Health
Nepean Blue Mountains
Local Health District

Roses in the Ocean
stemming the tide of suicide

Towards Zero Suicides
Co-Design of Alternatives to ED
Participant Information Pack

"People that have had the actual experience of suicidality need to be involved in determining what, how an alternative to clinical services looks, how it will feel, how it will operate, and hopefully how it will work to start to bring down the incidence of suicide in this region."
– Bruce McMillan, Lived experience

"Listening is a hard thing for some professionals to do because we are trained to focus on words and linear events; but as humans, we all share and understand things best through stories.

Great co-design is built on stories told by many people. Often, it is motivated by peoples' desire for health services to be better for others, including those who are not yet served. "
– Dr David Alcorn,
Clinical Director- Mental Health Service ISLHD

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WELCOME AND BACKGROUND TO PROJECT

Suicide affects everyone and we all have a role to play in suicide prevention.

Australians from across all sectors and communities have been working hard for many years to address the devastating impact of suicide. It is now recognised that substantial change is required to improve current services for people in crisis and develop alternative supports to better meet people's needs.

Since 2018, the NSW state government has invested in innovative suicide prevention initiatives that aim to contribute to the aspirational goal of "zero suicides" across the state. These initiatives are called the *Towards Zero Suicides* initiatives and sit under the Strategic Framework for Suicide Prevention 2018-2023.

The NSW Ministry of Health has allocated funds to the Local Health Districts (LHDs) for a number of the Toward Zero Suicides initiatives, including:

1. **Zero Suicides in Care** - supporting the re-design of current services to prevent suicides among people accessing public mental health services, whether they be within hospitals or in the community.
2. **Alternatives to ED**– providing an alternative to emergency departments (ED) for people experiencing a suicidal crisis. Safe Spaces will provide a welcoming, non-clinical environment for people to connect with peer workers and find information about a range of other supports.
3. **Suicide Prevention Outreach Teams** - providing immediate and follow-up care for people in the community experiencing a suicidal crisis.

The Ministry recognises that it is vital to involve people with a lived experience of suicide at every level of this project and ensure local co-design process determine the shape of these initiatives in individual LHDs. As such Roses in the Ocean has been contracted by the Ministry to establish twenty Lived Experience Advisory Groups across NSW and to lead the co-design of the Alternatives to ED safe spaces across the state.

Roses in the Ocean defines Lived Experience of suicide as …. having experienced suicidal thoughts, made an attempt on their life, cared for a loved one through suicidal crisis or been bereaved through suicide.

It is important that people with a lived experience relevant to individual initiatives are involved in co-design processes.

The Towards Zero Suicides initiatives provide a unique opportunity for the Local Health District to bring together a rich and diverse group of stakeholders to collaborate with the common purpose of designing supports that better meet the needs of people in suicidal crisis.

The Alternative to ED initiative calls for a local co-design process to determine the nature of a safe space that fits the specific needs of the community. Roses in the Ocean has developed a co-design process specific to co-designing with people with a lived experience of suicide to establish services for community. Our process is based on the Experience Based Co-design (EBCD) approach endorsed by the Agency for Clinical Innovation (ACI).

The Ministry has developed guidelines and directives of essential elements for the Alternative to ED initiative and the Suicide Prevention (SP) Peer Workforce that will staff them, which will be provided to all participants prior to the co-design commencing. These provide some key components for the initiatives, such as being non-clinical with a non-clinical workforce, that must be adopted into local co-design. It is also recognises that more boundaries may emerge during the co-design process which will be explored with participants as they emerge.

This Information Pack has been developed to help support the local co-design of the Alternative to ED initiative within LHDs.

We warmly welcome the contributions of all who seek to help reduce suicide attempts and deaths. We genuinely believe in aspiring to zero suicides, understanding that we will not save everyone, but we can save many, and appreciate all who share in the journey towards making this a reality.

We believe that suicide prevention activities are made more effective and efficient when developed through a broad range of perspectives. People who have their own experiences of suicidality and those who provide support want things to improve. Many have experienced how the current support systems have caused additional distress and trauma. We want to hear all your perspectives.

The current experience and need for an alternative

People's experience presenting to ED with suicidality is currently being examined in an Australian research study. Preliminary results show that less than 25% of participants reported that they were willing to return to the ED for a future crisis. This willingness to return was strongly related to how positive or negative their experience of crisis care was.

For a while now people with lived experience of suicide have said that although the supports currently available are good, they are not meeting all of their needs. People with previous or current experiences of suicidal crisis often require a range of ongoing supports, particularly when feeling distressed and alone. The services currently available to people when they are in crisis are either telephone support lines or presentation to ED. While these services can be enormously beneficial, many people do not require a clinical response or have found a crisis management approach to their distress unhelpful.

Safe Spaces: what are they and what is the evidence?

Alternative supports known as Safe Spaces are now being developed that take a non-clinical approach to reducing distress in warm, welcoming environments. Safe Spaces are typically operated by peer workers with their own lived experience of suicidal crisis and are open outside of usual hours, including weekends. Visitors can attend a Safe Space to chill out by themselves or with others, have a cuppa and a chat with a peer worker, engage with various sensory activities, work on safety planning, and find out about other local resources and be warmly connected to these. Examples of Safe Spaces already operating in Australia include St Vincent's Safe Haven Cafe in Melbourne and the Brisbane North PHN's Safe Space Network.

According to the Agency for Clinical Innovation (ACI), the benefits of peer support in the health context potentially include: improving social and psychological wellbeing, reducing stress families and carers; improving knowledge and health literacy; and increasing access to services (ACI Consumer Enablement Guide, 2020).

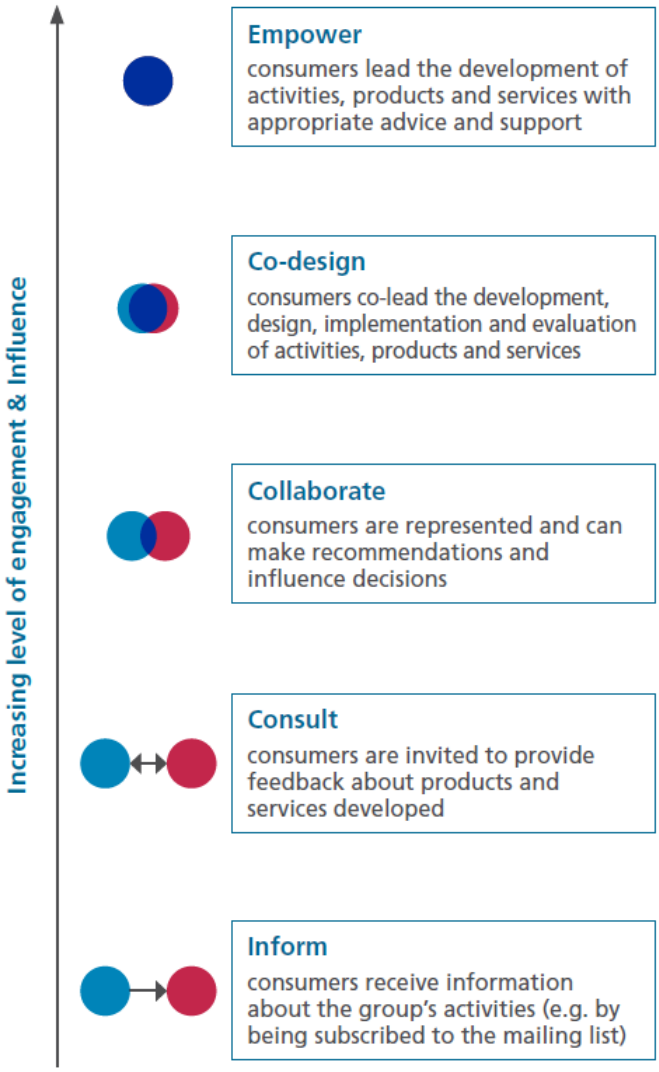
Peer operated Safe Spaces are also beginning to be recognised for their potential to "increase meaningful choices for recovery", as well as to reduce the mental health system's need to rely on "more coercive, less person-centred modes of service delivery" (Croft & Isvan,2015). One study of the same authors found that people who utilised 2nd Story, a residential peer respite program in the US, had a 70% lower use of in-patient or emergency services post-respite compared to people who had not used the support.

What is co-design?

'Co-design' is a fancy word for describing a method of improving or designing services. The thing that is fundamentally unique to this method is how it involves a diverse range of people with lived experience and people who provide services. Co-design means inviting them all to work alongside each other to decide how services could be delivered to better meet the needs of the community.

Key points about co-design:

- It involves exploring, developing and testing solutions to address a co-defined problem or challenge – e.g. designing new support services or improving existing ones.
- It must involve people from a diverse range of perspectives, including people who use, or support others to use, support services (they are experts by experience and must play a key role in shaping the services they use), and people who provide support services. All contributions are valued equally.
- It is ongoing – co-design does not stop once a solution/s are agreed on. Services are evaluated and monitored. Outcomes are fed back to co-design participants who continue to shape and improve the service in an ongoing way.
- It requires transparency about hard boundaries or requirements for the project/service being co- designed - these must be clearly communicated to all participants from the beginning or as soon as possible.
- It requires a commitment by decision-makers to:
  - allocate sufficient time and resources to support the process (including paid participation for people with lived experience, and resourcing to enable staff to participate within work time);
  - implement the designed service / improvements agreed on by co-design participants; and
  - build in ways for people to provide feedback and continually shapes the service.



Most importantly, co-design is more than consultation.

Participation levels figure
Source: Agency for Clinical Innovation
A Guide to Build Co-design Capability

Roses in the Ocean principles of co-design

Roses in the Ocean Principles of co-design
Equal partnership People with lived experience work together with all other stakeholders in the co-design process with a genuine commitment to equal power sharing.
Honest conversation All stakeholders are empowered to speak their truth in a safe and supportive environment, where everyone's experiences and perspectives are respected and valued.
Inclusion Genuine inclusion of all voices is supported and enabled in a culturally safe way through the all phases of the co-design process.
Shared decision making Opportunity is provided for all stakeholders to hear a diverse range of perspectives, develop a common understanding of the issues, collectively explore solutions, and arrive at a place of shared decision making.
Innovation Bold ideas are actively encouraged and creatively captured, in the context of clear communication about the hard boundaries of a co-design initiative. No ideas are lost and will fed back to commissioning agencies and service providers to improve other programs and services.
Purposeful involvement Purposeful identification and engagement of key stakeholders sees the right people at the table, with a clear sense of common purpose and a collective focus on the needs of the people who will directly benefit from the program or service.
Integration Together, people blend their experiences and perspectives in a productive way that achieves an outcome supported through integration with other appropriate touchpoints.

Aligned with ACI Principles

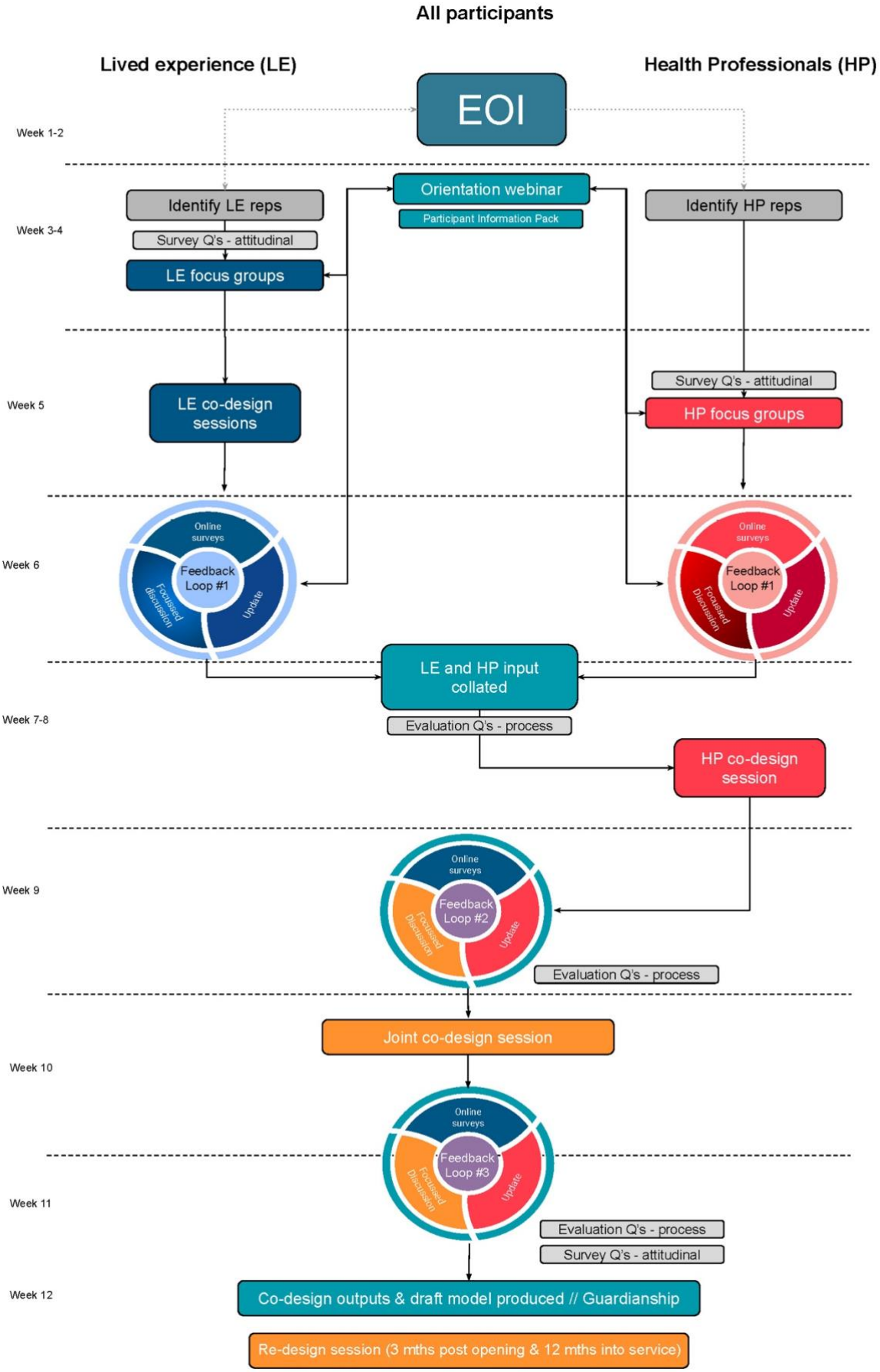
Why do co-design?

- It encourages a sense of collective ownership and community 'buy-in' for the service models that emerge from the process.
- It's more likely that potential challenges will be raised and addressed before services are implemented.
- There's a commitment to monitoring and evaluating the solutions generated by the process in an ongoing way and so the service will be continuously improved.
- The process doesn't just identify the issue, it works to find an agreed solution to it.
- So, the perspectives of people who provide services, as well as people who might use these services, are heard and respected.
- It fosters cooperation and trust between local service providers and service users that has value for the individuals and communities involved beyond the co-design process.
- When done well, the evidence shows that it's more likely to produce services that are efficient, effective and sustainable.

Who's involved in co-design?

To produce the best possible service model, the co-design should include a wide range of perspectives, incorporating what's important to those who will use the service, those who will work in the service, and those who will help connect people with the service.

Roses in the Ocean Co-Design Process



Commitment to ongoing co-design embedded into service model

Paid Participation

Roses in the Ocean and the NSW Ministry of Health recognise the time and efforts in sharing your lived experience to help improve service delivery to your local LHD. Participants from the community are generally volunteers, your contribution is highly valuable, and we believe participants should be paid for generously providing their lived experience expertise.

Roses in the Ocean will be liaising with your LHD on your behalf to arrange payment for your participation in the co-design process. The rate paid is determined by individual LHDs.

You will be eligible to claim 15 hours of your time which allows time for attending codesign focus group conversations, sessions and feedback loop webinar attendance and survey contribution.

If your LHD chooses to have Roses in the Ocean administer the Paid participation we will provide you with a Paid Participation form and the required Australian Taxation Office form.

Self-Care

What do we mean by self-care?

"Self-care" can be understood in many different ways. In its simplest form, the term refers to our ability as human beings to function effectively in the world while meeting the multiple challenges of daily life with a sense of energy, vitality, and confidence. Self-care is initiated and maintained by us as individuals, it requires our active engagement.

The term "self-care" spans a full range of areas: physical, emotional, intellectual, and spiritual. Some visualise these areas by thinking in terms of mind, body, and spirit, or feeling, and behaving. It can be referred to as "wellness", a "healthy balance", "resilience", and sometimes simply, mental health. It is important to note though, that no matter how self-care is defined, in the end, all of these different aspects are interconnected and failure to take care of oneself in one area can lead to consequences in another.

There is no formula for self- care. Each "self- care plan" will be unique and change over time. Ultimately, we must listen to our own bodies, hearts, and minds, as well as to the voices and messages from trusted family and friends, to ensure we are giving ourselves the best 'self-care' we can.

For those of you who already have a self-care plan, we ask that you take some time to review it and update if necessary as you prepare to embark on this co-design process. For those who do not have one in place, you may like to use the Roses in the Ocean self-care plan template at Appendix 1.

The Power of Language

It is widely accepted that the inappropriate use of language when describing suicide and discussion of method, can have a significant impact on people who have a lived experience of suicide, and other members of the community. It is often attributed to fuelling the stigma, prejudice and fear that we still experience surrounding suicide. This in turn can prevent people from seeking help, and indeed reaching out to help others too.

For this reason, we must ensure that when talking about suicide we do not describe 'how' someone took their life, nor do we discuss specific details about a suicide attempt.

The following guide below outlines alternative language:

Do say	Don't say	Why?
'non-fatal' or 'made an attempt on his/her life'	'unsuccessful suicide'	To avoid presenting suicide as a desired outcome or glamorising a suicide attempt.
'took their own life', 'died by suicide' or 'ended their own life'	'successful suicide'	To avoid presenting suicide as a desired outcome.
'died by suicide' or 'ended his/ her own life	'committed' or 'commit suicide'	To avoid association between suicide and 'crime' or 'sin' that may alienate some people.
'concerning rates of suicide'	'suicide epidemic'	To avoid sensationalism and inaccuracy.
A person is 'living with' or 'has a diagnosis of' mental illness	'mental patient', 'nutter', 'lunatic', 'psycho', 'schizo', 'deranged', 'mad' 'spinner'	Certain language sensationalises mental illness and reinforces stigma.
A person is 'being treated for' or 'someone with' a mental illness	'victim', 'suffering from', or 'affected with' a mental illness	Terminology that suggests a lack of quality of life for people with mental illness.
A person has a 'diagnosis of' or 'is being treated for' schizophrenia	A person is 'a schizophrenic', 'an anorexic'	Labelling a person by their mental illness.
The person's behaviour was unusual or erratic	'crazed', 'deranged', 'mad', 'psychotic'	Descriptions of behaviour that imply existence of mental illness or are inaccurate.
Antidepressants, psychiatrists or psychologists, mental health hospital	'happy pills', 'shrinks', 'mental institution'	Colloquialisms about treatment can undermine people's willingness to seek help.
Reword any sentence that uses psychiatric or media terminology incorrectly or out of context	'psychotic dog', using 'schizophrenic' to denote duality such as 'schizophrenic economy'	Terminology used out of context adds to misunderstanding and trivialises mental illness.

(Table taken from: EveryMind)

Whilst we understand that no one intentionally uses language, phrases and conversation to bring distress to others, we do need to be very aware of the conversations we have. At every opportunity, it is important that we improve the suicide literacy of the community including the use non-stigmatising and safe language when discussing suicide.

Further guidelines regarding terminology and discussion of mental health in the media can be accessed through the MindFrame website. Another article of interest is Suicide and language: Why we shouldn't use the 'C' word, by Susan Beaton, Dr. Peter Forster and Dr. Myf Maple.

Person centered language

A new, more person- centered language is emerging in suicide prevention. For example:

Instead of	Consider saying
Patient	Person, participant, guest, visitor, attendee.
Facility	Space, building, location, haven, place, locale, venue, centre, safe space, hub, service, café.
Referral	Link, recommend, connect, offer ideas, options, pathway, invitation, support.
Exclusion criteria	Safety boundaries, mutual expectations, appropriateness, aim of the service, is this the best place for the person?
De-escalation	Addressing the person's need in that moment, conversation, relationship building, empathy, connection, calming, grounding, reducing distress, positive engagement.
Risk management	Safety plan, working with someone to stay safe, dignity of risk, recovery plan, keeping well.
Beds	Places, spaces, place to rest.
Recovery	Journey, discovery, healing, resilience, strengths, positivity, hopefulness.
Triage	Welcome, wellness check, prioritisation, what is important right now, planning, talking, listening.
Assessment	Discussion, what is needed right now, listening to full story, collaborating, understanding.

FAQs: Participating in co-design

What should I consider before deciding to participate?

Even with the best intentions, co-design processes don't always live up to people's expectations. This can happen for a range of reasons, including time pressure and a lack of resources. More importantly, when there isn't a commitment by everyone involved to genuine co-design values and principles, not only are services not being improved, it can lead to increased cynicism about the possibility of change.

A person with lived experience who was involved in a recent local co-design project who had felt "shut down and ignored" by the health system in the past, felt further let down by having their expectations raised, then finding out the service model didn't reflect the ideas generated through the designing phase. The same experience can be felt by health professionals who share their own experiences and ideas.

While there is a genuine commitment to co-design by the various decision-makers and managers in the local region, it is important for people to be aware of the potential challenges before deciding to participate. However, it is important to remember that there will be lots of opportunities for participants to provide feedback throughout the process, feedback loops are built in to check that our understanding of people's input is right, and we commit to sharing what we know about the 'hard boundaries' of these initiatives as soon as we know them.

We will also be undertaking an evaluation of the co-design process itself, and strongly encourage participants to send feedback to us at bridget@rosesintheocean.com.au

How can I participate?

There are a number of options for how you can contribute including:

- Online focus groups
- Online webinars & surveys
- Sharing output from the co-design with your networks; and
- Staying informed via email.

Spaces for the online or face to face co-design process are limited. Participants will be chosen to ensure a diverse group of people who reflect the demographics, priority populations, lived experience and key stakeholders of the LHD region.

Everyone who is not able to join the actual small groups are encouraged to contribute via a focus group, online webinars or surveys, and all contributions will be regarded equally.

What will be expected of me?

- Be fully informed and prepared to contribute – this includes
    - Watching the Orientation webinar.
    - Reading this Information Pack
    - Reading the Ministry of Health's Guidance documents.
    - Reviewing feedback loop information on co-design process
- Make time to participate in all sessions

- Commitment to the values and principles of co-design, including a commitment to:
  - work towards solutions and actively contribute ideas
  - openness and curiosity and to respect others as equal partners.
- Be honest and open about your experiences and perspectives – but only as much as you feel comfortable doing.
- Tell others about the project and its outcomes so that the whole community can be involved in supporting the new service and providing feedback in order to keep improving it.
- Be able to let someone know if you need support
- Participate in the evaluation process
- Send feedback about the co-design process to bridget@rosesintheocean.com.au
- Enjoy the process!

What supports are available?

We encourage all participants to reflect on what supports are available for you prior to getting involved so you can lean on them if you need to at any time during the co-design process. These supports could be natural supports, like friends and family, or support services.

Throughout the co-design process, all focus group participants will be introduced to and have access to a Roses in the Ocean mentor, who will be there to answer your questions and provide extra support should you feel you need it. Reach out to Roses in the Ocean if you would like to speak to your mentor.

There are also a range of national helplines that you may like to reach out to if you feel you require extra support.

Kids Helpline: 1800 551 800 | kidshelpline.com.au

Lifeline: 13 11 14 | lifeline.org.au

Suicide Call Back Service: 1300 659 467 | suicidecallbackservice.org.au

Beyond Blue: 1300 24 636 | beyondblue.org.au

Headspace: 1800 650 890 | headspace.org.au

ReachOut: https://au.reachout.com/

Everymind https://everymind.org.au/need-help

QLife: 1800 184 527. https://qlife.org.au/resources/chat

How can I provide feedback on the co-design process?

Evaluation of the co-design process will include participant surveys for online focus group / co-design session participants, as well as the option for all participants to provide general feedback.

Can I invite others to be involved?

Yes, absolutely. Please feel free to encourage your colleagues or friends or anyone who's interested in suicide prevention to get involved in the co-design process. The more people we have contributing to the shape of these new services, the more likely they are to meet people's needs.

Have the locations and number of Safe Spaces across the Local Health District (LHD) been identified yet?

There will be twenty Alternatives to ED safe spaces established across NSW through this project with at least one in every LHD region, and two in the geographically larger regions. The actual location within each LHD will be informed by the co-design process and influenced by the amount of funding available. While this means we aren't able to establish Safe Spaces all across the LHD region, this is an important step in improving the options people have to seek support.

Are Safe Spaces going to be supporting all age cohorts?

The co-design process will inform what ages are able to be supported by the Safe Spaces but it hoped that they assume a 'no wrong door' approach and be in a position to connect anyone to the most appropriate and useful supports if the safe space if not able to provide the support they are looking for.

Appendix 1 – Personal Self Care Plan (template)