

# Working with Consumers: A person-centred innovation strategy

JULY 2021

## About the artwork

The artwork within this Strategy is called 'Meeting Here'. It demonstrates a representation of the CIRCE Patient Partnership and Codesign program under the Agency for Clinical Innovation.

The artwork uses key cultural motifs of circular objects referencing meeting place to inform the practices in which the Strategy aims to highlight: Openness; respect; empathy; implementation; and solutions. These key words have helped form the artwork. It depicts the shared journey taken by those working in Health NSW and the Indigenous communities in NSW, when they engage in partnership.

The key process in the artwork finds a journey beginning from the centre that develops a set of pathways opening to all markings across lands and waters to create new paths and learn from the communities in and amongst those areas. This aims to demonstrate a process of learning and teaching between communities and through these experiences, all those involved will have worked together, aiming for greater health, success, inclusion and sustainability.

'Meeting Here', uses a set of blue tones to demonstrate the ways in which colour can be incorporated through the imagery, and it also creates an element of fluidity that sees the artwork closely related to NSW rivers and oceans.

Kamilaroi/Gamilaraay man Dennis Golding is a Sydney-based artist who also works as the First Nations Creative Producer at Australian Design Centre. Completing his Fine Arts Honours program at UNSW Art & Design, Dennis has developed a creative practice that explores empowering representations of identity and race.

If you would like to find out more about commissioning Dennis Golding for ACI resources and/or publications, please contact Phil Orcher, Aboriginal and Cultural Diversity Engagement Officer [Phillip.Orcher@health.nsw.gov.au](mailto:Phillip.Orcher@health.nsw.gov.au)



## Agency for Clinical Innovation

1 Reserve Road St Leonards NSW 2065  
Locked Bag 2030, St Leonards NSW 1590

T +61 2 9464 4666 | F +61 2 9464 4728  
E [aci-info@health.nsw.gov.au](mailto:aci-info@health.nsw.gov.au) | [www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au)

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Aboriginal Artwork By Dennis Golding.

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# Introduction

## Working with consumers in innovation

This document represents an organisational strategy about how the Agency for Clinical Innovation (ACI) partners and works collaboratively with consumers and communities at all levels. Such engagement is at the very heart of what we do. It is a key direction in our Strategic Plan 2019–2022 'Engaging patients, clinicians and managers', which incorporates person-centred innovations; fostering a stronger clinical voice and empowering patients, carers, families and communities.<sup>1</sup>

This strategy builds on the significant work and achievements the ACI has made in engaging consumers and replaces the ACI Patient Experience and Consumer Engagement: A Framework for Action 2015–2017.<sup>2</sup> The Framework guided the work of the Patient Experience and Consumer Engagement (PEACE) team at the ACI. This new strategy marks a commitment by ACI staff to strengthen the ways in which we partner and work collaboratively with consumers and communities at all levels. The strategy outlines the principles, resources, skills and capability needed for ACI Networks, Institutes, Taskforces and Teams to work effectively with consumers and use direct consumer experience to inform ACI activities.

It has been prepared by the ACI Clinical Innovation, Redesign and Consumer Engagement (CIRCE) team.

## About this strategy

### Our vision

Positive outcomes happen when every person matters and is actively engaged in their own health, healthcare innovation and improvement.

### Principle

The principle guiding this strategy is to strengthen the value of lived experience. The strategy outlines how ACI can partner and work collaboratively with consumers and communities to support innovation, design and implementation of healthcare improvement in NSW. In the context of this document, the term 'consumer' is inclusive of people, families, carers and communities who are current, previous or potential users of health services.

### Our commitment

The ACI values the passion, wisdom and insight that people with health conditions and their loved ones (patients, carers, families) bring. This patient-centred approach encourages people and their supports to be involved in all aspects of their healthcare; including decision-making and helping them to achieve what matters most to them. The ACI also encourages and values the insightful feedback that people and their loved ones can provide on the NSW health system. Working with people who have this 'lived experience', and with clinicians, helps ACI to achieve our vision to create the future of healthcare, and healthier futures for the people of NSW.

We have also made a commitment to work in partnership with Aboriginal people to achieve the highest level of health possible for individuals, families, and communities. This commitment means we will prioritise building respectful relationships with Aboriginal communities to deliver sustainable health outcomes.

Hand in hand with this is a commitment to building consumer and staff capability and capacity to work in a different way.

### Approach to developing the strategy

This strategy was developed in partnership with the ACI Consumer Council and a working group of consumers and staff at ACI who are leaders in patient experience and consumer engagement.

### What is included in the strategy

The strategy includes three sections that are key to embedding engagement in person-centred innovation as every day practice.

- Section 1 outlines a shared understanding of consumer engagement, patient experience and articulates a range of roles for engagement at the ACI.
- Section 2 outlines four dimensions for development across teams at ACI.
  1. Focus on what matters: to people, communities and priority populations who use health services, to understand and improve patient experience of healthcare
  2. Champion person-centredness: to support people to be partners in their own care and treatment to ensure self-determination in their own health needs

3. Reach out: to people who use services and work collaboratively and in partnership to support innovation, design and implementation of healthcare improvements in NSW
  4. Value culture and diversity: include people from all walks of life and from different communities in all our work.
- Section 3 outlines how we support and embed engaging people in person-centred innovation in everyday practice: this includes the culture, systems, processes and resources needed to turn engagement into every day practice – at all levels of ACI.



**Section 1:**  
**Shared understanding**

Consumers together with health professionals are playing a far greater role than ever before in supporting innovation, design and implementation of healthcare improvement. This reflects the increased importance and value placed on the consumer voice, lived experience and the need for health professionals and organisations to engage and work in partnership with consumers and communities.<sup>3</sup>

Patient experience and consumer engagement are different but closely connected terms that relate to valuing the lived experience and knowledge of patients, consumers, families, carers and communities.

Patient experience is defined, by the Beryl Institute, as the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care. The Beryl Institute, a global community that focuses on improving the patient experience, provides an Experience Framework which describes eight strategic lenses that impact or influence patient experience. These lenses are culture and leadership; infrastructure and governance; patient, family and community engagement; staff and provider engagement; environment and hospitality; innovation and technology; policy and measurement; and quality and clinical excellence.<sup>4</sup>

Consumer engagement is an activity which occurs with or by consumers and communities, as opposed to, about or for them.<sup>5</sup> In healthcare, engagement may occur across individual and collective levels.

- Individual: direct point of care
- Collective: service, improvement, governance, policy making and research.

Figure 1 identifies the ACI's commitment to engaging with consumers, the community and staff in terms of the individual and collective. The ACI's commitment to partnering and working collaboratively with consumers and the community includes a focus on health literacy for all and considering the impact of the social determinants of health. The ACI's model of engagement is underpinned by a commitment to building the capability of staff, consumers and the community in partnering effectively; and creating an environment in which individuals and groups can reflect on, and continually improve their joint ways of working.

Figure 1: Partnering and working collaboratively on what matters

Consumer, community and staff engagement	
Direct care, treatment	Service design, improvement, governance, research
<b>Individual</b> Consumers, families and communities are active partners in their own health	<b>Collective</b> Consumers, families and communities are partners in health innovation and improvement
<p><b>We champion evidence-based and person-centred approaches that will enable people to manage their own health and wellbeing.</b></p> <ul style="list-style-type: none"> <li>• Implementing and evaluating patient reported outcome measures system-wide</li> <li>• Building capability to use consumer enablement approaches and tools, such as:                             <ul style="list-style-type: none"> <li>– tackling shared decision making as a complex system challenge</li> <li>– addressing social determinants of health</li> <li>– using telehealth to provide access</li> <li>– gathering experiences of individual care to influence health innovation and improvement.</li> </ul> </li> </ul>	<p><b>We meaningfully engage with consumers and partner with them to increase their influence in health innovation and improvement. We value different types of knowledge and evidence.</b></p> <ul style="list-style-type: none"> <li>• Partnering with consumer representatives</li> <li>• Building collaborative partnerships at all levels and using the spectrum of engagement</li> <li>• Using cultural practices and protocols for engagement</li> <li>• Using person-centred innovations and co-production (including experience-based co-design and co-design) to truly partner</li> <li>• Implementing patient reported experience measures statewide to improve what matters most</li> <li>• Producing health literate print, audiovisual, website and social media content</li> <li>• Integrating social determinants as a key component of care</li> <li>• Bringing together research, empirical and experiential evidence</li> </ul>

HEALTH LITERACY – Universal precaution approach

SOCIAL DETERMINANTS OF HEALTH – Equity to ensure equality

To create the future of healthcare, and healthier futures for people of NSW

CAPABILITY
REFLECTION
CAPACITY



The Consumer Health Forum of Australia identifies that the role of consumers is not one-dimensional: Consumers fulfil different roles depending on the setting and context in which they work and interact<sup>6</sup>.

The ACI staff and consumers can use these roles as a basis for determining the level of engagement that is appropriate in any given project or interaction (see Dimension 3 on page 11 for further information regarding levels of engagement).

Table 1 shows eight key roles that describe the many and varied functions fulfilled by consumers.

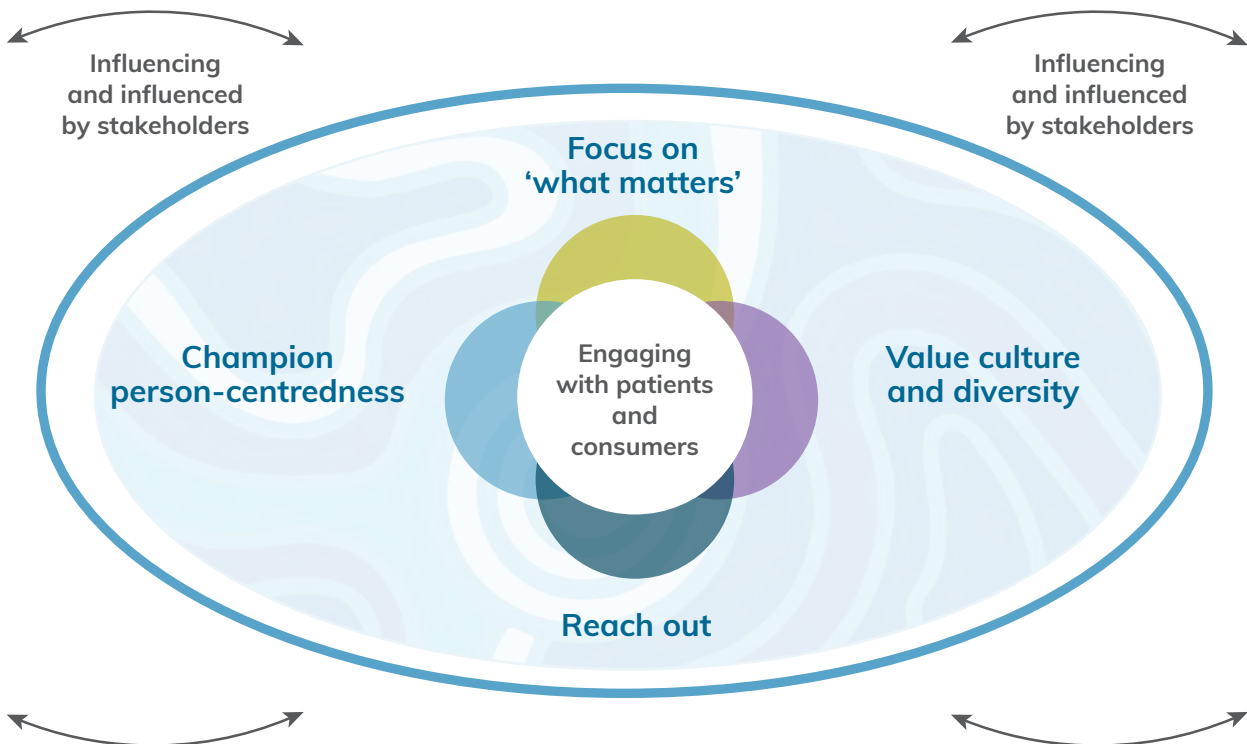
**Table 1: Roles of consumers**

System level	Organisation level	Point of care level
Change agent	Co-designer	Expert patient
Policy influencer	Research collaborator	Payer and contributor
Community mobiliser	Educator	

The next section outlines the four dimensions that are important for ACI teams to consider in partnering with consumers and the community and working collaboratively on what matters (Figure 2).

Partnerships and working collaboratively influence, and are influenced by, consumers and staff in determining how they engage and work with each other.

**Figure 2: Vision – Consumers are equal partners in healthcare**





## **Section 2: The four dimensions**

## Dimension 1: Focus on what matters

Focusing on what matters requires a shift in conversation from 'What is the matter with you?' to 'What matters to you?' What matters to consumers might include:

- being treated with compassion, respect and dignity
- having practical and emotional support
- being involved in making decisions about care and treatment
- access to convenient and responsive healthcare
- having a safe, clean and comfortable place to be
- continuity and consistency of care and treatment.

For Aboriginal communities, *Aboriginal health means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community.*<sup>7</sup>

A focus on what matters and improving patient experience is essential to high quality and safe healthcare.<sup>3</sup>

At ACI, this means we champion and support the statewide rollout of patient reported measures (PRMs). This ensures consumers are able to give direct and timely feedback to clinicians on what matters most at the point of care. We support clinicians in using PRMs and experiences to influence service improvement and redesign.

We also elevate the importance and value of lived experiences by bringing together patient experience and experiential evidence, with empirical data and scientific literature in all our work. This means we systematically gather what matters in a rigorous and transparent way and always look for opportunities to contribute to the knowledge base about patient experience, co-design and consumer engagement.

## Dimension 2: Champion person-centredness

A critical part of what matters to people who use health services, and their loved ones, is the extent to which they can be true partners in their own care and treatment. This 'person-centredness' means a few things in practice.

It means valuing consumers as people and knowing their needs go beyond the health condition they live with, or for which they present to health services. Understanding the relationship between health, wellbeing and personal factors such as employment, housing, education and social support is a key component of high quality healthcare. This is known as the social determinants of health. Recognising and integrating social determinants of health into our work at ACI enables consumers' voices and experiences to be heard, and promotes high quality healthcare. More information about the impact of social determinants of health on an individual's health and wellbeing is available on the social determinants of health page on the ACI website.

Person-centredness is also about supporting people's confidence, skills and knowledge to be actively involved with, and influence, their own health, wellbeing and care. This includes consumers being actively involved in making informed and preference-based decisions about their care and treatment.<sup>9</sup>

The Australian Commission on Safety and Quality in Healthcare identify that key strategies to include patients to become partners in their own care include:

- providing health information in engaging and accessible formats, such as print, mobile, apps and online channels
- eliciting and documenting individual needs, preferences and goals

- using patient decision aids
- encouraging and prompting patient questioning during clinical encounters
- providing education to support self-management.<sup>9</sup>

At ACI, this means we champion and promote consumer enablement approaches across NSW Health. We include shared decision making as the bridge between evidence-based practice and person-centred care in all clinical guidelines, pathways and models of care. We also share learning by publishing case studies and articles to generate and contribute to the evidence about patient experience and consumer engagement.

The ACI can continue to champion person-centredness by:

- enhancing the value of consumer enablement approaches within NSW Health including self-management, health coaching and health literacy. A consumer enablement guide and other related resources are available on the ACI website
- implementing patient reported measures across NSW Health via the HOPE system. See Patient reported measures on the ACI website.
- building awareness of health literacy. See Health literacy on the Clinical Excellence Commission website.
- actively disseminating existing resources that support the use of shared decision making in clinical practice
- building awareness and capability of clinicians and consumers to use shared decision making processes and decision aids in clinical practice
- embedding shared decision making in clinical guidelines, models of care and practice standards.

### Dimension 3: Reach out

Consumer engagement is about working with consumers as true partners in innovation, design and implementation of healthcare improvement. Working collaboratively and in partnership with consumers and communities helps the ACI to:

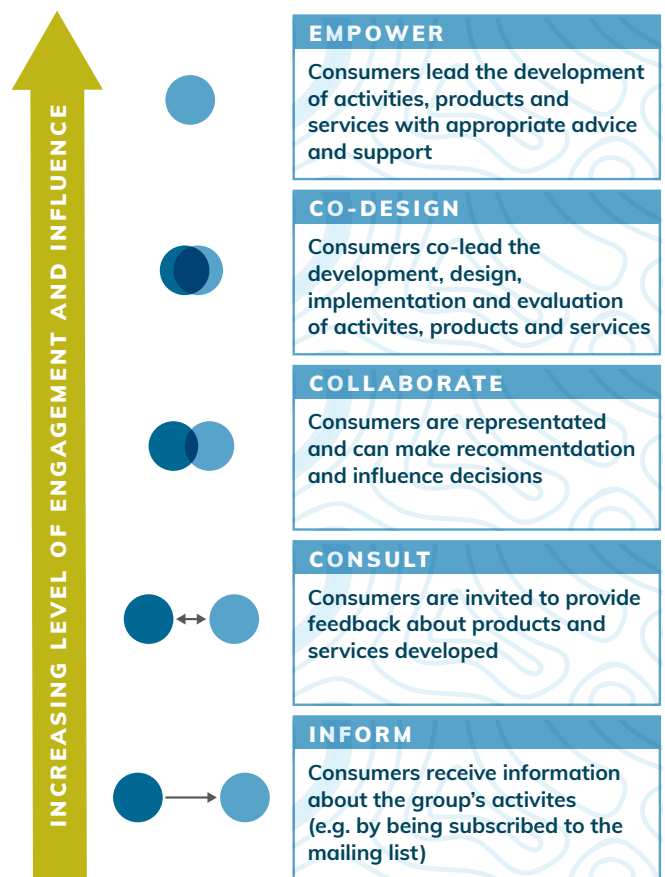
- identify emerging issues
- consider new perspectives
- build trusting relationships
- shift power dynamics
- improve decision-making quality, transparency and accountability.

Consumer engagement can be viewed as a continuum, ranging from low-level to high-level engagement. The International Association for Public Participation's public participation spectrum, adapted by the ACI for healthcare redesign (Figure 3), describes five levels of engagement ranging from providing information about services available (low-level) to co-designing and empowering consumers to lead the development of services, products and activities (high-level).

There are valid reasons to use consumer engagement approaches across the spectrum. The best approach should be chosen based on the nature of the project, the time and resources available to support engagement and the quality of existing relationships between consumers and other stakeholders.

Higher levels of participation are not always better – it is more important to be clear about the type of engagement being undertaken, why that level of engagement has been chosen and to deliver on the promises made to consumers. Collaborative and co-design approaches are well-suited to many of the complex system challenges the ACI is responding to and ACI staff will be supported to build their capabilities.

Figure 3: ACI spectrum of engagement



Source: Adapted with permission from the International Association for Public Participation (IAP2) (June, 2018)

#### Ways the ACI can continue to reach out

- Working collaboratively with the ACI/CEC Consumer Council around consumer engagement.
- Implementing targeted and transparent recruitment processes for consumer roles.
- Developing a consumer engagement plan at the start of key projects.
- Using and supporting NSW health staff to use, engagement methods from across the whole spectrum of participation.
- Creating pathways for consumers and communities to set priorities and initiate projects and supporting similar in local health districts and specialty health networks.
- Seeking feedback from consumers and communities on their experiences of engagement and building the capability and confidence of clinicians to do the same.
- Regularly reporting back on how consumer engagement has influenced ACI work.

## Dimension 4: Value culture and diversity

There are a number of reasons why it is important to respect and respond to culture and diversity in focusing on what matters, championing person-centredness and reaching out.

There are many cultures, religions and languages in NSW. Most people identify with more than one cultural status in terms of race, ethnicity, country, sexuality and gender. People bring a wide range of wisdom, insight and perspectives informed by many cultural backgrounds, identities and experiences. These are crucial to developing a health system where every person can access healthcare that is culturally safe and appropriate to their needs and preferences.<sup>8,10</sup>

In our work at ACI we strive to engage meaningfully with people who reflect the diversity of the population, including the following groups:

- Aboriginal people
- people from culturally and linguistically diverse communities
- residents of rural, regional and remote communities
- people with lived experience of mental illness or distress
- people who use alcohol and other drugs
- people with disability and those who are deaf
- people living with chronic illness
- people with caregiving responsibilities
- lesbian, gay, bisexual, transgender, gender diverse, intersex, queer, asexual and questioning (LGBTIQ+) people
- people living with HIV/AIDS and others whose diagnoses may attract stigma or discrimination.

There are barriers that people from different communities may face when trying to get the care they need or when engaging with our work. These may be practical, such as accessibility or availability of interpreters. They can also be experiential, for example historical mistrust, fear of stigma, lack of cultural safety, or conscious and unconscious biases held by health professionals. It is important to identify people and communities likely to be most affected by a project's outcome or specific groups who may be affected differently.

This includes:

- assessing impact with Aboriginal people and communities and through the completion of the Aboriginal health impact statement
- learning about different communities by researching migration and refugee experiences, cultural and religious practices and the political history.

Aboriginal health impact statements should reflect the following principles:

- trust and cultural respect
- recognition of the cultural values and traditions of Aboriginal communities
- holistic approaches to the health of Aboriginal people
- valuable and unique role of Aboriginal community controlled health services
- participation of Aboriginal people at all levels of health service delivery and management
- partnership with Aboriginal communities through Aboriginal community controlled health services and the Aboriginal Health and Medical Research Council of NSW.<sup>11</sup>

At the ACI, this means we collaborate meaningfully with consumers and communities, enabling us to work with difference, be curious about diverse perspectives and work creatively and collaboratively to reduce barriers to engagement. To do this we take time to learn about cultural norms and appropriate ways to connect. This means valuing local knowledge, expertise and experiences and asking the question: What is the best way to connect with and learn from your community?

#### **Ways the ACI can continue to value culture and diversity**

- Asking consumers about their accessibility needs and being solution-focused to accommodate their needs.
- Allocating time and budget to support inclusion when planning engagement activities.
- Using technology to enable participation by consumers who are unable to attend in person.
- Identifying priority populations for specific networks and projects, and proactively recruiting consumers with relevant lived experiences.
- Providing relevant culture and diversity training to staff and clinical network members (for example, Aboriginal cultural competence, LGBTIQ+ inclusion or disability rights).
- Ensuring that when demographic data is collected, this is done respectfully and with cultural safety and inclusion in mind.
- Building strong reciprocal relationships with community organisations which support us, and local health districts and specialty health networks, to build cultural and diversity knowledge and skill.
- Supporting local health district and specialty health network project teams to engage with Aboriginal health impact statements.



# Section 3: Everyday practice



This section is about the culture, systems, processes and resources that are needed to support this work and turn engagement with consumers and communities into everyday practice at the ACI.

### Everyone’s responsibility

We have an opportunity to continue to pioneer and test new ways to partner and work collaboratively with consumers and communities. We are working to further develop the culture, systems and processes required. This work is everyone’s responsibility.

At the ACI, this means we will engage an executive level sponsor with responsibility and accountability for overseeing the implementation of this strategy.

We will engage with ACI staff and clinical network members to implement the strategy in ways that meet their needs and enable them to work effectively with the strategy.

### Working together

Developing an enabling and collaborative culture is a principle that the ACI employs in all its interactions. Collaboration is valued, authorised and modelled at all levels.

Strengthening our capacity to work together includes reflecting on the following questions:

- Individually, how can I connect with other people or teams within the ACI for support?
- Individually and in teams, how can we model collaborative leadership behaviours among staff, consumers and communities?
- In teams, how can we work on what matters together?

- In teams, how can we foster collaborative relationships among staff, consumers and communities?
- Collectively, how can we form strategic partnerships with external partners and organisations who can support consumer engagement?
- Collectively, how can we show that we value the knowledge and skills of consumers and recognise their expertise in their own healthcare as a legitimate form of knowledge?

### Valuing innovation

Healthcare organisations are faced with unprecedented challenges to improve quality, increase efficiencies and reduce costs. Innovation is essential to ensure the sustainability of delivering quality healthcare.<sup>12</sup> Innovation can come from where we least expect it and from the thoughtfulness, spirit and courage of people at all levels of healthcare.

At the ACI, this means we capture emerging innovations, assess the evidence and evaluate the potential to implement across the system to transform the way people work together.

We work in partnership with leaders in the field, engage with the evidence and connect with national and international communities of thinking and practice to enhance patient experience and consumer engagement in NSW Health.

As a learning organisation we will celebrate and build on exceptional practice and take steps to improve how we collaborate and work in partnership with consumers and communities.

## Building capability

We will invest in capability for consumers and staff to build the skills, mindset and confidence to work collaboratively and in partnership to support innovation, design and implementation of healthcare improvement in NSW. Building capability involves having access to expertise and mentoring as well as being empowered to use knowledge and skills.

It is important that we support the consumers we engage (including practical and emotional, accessible information and opportunities, learning and development, reimbursement and need for flexible and ongoing involvement opportunities). Such support may include, but is not limited to:

- clarifying the role of consumers in different pieces of work and presence on committees
- orientation for consumers to the organisation and the role (including privacy requirements)
- ongoing training opportunities, tailored to the level of engagement employed and the needs of individual consumers
- meeting ongoing needs for support, identified in partnership with consumers
- considering consumer needs in setting up group and meeting processes
- targeting existing resources to consumers and patient experience that are made available and promoted widely
- using co-design methods in development of new resources to ensure their relevance and appropriateness for consumers
- working with trauma-informed practices.

ACI staff and clinicians also need to have access to resources, training and ongoing development opportunities. These may include, but are not limited to:

- information regarding the different levels of engagement that can be used and how each could look in practice
- training in engagement and co-design methods and support to develop and use those skills in a safe environment
- building capability in gathering and using patient experience and supporting clinicians to do the same
- acknowledging the value of our consumers' knowledge, skills and stories
- creating processes and attitudes to partner with consumers in an environment where everyone is equal
- developing options and processes for recruitment of consumers that can be tailored to individual team needs
- access to support resources such as *A guide to build co-design capability*
- using co-design methods in development of new resources to ensure their relevance and appropriateness for staff
- engaging culturally diverse communities and consumers.

## Conclusion

The ACI has a long history of engaging with consumers and enabling clinicians to incorporate patient experience into clinical decision-making and improvement. This strategy aims to build on the foundations, set a benchmark and enable ACI to deliver a consistent quality of consumer engagement over time.

In particular, considering mechanisms for capturing and using ongoing feedback from consumers will assist the ACI in targeting improvement efforts. These efforts will ensure that our engagement with consumers is strengthened and the value to the ACI's work of collaborating with consumers is recognised and acknowledged.

There is a further need to establish a governance approach to consumer engagement, and to develop a measurement framework to monitor our progress and measure success of engagement efforts.

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Craig Cooper	ACI Consumer Council
Anne Darton	Manager, Statewide Burn Injury Service
Tara Dimopoulos-Bick	Manager, Patient Experience and Consumer Engagement
James Dunne	Program Manager – Clinical Redesign Project Implementation
Pat Frances	ACI Consumer Council
Bridget Foley	ACI Consumer Council
David Gilbert	International Patient Leader, UK
Kiel Hennessey	Manager, Chronic Care for Aboriginal People
Olivia Hibbit	Network Manager, Acute Care Projects Team
Adam Johnson	ACI Consumer Council
Jamie Macdonald	Project Officer, Acute Care Projects Team
Phil Orcher	Project Officer, Patient Experience and Consumer Engagement
Regina Osten	Program Manager, Primary and Chronic Care
Jennie Pares	Manager, Health Economics and Evaluation
Jacinta Patterson	Project Officer, Patient Experience and Consumer Engagement
Mae Rafrat	ACI Consumer Council
Tomas Raton	ACI Consumer Council
Sophie Sharman	Project Officer, Patient Experience and Consumer Engagement
Ro-Ann Stirling-Kelly	ACI Consumer Council
Violeta Sutherland	Manager, Urology and Gynaecological Oncology Networks
Sharon Taylor	ACI Consumer Council
Joyce van Akkeren	ACI Consumer Council
Raj Verma	Director, Clinical Program Design & Implementation
Rob Wilkins	Manager, Palliative Care Network
Coralie Wales	ACI Consumer Council

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.

We also work 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.

Our innovations are:

- person-centred
- clinically-led
- evidence-based
- value-driven.

[www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au)



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**CLINICAL  
INNOVATION**

*Our vision is to create the future of healthcare,  
and healthier futures for the people of NSW.*