

Towards Zero Suicides Co-design Participant Information Pack Illawarra Shoalhaven 2020

“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

Welcome

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.

The Ministry recognises that it is vital to involve people with a lived experience of suicide at every level of this service re-design and co-design, and a local co-design process will determine the shape of these initiatives in the Illawarra Shoalhaven. For more information on who is meant be people with lived experience please see '[Who is involved in co-design](#)' section below.

The *Towards Zero Suicides* initiatives provide a unique opportunity for the Illawarra Shoalhaven Suicide Prevention Collaborative (the Collaborative), in partnership with the Illawarra Shoalhaven Local Health District and the Primary Health Network, 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.

A local co-design process, based on the Experience Based Co-design (EBCD) approach endorsed by the Agency for Clinical Innovation (ACI), will determine the shape of these new supports. This co-design will be a genuine collaboration between those who provide supports and those who use them.

This toolkit has been developed to help support the local co-design of the Towards Zero Suicides initiatives in the Illawarra Shoalhaven.

The toolkit includes information on:

- 1) Background to the project
- 2) What is co-design?
- 3) Illawarra Shoalhaven co-design process: Safe Spaces

We warmly welcome the contributions of all who seek to help reduce suicide deaths and attempts. We genuinely believe in the goal of zero suicides, 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. Both people who have their own experiences of suicidality and those who provide support want things to improve. Both have experienced how the current support systems have caused additional distress and trauma. We want to hear all these perspectives.

Background to project

The NSW Ministry of Health has now allocated funds to the Illawarra Shoalhaven for a number of their [Towards 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. **Safe Spaces** – 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. **Assertive Suicide Prevention Outreach Teams** - providing assertive immediate and follow-up care for people in the community experiencing a suicidal crisis.

The Ministry has provided guidelines and essential elements for each of these initiatives which will be sent to all participants prior to the co-design commencing. These provide some initial boundaries for the initiatives that must be considered during the local co-design. It is also recognised that more boundaries may emerge during the co-design process – any additional boundaries will be communicated with participants as soon as possible.

The current experience & need for an alternative

Between 2007 and 2016, over 6,500 people were hospitalised in the Illawarra Shoalhaven with intentional self-harm (Black Dog Institute, 2019). This is approximately 15 times the number of suicide deaths for the same period.

People's experience presenting to ED with suicidality is currently being examined in a 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 local 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.



“(We need) a genuine alternative for people like me who have been through the system and have found that very traumatic and don’t want to go back, but also even more importantly, for people to avoid ever having exposure to that system in the first place”

- Carrie

Lived experience

The formation of a local ‘Safe Space’ working group in response to this need for an alternative was showcased by the NSW Mental Health Commission. See full video here: <https://youtu.be/VPNbtNuSFxE>.

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 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 ([Croft & Isvan, 2015](#)).

The Collaborative hopes to achieve a mix of Safe Space supports for our region (see below), including the drop-in spaces being funded through the Safe Spaces (alternatives to EDs) initiative.

Peer support groups

Regular groups open to anyone with a lived experience of suicidal distress.



Warm line

An alternative to traditional crisis lines where peers provide emotional support and information about local supports.



Spaces open extended hours to provide a genuine alternative to ED. People can chat with a peer worker or just take some time out for themselves.



Drop in spaces



Residential spaces where people in crisis can stay for up to a week in a warm, welcoming environment.

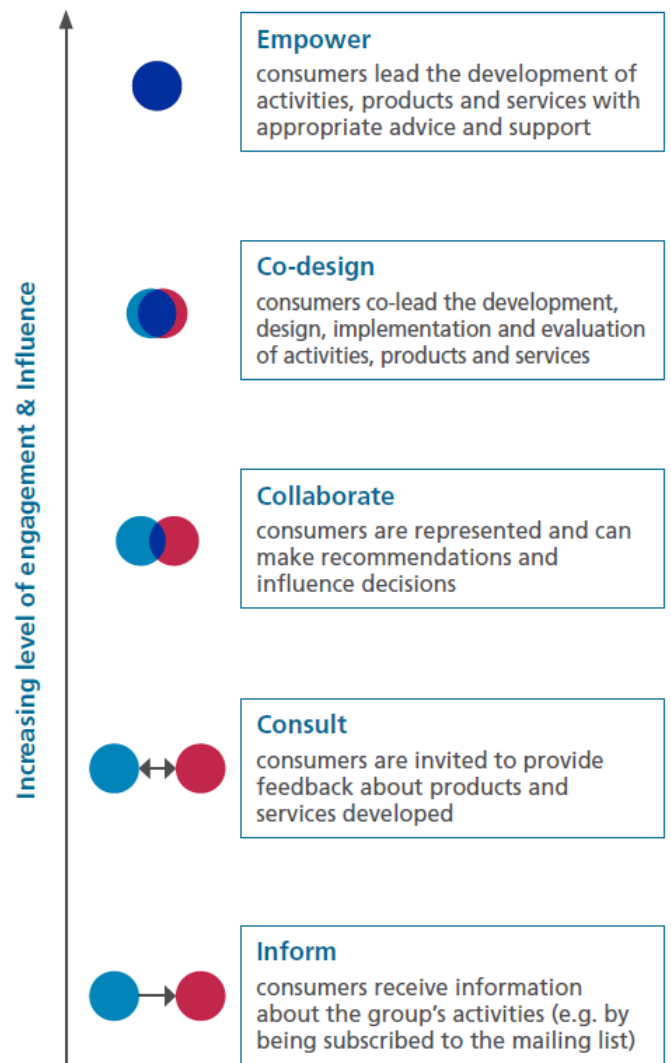
Peer Respites

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.

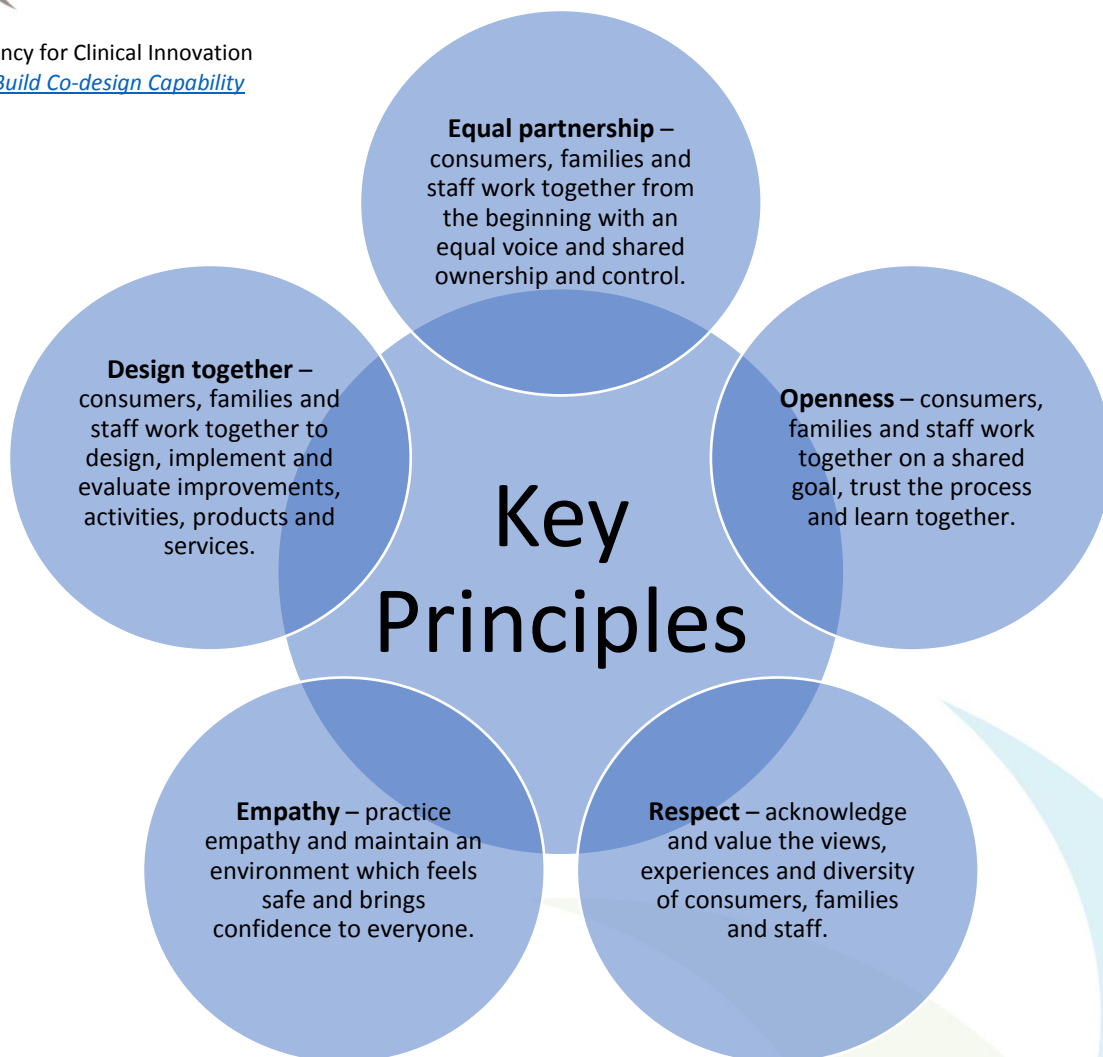


Participation levels figure

Source: Agency for Clinical Innovation
[A Guide to Build Co-design Capability](#)

Importantly, co-design is more than consultation.

Source: Agency for Clinical Innovation
[*A Guide to Build Co-design Capability*](#)



Why do co-design?

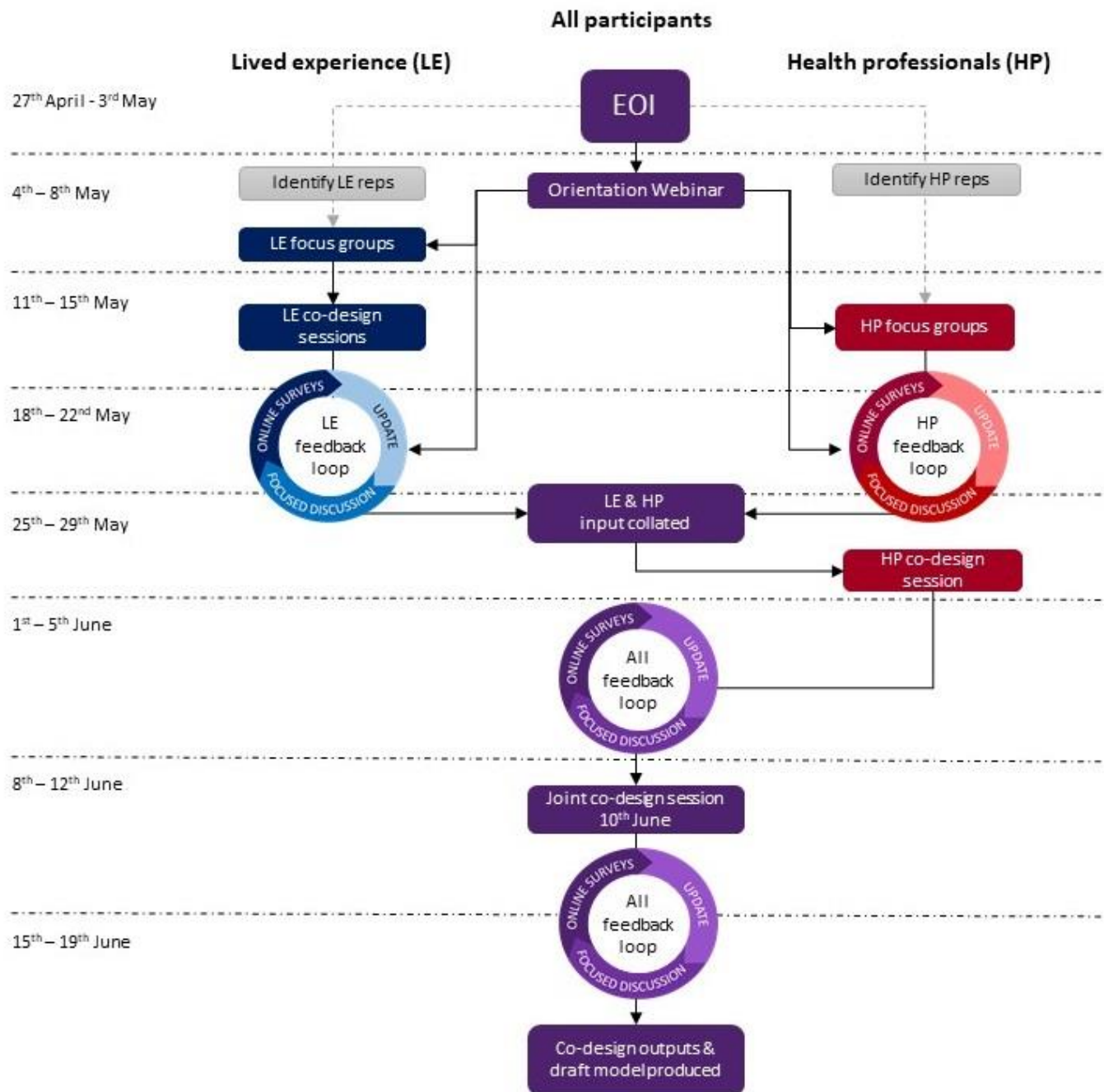
- It encourages a sense of collective ownership and community 'buy-in' for the service models that emerge from the process.
- It's more likely that potential challenges will be raised and addressed before services are implemented.
- There's a commitment to monitoring and evaluating the solutions generated 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.



Illawarra Shoalhaven co-design process: Safe Spaces



Commitment to ongoing co-design

One requirement of the service model is to build in ways for people to provide feedback that continually shape how support is provided. The process above will determine the shape of the initial service model, however the co-design process will continue as the service is implemented.

Participating in co-design - FAQs

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 on how the process is going for you at any time to the Collaborative's website (see contact details below or visit the 'Contact us' page on the website:

<https://www.suicidepreventioncollaborative.org.au/contact-us/>

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 focus groups are limited. Participants will be chosen in a way that makes sure we are drawing together a diverse group of people to represent the Illawarra Shoalhaven from a lived experience and health professional perspective.

All contributions will be regarded equally – whether you contribute via a focus group, online webinars or surveys.

What will be expected of me?

- Be fully informed and prepared to contribute – this includes accessing information on the Collaborative’s website:
 - Watching the Orientation webinar.
 - Reading the Ministry of Health’s Guidance documents.
 - Reviewing updates on co-design process and the draft service model being produced.
- Make time to participate.
- Commitment to the values and principles of co-design, including a commitment to:
 - work towards solutions and actively contribute ideas about how to improve supports (instead of just criticising how things are now).
 - 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 (see ‘What supports are available’ for example support options).
- Participate in the evaluation process, including completing online surveys for focus group participants.
- Send feedback about the co-design process to the Collaborative as soon as possible so that it can be improved.
- Have fun!

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.

If you are in need of additional support, you can find a list of available support services on the Collaborative’s website:
<https://www.suicidepreventioncollaborative.org.au/need-help/>

If you are having trouble with the process itself, please contact the Collaborative:
<https://www.suicidepreventioncollaborative.org.au/contact-us/>

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.

We also strongly encourage all participants to send feedback on how the process is going for you to the Collaborative’s website at any time. Please see contact details below or visit the ‘Contact us’ page on the website:
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Additional FAQs that come up during the co-design process will be published on the Collaborative’s website:
www.suicidepreventioncollaborative.org.au/TZS