

Patient Experience and Consumer Engagement: A Framework for Action

Understand, Act, Empower

AGENCY FOR CLINICAL INNOVATION

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- ACI Consumer Council
- ACI Consumers
- ACI Network, Taskforce and Institute Managers
- ACI Patient Experience and Consumer Engagement Team
- ACI Knowledge Manager
- LHD Community & Consumer Participation Managers
- State-wide Multicultural Health District Managers
- NSW Multicultural Health Communication Service
- Health Consumers NSW
- Stroke Recovery Association

About the ACI

The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this by:

- Service redesign and evaluation applying redesign methodology to assist healthcare
 providers and consumers to review and improve the quality, effectiveness and efficiency
 of services.
- Specialist advice on healthcare innovation advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment.
- Initiatives including Guidelines and Models of Care developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system.
- Implementation support working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW.
- *Knowledge sharing* partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement.
- Continuous capability building working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care.

www.aci.health.nsw.gov.au

Foreword

The NSW Agency for Clinical Innovation (ACI) strongly supports the engagement of patients and consumers to design, promote and implement a person-centred approach to health care in NSW. Since its inception, the ACI has offered consumers a seat at the table in our Networks, Taskforces and Institutes to ensure that the patient voice is at the heart of what we do.

The establishment of the Patient Experience and Consumer Engagement (PEACE) team demonstrates the ACI's commitment to consumer-led redesign of healthcare. The PEACE team supports the ACI's Networks, Institutes and Taskforces to capture consumer input and harness direct patient and staff experience to inform ACI activities. This Framework provides valuable information, guidance and resources to enable this approach. I am pleased that the development of the Framework has modelled a codesign approach; involving members of the ACI Consumer Council from its conception and at all stages of development.

Implementing this Framework and achieving its vision will involve all parts of our organisation and partners in the NSW health system. I encourage readers to take this opportunity to increase their knowledge and understanding of how to work respectfully and effectively with patients and consumers.

This framework and associated toolkits and resources are also available on the ACI website so that our colleagues have access to the most up-to-date information about best practice, evidence based patient experience and consumer engagement: www.aci.health.nsw.gov.au.

Dr Nigel Lyons

Chief Executive

Glossary/ Definitions

Culturally and Linguistically Diverse Backgrounds (CALD)	The term is commonly used to describe people who have a cultural heritage different from that of the majority of people from the dominant Anglo-Australian culture.		
Carer	Someone who provides personal care, support and assistance to a person with an ongoing illness, disability or condition.		
Clinician	Clinicians are health professionals working in the NSW Health system who provide care to patients. Clinicians include medical, nursing and allied health professionals.		
Codesign	Codesign is a way of improving healthcare services for patients by bringing together all stakeholders and consumers in partnership, to develop health services that best meet the needs of consumers and carers in the most effective way possible.		
Community members	Individuals, groups of people or organisations including consumers, their families and carers, members of organisations that support or represent community groups, and the wider community itself. Community members comprise diverse groups including Aboriginal people, people from multicultural backgrounds, people with a disability, younger people and older people, and people who are marginalised or vulnerable.		
Consumer	People who use, potentially will use or have previously used NSW Health services, as well as their carers and families.		
Consumer engagement	Consumer engagement is the process for incorporating consumer and community aspirations and needs into decision making and service planning, delivery and evaluation.		
End-user experience	End-user experience is the total experience of health care from the perspective of patients, consumers, carers, family members and staff members.		
Local Health Districts (LHD)	Local Health Districts in NSW are responsible for providing health services in a wide range of settings, from primary care settings in the remote outback to metropolitan tertiary hospitals and health centres.		
Health literacy	The ability to understand and use various kinds of information such as books, information sheets, newspapers, magazines and brochures. It also includes the knowledge and skills required to locate and use information including tables and charts.		
Model of Care	A multifaceted concept which broadly defines the way health services are delivered.		
Non-government and community based organisations	Non-government organisations and community-based organisations are not for profit organisations that exist independently of government but may receive financial or other assistance for services that are required by the government.		

Numeracy	A component of health literacy whereby the consumer has the knowledge and skills required to manage and respond to mathematical situations such as medication management.				
NSW Health	 NSW Health refers to the NSW public health system. It includes: 15 Local Health Districts and 3 Specialty Networks. NSW Ministry of Health, which supports the executive and statutory roles of the NSW Minister for Health. The Pillars including the Agency for Clinical Innovation (ACI), Bureau of Health Information (BHI), Cancer Institute NSW, Clinical Excellence Commission (CEC), Health Education and Training Institute (HETI), NSW Kids and Families. Other statewide or specialist health organisations such as NS' Ambulance and NSW Health Pathology. 				
Patient	A person currently receiving health care.				
Patient experience	The patient's interpretation and evaluation of everything they see, feel and hear while receiving care from a health facility. Patient experience impacts the whole patient journey, from pre-care to clinical care to follow up care and everything that happens in the 'gaps'.				
Patient Experience Trackers (PETs)	The Patient Experience Tracker (PET) is a small electronic hand held device used to collect patient and staff feedback at the point of care.				
Patient Reported Measures (PRMs)	Patient Reported Measures (PRMs) are tools that allow patients to report on their perception of their health and their experience of health care and health services.				
Person-centred care	Person-centred care is health care that involves the patient, their carer and family; and is respectful of and responsive to the preferences, needs and values of patients and consumers. Person-centred care may also be referred to as patient-centred care, client-centred care or consumer-centric care.				
Staff member	A staff member is an employee of NSW Health or clinician providing services within NSW Health facilities. Staff members include medical, nursing and allied health professionals; managers and administrators; and support staff. There are around 105,000 full-time equivalent staff members who make up the NSW health workforce.				
Staff experience	The staff member's interpretation and evaluation of everything they see, feel and hear while delivering care within a health facility.				
Way-finding	A component of health literacy whereby the consumer has the ability to understand and use information, such as signage or directions, to find their way through the health setting, such as navigating through a hospital.				

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1. Introduction

The NSW Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. The ACI Patient Experience and Consumer Engagement (PEACE) team promotes meaningful consumer engagement and the capture and use of patient, carer and staff experience in health care provision and improvement to support NSW Health to deliver person-centred care. The PEACE team offers information, advice, resources and tools to drive local innovation and transformational change across the NSW health system.

2. Vision

Our vision is for consumers to be equal partners in health care provision and improvement in NSW. This means that patients, carers, family members, staff and community members can choose to participate in health care planning, design, delivery, monitoring and evaluation; with levels of participation varying from providing one-off feedback to being involved over longer periods in more complex projects.

The importance and value of involving the patient, carer and family in health care planning and decision-making, and providing person-centred care, is recognised in the literature and national and international health care policies. Consumer participation in health care can occur at the individual, service and system level. The *individual level* refers to shared decision-making between consumers and clinicians in health care planning, treatment and management. The *service level* involves consumers participating as part of a team in health service design and quality improvement. The *system level* involves engaging consumers and community members in system-wide health policy and program development.

Our goal is to empower patients, carers and family members to participate in care planning and decision-making at an individual, service and system level in order to deliver person-centred care. Person-centred care is health care that is respectful and responsive to the needs, preferences and personal circumstances of the patient, carer and family members.

The ACI PEACE team works with clinicians, consumers and managers to promote and facilitate the achievement of this vision; with a focus on improving patient outcomes and experience and encouraging meaningful consumer and community engagement.

3. Background

3.1 Evidence

The evidence shows that consumer participation leads to better quality of care, improved health outcomes and more accessible and effective health services. Person-centred care has been associated with benefits for patients and carers, such as improved quality of life and satisfaction with care and increased confidence managing their condition. Clinicians also report improved satisfaction with care and better clinical outcomes, particularly for people with chronic disease. Benefits for the system include improved follow-up; fewer tests; and reduced hospital readmission rates and length of stay.

The patient's experience with the health system is also an important and meaningful measure of quality of care.⁴ A growing body of evidence shows that patients' experience of care has a direct correlation to their health outcomes and that staff experience affects the performance and efficiency of the whole system. Patients often use different measures to health care workers to assess their health experience. For example, patients measure the quality of care provided against the level of dignity and respect they received, whereas staff may use how well they worked together as a team to judge coordination of care.

Foundational research by the Picker Institute (1993) identified the following eight principles of person-centred care, which were developed and refined through extensive focus groups and a review of the literature:⁵

Figure 1: Principles of Person-Centred Care



3.2 NSW community

The NSW community is diverse. There are currently over 7.2 million people living in NSW; of these, 2.5% identify as Aboriginal and/or Torres Strait Islander, over 30% were born overseas and nearly 1 in 4 people speak a language other than English at home.⁶

3.3 Policy context

New South Wales, national and international health policy recognises that quality health care is person-centred. The NSW State Health Plan emphasises the provision of person-centred and integrated care, "with a focus on empowering patients as a key partner in decision-making". This direction is supported by the Australian Commission on Safety and Quality in Health Care's National Safety and Quality Health Service 'Standard 2: Partnering with Consumers', which requires the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services. **

As the NSW population ages and lifestyles change, more people are living with multiple long-term conditions that can affect their health, quality of life and ability to function. As a result, they may need access to a range of health and hospital services. The last few decades has seen a change in focus to developing health care systems that aim to keep people healthy, rather than just treating people when they are sick, in order to improve outcomes and

enhance sustainability. There is recognition of the need to deliver 'the right care, in the right place, at the right time' for everyone and, where possible, to provide care closer to home in the home or primary and community health care settings.

The consumer is the only constant throughout the patient journey. They are therefore the experts in terms of identifying their desired health outcomes and experiences of illness and care, and their expertise should be sought and respected in order to improve the quality of care. Shared decision-making, support for self-management and proactive communication are key features of person-centred health care.⁹

3.3.1 NSW Health Initiatives

The NSW health system recognises the importance of consumer engagement and patient experience in developing person-centred care. Examples of efforts to develop person-centred care at a statewide and local level include:

- Local Health District (LHD) Community and Consumer Participation, Carer Support, and Multicultural Health Units, provide direct linkages to consumers and community members who want to be involved in health care decision-making, including through membership to committees.
- ACI partnerships to redesign, develop, implement and evaluate new products to improve the experience of care for patients and the delivery of efficient health services for all.
- The Small Acts of Kindness initiative aims to support NSW Health staff to consider how
 they can demonstrate small acts of kindness every day. The initiative includes a short film
 created by the Ministry of Health's Nursing and Midwifery Office which aims to highlight
 the importance of compassionate care. The film is available at:
 http://www.heti.nsw.gov.au/news/small-acts-of-kindness/.
- Clinical Excellence Commission (CEC) "Partnering with Patients" Program works with LHDs to assist in transforming services to include patients and family as care team members and improve consumer engagement to promote safety & quality in health care.
- Nursing and Midwifery Office (NAMO) Essentials of Care Program is an approach to
 practice that requires that all stakeholders (patients, carers, staff and families) to have
 opportunities to participate and be included in decisions about effective care using
 approaches that respect individual and collective values.
- The Ministry of Health funds state-wide specialist multicultural units including the NSW Multicultural Health Communication Service, Multicultural HIV/AIDS and Hepatitis Service, NSW Transcultural Aged Care Services, the Diversity Health Institute and the Transcultural Mental Health Centre.
- Bureau of Health Information (BHI)'s NSW Patient Survey Program gathers information from patients across NSW about their experiences with services in hospitals and other health care facilities.
- The NSW Integrated Care Strategy includes real time patient feedback (Patient Reported Measures [PRMs]) as a statewide enabler.

3.4 Our approach

The PEACE team aims to enable the achievement of our vision by promoting and facilitating:

• The capture, analysis and use of patient, carer and staff member experiences (patient experience).

- Meaningful consumer and community engagement (consumer engagement).
- Consumer capability development.
- Building key partnerships and relationships.

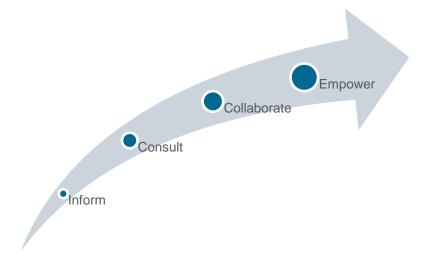
The PEACE team supports consumers choosing to be equal partners by providing opportunities to build knowledge and skills allowing them to participate confidently and more fully in health care provision and improvement at the individual, service and system level. Patient experience and consumer engagement should be sought in the planning, design, delivery, monitoring and evaluation of health care in order to empower consumers to improve the quality of care. There is no one-size-fits-all approach but rather a process needs to be undertaken that matches the approach to the needs of consumers and the aims and objectives of the particular project, service or setting.

The PEACE team offers information and advice as well as a range of methods and tools that can be utilised as part of standard practice, or where project specific needs exist in service redesign and quality improvement, to develop person-centred care.

3.4.1 Consumer engagement

Consumer engagement is the process for incorporating consumer and community aspirations and needs into decision making and service planning, delivery and evaluation. Onsumers and community members should be partners in health care planning, design, delivery, monitoring and evaluation in NSW. Consumer engagement commonly occurs at a number of levels; starting at inform, before moving to consult, involvement and collaborate, and then on to empower.

Figure 2: Levels of engagement



The levels of engagement have also been expressed by the Australian Commission on Safety and Quality in Health Care (ACSQHC) as a continuum of participation (Figure 3). The continuum describes the extent of consumer participation in organisational activities and decision-making, and provides examples of how this might occur in practice.

Figure 3: Continuum of Participation¹²

	Information	Consultation	Partnership	Delegation	Control
Description	The organisation develops or adopts a policy, plan or program and provides information about this to the consumers and/or carers and the community.	The organisation identifies an issue and proposes a policy, plan or program which responds to the issue. It then provides information to consumers and/or carers and the community on that proposal and seeks views and comments with a view to maximising acceptance.	The organisation identifies an issue and presents a tentative policy, plan or program which responds to the issue. The organisation seeks active involvement and feedback from consumers and/or carers and the community which is incorporated into the plan.	The organisation identifies an issue, presents this to consumers and/or carers and the community for them to make decisions or propose actions to address the issue.	The organisation asks consumers and/ or carers and the community to identify an issue and make all the key decisions on the development of solutions to address the issue. The organisation supports them to accomplish this.
Examples	Giving: Flyers, mailouts, factsheets, press releases, brochures, newsietters, public displays, websites, public meetings Gathering: Surveys, phone-ins, focus groups, in-depth interviews, suggestion boxes	Workshops Consumer representatives on management committees, advisory groups Public meetings/ patient forums Online discussion groups Circulation of proposal for comment Conferences or seminars Evaluation surveys	Strategic alliances built utilising a combination of other methods (including those mentioned in Information and Consultation) for example: workshops consumer representatives on committees or advisory groups round tables patient forums surveys focus groups	Shifting some or all of decision making on particular issues to consumers. For example: spending on specific budget items, management of particular programs by consumers eg. mental health consumer advisory groups	Community appointed management committees eg. Aboriginal Community Controlled Health Organisations

The ACI generally informs, consults and collaborates with consumers. Consumers are members of ACI Networks, Taskforces and Institutes and regularly provide valued input into ACI activities. There are currently more than 70 consumers directly involved in the ACI; including patients, carers and representatives of non-government and community based organisations.

Examples of how the ACI engages with consumers at different levels include:

- Inform: consumers who are members of ACI Networks, Taskforces and Institutes
 receive information about the group's activities e.g. by being subscribed to the mailing
 list.
- Consult: consumers are invited to provide feedback about products and services developed by the ACI or the Network, Taskforce or Institute either through membership to Network or by being part of a community based organisation involved in the ACI.
- Collaborate: consumers are represented on ACI governance bodies, including the Consumer Council and Network, Taskforce or Institute Executive Committees, and can make recommendations and influence decisions regarding ACI and Network activities, products and services.
- **Empower**: this is where consumers co-lead the development, design, implementation and evaluation of ACI activities, products and services e.g. initial co-design projects.

The PEACE Team is responsible for building the capacity and network of consumers involved in the ACI and strengthening their contribution across organisation's activities. In doing so, the PEACE team will encourage and support a greater move towards 'empower' by

modelling and promoting methodologies such as co-design. Co-design improves healthcare services for patients by bringing together all stakeholders and consumers in partnership, to develop health services that best meet the needs of consumers and carers in the most effective way possible.

Consumers may be identified and engaged to participate in the ACI's activities by:

- Self-identifying via the ACI website or an open Expression of Interest process.
- Clinicians and peers already involved in the ACI.
- LHD colleagues including Community and Consumer Participation Managers, Carer Support Units, Multicultural Health Managers and CALD Statewide Services.
- Organisations that represent consumers and have consumers as their members including non-government and community based organisations such as Health Consumers NSW, Carers NSW or condition/disease specific organisations.

The PEACE team is committed to ensuring that the ACI identifies and engages consumers in a thoughtful and respectful manner that matches the level of consumer engagement to the interest of the consumer and the aims and objectives of the project or activity. Consideration should be given to supporting consumers to participate at the level they are comfortable and in a way that adds value to the consumer and the Network, Taskforce or Institute.

3.4.2 Patient experience

Patients, carers and family members are the end-users of our health care systems and processes. The healthcare journey of patients and staff members comprise the 'end-user experience' of our health systems and processes. It is important to understand the experiences of patients and staff members in order to improve health care and deliver person-centred care. This ensures we have a complete perspective of how our health systems and processes are working and interacting; and provides valuable insight into what we can do to design, plan and evaluate improved and innovative systems.

The health care journey and 'end user' experience is influenced by the interactions, communication, systems and processes that occur at an individual, service and system level.

A person centred, positive end-user experience is influenced by:

- Respectful interactions.
- Regular and clear communication.
- Collaboration and cohesion between patients, carers, their clinician and the wider care team.

The achievement of this is influenced by individual attitudes, behaviours and relationships as well as access to supportive communication and enabling systems and processes such as information technology, policy and regulations, and appropriate incentives and disincentives.

The key to improving the end user experience is to capture and understand patient and staff experience across the health care journey so that it can be applied to health care provision and improvement. The phases to understanding patient experience include: 13

- 1. Identifying emotions: how people feel during their journey.
- 2. Finding the 'touch points': moments of engagement and disengagement with health care or health service.
- 3. Mapping the emotions (highs and lows) to the touch points.

The following methods and tools may be used to capture patient experience:

- Surveys: paper or electronic including Patient Experience Trackers (PETs).
- Stories: obtained by in depth interviews or conversations that may be audio or video recorded.
- Focus groups with patients and staff members.
- Observation and 'shadowing' of patients or staff members at specified points/ stages
 of the health care journey.
- Story boards of the patient with photos or pictures and information relevant to the patient.
- Patient and staff rounding: involves gathering information in a structured way by having conversations with staff and patients.¹⁴

The methods and tools may be used separately or in combination. Choice of method and tool will depend on the nature and purpose of the project or activity and the needs and preferences of patients and staff members.

Figure 4: Patient Experience Tracker



4. How we work

The purpose of the PEACE Framework is to provide a single point of coordination and access to information, resources and tools that support the ACI to engage consumers and capture patient experience in its activities. The goal is to translate project specific information into transformational change across the health system by capturing, analysing and applying patient experience and consumer engagement data to inform and drive sustainable change.

The PEACE Framework and associated toolkits will be available as online resources on the ACI website so that ACI and NSW Health colleagues can easily access, navigate and utilise the information. This will also mean that the information can be updated as new resources become available and enable linkages to other organisation's web resources.

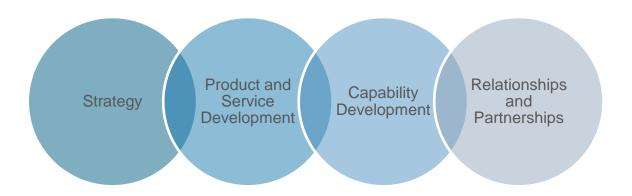
The PEACE Framework provides an opportunity for the ACI and NSW Health to:

- Step back and think about why we engage consumers and seek patient experience.
- Make decisions in partnership with consumers.
- Involve consumers early.
- Make our aims and objectives clear.
- Provide feedback on the difference consumer input and patient experience has made.
- Share the lessons learned and build in a continuous learning and improvement.

The main responsibilities of the PEACE team are to:

- Ensure that the ACI's strategy and product and service development are informed by patient experience and include consumer engagement.
- Develop the capability of consumers involved on ACI Network, Taskforces and Institutes.
- Promote cultural change within the organisation through the development of strategic partnerships and relationships.

Figure 5: PEACE responsibilities



4.1 Structure of the PEACE Team

The ACI's overall purpose is to design and drive evidence based innovation to ensure appropriate, effective and sustainable person-centred health care. The ACI aims to equip clinicians, consumers and managers involved in its Networks, Taskforces and Institutes with the tools and capacity to preserve and support their critical role in the design and implementation of innovative healthcare. ¹⁵

In July 2014, the PEACE team was established to support and guide the ACI's strategic direction by promoting meaningful consumer engagement and harnessing patient and staff experience in health care redesign and improvement. The PEACE team aims to be flexible

and responsive to emerging evidence and the changing needs of the ACI, NSW Health and the NSW population; whilst at the same time ensuring that the consumer voice is at the heart of all we do.

The ACI's strategic direction relies on the PEACE team to:

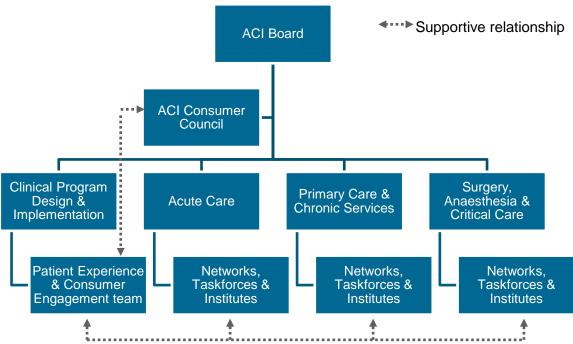
- Be forthright and impartial with advice sought from the ACI Consumer Council.
- Build and maintain strong relationships with key stakeholders including consumers involved in the ACI, ACI Networks, Taskforces and Institutes, Local Health Districts and Specialty Networks, NSW Ministry of Health and Pillars, and non-government and community based organisations, particularly Health Consumers NSW.
- Access emerging evidence and information describing innovative, effective and sustainable consumer engagement and patient experience strategies.

4.1.1 The ACI Consumer Council

The ACI Consumer Council was established in July 2010 to provide the ACI Board with expert advice regarding consumer and community engagement and represent the interests of ACI consumers. The Consumer Council is chaired by a Board Director and provides regular reports to the Board. The ACI Chief Executive is a member of the Consumer Council.

Consumer representative members (6-10) are appointed to the Consumer Council for a twoyear term through an open Expression of Interest process. Appointments to the Consumer Council are made with consideration of appropriate representation and equity, expertise and skill-mix. The Consumer Council is expected to communicate and consult with consumers involved in ACI Networks, Taskforces and Institutes and to develop relationships and linkages with other internal and external stakeholders in accordance with the ACI's strategic direction.

Figure 6: ACI Organisational Chart for PEACE



4.2 PEACE Framework Strategy

The PEACE Framework strategy underpins the organisation's ability to capture, analyse and apply the 'right patient experience/consumer engagement' at the 'right time' across a range of issues, programs and projects by:

- Supporting the ACI Consumer Council to further develop its role as an engaged advisory-based group.
- Strengthening strategic linkages and partnerships across the NSW Health sector including the Ministry of Health, Pillars, LHD/SHN, NGOs and community based groups.
- Growing relationships with new ACI Consumers and consumer groups.
- Facilitating leading edge consumer engagement by matching the needs of the issue/program/project with the appropriate consumer voice, reflecting a fluid process that adds value to both parties and asks critical questions such as "what is best for the patient?" and "what is best for the system?".
- Supporting the trial and evaluation of different approaches to consumer engagement including but not limited to a range of consultation styles such as project specific short-sharp advice and direct observation.

4.3 Product and service development

The Agency for Clinical Innovation (ACI) has established Networks, Taskforces and Institutes to foster collaboration and support healthcare innovation across the NSW health system. ACI Networks, Taskforces and Institutes develop a range of products and services; particularly flexible, evidence-based person-centred models of care.

The PEACE team provides the ACI and its Networks, Taskforces and Institutes with access to a single point of coordination and advice to embed consumer engagement and patient experience into its products and services, including models of care. By applying the redesign methodology in combination with appropriate resources and tools, the PEACE team encourages ACI Networks, Taskforces and Institutes to engage with consumers to capture and use patient experience at all stages of product and service initiation and planning, design, implementation and evaluation.

Figure 7: Redesign methodology

PROJECT INITIATION	DIAGNOSTIC	SOLUTION DESIGN	IMPLEMENTATION	SUSTAINABILITY
Build and validate the case for change by understanding the current patient and/or consumer experience.	Select the appropriate range of tools to capture and unpack the patient and/or consumer experience (pretest).	Develop and test person-centred solutions in partnership with patients and/or consumers. A codesign approach should be used where	Implement person centred solutions in partnership with patients and/or consumers.	Optimize monitoring and evaluation using appropriate tools to capture, analyse and apply patient and/or consumer experience
		appropriate.		(post-test)

ACI Networks, Taskforces and Institutes can access information, advice, resources and tools from the PEACE team to support this process which include:

- Surveys paper and electronic including Patient Experience Trackers (PETs)
- Patient stories and interviews
- Rounding
- Patient experience videos
- Focus groups
- Codesign
- Patient Reported Outcome Measures (PROMs)
- Patient Reported Experience Measures (PREMs)

4.4 Capability development

The PEACE team aims to support, enable and empower consumers to participate in the ACI and wider healthcare innovation in NSW. The focus is on meaningfully engaging a broad range of consumers in the work of the ACI and building their capability to contribute to, influence and impact the ACI's strategic direction, activities and product and service development.

The PEACE team seeks out opportunities to meaningfully engage with and develop capability among consumers by:

- Obtaining expert and strategic advice from the ACI Consumer Council.
- Collaborating with ACI Networks, Taskforces and Institutes to develop strong and supportive relationships with consumers including by assisting with the identification, recruitment and engagement of consumers in a range of activities that add value to both parties.
- Developing relationships, sharing information and learning from with people and organisations with expertise including consumer and community based organisations (including NGOs), LHD Consumer and Community Participation Managers and Multicultural Health Managers, NSW Ministry of Health and Pillars.
- Accessing priority and 'hard to reach' populations including Aboriginal communities, culturally and linguistically diverse (CALD) communities, rural and remote communities, and socially and economically disadvantaged people.

The support offered to consumers is varied and depends on the needs and interests of consumers. Support from the PEACE team includes:

- Orienting consumers to the ACI, NSW Health and what it means to be a consumer representative.
- Being an additional point of contact for information (verbal, written, internet), advice and support in conjunction with the relevant ACI Network, Taskforce or Institute Manager.
- Organising specific events, education and training to support consumers to network and develop skills.
- Providing opportunities for consumers to get involved in activities outside of their Network, Taskforce or Institute including attending conferences and events; capturing their patient experience or journey using a number of methods/formats; participating in other groups or committees such as the Consumer Council.

- Reporting and providing feedback on patient experience and consumer engagement at the ACI.
- Developing peer support models and connections including with the Consumer Council and consumer and community based organisations.
- Providing virtual and face-to-face social network opportunities.
- Reimbursing consumers for expenses incurred as a result of participating in ACI PEACE team activities.
- Linking health literacy resources.

4.5 Developing partnerships and relationships

NSW Health's *Towards 2021* focuses on creating a more connected health system across primary and acute settings by:

- Empowering patients to be partners in their care.
- Targeting investments in new models of integrated care.
- Investing in enablers to inform and support the delivery of the integrated care.
- Strengthening partnerships with the primary and community care sectors for a seamless care experience.

'Culture change' which fosters the open exchange of information in plain language, values the development of meaningful relationships between partners and encourages people to communicate and question decisions as required.

4.5.1 Organisational Culture Change

Cultural change at the ACI organisational level is also required. The PEACE team works to promote behaviour and culture change by facilitating opportunities for consumers and clinicians to work together to actively shape the direction of NSW Health and deliver more compassionate and person-centred care. The PEACE team role models the value and benefits of consumer participation and leadership through transparent communication, education and capability development (including support for increased health literacy), and the long-term commitment to a belief in shared goals. In this way change is supported over time and is sustained, resulting in the patient and consumer voice being heard, valued and considered equally important in the decision making process.

A commitment to progress in this area is demonstrated by:

- Working with key partners to promote behavioural and cultural change to ensure consumer input and consumer leadership in healthcare redesign is valued.
- Modelling flexible approaches to facilitate consumer engagement in its Networks,
 Taskforces and Institutes and across all levels of the organisation.
- Providing education and up skilling on the benefits of cultural change.
- Encouraging the use of measures to demonstrate the value of the consumer-clinician partnership at every level of the organisation.
- Top down and bottom up commitment to change.
- Matching consumer needs with organisational needs to facilitate a mutually beneficial arrangement.

Figure 8: Examples of approaches to support cultural change within the ACI and NSW Health

ACI Board & Executive

- Include a patient story or video in meetings
- •Endorse patient experience and consumer engagement strategies and methodologies
- •Receive advice from the ACI Consumer Council
- •Undertake 'rounding' of staff and consumer representatives

ACI Staff

- •Obtain and use advice, information, resources and tools regarding patient experience and consumer engagement
- Provide tangible support to consumers
- •Consult with and seek advice from consumers including by developing communication tools and surveys

ACI Networks, Taskforces & Institutes

- Promote consumer membership
- Appoint patients and consumers to committees
- Develop relationships with NGOs and community organisations
- •Seek consumer input and patient experience in all projects
- Undertake codesign with patients and consumers

Local Health Districts & Specialty Networks

- •Resource support units for consumers, community members, carers and priority populations
- Appoint patients and consumers to committees
- Executive leadership and support for patient experience and consumer engagement
- •Identify champions and recruit a workforce

NSW Health Services

- Encourage compassionate care and small acts of kindness
- Promote person-centred care including shared decision-making
- •Use qualitative (patient stories) and quantitative approaches (surveys and measures) to understand and act on patient experience
- •Establish patient feedback mechanisms including compliments and complaints processes

NSW Ministry of Health and Pillars

- Develop Patient Reported Measures (PRMs)
- •Create a repository of patient experience and consumer engagement information, resources and tools; including patient stories and videos
- •Disseminate innovations and examples of good practice across the system

4.6 Working with the PEACE team

The PEACE Framework provides the ACI with information about how to embed patient experience and consumer engagement in its activities. Where more direct support is needed, the PEACE team can be engaged by ACI Networks, Taskforces and Institutes, or key partners at the following levels:

• **Advice**: provide general advice about consumer engagement and patient experience can be provided on an ad hoc or project specific basis.

- Advice and approach: provide advice coupled with a recommended approach (or method/ strategy) for obtaining patient experience or engaging consumers.
- Advice, approach and tools: provide access to tools to implement the advice and the recommended approach.
- Advice, approach, tools and practical assistance: supplement the advice approach and tools with human resources to assist with implementation.

5. How we will know we have achieved the vision

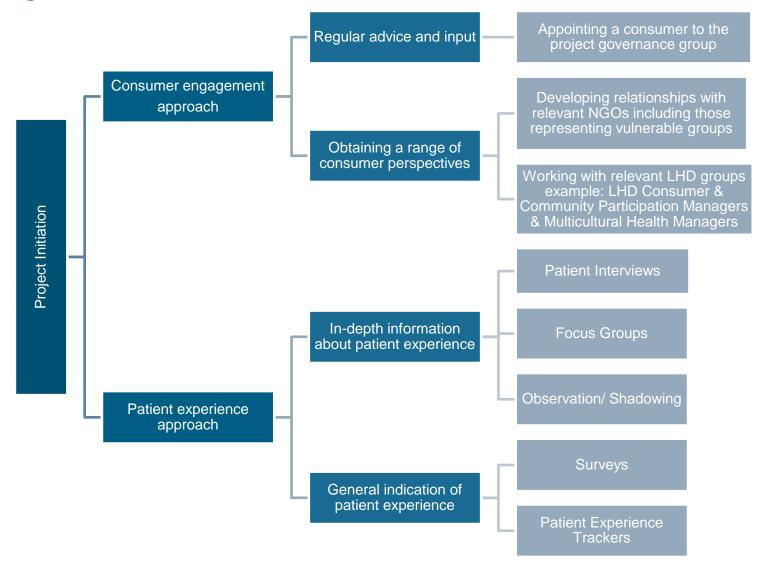
5.1 Monitoring & Evaluation

The PEACE Framework will be monitored and evaluated internally on an ongoing basis. ACI Portfolios and the ACI Executive will play a key role in monitoring the use of the PEACE Framework by sourcing the presence of patient experience and consumer engagement data in projects and product development as part of the review and approval process.

Evaluation of the PEACE Framework will involve:

- Annual review of the volume of projects the PEACE Team has been involved in, from basic involvement (advice only) through to more complex involvement (strategy, approach, tools and resources).
- Measure of website traffic (internal and external) and website analytics (user location, frequent users, searches).
- Development of new toolkits.
- NGO's and community group member consultations, projects involved in and level of contribution.
- Survey of consumers engaged with ACI.

6. Matching tool



7. Appendices

- 7.1 Consumer Engagement Toolkit
- 7.2 Patient Experience Toolkit
- 7.3 Priority Populations Toolkit
- 7.4 Developing Patient Information Guide
- 7.5 Commonly used Acronyms List
- 7.6 Consumer Council Fact Sheet
- 7.7 List of ACI Key Stakeholders for PEACE

8. References

¹ Australian Commission on Safety and Quality in Health Care (ACSQHC). (2011). Patient-Centred Care: Improving quality and safety through partnerships with patients and consumers. ACSQHC, Sydney.

² Adapted from the Institute of Medicine. (2000). *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academy Press, Washington.

³ Consumer Focus Collaboration. (2001). *The Evidence Supporting Consumer Participation in Health*, Commonwealth Department of Health and Aged Care, Canberra, Australia.

⁴ Australian Institute of Health and Welfare. (2014). *The measurement of patient experience in non-GP primary health care settings*. Cat. no. WP 66.Canberra: AIHW.

⁵ The Picker Institute. (1993). *Principles of Patient-Centered Care*. Available at: http://cgp.pickerinstitute.org/?page_id=1319.

⁶ Australian Bureau of Statistics. (2011). National Regional Profile: New South Wales.

⁷ NSW Ministry of Health. (2014). *NSW State Health Plan: Towards 2021*. NSW Ministry of Health, Sydney.

⁸ Australian Commission on Safety and Quality in Health Care (ACSQHC). (2011, September). *National Safety and Quality Health Service Standards*. ACSQHC, Sydney.

⁹ The Health Foundation. (2014, March). Helping measure person-centred care: A review of evidence about commonly used approaches and tools used to help measure person-centred care. The Health Foundation, London (UK).

¹⁰ WA Health. (2007). Consumer Carer & Community Engagement Framework.

¹¹ Adapted from Carman, K. L. Dardess, P., Maurer, M., Sofaer, S., Adams, K., Betchel, C. & Sweeney, J. (2013). Patient and family engagement: A Framework for understanding the elements and developing interventions and policies. *Health Affairs* 32(2): 223-231.

¹² Australian Commission on Safety and Quality in Health Care. (October 2012). *Safety and Quality Improvement Guide Standard 2: Partnering with Consumers*. Sydney. ACSQHC, 2012.

¹³ Lynne Maher presentation. (11 November 2014). Patient Experience and Co-design.

¹⁴ The Studer Group. (2005). The Magic of Rounding.

¹⁵ Agency for Clinical Innovation. (2012). *Strategic Plan 2012-2015*. ACI, Sydney.