

# A Guide to Build Co-design Capability

Consumers and staff coming together to improve healthcare



The Agency for Clinical Innovation (ACI) is the lead agency for innovation in clinical care. We bring consumers, clinicians and healthcare managers together to support the design, assessment and implementation of clinical innovations across the NSW public health system to change the way that care is delivered.

The ACI's clinical networks, institutes and taskforces are chaired by senior clinicians and consumers who have a keen interest and track record in innovative clinical care. The ACI strives for innovations that are person-centred, clinically-led, evidence-based and value-driven.

The ACI also works closely with the Ministry of Health and the four other pillars of NSW Health to pilot, scale and spread solutions to healthcare system-wide challenges. We seek to improve the care and outcomes for patients by re-designing and transforming the NSW public health system.

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# Contents

<b>Preface</b>	<b>iii</b>
<b>Introduction</b>	<b>1</b>
<b>Purpose</b>	<b>2</b>
Why is this guide needed?	2
Language used in this guide	2
<b>Background</b>	<b>3</b>
What is the policy context?	3
How was the guide developed?	3
<b>Co-design: definition and principles</b>	<b>5</b>
What is co-design?	5
What are the principles?	6
Where does co-design sit on the participation ladder?	6
When is co-design a good fit?	7
Who might be involved in a co-design team?	7
<b>Core capabilities for co-design</b>	<b>8</b>
<b>Service enablers</b>	<b>13</b>
A culture that recognises engagement and participation is everyone’s responsibility	13
Strong leadership	13
Being brave and courageous	14
Development of infrastructure support	14
Continuous evaluation	16
<b>Guidance for executives involved in co-design</b>	<b>17</b>
How will you contribute to the success of this work?	17
What are you doing and saying that will let others know that you support this work?	17
What do you need to be successful?	17
Barriers that you may face and how to overcome them	17
<b>Guidance for people with a lived experience of a health condition</b>	<b>18</b>
How will you contribute to the success of this work?	18
What are you doing and saying that will let others know that you support this work?	18
What do you need to be successful?	18
Barriers that you may face and how to overcome them	18
<b>Guidance for staff in a co-design team</b>	<b>19</b>
How will you contribute to the success of this work?	19
What are you doing and saying that will let others know that you support this work?	19
What do you need to be successful?	19
Barriers that you may face and how to overcome them	19

<b>Guidance for co-design leads</b>	<b>20</b>
How will you contribute to the success of this work?	20
What are you doing and saying that will let others know that you support this work?	20
What do you need to be successful?	20
Barriers that you may face and how to overcome them	21
<b>Guidance for service managers involved in co-design</b>	<b>22</b>
How will you contribute to the success of this work?	22
What are you doing and saying that will let others know that you support this work?	22
What do you need to be successful?	22
Barriers that you may face and how to overcome them	22
<b>Customising co-design capabilities in the mental health context</b>	<b>23</b>
Trauma informed care principles	23
Recovery-oriented practices	25
The value of lived experience	25
<b>Resources</b>	<b>26</b>
Useful resources to support co-design	26
Useful resources to support a trauma-informed approach	26
<b>Acknowledgements</b>	<b>27</b>
<b>Glossary</b>	<b>28</b>
<b>References</b>	<b>29</b>

# Preface

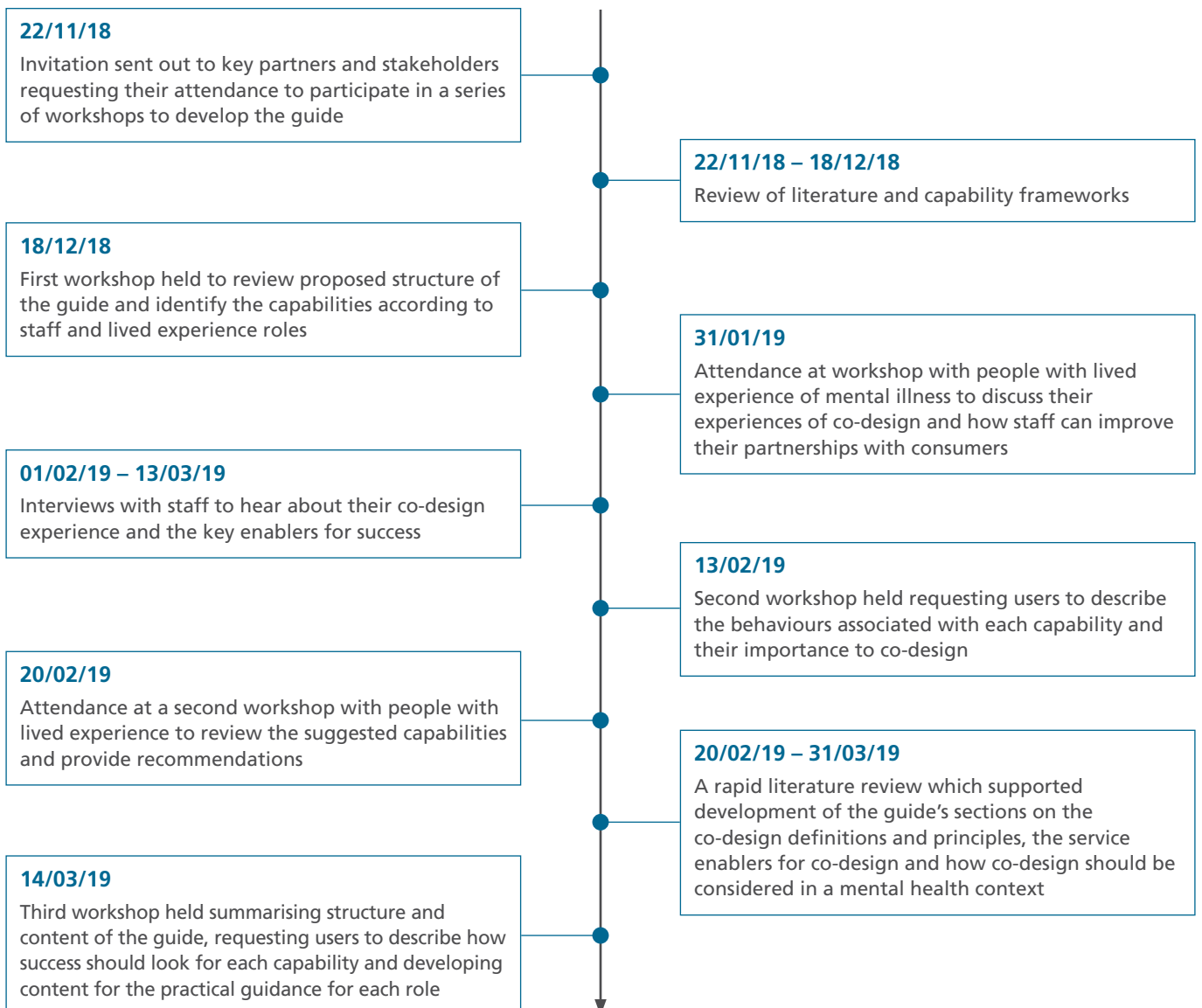
A Guide to Build Co-design Capability is a resource that is designed to support local health districts and specialty health networks partner with people with lived experience of a health condition to make healthcare improvements using co-design processes.

It has been developed by working with peer workers, clinicians, managers and executives from local health districts, peak organisations, the ministry of health, health and pillar organisations. It involved facilitating workshops where participants identified and co-produced core content of the guide, conducting interviews with staff that have had experience of co-design and presenting at workshops with people with lived experience of mental health issues to seek recommendations about successful co-design practices.

The process that the Agency for Clinical Innovation has followed to design and develop this guide is outlined below.

This guide is intended as a preliminary resource which has identified the core capabilities that will enable and support health services to strengthen their partnerships with people with lived experience.

The next phase of its development will be to consult more broadly with community groups and services to test the suitability of the capabilities and confirm whether they can be applied to health services in NSW. As a result, this guide will continue to be refined and adapted to reflect the outputs of the consultation process.



## Introduction

There is an expectation that health services partner and work collaboratively with people with lived experience of a health condition as well as carers, families and kinship groups to design services and systems of care.

It is well known that current methods of participation and partnership across organisations and their services can be extremely variable and often inconsistent.

Co-design is becoming a common global practice in health service delivery as organisations and leaders recognise the value of lived experience.

***Co-design is important in mental health services because it challenges the status quo, addresses well known power imbalances that exist across many levels and ensures the voice of people with lived experience is a co-driver of change, innovation and leadership. The evidence shows that using co-design creates safer, higher quality and more efficient care.***

– Workshop participants

Co-design goes beyond the more traditional partnering methods. It involves consumers from the outset, identifying issues and throughout the design of services, to ensure that the services reflect their needs and preferences for improvement. Co-design can enable consumers to become equal partners with managers and clinicians in the improvement process.

***Having a voice is important in co-design and healthcare improvement because silence condones. Without a voice there can be no change.***

– Living Labs

## Purpose

This document is a guide to the capabilities, demonstrated behaviours, key actions and service enablers that support co-design to occur successfully at individual and organisational levels.

This document is for health services that want to partner with people with lived experience of a health condition to make healthcare improvements using a co-design method.

It will be useful for the following groups:

- people with lived experience of a health condition and carers, families and kinship groups (part of the co-design team)
- staff, including but not limited to clinicians, peer workers, project managers and other relevant non-health staff (part of the co-design team)
- co-design leads, including but not limited to redesign leads, community participation managers, peer workers and quality improvement leads
- service managers
- executives
- health services.

Although it has been produced within the context of a review of seclusion and restraint, the information included in this guide can be applied more broadly to all NSW health services to develop capability in using co-design as an improvement approach.

### Why is this guide needed?

There are a number of toolkits, resources, principles and case studies that offer guidance on the co-design method. Although this published guidance is valuable, there is a requirement to establish the relational capabilities (skills, knowledge and behaviour) that support successful co-design practice.

This guide is intended to complement the vision articulated in the Mental Health Commission of NSW's Lived Experience Framework, which aims to embed lived experience across mental health and social services systems in NSW.

### Language used in this guide

Language is powerful; it creates meaning and is a vehicle of culture. Language used to describe people with lived experience of mental health issues in the past has often been negative, disempowering and stigmatising.

This guide uses the following terms wherever possible:

- 'people with lived experience'
- 'people with lived experience of a health condition'
- 'people with lived experience of mental health issues and carers, families and kinship groups'
- 'consumer' and 'patient' (used when referring to government policy, reports, and literature resources).

Collectively, these terms refer to people who have experienced or who currently have a lived experience of a health condition.

These terms are taken from the Lived Experience Framework, in recognition of its co-design development process and its use of respectful and inclusive language.<sup>1</sup> They are also used based on feedback received during the consultation process when developing this guide.

It is acknowledged that the term 'engagement' is not a preferred term by people with lived experience of mental health issues. The consultation process also highlighted this, and as a result, the terms 'participation', 'partnering' and 'collaboration' are used as alternatives whenever possible. There are instances throughout the guide where 'engagement' is used to reflect the language in government policy, reports, and literature resources.



## Background

### What is the policy context?

One of the key principles of NSW Health's action to prevent seclusion and restraint of mental health consumers is to engage consumers, carers and their families in co-designing prevention initiatives.

The *Review of Seclusion, Restraint and Observation of Consumers with a Mental Illness in NSW Health Facilities* led to the development of 19 recommendations which were accepted by the NSW Government.<sup>2</sup> Recommendation 12 states that consumer and carer co-design and engagement should occur at all levels of the health service. It outlines the need to promote meaningful engagement between staff, consumers and carers across NSW Health facilities.<sup>3</sup>

The *Fifth National Mental Health and Suicide Prevention Plan* reinforces that consumers and carers have vital contributions to make and should be partners in planning and decision-making. This reflects the intent of the national mental health policy regarding consumer and carer participation – that is, 'Nothing about us, without us'.<sup>4</sup>

The *Lived Experience Framework* conveys a similar message, arguing that mental health and social services 'must embrace the participation, influence and leadership of people with lived experience of mental health issues and carers, families and kinship groups in service design, delivery, monitoring, reporting, research, evaluation and improvement activities'.<sup>1</sup> By embedding this vision across the system, it will strengthen services and achieve better outcomes for all people in NSW.

The Australian Commission on Safety and Quality in Health Care *National Safety and Quality Health Service Standard 2: Partnering with Consumers* is a formal structure and accountability mechanism for involving consumers in designing quality healthcare improvement.<sup>5</sup> In addition, *Standard 3: Consumer and carer participation of the National Standards for Mental Health Services* also mandates that consumer and carers are actively involved in the development, planning, delivery and evaluation of services.<sup>6</sup>

### How was the guide developed?

This guide was created using an iterative design process. This included:

- targeted interviews with stakeholders who had an in-depth understanding of co-design method and key partners identified within the implementation plan of the *Mental Health Safety and Quality in NSW: A plan to implement recommendations of the Review of seclusion, restraint and observation of consumers with a mental illness in NSW Health facilities*
- iterative workshops and feedback people with lived experience of mental health issues and staff to identify and co-produce elements, structure and content of the guide
- workshops with people with a lived experience of mental health issues who were involved in a randomised controlled trial of experience-based co-design (EBCD) to understand their experiences and input of the required capabilities to use the method
- a rapid and purposive international literature review
- organisational learnings from six EBCD improvement projects across NSW.

Three Agency for Clinical Innovation (ACI)-led workshops occurred from December 2018 to March 2019 to seek expertise and advice from representatives from:

- the Ministry of Health Mental Health Branch
- Being
- Mental Health Carers NSW
- the Mental Health Commission of NSW
- the Clinical Excellence Commission
- Health Education and Training Institute
- the Official Visitors Program
- clinicians, managers and peer workers from various local health districts.

The workshops and iterative feedback informed the role specific guidance within this guide as well as the core capabilities and their behavioural indicators which are considered integral to the co-design process.



The ACI also partnered with the University of Melbourne to attend two workshops with the Living Lab groups which consisted of people with a lived experience of mental health issues who have co-design experience. The Living Labs are managed by the University of Melbourne. They bring health service staff together with people who have lived experience of a service, role, or health condition. The labs enable participants to brainstorm ways to improve research, policy and practice in mental health and co-develop solutions to respond to mental health needs in the community.

In both sessions, participants provided feedback about their previous experiences of co-design and made recommendations about the support that should be provided to people with lived experience of mental health issues that want to be involved in co-design. The group also provided feedback and input on the capabilities suggested by staff at the other workshops.

# Co-design: definition and principles

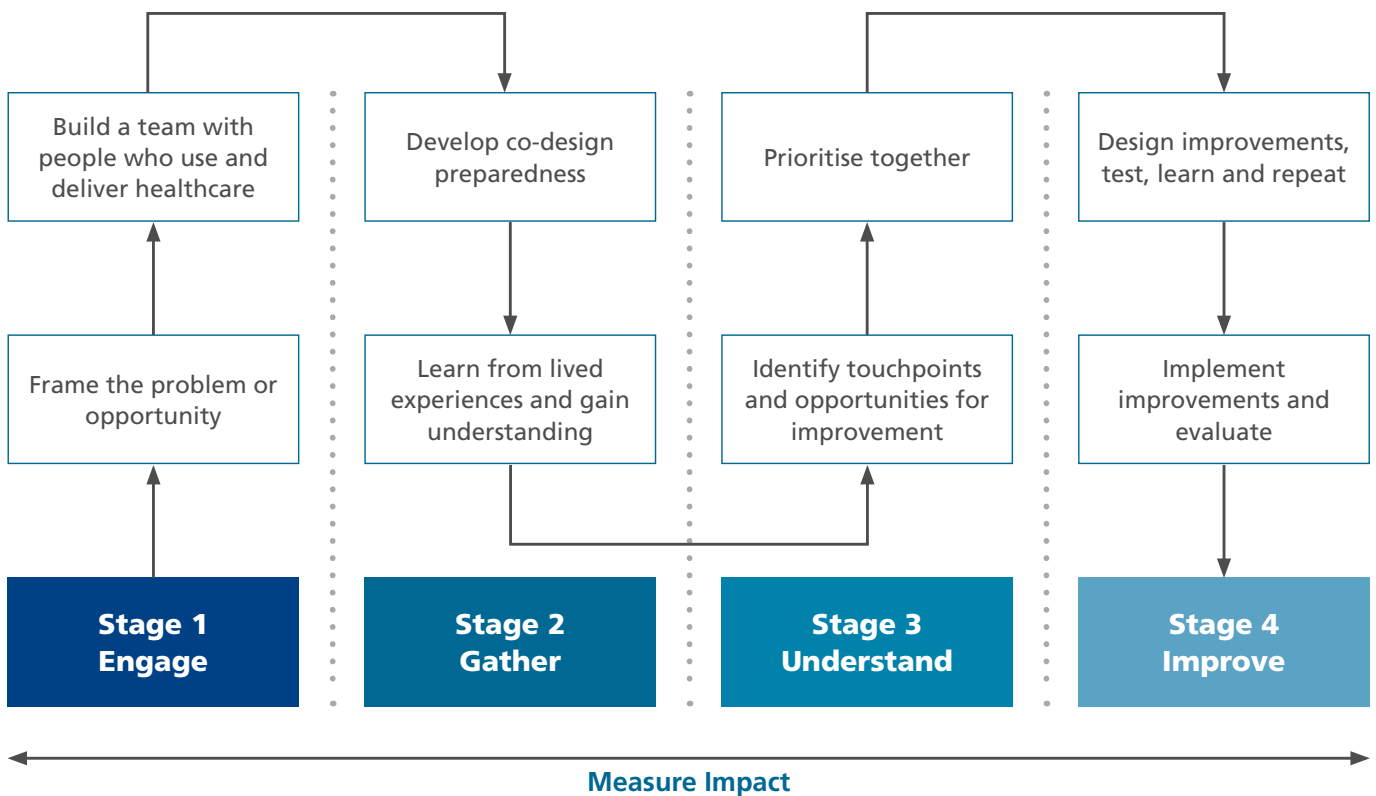
## What is co-design?

Co-design is a way of bringing consumers, carers, families and health workers together to improve services. It creates an equal and reciprocal relationship between all stakeholders, enabling them to design and deliver services in partnership with each other. Planning, designing and producing services with people that have experience of the problem or service means the final solution is more likely to meet their needs.<sup>8</sup>

This way of working demonstrates a shift from seeking involvement or participation after an agenda has already been set, to seeking consumer leadership from the outset so that consumers are involved in defining the problem and designing the solution.<sup>8</sup>

Co-design typically uses a staged process that adopts participatory and narrative methods to understand the experiences of receiving and delivering services, followed by consumers and health professionals co-designing improvements collaboratively (Figure 1).

**Figure 1. The co-design process**



## What are the principles?

Co-design is often considered more as a way of thinking than a process. It requires that organisations and individuals shift their mindset to embrace and embed the principles and values that it embodies.

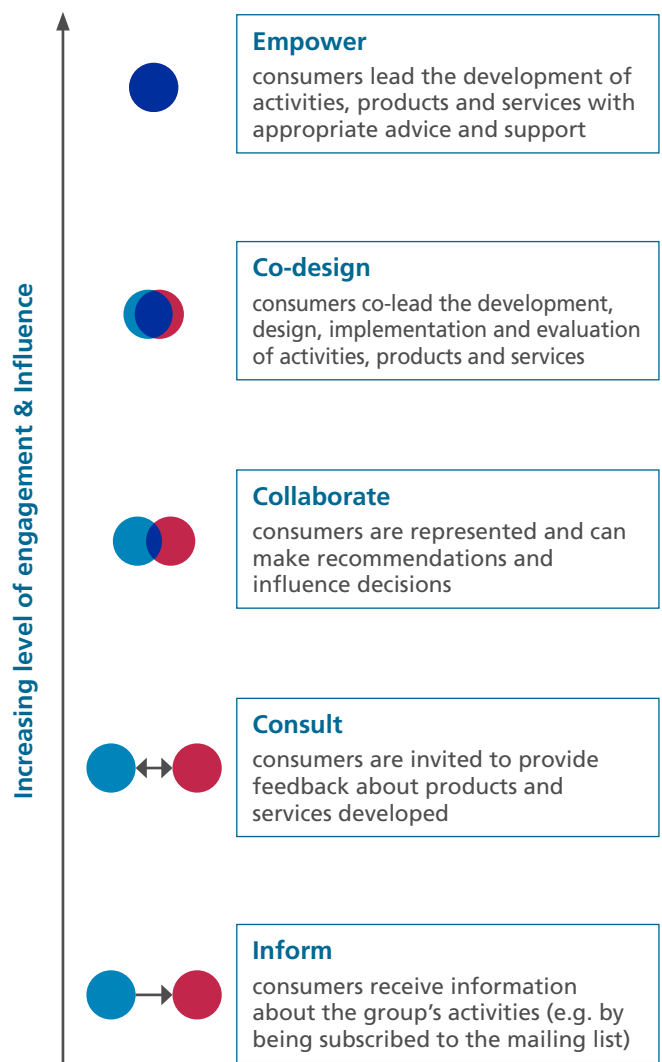
The ACI has defined the principles of co-design as the following.

- **Equal partnership** – Consumers, families and staff work together from the beginning with an equal voice and shared ownership and control.
- **Openness** – Consumers, families and staff work together on a shared goal, trust the process and learn together.
- **Respect** – Acknowledge and value the views, experiences and diversity of consumers, families and staff.
- **Empathy** – Practice empathy and maintain an environment which feels safe and brings confidence to everyone.
- **Design together** – Consumers, families and staff work together to design, implement and evaluate improvements, activities, products and services.

## Where does co-design sit on the participation ladder?

Co-design sits within a spectrum of participation levels. Figure 2 outlines the range of participation levels, such as provision of information, consultation, collaboration, co-design and empowerment. The higher levels, co-design and empower, are demonstrated when services have created an environment that promotes equal partnership, consumer leadership and values their knowledge and expertise.<sup>8</sup> Health services should be aiming to always seek the highest level that is appropriate and possible.

Figure 2. Participation levels



Source: Adapted by the ACI with permission from the International Association for Public Participation (IAP2)

## When is co-design a good fit?

It is important that services and organisations are honest about the level of consumer participation that can be achieved in each situation and that the concept of co-design is not misrepresented to describe participation that is on the lower levels of the participation ladder.

There will be certain situations where co-design may not be an appropriate approach. Examples may include:

- an outcome and/or solution has already been pre-defined
- the objectives are in conflict with what consumers see as important<sup>8</sup>
- a project that is time-critical
- the service is unable to obtain the lived experience expertise that is relevant to the project
- when there is no commitment to implementing and sustaining co-designed improvements
- when there is no 'buy in' from senior leadership.

If these situations arise, organisations may need to consider whether a more consultative or collaborative approach is more suitable.

## Who might be involved in a co-design team?

Co-design generally involves the people who are likely to be impacted by or will benefit from the process, either directly or indirectly.<sup>9</sup> It requires the careful selection of users based on their background and motivations to transform knowledge into innovative outcomes. Co-design is inherently a team based process; it involves users working together to design a new product or service, with everyone making full use of each other's knowledge, resources and contributions, to achieve better outcomes or improved efficiency.<sup>10</sup>

### Team members

- **People with lived experience and carers, families and kinship groups** – Individuals who have lived experience of a service, role or condition or are a carer or family member supporting the person. Consideration should also be given to the number of participants involved to ensure that there is a balanced representation of consumers and carers on the team.
- **A co-design lead** – This role is vital for co-design to be successful. It will require an in-depth knowledge of co-design and be responsible for facilitating and leading the project or process. The individual's knowledge of co-design is more important than their professional position within the organisation.
- **Staff (clinical and non-clinical)** – Staff either working in the service or affected by the co-design process. This can include subject matter expertise in both a clinical and managerial capacity.
- **Executives** – A senior team member who will sponsor, enable and endorse the co-design process. This individual is unlikely to be part of the team, nonetheless, the support is critical to the sustainability of the project.

## Core capabilities for co-design

This section articulates the capabilities and behaviours that would support people to participate successfully in a co-design process, and focus strongly on the relational capabilities that underpin effective co-design. The capabilities are applicable to all members of the co-design team, including executive sponsors.

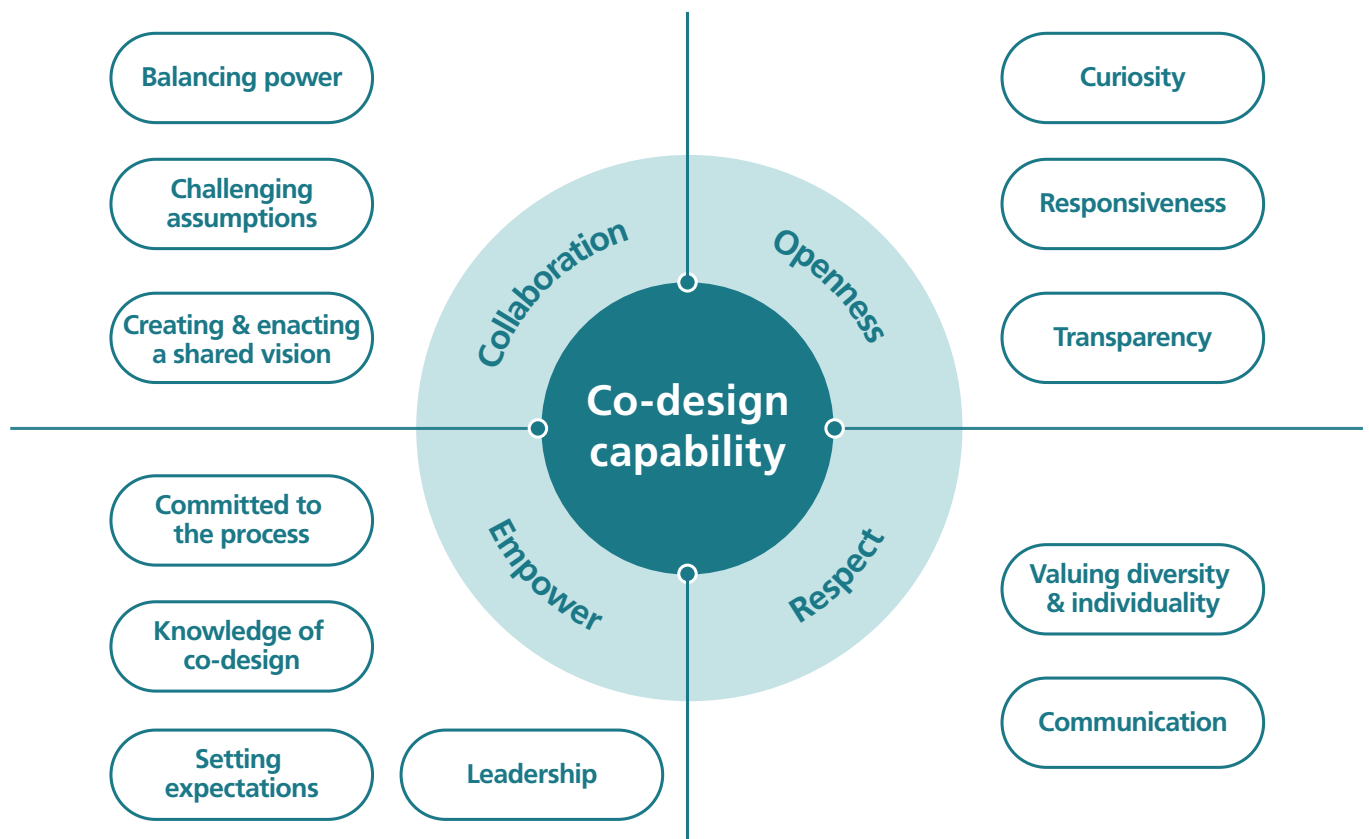
Each capability has been categorised according to the NSW Health core values, reinforcing a common vision and shared belief that all organisations in NSW Health

should strive to personify. The behaviours described are accompanied by descriptors of how organisations can observe success and key actions that demonstrate good practice.

The capabilities were identified and co-produced with participants during the workshops when developing this guide.

Collectively this information works together to support the implementation of good co-design practice.

**Figure 3. core capabilities**



**Table 1. NSW Health Core Value: Openness**

Is a state of mind, enabling colleagues to share ideas and communicate clearly. We strive to be approachable, actively listen and encourage others to contribute and speak up. We offer and receive constructive feedback. This ensures others feel their contribution is valued, even when there are disagreements. <sup>11</sup>	
Capability	Individual behaviour
<b>Responsiveness</b>	<p>I am open to feedback from everyone in the co-design team</p> <p>I am able to change my course of action based on experiences and data in a purposeful and thoughtful way</p>
<b>Curiosity</b>	<p>I am non-judgmental, curious and respectful</p> <p>I am able to ask difficult questions in a considerate way</p> <p>I am enthusiastic about change and I don't have existing solutions</p> <p>I will explore opportunities to the fullest</p>
<b>Transparency</b>	<p>I speak with meaning and passion</p> <p>I always share all information whether it is good or bad</p> <p>I am consistent in my messaging</p> <p>I am able to show vulnerability and share power</p>
What does good practice look like?	
<ul style="list-style-type: none"> <li>• Sharing data and outcomes openly</li> <li>• Matching communication and methods of collaboration to individuals needs and preferences</li> <li>• Role modelling the need to press pause during discussion to check if people are in agreement</li> <li>• Creating a safe space that will allow everyone to express their opinions and valuing them equally</li> <li>• Recognising that there are power imbalances and working together to shift the dynamic</li> <li>• Supporting people to be open and examine their own assumptions and biases</li> <li>• Ensuring there is transparency and agreement from the beginning about how decision making processes will work</li> <li>• Being transparent about the co-design process including methods used, decisions, and outcomes</li> <li>• Being open to change even when the solution is not defined</li> </ul>	

**Table 2. NSW Health Core Value: Respect**

Is a reminder to treat others as we would like to be treated ourselves. It is important to be mindful of each other's capabilities, regardless of role or grade. We care about the different perspectives and backgrounds in our workplace, and are thoughtful of our impact on others. <sup>11</sup>	
Capability	Individual behaviour
<b>Valuing diversity and individuality</b>	I am understanding and I value individual differences I am empathetic and non-judgmental
<b>Communicating openly</b>	I listen to understand in the spirit of working together I ask questions to get people to think about the impact on others I can share my experiences and ideas without fear of judgement
What does good practice look like?	
<ul style="list-style-type: none"> <li>• There is a policy for compensating people with lived experience of a health condition and carers for their time and input into the co-design process</li> <li>• People with lived experience of a health condition and clinicians will feel empowered to speak up</li> <li>• There is a breakdown of traditional power relations and professional hierarchies with an understanding that 'expertness' comes from a range of sources</li> <li>• Agreement is made at the beginning of the process around equal participation and involvement. This is also renewed regularly.</li> <li>• There is a plan for how conflict will be managed respectfully and it is discussed and agreed at the beginning</li> <li>• Making co-design resources accessible to different groups</li> <li>• People are free to be authentic and honest without fear of consequence and judgement</li> <li>• Respect for particular expertise, experiences and reasons for involvement</li> <li>• Ensuring that there are equal numbers of staff and people with a lived experience of a health condition on the co-design team</li> <li>• Recognising and reducing barriers to participation</li> </ul>	



**Table 3. NSW Health Core Value: Empowerment**

<p><b>Enables a sense of purpose in our work. It is achieved through taking responsibility for our performance and behaviour. We celebrate our achievements. We also reflect upon what may not have met all expectations and learn from that experience. In doing so, we create a positive environment in which people are encouraged to grow, develop and succeed.<sup>17</sup></b></p>	
Capability	Individual behaviour
<b>Commitment to the process</b>	<p>I am present physically and mentally</p> <p>I will make time and resources available to support the co-design process</p> <p>I will be open to a different way of collaborating and ask questions if I am unsure</p> <p>I am motivated to see a service improvement</p>
<b>Setting expectations</b>	<p>I am clear about the objectives, roles and responsibilities of all individuals participating in the co-design process</p> <p>I recognise my strengths, boundaries and vulnerabilities</p>
<b>Knowledge of co-design</b>	<p>I understand the process</p> <p>I know how to apply the method appropriately using relevant tools and techniques</p> <p>I support the principles of co-design</p>
<b>Accountability</b>	<p>I am responsible for my own actions and will be proactive in addressing risk</p> <p>I will be accountable to the people in my co-design team</p> <p>I will be accountable to the outcomes of the co-design process</p>
<p><b>What does good practice look like?</b></p>	
<ul style="list-style-type: none"> <li>• Trust is placed in the expertise of participants</li> <li>• Recognition of the power imbalances, space to explore and balance them</li> <li>• There is a feeling of confidence, equity, inclusion, trust</li> <li>• There is support and training provided to build capacity to contribute to the process</li> <li>• There is an understanding of the common barriers to using a co-design method and an active commitment to address them</li> <li>• Language used is inclusive and respectful with no jargon or acronyms</li> <li>• Creating a culture where you can learn from mistakes and share it</li> <li>• Everyone feels that they have a voice and will be heard</li> <li>• Everyone is familiar with and understands co-design</li> <li>• Publicly accessible 'vision statement' with commitment of action</li> <li>• Everyone is given the time to participate and are provided with different ways to be involved and support the co-design process</li> <li>• Everyone's contributions are acknowledged and valued</li> </ul>	

**Table 4. NSW Health Core Value: Collaboration**

<b>Support and assist others and acknowledge that it's ok to ask for advice or support</b> <b>Share knowledge, information and lessons learnt</b> <b>Demonstrate teamwork and ensure an inclusive approach<sup>12</sup></b>	
<b>Capability</b>	<b>Individual behaviour</b>
<b>Balancing power</b>	I acknowledge everyone's contributions and lived experience as equal I seek the views and experiences of others I will let go of and let in power I will approach the collaboration with compassion and care for others
<b>Challenging assumptions</b>	I am sensitive and understanding when resolving conflicts and disagreements I listen and value everyone's views and enquire to their beliefs and assumptions I take time to understand and question my own assumptions and beliefs I reflect on the collaboration to understand what is working well and not working well
<b>Creating and enacting a shared vision</b>	I will ensure there is shared understanding about the way we are working
<b>What does good practice look like?</b>	
<ul style="list-style-type: none"> <li>• Everyone involved feels represented in the final product and comfortable and ready to take action on the outcome</li> <li>• A sense of unity and trust within the co-design team</li> <li>• Embedding reflection through the co-design process.</li> <li>• Enables process to move forward and recognise change is a dynamic process that needs to be managed</li> <li>• Modelling collaborative practices at all levels</li> <li>• Making sure the right groups are represented</li> <li>• Ensuring people involved in the co-design process have relevant lived experience</li> <li>• Deciding together the principles that will underpin the collaboration</li> <li>• Creating time and space to reflect on the collaboration; surfacing and discussing concerns or issues and where possible resolving these together</li> <li>• Sharing knowledge and information about co-design to everyone</li> </ul>	

## Service enablers

The *National Safety and Quality Health Service Standard 2: Partnering with Consumers* provides a framework for active partnership with consumers by health service organisations in Australia. It requires the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services. The standard enables organisations to ensure that services are more accessible and appropriate for consumers.<sup>4</sup>

To support active partnership and successful co-design processes, services will require a collaborative and supportive culture to bring systemic and sustainable impacts to healthcare.<sup>13</sup> A collaborative culture that is respectful of inclusion, collaboration and the value of lived experience will lead to improved experiences and set the foundations for a successful co-design process.

A supportive environment, in the context of fostering meaningful partnerships with consumers, can be known as an 'engagement capable environment' where an organisation creates an environment that embeds meaningful engagement throughout the core work of the organisation.<sup>14</sup>

There are a number of essential enablers that are required of the organisation to ensure effective consumer participation in co-designing improvements to services.

### **A culture that recognises engagement and participation is everyone's responsibility**

Meaningful and effective engagement and participation needs to be supported by strong community and workplace culture underpinned by shared values. Organisations should consider developing a mandate that outlines a commitment to co-design and ensures that all staff understand and adhere to an overall philosophy of partnership in care and services.<sup>15</sup> There needs to be a cultural transformation in the workplace where staff believe in designing and delivering solutions with patients rather than to or for them. Partnership should be seen as everyone's business, from the senior leadership team to frontline workers. It is, however, acknowledged that a manager's role is crucial as they will champion and embody the partnership model.

Where organisations endorse a culture that is focused on improving staff satisfaction, this will in turn lead to increased patient satisfaction. The National Mental Health Commission argues that 'a major factor in building, measuring and demonstrating strong, high performing culture is the alignment of experience and satisfaction between staff and people, their families and other support people who use systems and services'.<sup>16</sup> If the organisation can build a culture in its workforce that understands the benefit that partnership with patients' bring, this will greatly improve their ability to embed co-design as a way of working.

### **Strong leadership**

Organisational leaders need to develop strong, inspired and highly persistent leadership to overcome barriers to engagement and to demonstrate what it looks like in practice.<sup>17</sup> This involves clearly articulating the organisation's goals related to partnerships and promoting the concept of shared leadership throughout the workplace.

Leadership without a clear vision and strategic focus will be unable to truly transform an organisation. There is a requirement for organisations to continuously build the leadership capacities of the workforce to ensure people at all levels work respectfully with each other, including people with lived experience of a health condition, and that they recognise the specific value that lived experience can add.<sup>16</sup>

People with lived experience of a health condition and carers, families and kinship groups may also want to take on leadership roles and should be given the opportunity to co-lead and be equal partners in the decision-making process. This could include co-facilitating the meetings with the co-design team.

The challenge of strong and inspired leadership is outlined in the review of seclusion and restraint, as Recommendation 1 states that 'high-performing health services require clinical and collaborative leadership ... NSW Health must establish and adopt an integrated leadership development framework applicable to all staff at all stages of their career'.<sup>16</sup>

The *NSW Health Leadership Framework* should be embedded across all NSW Health organisations to support the practice of shared leadership.

## Being brave and courageous

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.<sup>19</sup>

An example of bravery and courage can be seen at Kingston General Hospital in Ontario where the executive team over several years integrated patients into every layer of the organisational structure. The hospital implemented a range of changes in practice to improve communication and partnership between staff, people with a lived experience, carers, families and kinship groups.<sup>17</sup>

Leaders will also need to be brave and courageous, as commitment and support will often be required without them always knowing the co-design outcomes in advance.

## Development of infrastructure support

### Recruitment

There is a need to ensure that people with lived experience of a health condition that are selected to support the co-design initiative are suitable and will possess the necessary lived expertise of the condition or service. There may be specific staff within the organisation, such as community participation managers or an equivalent role, who have existing contacts with patient partners and may be able to support the selection process.

An example of this can be seen across organisations in Quebec, Canada, where recruitment begins with the identification of potential patient partners via clinicians, patient associations or calls via social media. Their recruitment was based on predetermined criteria which clearly specified the role requirements, qualities and skills that were needed.<sup>15</sup> Additionally, the methods included employing a diverse range of patients which ensured a balanced representation of age, gender, socioeconomic condition and health status.<sup>17</sup>

The *Lived Experience Framework* advocates for organisations to 'review, develop, and implement paid participation policies for people with a lived experience ... carers, families and kinship groups'.<sup>1</sup> At present, there is considerable variation in practice across organisations when it comes to compensating patient partners, which demonstrates the inequity that exists.

There are some useful resources that are available to support organisations to determine the conditions under which patient participation should be paid:

- Australian National Mental Health Commission. *Paid participation policy for people with a lived experience of mental health difficulties, their families and support people*<sup>20</sup>
- Canadian Change Foundation. *Should Money Come Into It? A Tool for Deciding Whether to Pay Patient-Engagement*<sup>21</sup>
- INVOLVE (funded by the National Institute for Health Research in the UK) guidelines that set out fair payment for participants.<sup>22</sup>

In addition to recruiting patient partners, services and organisations will need to hire staff that can stimulate and support collaboration among patient, managers and clinicians. Clearly defined roles and responsibilities for both staff and patient partners are a distinguishing feature of engagement-capable environments.

### Training

The ACI's consultation process with the Living Labs identified training as a significant enabler in aiding the ability to effectively contribute to the co-design project. Training prior to the project's start provided the people with lived experience of a health condition with an opportunity to ask questions, learn about co-design and gain a better understanding of what was expected of them.

Training and development in health literacy is one way of supporting people to be involved as equals when they are working with health professionals.<sup>26</sup> The National Mental Health Commission has identified some examples of other capacity building strategies that can support patient partners, including:

- availability of co-designed practice guidelines and training programs
- providing scholarships for training, skill development through recovery colleges
- scholarships to attend conferences and training initiatives.

Staff will also require training to develop their knowledge of the co-design process, as well as access to the tools and techniques to support the application of co-design. This will increase their confidence and ability to contribute or lead the co-design process. Training of the whole co-design team together (including both staff and patients) is preferable to enable team building and cohesion.

Mentorship of patient partners, either from experienced partners or staff members, provides them with an important peer support network and helps build individual capacity to engage more effectively. Identifying a 'buddy' system or key contact outside of the co-design meetings offers patients a safe and comfortable space for them to be open about their feelings or ask questions when they are unsure.

### **Governance committees**

Governance committees also play an important role in framing co-design as an important priority within an organisation. Committees embed the commitment to co-design by ensuring there is an adherence to the partnership approach and to the structured methods that need to be implemented.<sup>15</sup> The committees act as the decision-making body and will steer executives and service managers in the direction that is needed to meet the organisation's strategic vision.

Organisations are encouraged to consider employing patient partners as committee members. This will enable them to make decisions that will represent the patient voice.

### **Capacity for time and intellectual space**

An authentic co-design process requires time and effort. It is important that services and organisations take this into account before committing themselves to a co-design initiative. Understanding the mechanics of co-design requires assurance that the co-design lead will take the time to listen fully and not put process and timelines ahead of participants.<sup>24</sup>

In the first instance there needs to be time dedicated to educating organisational leaders to support their understanding of co-design, as well as securing their commitment to the co-design process. Without executive sponsorship, the co-design project is likely to fail.

Organisations and their leaders also need to provide time to the individuals or teams who will be involved in the co-design process and need to ensure this is separated from the direct care delivery to patients. To support this process, leadership buy-in will be required to dedicate percentage of staff time to the co-design process.<sup>24</sup>

### **Mechanisms for participation**

Services should be exploring alternative ways to communicate with patients and consider how they can broaden the ways in which they involve patients during the co-design process.<sup>24</sup>

There are a number of methods in place that have been identified by the National Mental Health Commission for participation.<sup>23</sup> These include:

- formal, one-off mechanisms, such as focus groups, consultation surveys or ongoing advisory groups
- informal mechanisms, such as casual discussions, online and paper-based feedback tools which include a patient or carer's experience of a service
- brainstorming ideas or discussions around how to develop service or programs during other meetings
- project-based methods, where people are involved in a working group, or participating to develop a specific project and making decisions around the project
- technology based mechanisms, including web-based engagement platforms, interactive forums, discussion boards or feedback channels
- targeted mechanisms, to engage with specific groups of people to obtain their views and increase their involvement or participation, information sharing, and volunteering opportunities.

Providing different options of ways to be involved in co-designing services will enable better engagement and participation with wider groups of people to receive their views, ideas and expertise.

### **Commitment to quality improvement**

Organisations should be curious and willing to continually learn and make improvements to healthcare delivery.

The co-education of patient partners, staff and clinicians on quality improvement and change management creates a common language. It is crucial that frontline staff are provided with the time and support to learn quality improvement methods, otherwise very little change will occur.<sup>17</sup>

## Continuous evaluation

Evaluation is another vital mechanism for organisations to stay agile and committed to continuously improving their ways of working. It is important to understand the outcomes and impacts of engagement and participation, as it provides teams, individuals and organisations with an opportunity to reflect on their relationship and learn how to better engage with one another.

Services should have access to data that can measure improvements in patient experience and clinical outcomes to assess the progress of the work. The availability of data can enable organisations and services to hold their staff accountable for using the data to drive the next stages of the co-design initiative.

Evaluating the contribution of patient partners and professionals as well as their experience of the work conducted together is just as important as the co-design process itself. The evaluation process can be used to acknowledge and recognise the commitment of the co-design team and the impact their involvement has had.<sup>15</sup> Feedback and assessment of the co-design initiative should be a continuous process.

## Guidance for executives involved in co-design

As an executive leader, you will play a critical role throughout the co-design process.

Your role is key to enabling the transformation of an organisation's culture by building a shared vision, articulating expectations and helping embed person-centred values as a strategic focus. You will need to communicate to all staff the need for change and explain how a service will benefit from partnering and working in collaboration with consumers.<sup>17</sup>

### How will you contribute to the success of this work?

- Providing sponsorship and leadership
- Setting expectations that co-design is part of the project
- Providing flexibility and time for staff to participate
- Accepting a level of risk and not knowing the outcome
- Being personally engaged through action
- Establishing a working group to implement the co-design strategy
- Assisting with overcoming barriers
- Making the co-design project a priority.

### What are you doing and saying that will let others know that you support this work?

- Acknowledging and communicating the work that has been done through multiple channels, e.g. email communication and in person rounding
- Consistent messaging regarding objectives and vision
- Connecting professional networks when the work of project teams requires the input of other staff or services
- Being present and visibly connected to the work
- Establishing a governance structure that includes consumer representation
- Committing resources
- Being present for webinars or project meetings as required
- Authorising sharing of data and project progress
- Celebrating progress with other stakeholders.

### What do you need to be successful?

- An ability to articulate a rationale to use co-design
- Knowledge of co-design in the context of the service
- A project lead with a strong knowledge of co-design
- To be open minded and accountable
- Demonstrate personal belief in the co-design process, and troubleshoot if required.

### Barriers that you may face and how to overcome them

- **Resistance to change** – This may be managed by being inclusive and transparent about your vision and demonstrating your commitment.
- **Resources and timeframes** – This may be overcome by starting small and with realistic timeframes.
- **Lack of knowledge about co-design** – This may be overcome by seeking out co-design expertise and receiving training.
- **Selling co-design as a concept** – This may be overcome by articulating a commitment to the vision, rationale (why) and process.
- **Other priority work** – This may be overcome by allocating specified time for improvement work.



## Guidance for people with a lived experience of a health condition

This section is for people with lived experience of a health condition, their carers or family members who are participating in co-design.

Your input will have the ability to destabilise the status quo, introduce fresh perspectives and catalyse innovation.<sup>25</sup> There will be a broad variety of roles that you can play in improvement activities, such as planning, designing, advising, evaluating, recruiting and training.<sup>13</sup> A number of these roles will demonstrate leadership capabilities.

### How will you contribute to the success of this work?

- Sharing personal lived experience that creates insight for others
- Understanding and articulating where the system has failed
- Suggesting possible solutions
- Providing honest feedback
- Providing a non-service or non-clinical viewpoint.

### What are you doing and saying that will let others know that you support this work?

- Speaking up and contributing ideas
- Being present at all meetings, engaging and listening to others
- Working and listening to understand the perspectives of others
- Remaining actively engaged even if your perspective is confronting for staff.

### What do you need to be successful?

- Courage and willingness to speak up
- Coaching and mentoring (if you are new to co-design)
- Flexibility regarding the meetings, i.e. time, location and mechanism (provided by the organisation)
- Peer support – the presence of other people with lived experience of a health condition at meetings and a project ‘buddy’ to debrief with after each session

- Clarity of your role and purpose of involvement
- Training on co-design method
- A passion to improve the service and patient experience
- An understanding of the way health services operate and their timeframes regarding improvement processes
- A safe and supportive environment
- A pre-meet with the other team members to get to know one another.

### Barriers that you may face and how to overcome them

- **Inflexible processes and unwillingness of others to be flexible** – This may be overcome if time is provided at the beginning of the process for all participants to talk through the barriers they anticipate.
- **Not feeling safe** – This may be overcome by using peer support to check in frequently during the process and agreed ways of working.
- **Facing stigma** – This may be overcome if all members agree to work together, and suggest different options for involvement in the co-design process that enable anonymity if that is preferred.
- **Feeling isolated if you are the only consumer or carer representative** – Recommendations should be put forward to the service for flexible meeting times, remuneration for participation and a balanced representation of consumers and/or carers on the co-design team.
- **Being heard by the team** – This may be overcome by advocating weighted voting on key discussions.

## Guidance for staff in a co-design team

This section is for clinicians, project leads, peer workers and other non-health staff who may be identified as relevant to the needs of the co-design initiative.

Your role will be to share your professional experience or subject matter expertise and actively input into the process. This will involve activities such as: attending meetings, researching information, representing colleagues within your departments and acting as a co-design champion. This requires a commitment to see the project through and work in a co-design way until the very end.

### How will you contribute to the success of this work?

- Representing colleagues in the work and communicating back to them
- Sharing your professional lived experience on the issue and knowledge of how the service operates
- Reading papers, attending meetings, voicing views
- Being committed to the process
- Working collaboratively with the group.

### What are you doing and saying that will let others know that you support this work?

- Listening and respecting other's opinions
- Promoting co-design to colleagues and its benefits
- Engaging in the discussion with the co-design team without dominating the conversation
- Supporting everyone having a voice
- Recognising the expertise of everyone in the team
- Being fully invested when in the room, with no distractions from other aspects of your day job
- Asking respectful questions and being curious.

### What do you need to be successful?

- An understanding of co-design rationale, its successes and benefits
- An explanation and examples of how co-design works in practice
- An open, flexible and respectful attitude
- To learn from others that have been involved in co-design
- To be prepared to not be the expert and work with others in a different way
- To be prepared to hear challenging information
- An appreciation of the power dynamics within the co-design team
- To have trust in the process.

### Barriers that you may face and how to overcome them

- **Time pressure** – This may be overcome by committing to one systemic improvement initiative, allowing sufficient time in your diary and negotiating cover.
- **Sharing the equal space if used to being in a position of authority** – This may be overcome by being guided by the facilitator and listening actively.
- **Conflicts existing from what you have previously been taught** – This may be overcome by being open minded, flexible and educating yourself about the co-design process.

## Guidance for co-design leads

This section is for co-design leads, who have the necessary technical skills to drive forward and lead the improvement process.

Your role will require an in-depth knowledge of the co-design method and the ability to clearly communicate its principles and benefits. You will be required to provide updates on the project's progress to the service manager and executive sponsor, and provide guidance and training to the other team members. Examples of duties include: appointment of team members, facilitating discussions, planning the process, teaching the method to the co-design team and senior staff members and engaging with relevant stakeholders.

### How will you contribute to the success of this work?

- Bringing technical knowledge of co-design, quality improvement, project and change management methods and skills and provide training as required
- Managing power dynamics in a thoughtful and inclusive way, through strong facilitation
- Acknowledging that you are a 'process' expert and empower 'content' experts to step up
- Planning and allowing for adequate time
- Challenging norms and bias
- Checking in and reviewing where people are at or how they are feeling
- Considering potential project team and develop an expression of interest for applicants
- Facilitating different activities for data collection and solution generation
- Coordinating meetings and meeting papers
- Being flexible.

### What are you doing and saying that will let others know that you support this work?

- Using technical skills in a flexible way that facilitate the group's work
- Facilitating the discussion in an impartial way and enabling other team members to co-facilitate, e.g. peer workers or people with a lived experience

- Empowering people with a lived experience to co-lead the process
- Coaching the co-design team members
- Communicating clearly and exclusively between the co-design team and other stakeholders
- Applying project rigor
- Creating safe environments for trust and collaboration
- Creating momentum for moving the project forward as well as implementation
- Promote benefits of a co-design approach and their outcomes
- Positive attitude and ability to motivate other team members
- Looking for opportunities to celebrate achievements
- Being open, inclusive and transparent at all times.

### What do you need to be successful?

- Allocated time
- Executive sponsorship and clear directions from the service manager
- Strong facilitation, interpersonal, organisation, coaching and project management skills
- Emotional intelligence
- The trust of the co-design team and credibility
- Funds to compensate people with lived experience of a health condition who attend the meetings
- An ability to articulate core behaviours that support co-design
- A thorough understand of co-design principles and processes
- To be able to show the link between the organisations' priorities and those of the co-design team – i.e. what's in it for me
- Conflict management skills and ability to have crucial conversations.

## Barriers that you may face and how to overcome them

- **Unrealistic timeframes, expectations and competing demands** – This may be overcome by managing and advocating for some flexibility or making adjustments to the method.
- **Lack of executive support** – This may be overcome by setting up regular meetings with service manager and executives to secure and maintain sponsorship.
- **Resistance from people who disagree with co-design practices** – This may be managed by sharing an example of a positive co-design outcome, identifying a case for change and highlighting quick wins, or involving them in the process.
- **Not enough access to people with lived experience of a health condition to meet co-design requirements** – This may be overcome by working with staff that have existing relationships with people with lived experience of a health condition and using existing engagement mechanisms or the organisation keeping a database of potential co-design participants.
- **Not obtaining input from teams** – This may be overcome by encouraging, involving and setting values and expectations for the co-design team.

## Guidance for service managers involved in co-design

This section is for service managers, who act as the sponsors to enable the co-design lead to effectively lead the improvement process.

You will be responsible for providing the executive sponsor and relevant committees with key updates on project progress as a project level sponsor. Your main duties include: setting clear objectives with the co-design team, recruiting people with lived experience of a health condition and other team members, overseeing project timelines and progress and getting buy in from other key stakeholders.

### How will you contribute to the success of this work?

- Coaching and supporting the co-design lead and team to adhere to co-design
- Proactively engaging with the team, executive sponsor and other stakeholders
- Appointing someone with expertise to lead the co-design team
- Displaying leadership (facilitating and enabling to promote and maintain the work)
- Authorising budget and resources
- Giving permission and supporting staff to be involved
- Ensuring necessary resources are available
- Making the co-design process a priority.

### What are you doing and saying that will let others know that you support this work?

- Giving a convincing rationale to staff members and co-design team: what's in it for them?
- Championing co-design, and actively demonstrating commitment through action
- Helping to reinforce the goal
- Providing time for staff to participate
- Being an ambassador
- Communicating in consistent, clear, and multi-level ways.

### What do you need to be successful?

- Commitment from executive leaders
- A reasonable timeframe
- Clear mutual expectations which include budget and approach
- An understanding of co-design and how it has worked elsewhere
- Engagement with clinical leaders and teams to secure their buy in throughout the project
- To identify champions in the team who will promote co-design.

### Barriers that you may face and how to overcome them

- **No resource allocation** – This may be overcome by having an organisational strategy for co-design, setting realistic scope e.g. timeframes that are negotiated and backfilling of staff to enable them to participate.
- **Poor sponsorship** – This may be overcome by agreeing on clear upfront mutual expectations that are followed up in writing with regular diarised appointments.
- **Engagement with staff** – This may be overcome by a clear and transparent inclusive approach that includes executive support.
- **Lack of knowledge or experience** – This may be overcome by identifying key individuals who know co-design and learning from them.

## Customising co-design capabilities in the mental health context

It is important that co-design is considered in a particular light in the context of mental health because there are likely to be considerable power imbalances between people with a lived experience of mental health issues and other participants within the co-design team.

People with a lived experience of mental health issues who are involved in the co-design process often use their own experiences to inform their work. Professionals may not always value lived experience as legitimate knowledge and expertise and may have difficulty learning from them and positioning them as leaders.<sup>13</sup>

Participants of the co-design team need to be sensitive and aware of past traumas that people with a lived experience of mental health issues have faced in relation to power and the implications this may have on the individual's contribution to the co-design process.

There are key principles that underpin genuine collaboration between staff and people with a lived experience of mental health issues: trauma informed care principles, recovery-oriented practices and the value of lived experience.

### Trauma informed care principles

Trauma informed care can be described as services having an awareness of and sensitivity to the way in which people with a lived experience's needs can be understood in the context of their trauma history.<sup>26</sup>

Becoming a trauma-informed service is considered a process. It has been conceptualised into four stages.

1. Trauma aware: Staff understand trauma, its effects and survivor adaptations.
2. Trauma sensitive: The workplace can operationalise some concepts of a trauma-informed approach.
3. Trauma responsive: Individuals and the organisation recognise and respond to trauma enabling changes in behaviour and strengthening resilience and protective factors.
4. Trauma-informed: The culture of the whole system, including all work practices and settings reflects a trauma-informed approach<sup>27</sup>

During the consultation process of this guide, workshop participants identified and produced the key behaviours associated with the trauma informed care principles and explained their significance to co-design. Trauma informed care is founded on five core principles (Table 5).

**Table 5. Core principles of trauma informed care**

Principle	Behaviour	Co-design context
<b>Safety</b>	<ul style="list-style-type: none"> <li>• Treats everyone equitably</li> <li>• Steps in when something might be unsafe</li> <li>• Enquires about the wellbeing of others</li> <li>• Works at the right pace for others</li> </ul>	<p>Important to acknowledge how past trauma can impact on participants’ physical and psychological safety acting as barriers to engage and participate. Safe engagement and participation means that people with lived experience of a health condition feel comfortable being involved and speaking about their experience because the behaviours and actions of others demonstrate respect and a willingness to listen and learn.<sup>16</sup></p>
<b>Collaboration</b>	<ul style="list-style-type: none"> <li>• Listens and responds</li> <li>• Accepts views of others</li> <li>• Asks questions and is curious</li> <li>• Responds to facts and feelings</li> <li>• Is present and mindful</li> <li>• Works for a shared purpose</li> </ul>	<p>Genuine collaboration is the foundation principle of a co-design process. It creates an opportunity for a broad range of insights to establish new priorities, plans and strategies for improvement. Doing things with participants rather than doing things to them is an important approach. Partnering with them around what they think is best for them, helps avoid re-traumatisation and triggering of past trauma experiences as they are provided with a sense of control.</p>
<b>Empowerment</b>	<ul style="list-style-type: none"> <li>• Demonstrates acceptance of others</li> <li>• Draws out and includes others’ views</li> <li>• Identifies and builds on peoples’ strengths</li> <li>• Identifies and recognises the value of lived experience</li> <li>• Involves the right people as early as possible</li> </ul>	<p>Through empowerment, participants feel that their contributions are valued in a safe environment that promotes equality. Acknowledging participants’ strength and resilience can build confidence and empower them to be actively involved.</p>
<b>Trustworthiness</b>	<ul style="list-style-type: none"> <li>• Communicates project info, roles, expectations, value and purpose</li> <li>• Reliable and follows through</li> <li>• Provides feedback on decisions</li> <li>• Consistent in communicating lessons learnt</li> </ul>	<p>Trustworthiness provides a safe space where people feel comfortable to share and participate. It contributes to balancing power. Past trauma experiences are often experienced as a violation of trust which makes it hard for them to trust in health professionals. Fostering a compassionate, trusting and open communication can assist in building trust.</p>
<b>Choice</b>	<ul style="list-style-type: none"> <li>• Provides options for participation</li> <li>• Is aware that choice can lead to uncertainty</li> <li>• Defines where there is and is not choice</li> </ul>	<p>Participants who have experienced trauma have had their power, voice and choices taken away from them. Providing clear choices and giving back control of their care where possible is fundamental to building authentic partnership as it creates flexibility and balances power imbalance.</p>
<b>Culture and gender</b>	<ul style="list-style-type: none"> <li>• Open to different cultural and gender views and perspectives</li> <li>• Includes differing opinions and ideas</li> <li>• Aware that people are influenced by their cultural and gender identities</li> </ul>	<p>Acknowledging the impact of racism, colonisation and discrimination can address any barriers to being involved. Enabling participants to identify their cultural and gender identities can empower them to offer their unique perspectives.</p>



## Recovery-oriented practices

Recovery-oriented mental health supports people to recognise and take responsibility for their own recovery and wellbeing and to define their goals, wishes and aspirations.

The principles of recovery oriented mental health practice are relevant to all of the 10 national standards and apply to the whole mental health service system.

### Behaviour

- Recognise and embrace the possibilities for recovery and wellbeing created by the inherent strength and capacity of all people experiencing mental health issues.
- Maximise self-determination and self-management of mental health and wellbeing.
- Assist families to understand the challenges and opportunities arising from their family member's experiences.<sup>28</sup>

### Co-design context

Recovery oriented practice is centred on, and adapts to, the needs of the people. It recognises the values and contributions that a person with lived experience of mental health issues can provide during the co-design process.

## The value of lived experience

The value of lived experience of people with mental health issues and carers, families and kinship groups is recognised across services and communities.<sup>1</sup>

### Behaviour

- Encourage efforts to be brave, generous and curious in spirit.
- Seek out opportunities to learn and improve.
- People with lived experience of mental health issues and carers, families and kinship groups work together with service providers as equal partners.<sup>1</sup>

### Co-design context

People with lived experience of mental health issues, carers, families and kinship groups bring valuable expertise as members of the co-design team in generating a range of ideas to solve problems in service or care delivery. Services that respect and support their leadership recognise their contribution to the co-design process.

### Useful resources to support co-design

- ACI clinical redesign methodology and fact sheets:  
<https://www.aci.health.nsw.gov.au/resources/redesign/redesign-factsheets/redesign-methodology-for-improvement-and-innovation>
- ACI experience based co-design (EBCD) toolkit:  
<https://www.aci.health.nsw.gov.au/networks/peace>
- Consumer Health Forum of Australia's EBCD toolkit:  
<https://chf.org.au/experience-based-co-design-toolkit>
- The Point of Care Foundation's EBCD toolkit:  
<https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>
- The Kings Fund Collaborative Pairs Program  
<https://www.kingsfund.org.uk/publications/patients-partners>
- Commissioning Mental Health Services: A Practical Guide to Co-design  
<https://www.cesphn.org.au/preview/our-region/1270-commissioning-mental-health-services-a-practical-guide-to-co-design-august-2016/file>
- Western Australian Council of Social Service (WACOSS) Co-design Toolkit  
<https://wacoss.org.au/library/wacoss-co-design-toolkit/>
- Inside Out and Associates Australia  
<https://insideoutconversations.com.au/what-we-do/customised-training/>

### Useful resources to support a trauma-informed approach

- Trauma-Informed Events Checklist and Policy and Protocol  
[http://www.mhcc.org.au/wp-content/uploads/2018/05/ticp\\_checklist\\_v4\\_20180222.pdf](http://www.mhcc.org.au/wp-content/uploads/2018/05/ticp_checklist_v4_20180222.pdf)
- Trauma-informed care and practice (TCIP)  
<https://www.mhcc.org.au/project/trauma-informed-care-and-practice-ticp/>
- Blue knot foundation: Trauma-informed Care and Practice  
<https://www.blueknot.org.au/Workers-Practitioners/For-Health-Professionals/Resources-for-Health-Professionals/Trauma-Informed-Care-and-practice>
- What is trauma-informed care and how is it implemented in youth healthcare settings?  
<https://www.orygen.org.au/Training/Training-areas/Trauma/Clinical-practice-points/What-is-trauma-informed-care-and-how-is-it-impleme>

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- Bankstown-Lidcombe Hospital
- Sutherland Hospital
- Macquarie Hospital
- Health Education and Training Institute (HETI)
- Consumer Peer Workforce Committee

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## Glossary

<b>ACI</b>	Agency for Clinical Innovation
<b>EBCD</b>	experience-based co-design

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