all of whom have a lived experience of suicide).



TRUST & SAFETY

Statement of Commitment: We are dedicated to establishing and maintaining authentic relationships of trust and an environment of physical, emotional, and cultural safety.

Effective engagement and partnership with people with lived experience of suicide is only possible if there is a systematic effort by an organisation and its staff to establish and maintain relationships of trust. It is common for people with lived experience to have had hurtful and even profoundly harmful experiences when seeking support for themselves or others that have traumatised and disempowered them.

This is especially true for people whose low levels of trust are a direct result of being subject to involuntary treatment within public mental health services, or negative and demeaning responses in other health settings such as general practice and emergency departments. The same applies for individuals whose experiences of stigma and discrimination have been traumatically compounded through their contact with mainstream services, including First Nations people and people who identify as LGBTIQ+.

Relationships of trust can only be built with people with lived experience of suicide when they are considered autonomous experts of their own lives and given choice and control to determine what they need.

A fundamental enabler to building trust is to create an environment that is safe and supportive for the unique needs of people with lived experience of suicide. What constitutes a safe environment can be highly subjective and dependent on an individual's unique set of life experiences. There are, however, some specific measures that can be implemented that will contribute to creating a safe and supportive space for everyone to share their deeply personal experiences openly and honestly. If these conditions are met, people with lived experience of suicide are much more likely to feel comfortable sharing their insights and contributing to the engagement process in a positive and effective way.

It is important to note that 'safety' in the context of lived experience of suicide is often assumed to mean safe in the traditional clinical sense – that people with lived experience of suicide are inherently vulnerable and need to be 'risk managed'. Many people with lived experience of suicide recognise that the greatest risk to the safety of a person with lived experience is to not have their experiences acknowledged and validated and their voices heard. People with lived experience have often developed profound levels of resilience to speak openly about, and listen to others speak openly about, their experiences of suicide. Safety includes being able to access support, even in times of crisis, without the fear of, or experience of, coercive, stigmatising or harmful responses that increase despair and hopelessness. Further, safety must be understood in holistic terms - encompassing physical, emotional, psychological, and cultural forms of safety. This is especially important in the context of ensuring Aboriginal Self-determination.

What people with lived experience of suicide say

TRUST & SAFETY
feels like

"Trust & safety are achieved through presence. Being fully present with ..."

"...Actually having organisations listen & take in what we say about the lived experience viewpoint."

"Feeling comfortable to be me."

RESPECT & COMPASSION

Statement of Commitment: We are dedicated to honouring our common humanity, respecting difference, and treating others with compassion.

The fundamental human right of all people to be treated with respect and dignity is a core principle that should guide all aspects of engagement with people with lived experience of suicide. This is especially important because many people with lived experience have been disempowered either because of their rights being explicitly denied, or through the prejudice and stigma surrounding suicide. This must extend to all forms of engagement and partnership, from service use to consultation and co-design processes. Respect must include honouring the unique nature of each individual and therefore the diversity of each person's experiences and perspectives. Appreciating the full breadth and diversity of lived experience of suicide means respecting the full breadth and diversity of people's experiences, bodies, and cultures, as well how these various aspects of someone's identity intersect in complex ways with their lived experience.

It is also necessary for dominant power holders to develop a deep understanding of the role of trauma in the development of suicidality, as well as the trauma associated with a person's experiences of seeking support or supporting someone to do so within mainstream clinical services. Further, suicide bereavement needs to be understood as a traumatic loss that has ongoing impacts throughout all life stages and life transitions of a person who has lost a loved one to suicide. The ways in which this complex trauma leaves an intergenerational legacy within families and communities must also be understood. This requires staff to cultivate respect and compassion for people who may express their trauma through strong emotional responses when being exposed to further stigma and prejudice. It requires each and every person involved to connect to the common humanity of suffering without judgement and with genuine curiosity in order to be open to, and acknowledging of, the deep hurt and harm people have experienced.

What people with lived experience of suicide say

RESPECT & COMPASSION

feels like

"Compassion is knowing someone will sit with me & understand life is not always straightforward – it is complicated. Someone who does not have high expectations but trusts me to be resilient and capable despite my experience – someone who empowers me to grow & use my experience to make a difference."

"... having someone from a different background hear my story & listen without judgement- regardless of their own view."

"Feeling believed, heard & validated with empathy."

"...being able to offer your views even if perhaps not everyone agrees. Offering your reasoning behind your views. With respect."

COLLABORATION & POWER SHARING

Statement of Commitment: We are dedicated to showing humility and generosity to create space for others to meaningfully contribute.

Genuine engagement and partnership of people with lived experience of suicide is grounded in a deep commitment to collaboration and power sharing. Sharing power is the core principle of co-design and co-production. This is especially important when the distribution of power is particularly unequal, such as between service providers or commissioning agencies and people who have had unhelpful or harmful experiences seeking support, supporting someone to do so, or navigating the aftermath of a suicide. When power differences aren't named and owned, decision making remains wholly with traditional experts and existing power structures are maintained. As a result, established institutional practices that have been proven to be ineffective are reinforced and thus there is no service improvement or system change.

It is therefore vital that organisations (as the dominant power holders) critically reflect on, and actively seek to reduce, the power imbalances inherent in engaging people with a lived experience of suicide in their activity. This involves an ongoing commitment to rebalancing power in all aspects of an engagement process. This in turn requires cultivating a humble and generous approach to listening and learning from people with lived experience of suicide who bring different, but equally valuable, insights and expertise to the table. All stakeholders need to develop the capacity to view different perspectives with compassionate curiosity, seeking first to understand the deeper context of each other's worldview, and then a willingness to navigate differences in order to learn from others. It is equally important that the commissioning agency demonstrates its commitment to collaboration and power sharing by adequately remunerating people with lived experience for their time, energy, and expertise and resourcing any capacity building support required for people with lived experience to be able to contribute to change processes in an effective and sustainable way. This can include training to prepare for co-design or service development activities, or pre-briefing sessions so that people with lived experience have access to a complete prior understanding of the context of the service.

What people with lived experience of suicide say

COLLABORATION & POWER SHARING

feels like

"Knowing the value and power of your lived expertise but moving through the world with kindness & humility. Focussing on understanding & learning from others rather than being quick to judgement. Remembering that we never know the struggles of others or what pain lies beneath the smile."

"My input & contributions are seen heard and valued, not dismissed or treated less because of my lived experience."

"Listening & being present. Asking & inviting people to be involved, to share their expertise, proactively creating opportunities for involvement widely."

"Listening to someone's views & their solution without judgement - offering your own view in a respectful way - we can be different and get along."

TRANSPARENCY & ACCOUNTABILITY

Statement of Commitment: We are dedicated to ensuring all our communications & actions are honest, open, and transparent & we hold ourselves accountable for them.

A vital part of engaging people with lived experience of suicide is ensuring that all communications are open, honest, clear, and transparent. Continuous communication also acts as a key accountability mechanism. Building trust and credibility with people with lived experience only occurs when the value of their contributions is acknowledged, and this includes keeping them updated about how their contributions are being used. This requires ongoing and continuous communication with lived experience participants before, during and after the active engagement phase.

When engaging people with lived experience of suicide it is also imperative that there is complete transparency as to the purpose of the engagement. If desired outcomes have already been determined by those with decision making power prior to engagement, or if there are any hard parameters that may constrain the capacity for the input of people with lived experience of suicide to be meaningfully utilised, these must be communicated upfront or as they emerge. Failure to respect the importance of transparency will inhibit the quality of engagement, breach the trust of the participants, and jeopardise future engagement and partnership opportunities. It is also essential that any outputs generated by a consultation or co-design process are fed back to lived experience participants to confirm that what was shared has been captured accurately. It also demonstrates respect for the often very personal input that people provide, and for the time that participants have given to contribute to the process. This will also build engagement with the project and inspire a sense of collective ownership over its success.

It is inevitable that there will be challenges in bringing together a broad range of stakeholders with varying experiences, expertise, insights, expectations, and preconceived ideas around a shared purpose. Relationships based on the foundational principle of accountability are core to ethically navigating the challenges inherent in complex change processes. Having the humility to own your mistakes or shortcomings and take accountability for your words and actions will result in more meaningful and effective engagement by all parties.

What people with lived experience of suicide say

TRANSPARENCY & ACCOUNTABILITY

feels like

“Being upfront about any hard boundaries – what is actually possible through this conversation/co-design? - & being humble and courageous enough to admit when you don’t know but are keen to learn.”

“...admitting when you’ve made a mistake - owning your actions and words.”

“My input is valued & not diluted to suit what an organisation agrees with or is comfortable facing up to.”

“To ask for insight is to ask a great price. People with lived experience of suicide offer, with courage, their story, learnings & advice – not to be wasted. One must mean what they say & do which they promise.”

DIVERSITY & INCLUSION

Statement of Commitment: We are dedicated to ensuring equitable and inclusive representation of the full breadth and diversity of lived experiences of suicide.

Diversity and inclusion are more than just a set of abstract principles; if these are to be meaningful, they must be linked to a tangible increase in diverse and inclusive representation in an organisation's suicide prevention activity. A genuine commitment to diversity and inclusivity requires substantial investment in time, money, and other resources for building in - rather than bolting on - engagement processes that are tailored to the unique needs of a range of culturally diverse groups and communities. This is especially important in the context of suicide prevention where people who already experience high levels of systemic stigma and discrimination have the traumatic impacts of this experience compounded through hurtful and harmful exposure to mainstream clinical services. This reinforces understandably low levels of institutional trust, so it is even more important for dominant power holders (such as government agencies commissioning lived experience engagement processes) to spend time building/re-building relationships of trust that are grounded in the humility to listen and learn from marginalised voices whose insights and wisdom are vital to meaningful culture change.

There is further consideration for diversity and intersectional perspectives that is required in the context of suicide prevention. The 'missing voices' that need to be engaged extend beyond culturally marginalised population groups to all people who have not or will never again access clinical services. Attention must also be paid to the heterogenous nature of lived experience of suicide which spans experiences of suicidal thoughts, suicidal crisis and/or attempt, caring for someone or being bereaved through suicide, as well as to the diversity found in the various individual, situational, and systemic factors that contribute to a person's experiences of suicidal distress.

A genuine commitment to include a rich and diverse range of lived experiences of suicide requires not only an appreciation of the way these experiences intersect with many other social and cultural features of people's lives and identities, but also adequate resourcing of recruitment and engagement processes customised to meet the nuanced cultural needs of everyone.

What people with lived experience of suicide say

DIVERSITY
& INCLUSION

feels like

"... recognising how we all grieve & survive differently. Embracing each person's uniqueness. Being able to work from a place of strength & unity, despite any difference."

"Great diversity and inclusivity values driven organisations literally ooze a palpable culture that says we are bold, we're humbly all different, but we're united for the common good & we want you here."

"... when someone leans in closer to hear & see you. To be a champion, an ally. Offering in return for your insights, the vulnerability to share in your story & the journey that comes with it."

REFERENCES

The Lived Experience of Suicide Engagement principles (and associated implementation toolkit) are informed by, and build on, the guiding principles articulated in a range of best-practice engagement and partnership guidelines, frameworks, and other guidance documents outlined below:

- Black Dog Institute's LifeSpan Lived Experience Framework.
- National Mental Health Commission's Consumer and Carer Engagement: a practical guide
- National Mental Health Commission's Sit beside me, not above me: supporting safe and effective engagement and participation of people with lived experience
- Mental Health Commission of NSW's Lived Experience Framework
- Victorian Department of Health and Human Services' Mental Health Lived Experience Engagement Framework
- University of Melbourne's Co-production: putting principles into practice in mental health contexts
- Agency for Clinical Innovation's A guide to build co-design capability: Consumers and staff coming together to improve healthcare
- Substance Abuse and Mental Health Services Administration (SAMHSA)'s Concept of Trauma and Guidance for a Trauma-Informed Approach
- Blue Knot Foundation's Organisational Guidelines for Trauma-Informed Service Delivery



Lived Experience of Suicide Engagement Principles

(LESEP) Guidance Document v1.2

Written by Roses in the Ocean



Roses in the Ocean
stemming the tide of suicide

☎ 1300 411 461

✉ enquiries@rosesintheocean.com.au

🌐 www.rosesintheocean.com.au

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