

Lived Experience of Suicide Summit 2021

**Defining Outcomes and Measuring Impact
in Suicide Prevention - Workshop Report**

Background

Development of an Impact Framework for Roses in the Ocean

Roses in the Ocean is developing an organisational Impact Framework (the Framework). The Framework will demonstrate how the work of the organisation translates to lasting impact across communities, sectors and systems.

The aim of the Framework is to enable Roses in the Ocean to better understand the impact of its work, design future services to maximise impact, and will guide how the organisation monitors, evaluates and reports on the impact of its activities.

Defining outcomes and measuring impact

Purpose of the Workshop

Beacon Strategies and Roses in the Ocean staff co-facilitated a workshop at the Lived Experience of Suicide Summit 2021 on 20 September 2021, hosted by Roses in the Ocean. 32 people attended this workshop.

This workshop was an opportunity to hear the voices of people with lived experience of suicide and understand outcomes of importance *for lived experience delegates*. We then explored the role of Roses in the Ocean in measuring and communicating the impact of lived experience of suicide in Australia.

The workshop was conducted over two sessions.

Session 1 of the workshop sought to gain a better understanding of the outcomes that are most important to:

- a person in crisis
- the community preventing suicide
- supporting loved ones and carers
- supporting people bereaved by suicide
- supporting people impacted by suicide (eg. first responders).

Session 2 of the workshop asked participants to explore the role of Roses in the Ocean in measuring and communicating the impact of lived experience of suicide in Australia. Session 2 also asked participants to consider the desired impacts and long-term changes that should be sought across the following key areas of impact:

- Advocacy and awareness
- Training and development
- Delivering training
- Co-designing services.

Workshop Session 1

Overview

Session 1 of the workshop sought to gain a better understanding of the outcomes that are most important to:

- a person in crisis
- the community preventing suicide
- supporting loved ones and carers
- supporting people bereaved by suicide
- supporting people impacted by suicide (eg. first responders).

Who are we sharing the space with today?

Utilising the Slido platform, attendees were asked to answer the question 'Who are we sharing the space with today?' by selecting one of or more of the following options:

- I have a lived experience of suicide - **68%**
- I have lost a loved one to suicide - **42%**
- I have cared for a loved one through a suicidal crisis - **35%**
- I have been impacted by suicide (but do not identify with the options above) - **10%**
- I do not have a lived experience of suicide - **3%**.

Defining outcomes

In supporting someone experiencing a suicidal crisis, what are the most important or desired outcomes?

Responses

- **Autonomy:** The person in crisis has their autonomy respected
- **Knowledge of supports:** The person in crisis knows about available supports that can assist them through their crisis
- **Non-judgemental listening:** The person in crisis is listened to and heard by the person/people supporting them through their crisis
- **Connection to community:** The person in crisis should feel supported and connected to their community
- **Safety in all its forms:** Safety was interpreted in multiple ways including; safety to speak; physical safety; emotional safety; and safety for the carer
- **Alive:** That the person in crisis is able to survive the crisis. This was repeated frequently
- **Reduced distress:** Reducing the immediate level of felt distress by the person in crisis was considered important
- **Strengths-based:** Support is given in a strengths-based manner
- **Understanding of lived experience:** Support is given in a way that is informed by an understanding of their experiences
- **Postvention/post-suicide support for carers:** Carers and others are given affirmation and appropriate supports if their intervention was not successful
- **Involving carers:** Carers are supported to take part in the conversation and empowered to intervene in a crisis

- **Manage risk with a stepped response:** Carers understand the difference between suicidal ideation, suicidal plan and intent - and each level of risk for the person in crisis is treated accordingly.

In preventing suicide within communities, what are the most important or desired outcomes?

Responses

- **Mental health literacy:** The community has a high level of mental health literacy
- **Removed stigma:** Stigma around suicidality and people experiencing crisis is removed.
- **Funding for services:** Services are well-funded
- **Community knowledge of support:** The community knows how to support a person at risk or experiencing a suicidal crisis
- **Community ability to support:** The community has an enhanced ability to support a person at risk or experiencing a suicidal crisis
- **Knowledge of services:** The community is aware of available services for a person in crisis
- **Supporting clinicians:** Supporting clinicians to provide support to a person in suicidal crisis
- **Access to services:** Services for people in suicidal crisis are more widely available and are easily accessible
- **Non-clinical spaces and non-government spaces:** Spaces are available to people in crisis that are not clinical spaces or government-defined spaces
- **Culturally safe spaces:** Spaces for suicide prevention are culturally safe for all
- **Community postvention:** Community-wide supports and interventions are available following a suicide
- **Targeting risk:** Services and funding are targeted to identified risk-factors for suicide
- **Not a burden:** The community supports people experiencing crisis to feel that they are not a burden on others or services
- **Meet them where they are:** There is no wrong door to suicide prevention and people are not expected to 'reach out'
- **Mental health first aid:** Mental health first aid is available through workplaces.

In supporting carers and loved ones of people who are suicidal, what are the most important or desired outcomes?

Responses

- **Culturally appropriate carer support:** Supports should be culturally appropriate
- **Support person/family contact:** The person in crisis is able to contact the carer or family
- **Age and stage appropriate support:** Support is appropriate to the age and life-stage of the person in crisis
- **Assistance to understand lived experience:** The carer is supported to understand how lived experience is valuable
- **Recognise that carers are not always best-placed to assist:** Understanding the limitations of a carer or family support person for a person in crisis
- **Services are accessible to carers:** Carers are able to easily access support services for themselves and others

- **Carers are supported:** Carers are informed and supported in their role, and service providers have a better understanding of the needs of carers
- **Individualised care:** Care meets the individual needs of carers
- **Training for carers:** Carers are provided with training to assist them
- **Respite for carers:** Carers receive respite from their caring responsibilities and are appropriately supported to take breaks
- **Peer support and networks:** Carers are enabled to engage with peers and form networks of support
- **Post crisis care:** Carers are given appropriate post-crisis support and care
- **No-fault support:** Carers are affirmed that no outcome for the person they support is their 'fault'
- **Consultation about the person's care:** Carers are consulted in the care of the person they support.

In supporting people who are bereaved by suicide, what are the most important or desired outcomes?

Responses

- **Awareness of prolonged grieving:** There is awareness that grieving and loss are ongoing for bereaved and extend beyond the initial grief period
- **Awareness of prolonged recovery:** Awareness that recovery for a bereaved person may take an extended period of time, and that for some full-recovery may not occur
- **Awareness of ongoing harms:** The needs of children affected by suicide are met and their voices are heard, and training is provided for those who care for these children
- **Support on the person's timeline:** Support is available for the bereaved at the times they need it, in the short and long term
- **Suicide prevention:** The risk to bereaved is recognised and there is support for suicide prevention
- **Reducing suicidal ideation:** Bereaved are supported to reduce their thoughts of suicide
- **Peer support:** Bereaved have access to compassionate peer-led support services
- **Community care:** The community are able to support the bereaved person
- **Culturally safe services:** Services are provided that take into account; Aboriginal and Torres Strait Islander identity, country of birth, religion, and how these translate into experiences of bereavement
- **Variety of support options:** A variety of options are available for the bereaved
- **Reduction of isolation:** The bereaved have a reduction in their level of isolation
- **Listened to:** Bereaved are listened to by those around them and those involved in their support and care
- **Support to grieve:** Bereaved are supported to grieve
- **Acknowledge and raise risk to bereaved:** There is awareness of the risk of suicide in the bereaved and this is handled appropriately
- **No-fault/blame approach:** Awareness and acknowledgement that there is no blame for the bereaved
- **Reduce stigma:** Stigma is reduced for the bereaved
- **Intergenerational trauma:** Intergenerational trauma is reduced and prevented
- **Support to reduce distress:** Bereaved are supported to reduce the distress they feel.
- **Options for non-clinical treatment:** Bereaved have options that include non-clinical treatments
- **Immediate access to support:** Bereaved have access to support services immediately

- **Sensitivity in support:** Support services for the bereaved are sensitive to the needs of the bereaved (such as support people who are not the same age as the person who suicided)
- **Bereaved are valued as voices in suicide prevention:** The bereaved have a voice in the area of suicide prevention and their experience and input is valued.

In supporting people impacted by suicide (e.g. first responders and health professionals), what are the most important or desired outcomes?

Responses

- **Support following crisis response:** First responders and medical professionals are supported in the immediate and longer term after attending a suicidal crisis or event
- **Support through vicarious trauma:** Are supported to deal with the vicarious trauma that they may experience in their work
- **Not responsible for actions of others:** Are supported to understand that they are not responsible for the actions of a person in crisis
- **Openness and collaboration:** Are supported to be open among their peers and others working with people experiencing crisis, and to collaborate as appropriate
- **Support without judgement:** Are able to talk about their own experiences without fear of judgement
- **Remove stigma in seeking care:** Stigma is removed around receiving their own mental health care, and professional harm (deregistration etc.) is removed
- **Debriefing:** Are able to debrief after an event
- **Self-care:** Are supported to utilise self-care where appropriate
- **Recognise their limitations:** Are encouraged to recognise their own limitations in dealing with suicide professionally, and the need to take advice and listen to people with lived experience
- **Alternate staff:** Are supported with alternate staff to enable them to take breaks from dealing with suicide
- **Psychological safety frameworks:** Are provided with psychological safety frameworks that help to ensure mental safety
- **Provide examples of positive outcomes:** Health professionals and first responders are provided with examples of positive outcomes from people who have experienced crisis and survived.

Breakout room conversations

Of the outcomes you provided or saw (in the above exercise) - what is the most meaningful outcome indicator that programs/services should be aiming for?

Responses

Safety is emphasised

- Safety - across many of the outcomes
- Safety for the individual and those around them.

Medical professionals and first responders are trained and equipped to deal with suicide

- Looking after first responders, their own suicidality, and vicarious trauma
- The pressing need is for response amongst first responders, training
- Support from vicarious trauma
- Suicide response training
- GPs; build their capacity and have them trained.

Reduce stigma and perceptions of 'burden'

- Stigma from first responders and supporting people
- Battle stigma and community attitudes
- Reduce stigma
- Letting people know they're not a burden.

People are connected to supports and made aware of these

- Connected to supports in local community
- [there are a] breadth of identifying supports
- Post-crisis support
- Supports and services
- Knowing where to turn
- Accessibility of support services.

Support emphasises listening and feeling, and allows people to grieve

- Listen rather than talk
- Listening is very important.
- People being heard and supported
- Allow them to feel and sit where they are
- Its okay to feel sad, its okay to be grieving
- Normalising thoughts and feelings.

Carers and bereaved are supported

- Carer and bereaved are supported to reduce self doubt and guilt
- Care, support and information for carers
- Are helped as a bereaved person.

Support is tailored to diverse needs

- People with neuro-divergence
- LGBTQIA+ needs
- LGBTQIA+ training, disability training, CALD training
- Tailored personalised
- Support needs to be individualised and tailored.

Indicators meet needs

- Recording statistics
- Not just immediate outcome indicators.

Support is trusted, immediate, coordinated and reaches out

- Not having to wait
- How do we reach people [directly]
- Coordinated response
- Trust when you engage with the service.

Other outcomes categorised as 'most important':

- **Psychosocial non-clinical supports**
- **Trajectory of ideation**
- **Mental health first aid**
- **Ownership of lived experience.**

Of the outcomes you provided or saw - what is the least meaningful outcome indicator that programs/service should be aiming for?

Responses

- "Safety and risk is automatically implied"
- Some [outcome measures] feel very old and not meaningful, and need to allow for proper measurement of how things are
- [Measures should look at] "How you best engage people, and not be just another checklist or other simple instrument"
- Comment from a participant was that they didn't want to answer this question as they were hesitant to pass any judgment on another person's responses. The rest of the participants agreed. So that session moved back to the 'most meaningful' question
- Other participants in other sessions had similar responses and were reluctant to comment.

Workshop Session 2

Overview

Session 2 asked participants to consider the desired impacts and long-term changes that should be sought across the following key areas of impact:

- Advocacy and awareness
- Training and development
- Delivering training
- Co-designing services.

Session 2 of the workshop also asked participants to explore the role of Roses in the Ocean in measuring and communicating the impact of lived experience of suicide in Australia.

Advocacy and awareness - What are the desired impacts or long-lasting changes of a lived experience organisation in advocacy and awareness activities?

Responses

Stigma reduction and culture change

- Reducing stigma
- Reducing stigma in healthcare
- Reduction of stigma
- Stigma reduction
- Culture change.

Putting lived experience at the table in decision making

- Being at the table in decision making, Lived experience at the table in decision making
- Representation of lived experience in decision making
- Being at the table in decision making.

Supporting all lived experience

- Supporting lived experience
- Encompassing all lived experiences.

Recognising and supporting intersectionality and diverse needs.

- Intersectionality and meeting diverse needs
- Intersectionality in advocacy.

Emphasising expertise in lived experience

- Emphasising expertise alongside experience
- Supporting expertise.

Advocacy for education in schools

- School education
- Training and education
- Advocacy for school education
- School education.

Other impacts of importance:

- **Advocacy and awareness**
- **Demedicalising experience**
- **Credentialing.**

Training and development - What are the desired impacts or long-lasting changes of a lived experience organisation in training and development?'

Responses

Training is frequent and available

- Frequent training opportunities
- Frequency of opportunities.

Training on language:

- Training on language
- Language used is important.

People with lived experience are safe and enabled

- Safety and safety in sharing experiences
- Those with lived experience are enabled to make a difference.

Peer lived experience groups are supported and well run

- Allowing attendance at peer lived experience groups
- Peer lived experience groups are well run and sustainable
- Lived experience groups.

Training is accredited, and consistently of high quality

- Consistency and quality of training
- Accreditation and regulation in training
- Ensuring consistency and quality of training.

Valuing all lived experience:

- Certification should not come at the cost of people with lived experience
- Validation for all lived experience.

Suicide is openly discussed

- Suicide should be openly discussed
- Suicide is more openly discussed.

Other impacts of importance:

- **Engage people in community roles**
- **Empathy is important**
- **Training should be implemented in small towns**
- **Engaging diverse communities with subject matter experts**
- **Experience is not equivalent to expertise.**

Delivering services - What are the desired impacts or long-lasting changes of a lived experience organisation in delivering services?

Responses

Services are designed for users rather than funders

- Service design for people
- Services are designed for users
- Avoid 'designing for funding'.

Change is measured

- Measurement is important
- Measurement is important .

Call lines should be included

- Call lines are included
- Call lines are utilised.

Suicide prevention services meet people's practical needs (housing etc.)

- Housing and other needs are considered
- Meet people's needs.

Services should meet diverse backgrounds and be intersectional

- Training and communication for people with diverse backgrounds
- Services are intersectional.

Lived experience creates credible services and should be supported with training

- Training for people with lived experience
- Lived experience provides credibility
- Credible services
- Lived experience is included
- Training for people with lived experience to provide services.

Other impacts of importance:

- **Services should be accessible from other services**
- **Empathetic services.**

Co-designing services - What are the desired impacts or long-lasting changes of a lived experience organisation in co-designing services?

Responses

Co-design should be accessible

- Should be accessible to those with lower computer skills
- Co-design is accessible to all
- Accessible.

Co-design should lead to services that are accessible and inclusive

- Services are accessible to people in regional areas
- Services should be available regionally
- Services should be safe for people with diverse backgrounds and experiences
- Inclusive of all diverse areas
- Services are safe for people with diverse backgrounds
- Lived experience organisations should deliver services.

Engaged health professionals should be involved in co-design

- Should include both people with lived experience and engaged health professionals
- Health professionals engaged in co-design should have skills and want to participate
- Engaged professionals should be involved in co-design.

Should empower and include people with lived experience

- Should empower and show strength of people with lived experience
- People with lived experience should be involved in design
- People with lived experience should be paid.

Should highlight a diversity of lived experience

- People with diverse experience should not be token participants
- Different perspectives are included
- Should include people with a diversity of lived experiences
- Diversity should be represented in co-design
- A diversity of lived experience is included
- A diversity of experiences in co-design processes.

Lived experience organisations should lead in co-design

- Lived experience organisations should lead co-design
- Organisations should have strength in co-design
- Lived experience organisations (eg. RITO) are leaders in co-design processes
- Lived experience organisations should lead co-design processes.

Genuine co-design should be standard

- Co-design becomes standard practice
- Co-design should be engaged, rather than consultation

- Co-design should be used widely.

Co-design should lead to useful services provided with care

- Co-design leads to better care
- Should lead to useful services
- Services are useful and helpful
- Meets diverse needs
- People are treated with care
- Services are helpful and accessible.

Co-design should lead to community buy-in

- Community buy-in
- There is community buy-in
- Co-design includes all.

Other impacts of importance:

- **Services should encourage help seeking behaviour**
- **Co-design leads to shifts in power dynamics**
- **Showcase co-design successes**
- **Lived-experience advisory groups should be supported to participate.**

Measuring and communicating impact - how can Roses in the Ocean measure and communicate the impact that lived experience of suicide makes?

Responses

Utilising a range of technologies and forums

- Invite people to voice their opinion on radio and forums and collect data
- Modern technologies like tik tok and things that speak to the next generation of advocates.

Using data

- Use validated measures that have been co-designed with people with LE or create new validated measures
- Measuring the impact of lived experience would probably be best analysed as qualitative data, with attempts to shift into quantitative data potentially opening doors to invalidation or re-stigmatising those people and their experiences
- Qualitative research with service users in how LE has helped or would have helped if available
- Value qualitative over quantitative measures.

Telling stories

- Sharing our stories
- Storytelling
- To make sure all different people and communities are heard and their individual needs met. To listen to many stories.

Recovery and good news stories

- Recovery focused storytelling/good news stories from recovery journeys of individuals.

Local and community networks and forums

- Measure - there needs to be a connection / partnerships with people on the ground in all areas of the country - eg local lived experience networks Communicate - national campaign / messaging and also through those local networks with clear messaging and calls to action
- Yes to the local lived experience networks
- Community forums hearing from people with LE Storytelling Case studies Surveys Research studies Community based feedback forums.

Communication that includes all voices and audiences

- Let every voice be heard and it's never a 'one size fits all' response
- Clearly knowing the audience and using their communication styles/preferences.

People with lived experience measure their own impacts

- Teaching those with a lived experience how to measure the impact that they are able to see in their own lives
- Encourage measuring the little victories that those with a lived experience encounter
- Increase in numbers to the roses in the ocean collective and those wanting to be part of the movement.

Communicate both successes and failures

- Case studies of when things have worked and not worked
- I think communication of the impact of the lived experiences should be as transparent as possible - yes, it is important and undeniably beneficial, but any downfalls/less-successful situations should still be communicated.

Lived experience is documented and made real

- Those not with a lived experience being more human and real
- Talking to people and listening to what they are saying and then either sit with the moment or respond appropriately. Then feedback
- Documentation and reflection of conversations/connections made through sharing lived experience.

Roses in the Ocean is an advocacy leader

- Being a voice to advocate for those with lived experience of suicide. Roses in the Ocean have a large voice on many levels within Australia and being able to use that to listen to those with lived experience and sharing that on a grander scale to affect funding and policy within governments and organisations
- Establish a single purpose advocacy sub set of Roses in the Ocean; communication with all media politicians and SPA members; and check against public awareness of Roses in the Ocean.

Other ways of measuring and communicating impacts of importance:

- **Use arts-based methodologies**
- **Learn from how others about their experience of advocacy**
- **Look forward to celebrate RITO 21st**
- **Ask organisations or government services if they know about the impact lived experience has contributed. In my experience, most won't even be able to tell you who sits on the board or who has contributed from a lived experience perspective**
- **Staff satisfaction surveying.**