



Co-designing with people with a lived experience of suicide

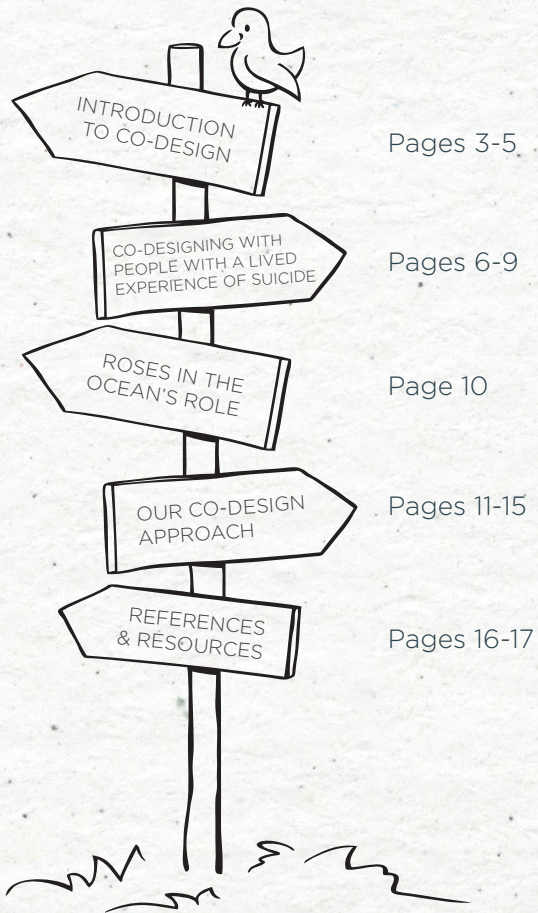
Planning Guide



Roses in the Ocean

stemming the tide of suicide

CONTENTS



INTRODUCTION TO CO-DESIGN	Pages 3-5
CO-DESIGNING WITH PEOPLE WITH A LIVED EXPERIENCE OF SUICIDE	Pages 6-9
ROSES IN THE OCEAN'S ROLE	Page 10
OUR CO-DESIGN APPROACH	Pages 11-15
REFERENCES & RESOURCES	Pages 16-17

"Being brave and courageous is considered a key principle and enabler of co-design. To be brave and courageous is believing that anything is possible. It is underpinned by optimism and a 'can do' attitude. It requires a shift in the usual way of doing things and understands that any challenge can be overcome with creativity and collaboration" (ACI, 2019, page 14).

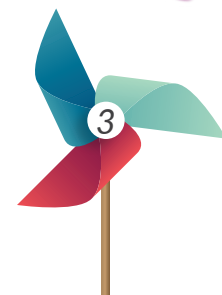
- NSW Government Agency for Clinical Innovation's 'A guide to build co-design capability'.

WHAT IS CO-DESIGN?

A process where a range of experts, including people with lived experience, collaborate to identify an issue and create a solution, typically a new service model.

The core belief behind the co-design approach is that service users, as experts by experience, should play a central role in designing the services they use.

It's a fundamentally 'iterative' process - the solutions generated in the designing phase are tested and evaluated with the original participants in an ongoing way.



ROSES IN THE OCEAN CO-DESIGN VALUES & PRINCIPLES



HONEST
CONVERSATION

EQUAL
PARTNERSHIP

ITERATIVE
DESIGN

INNOVATION

OUTCOMES
FOCUSED

PURPOSEFUL
INCLUSION

WHY DO CO-DESIGN?

By having service users and staff involved in the design process, it is more likely that barriers to implementation will be identified, and solutions found before services are established.

The process doesn't just identify the issue, it works to find an agreed solution to it.

When done well, the evidence shows that it's more likely to produce services that are efficient, effective and sustainable.

Local co-design processes build relationships of trust between community members that have meaning and value well beyond any individual project.

By bringing together a more diverse range of expertise to the design process, a wider range of ideas are generated and more creatively explored.

There's a commitment to genuine guardianship of co-design outputs and evaluating the solutions generated by the process in an ongoing way so the service will be continuously improved.

It encourages a sense of collective ownership and community 'buy-in' for the service models that emerge from the process.



CO-DESIGNING WITH PEOPLE WITH A LIVED EXPERIENCE OF SUICIDE



Equalising power in the context of collaboration between clinicians and people with lived experience, particularly those who have been subject to involuntary treatment and/or are currently engaged in local clinical service.

Engaging people with low levels of institutional trust and building relationships with these people when not part of the local community and in tight timeframes.

Establishing and maintaining commitment from service providers and commissioning agencies to guardianship of co-design outputs to ensure ongoing fidelity to these.

Challenges deserving of careful consideration and appropriate expertise.

Maximising the participation of such individuals, groups, and communities, particularly those who have experienced discrimination within other services and those who have had negative experience seeking help for themselves or others.

Including a diverse range of lived experience perspectives that are relevant to the focus of the co-design initiative; representative of specific demographic and geographic needs; and include people who have not/would not access existing services due to past experiences and/or stigma.

WHO SHOULD PARTICIPATE?

Co-design must involve people with a lived experience of suicide representing a diverse range of lived experience perspectives, as they are the people who know what currently works and doesn't work in terms of services and supports for people impacted by suicide. They will also be the ones most impacted by the outcome of a service or system improvement, either positively or negatively. Specifically, people with a lived experience relevant to the actual service or system improvement to be co-designed taking into account who the service is to serve, and specific demographics of the area in which it will serve.

Co-design should also include a diverse range of other stakeholders who have a vested interest in creating a service that will deliver an outcome identified by people with lived experience that will meet their needs. These stakeholders may include, but not be limited to service providers, health and social service professionals, Suicide Prevention Network members, community support services.

In all cases, there must be at least equal numbers of people with lived experience of suicide included in co-design, with the remaining positions available spread between all other stakeholders. No one group of other stakeholders should outnumber another.

Broader engagement of community is also important to the co-design process which is achieved through a number of Feedback Loops, webinars and surveys.



WHAT TO CONSIDER BEFORE UNDERTAKING CO-DESIGN

Key features of an effective co-design process:

- Depth and diversity of lived experiences of suicide including varied underlying contributing factors and inter-sectionalities are represented.
- Commitment to the iterative nature of the process for the life of the service.
- Sufficient organisational resources need to be made available, including time for participant recruitment and enabling space for all stakeholders to participate.
- Ensure relevant voices of lived experience are actively recruited including those who currently choose not to engage with services.
- The final service or service improvement must accurately reflect the service model blueprint borne out of the co-design.
- Senior executives and management need to have genuine understanding of co-design and actively champion the process.
- Clear communication by commissioning agencies about the hard boundaries of the project upfront to all participants.
- Co-facilitation of all co-design training and participant workshops by people with lived experience of suicide and expertise in co-designing with people with a lived experience of suicide.
- Paid participation of lived experience participants.
- Continuous open and transparent communication with co-design participants as part of the ongoing co-design.
- Co-design principles embedded into the service model and post implementation re-design implemented as part of the ongoing evaluation and improvement for the life of the service.

When people with lived experience aren't meaningfully included in co-design processes, this can leave them feeling unheard and further marginalised and disempowered.

Intending to do co-design and not committing to its values and principles will further breach the trust of the people involved (both staff and people with lived experience) and create even more cynicism about the possibility of change.



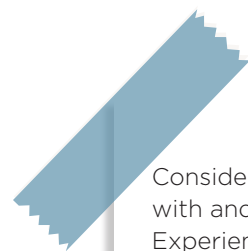
Examples of what happens when co-design is not done well.

A lived experience participant involved in a local suicide prevention service co-design said they felt “swindled” by not having the hard boundaries of the project communicated upfront then finding out that the service model they had helped designed was never going to be implemented.

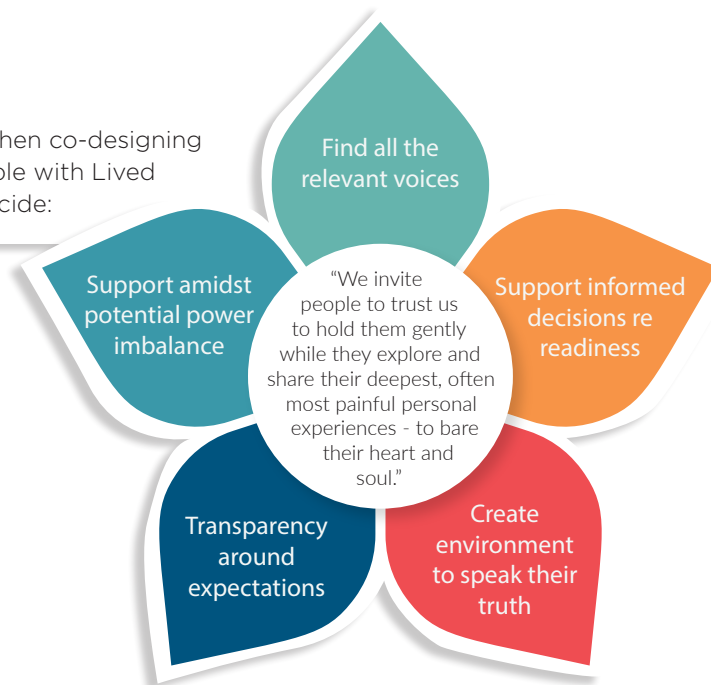
Another lived experience participant who had felt “shut down and ignored” by the health system was re-traumatised by having their expectations raised, then finding out the service model didn't reflect the ideas generated through the designing phase.



ROSES IN THE OCEAN'S ROLE

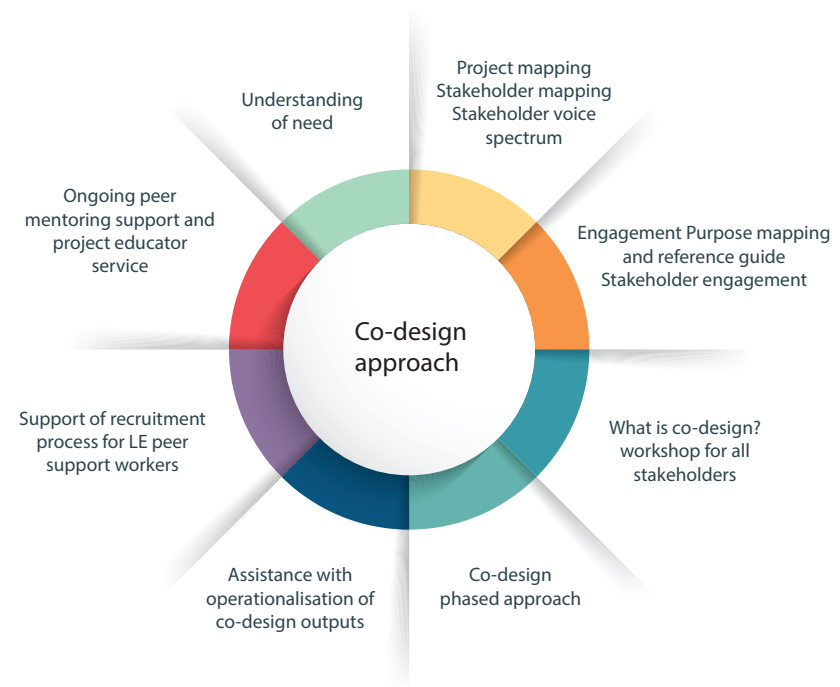


Considerations when co-designing with and for people with Lived Experience of suicide:



- Extensive experience in working with people with a lived experience of suicide
- Demonstrated capacity to develop and lead co-design initiatives
- Proven facilitation skills to ensure critical input from lived experience achieves optimum outcomes that will meet needs and wants of communities.
- Co-design of innovative programs and services to improve supports for people impacted by suicide.
- Advanced skills-based knowledge of trauma-informed and recovery-oriented practice.
- Creating a culture that facilitates and supports all co-design participants to be heard and all perspectives respected.
- Deep understanding of how language matters, and the way language is used can either be a barrier to people being able to meaningfully participate in co-design initiatives, or a powerful enabler of an inclusive, supportive and welcoming environment in which to share their perspectives.
- Attuned to power imbalances between service providers, traditional experts and people with a lived experience of suicide.
- Extensive experience supporting people in situations where power imbalances need to be sensitively and compassionately navigated to.
- Deep understanding of how to work effectively with marginalised individuals and groups in context of suicide prevention.

OUR CO-DESIGN APPROACH



Our approach is grounded in the values of Roses in the Ocean itself and is built on our co-design principles: honest conversation, equal partnership, inclusion, shared decision making, innovation, purposeful involvement, and integration.

Roses in the Ocean has invested time, expertise and resources into co-designing a co-design process specific to working with and designing services for, people with a lived

experience of suicide. Our approach aligns with the values and principles of co-design outlined by the Agency for Clinical Innovation and is informed by the Experience-Based Co-Design (EBCD) method.

We are very attune to the need to manage expectations and support people during periods and situations where power imbalances need to be navigated respectfully to achieve best outcomes for the end user.

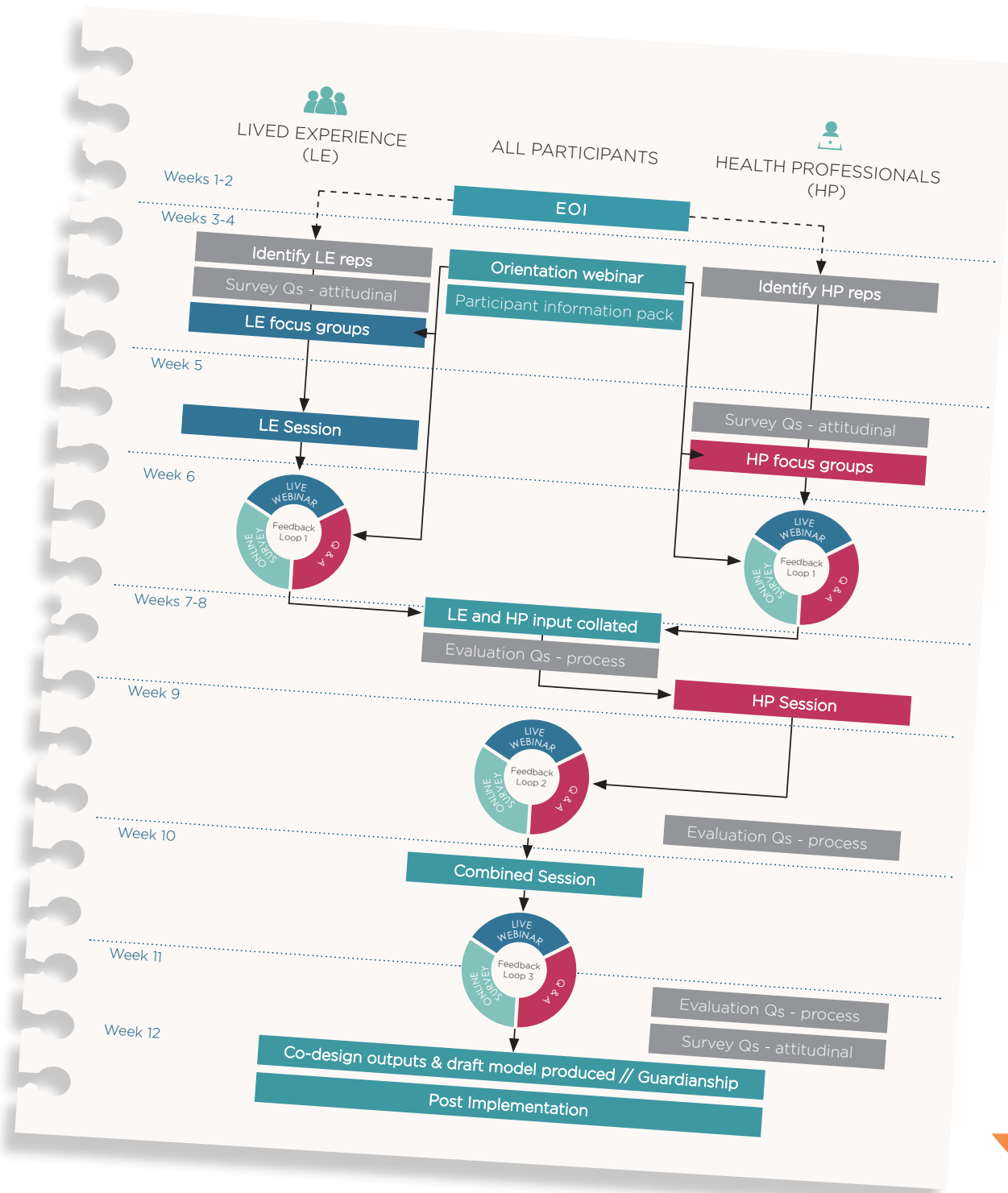


OUR CO-DESIGN FRAMEWORK & PROCESS

Roses in the Ocean has developed a co-design framework structured specifically to suit the suicide prevention context and to capture the iterative nature of genuine co-design. The core elements of this framework are:

- a specialised lived experience of suicide co-design facilitation team
- lived experience stakeholder mapping and engagement, including recruiting people with a lived experience of suicide relevant to the project and screening them for readiness to actively and meaningfully participate
- other stakeholder engagement in all phases of the co-design process, including people who are most affected by decisions about the types of services that are needed
- training for all stakeholders on co-design values, principles, and processes
- a commitment to internal and external evaluation of the co-design process and its outcomes
- customised resources / tools / activities relevant and appropriate for the co-design of programs and services to improve support for people impacted by suicide and informed by existing best-practice methods in the health and social services sectors
- a model of co-design grounded in the core values and principles of evidence-based co-design methodology that is committed to its fundamentally iterative nature







'Readiness to be involved' recruitment process ensures people make informed decisions regarding their involvement.

Full recruitment process including stakeholder mapping to ensure appropriate and diverse representation is engaged.

Feedback loops to create another channel for community input, increasing equity and access for 'missing voices'.

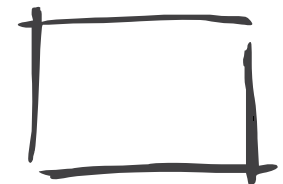
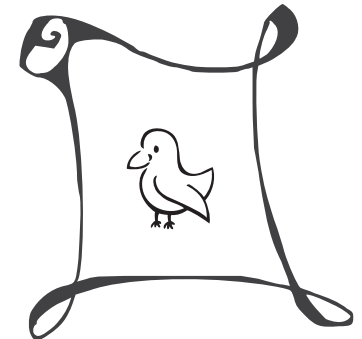
Face to face, virtual and blended delivery modes are available to suit individual and project needs.

Facilitation by experts with capacity to manage the sometimes complex power dynamics between clinicians and other traditional experts and people with lived experience of suicide.

Creation of a safe and supportive environment for people with lived experience of suicidal crisis, including lived experience mentor available throughout every session.

Facilitation of workshops by people with a lived experience of suicide specifically matched to the focus of the co-design.

Guardianship of co-design outputs to service model implementation.



Pre-design capacity building workshops for people with lived experience to utilize their voices with meaning and purpose.

Ability to adapt co-design process to meet individual needs of participants to ensure everyone can speak their truth.

Co-design team has deep understanding of what safety means in the context of suicide prevention initiatives – it doesn't mean treating people with lived experience as inherently vulnerable and needing to be risk managed.

Flexible range of options to connect with various stakeholders.

Customised co-design processes developed to rebalance power between traditional stakeholders and people with lived experience of suicide.

I just wanted to say a huge thank you for the opportunity to take part in the co-design process for the NSW post suicide support service. It's been an absolute privilege and invaluable to me as a learning experience to see co-design actually implemented in the way it should be (but so often isn't)! It gives me huge faith to know that the support service that is developed is and will be based on the voices of those with lived experience. To feel that my and our voice is truly heard and valued is wonderful in itself.

– Lived experience participant in post-suicide support service model co-design

REFERENCES & RESOURCES

Australian Healthcare and Hospitals Association and Consumers Health Forum of Australia. (2018) Experience Based Codesign: Toolkit. Canberra: Consumers Health Forum of Australia.

McKercher, K.A. (2020) Beyond Sticky Notes. Co-Design For Real: Mindsets, Methods and Movements. Sydney: Beyond Sticky Notes.

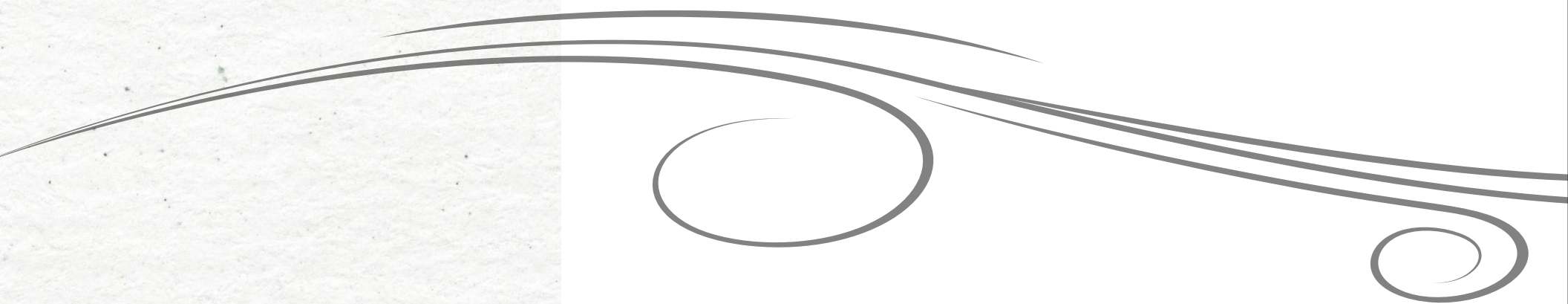
NSW Council of Social Services (2017) The Codesign Principles. Woolloomooloo: NCOSS.

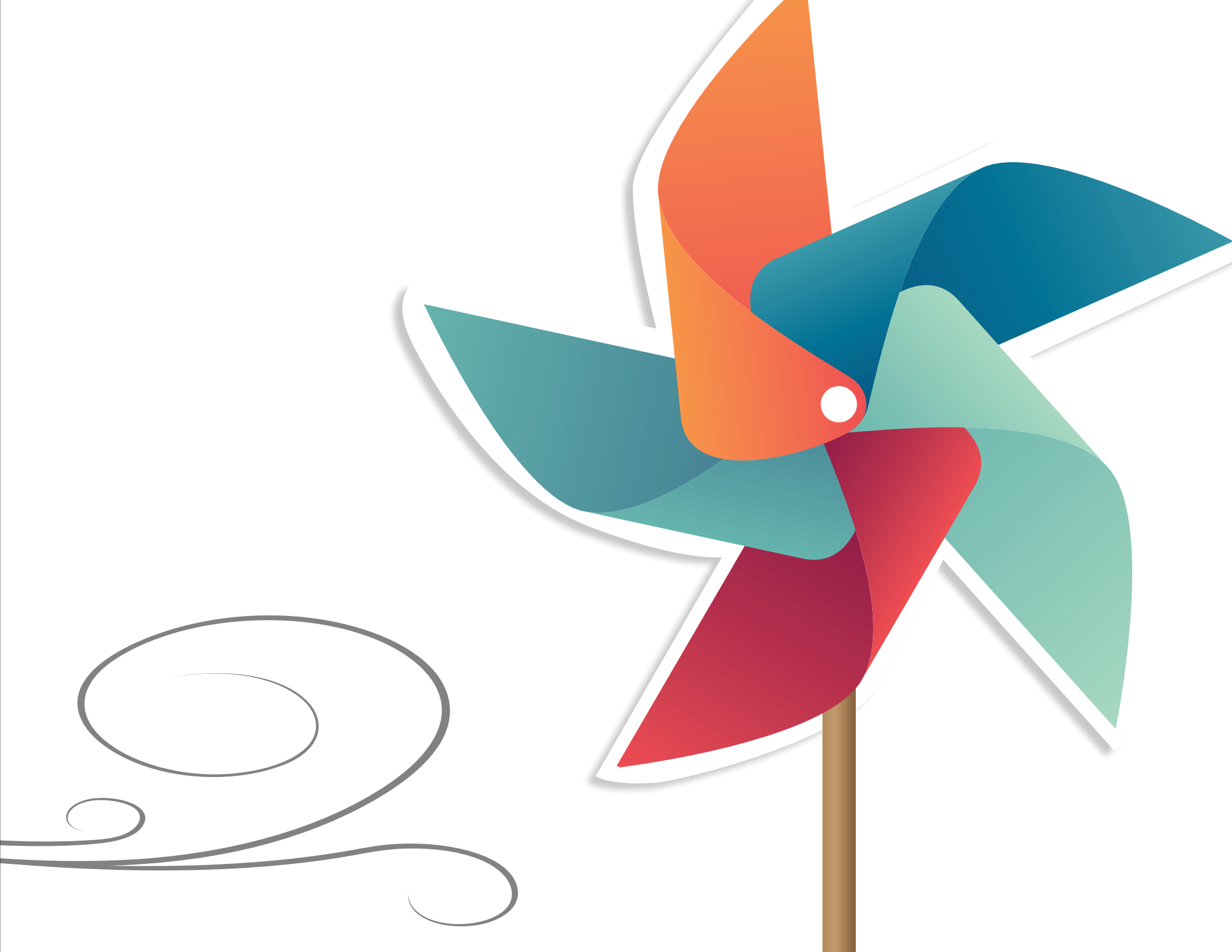
Patient experience and consumer engagement (2019) A Guide to build Co-design Capability: Consumers and staff coming together to improve healthcare. NSW Government, Agency for Clinical Innovation.


Roper, C., Grey, F. & Cadogan, E. (2018) Co-production: Putting principles into practice in mental health contexts. Creative Commons.

Social Care Institute for Excellence (2015) Co-production in social care: What it is and how to do it.

Western Australia Council of Social Services (WACOSS) (2017) Co-design Toolkit.







Co-designing with people with a lived experience of suicide

Planning Guide

Written by Roses in the Ocean