Elevating the Human Experience

Our guide to action for patient, family, carer, volunteer and caregiver experiences

NSW GOVERNMENT

Acknowledgements

NSW Health acknowledges the traditional custodians of the lands across NSW. We acknowledge that we live and work on Aboriginal lands. We pay our respects to Elders past and present and to all Aboriginal people.
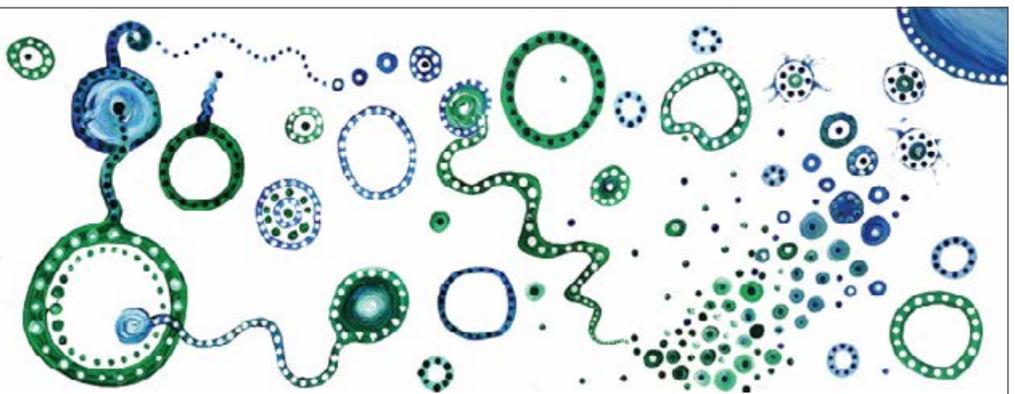
We acknowledge the Agency of Clinical Innovation for the use of this artwork

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Table of abbreviations

ACI	Agency for Clinical Innovation (a NSW Health pillar organisation)
BHI	Bureau of Health Information (a NSW Health pillar organisation)
CEC	Clinical Excellence Commission (a NSW Health pillar organisation)
CES	Carer Experience Survey
CINSW	Cancer Institute NSW (a NSW Health pillar organisation)
CoP	Community of Practice
ETHE	Elevating the Human Experience
HETI	Health Information and Training Institute (a NSW Health pillar organisation)
KPI	Key Performance Indicator
LHD	Local Health District
NSQHS	National Safety and Quality Health Service
PAM	Patient Activation Measure
PSP	Patient Survey Program
PRM	Patient Reported Measures
RFA	Request for Admission
SHN	Specialty Health Network
YES	Your Experience of Service

A message from the Chair of Health Consumers NSW

Health Consumers NSW welcomes the release of *Elevating the human experience: our guide to action for patient, family and carer and caregiver experiences*. This *Guide to action* emphasises the importance of people's experience of using health services and, most importantly, the link between a good experience of care and positive health outcomes. This work aligns with the vision of Health Consumers NSW to ensure that health consumers are involved in the planning, design and governance of health services in NSW.

Patient experience is more than just receiving good quality clinical care. It is the totality of all interactions with health services. For many people, their interactions with nonclinical staff, cleaners, porters and receptionists have as meaningful an impact as their interaction with clinicians. With this in mind, I am pleased to see that this *Guide to action* goes beyond the measuring of patient reported outcomes and experiences, as important as these metrics are, and recognises the importance of people's holistic experiences of care.

For most people, the most important aspects of their care are that they are treated with respect and kindness, their questions are answered, and they, their families and carers know what is going on and what to expect.

We look forward to the implementation of this *Guide to action* and the involvement of health consumers, patients, families and carers in the development and governance of local initiatives to improve patient partnerships throughout NSW.

John Garbutt
Chair
Health Consumers NSW

A message from the Deputy Secretary

I am pleased to introduce 'Elevating the Human Experience: Our guide to action for patient, family, carer and caregiver experiences.'

This *Guide to action* elevates NSW Health's ambition to ensure the people in our care as well as their carers have the best possible experiences when they interact with the NSW health system. Their experiences are of equal importance as their clinical outcomes.

This *Guide to action* details how NSW Health will achieve the vision and goals, guided by principles and building on the evidence about what works to improve experiences and ensure we evolve the way we partner with people during what can be daunting or stressful periods in their lives. Ensuring an exceptional experience of care can make a world of difference to recovery and ease the worries of loved ones.

According to the latest Bureau of Health Information patient surveys:[1]

- 93% of adults admitted to a NSW public hospital rated their care as 'very good' or 'good'
- 35% of admitted adults wanted to be more involved in decisions about their care and treatment.

Everyone working in the NSW public health system should be proud that so many people rate the standard of care so highly. However, more than ever before, patients and consumers want to partner in their care and help staff understand what is important to them. This *Guide to action* is a chance for all of NSW Health to focus on a shared goal – to provide consistent, compassionate and kind care across NSW, to every person, every time.

Delivering excellence in the emotional experience of people supports NSW Health to fulfil its mission to provide world-class clinical care. It also supports the NSW Premier's Priority to build great customer service and put consumers at the centre of everything that NSW Health does.[2]

However, critical to success will be positive workplace cultures and leadership across NSW Health. Culture and leadership enable positive experiences when people interact with the health system and their importance is reflected in this *Guide to action* .

I encourage you to use the *Guide to action* to review, plan and to consistently deliver personalised, high-quality care with kindness and compassion. Be relentless in your pursuit to provide exceptional experiences for everyone who interacts with NSW, every time.

Susan Pearce
Deputy Secretary, Patient Experience and System Performance
NSW Ministry of Health

Terminology

We

In this *Guide to action*, any reference to 'we' constitutes consumers, patients, clients and residents, their families and carers, volunteers and caregivers, such as those working in local health districts (LHDs) and specialty health networks (SHNs), at the Ministry of Health, across the NSW pillar agencies and other NSW Health organisations (identified in Table of Abbreviations). The use of this language is deliberate in emphasising the collective effort that is required of us all in creating truly exceptional human experiences.

Patient and consumer

The terms 'patient', 'client', 'resident' and 'consumer' are used interchangeably throughout this *Guide to action* to refer to all people who use our health services, as well as their families and carers.

Carers

A person is a carer if the person is an individual who provides ongoing personal care, support and assistance to any other individual who needs it because that other individual 'is a person with disability', has a 'medical condition, (including a terminal or chronic illness)', a 'mental illness', or is 'frail and aged'.[3]

Caregiver

The term 'caregiver' is used throughout this document to refer to the dedicated clinical and nonclinical staff and volunteers who work tirelessly every day to provide outstanding clinical care and outcomes, and world class customer service.

Human-centred care

Many terms have been used over the past 10 years to describe the focus on experience – patient-centred, person-centred and, more recently, human-centred. This term recognises that human experience (Figure 1) is supported and sustained by the fundamental principle of partnership and is therefore inclusive of the experiences of those receiving and delivering care as well as all who support them. This *Guide to action* refers to 'human-centred'; however, the intent remains the same – keeping patients, families, carers and caregivers at the heart of everything we do.

Partnerships

Throughout this *Guide to action*, we refer to 'partnerships' with different stakeholders. By 'partnerships' we mean activities that involve consumers or communities participating in or initiating service design and delivery, policy development, and health service governance and evaluation.

Consumer representative

A consumer representative (consumer advisor or 'Patient Leader') is a health consumer who has taken up a specific role to provide advice on behalf of consumers, with the overall aim of improving healthcare. A consumer representative is often a consumer member of a committee, project or event, who voices consumer perspectives and takes part in decision-making on behalf of consumers. Usually the person works with an LHD or consumer organisation, but they may also operate independently in some activities.

Figure 1:

What is the human experience?

Patient experience — Human experience — Staff experience
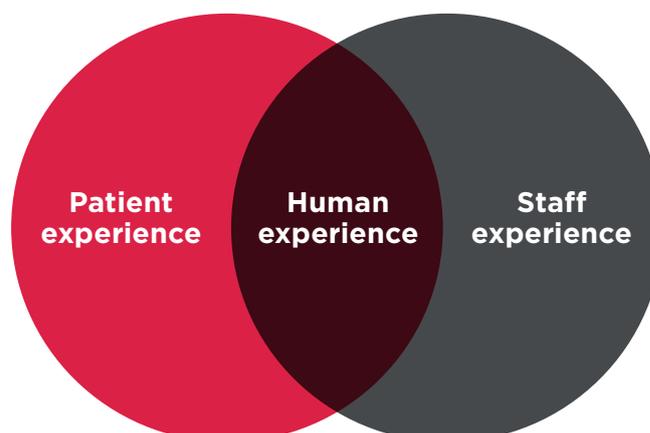
1 Vision and purpose

Defining 'patient experience'

The power of patient experience

In 2019 in NSW, nearly two million people stayed overnight in a hospital, three million visited an emergency department, more than 230 000 surgeries were performed and there were more than one million ambulance responses. NSW Health also delivered millions of outpatient, community health and mental health appointments. At the centre of every single one of those statistics is a patient and the people in their lives. Every one of those patients and carers had, in our language, a set of experiences and outcomes for the care we provided. How we delivered that care will have been as important to them as the care itself.

Across the state, our collective commitment to providing high-quality care with kindness, compassion and effective communication is demonstrated through hundreds of initiatives implemented by our staff. Improving patient experience is already a central theme of key statewide initiatives, such as Leading Better Value Care. This is, however, the first time NSW Health, in partnership with our consumers, have released a *Guide to action* dedicated to patient, family, carer and caregiver experiences. It is designed to build on existing foundations, to provide a common language and focus, and to help us partner to develop, align and prioritise action. It is intended to promote consistency and alignment for greater impact, while encouraging local leadership and implementation.

What is patient experience?

Patient experience is:

'...the sum of all interactions, shaped by our culture, that influence patient perceptions across the continuum of care.'

Adapted from the Beryl Institute

It focuses on interactions with the patient and their family as well as how those interactions made the patient feel. While memories of what happened during their health encounter will fade over time, they do not tend to forgot how staff made them feel.

The *Guide to action* acknowledges the criticality of outstanding clinical outcomes while signalling a future in which human experience can be invested in, prioritised and delivered on, so that patients and staff are supported across the continuum of care.

This first statewide *Guide to action* builds on existing work to outline a coordinated approach and transform us into a truly human-centred health system. The goal is to transform the way we partner with each other with mutual respect and understating. By doing so, we will set new standards for excellence in human experiences – *for every person, every time*.

Human experience is not a project, nor is it a single initiative. It is the outcome of the organisational alignment of people, processes and place towards a common goal of providing exceptional experiences for all patients, families, carers and caregivers, from the first touch point to the last.

The importance of patient experience

Patients, families and carers want outstanding clinical care and exceptional experiences. While clinical outcomes are critically important to patients, there are other aspects of care that patients and carers feel are also essential to high-quality care. These other aspects include seamless access to services; that patients are treated with kindness and respect; that they are safe; that they are communicated with in a way they understand; and that they trust in the people providing the care.

Positive patient experiences result in better patient outcomes. Positive patient experiences are critical to delivering high-quality care and supporting long-term positive health outcomes. The evidence tells us that positive patient and carer experiences are linked with improvements such as reduced hospital readmission rates, shorter lengths of stay, fewer serious safety events, fewer hospital-acquired complications, greater efficiency through streamlined processes, better self-reported general wellbeing and improved adherence to treatment and medication.[4,5,6,7,8,9]

Better patient experiences are an important part of achieving the quadruple aim. The quadruple aim of healthcare is comprised of improved patient experience, improved staff experience, better clinical outcomes, and more effective and efficient care. The evidence also tells us that there are direct causal relationships between them. Improved staff experience is a key driver of improved patient experience, and improved patient experience is a key driver of better outcomes.[10] Through this *Guide to action*, we hope to achieve the quadruple aim of improved experiences for patients, families and carers and, in the process, we hope to improve experiences for caregivers, drive improved health outcomes for the population, as well as improve the efficiency of the health system.

Better patient outcomes motivate our caregivers. We know that caregivers work in healthcare because of their intrinsic motivation to care. Encouraging a shift towards human-centred care increases staff engagement and positive workplace culture. This ultimately empowers teams to provide more positive patient experiences that enhance the delivery of equitable, high-quality, safe care and improved patient outcomes.

A unified vision of patient experience provides consistency for all patients. We know that there are areas of excellence in human-centred care across NSW – many of which have been featured in this document. We also know that there is opportunity to provide these experiences with consistency for every person, every time. Some groups, including young people, Aboriginal and Torres Strait Islander peoples and people with a mental health condition, report less positive experiences with the health system, particularly relating to respect, information and engagement.[11] There is also variation in experience between hospitals.

Better experiences drive greater satisfaction. Satisfaction is a measure of the perception of performance, examining how well the interactions experienced were delivered – from the admissions process, to the food provided and post-transition care. Since the patient experience includes all the interactions that patients have with the health system, satisfaction becomes the consequent patient evaluation of the care provided relative to their expectations. Put simply, you could say a patient's satisfaction is determined by the gap between the patient's expectations and their reality.

Our philosophy

- We are human beings, caring for other human beings.

- Caregiving is best achieved through kindness and compassion.

- Human-centred care is a journey that we achieve through constant innovation and improvement of the patient experience but it is worth the effort.

- Safe, accessible, high-quality care is fundamental to human-centred care.

- Care should meet people's needs holistically – for body, mind and spirit.

- Family, friends and loved ones are vital to the healing process.

- Access to understandable health information can empower individuals to participate in their healthcare.

- It is essential to give individuals the opportunity to make personal choices related to their care.

- Physical environments can enhance healing, health and wellbeing.

- Illness can be a transformational experience for patients, families, carers and caregivers.

Our vision and purpose

Vision for NSW Health

A sustainable health system that delivers outcomes that matter to patients and the community, is personalised, invests in wellness and is digitally enabled. This vision is underpinned by a strategic priority to deliver world-class clinical care, and aligns with the NSW Government's commitment to world-class customer service.

Our purpose for this work

This *Guide to action* exists to outline what the NSW health system can do together, in partnership with patients, carers and staff, to consistently create positive, personalised experiences.

Our aspiration

We aspire for the future of human experiences to:

- be designed collaboratively, in **partnership** with patients, carers, caregivers and the wider community to deliver care that meets needs, expectations and preferences of patients, families and carers

- evolve to view **consumers as 'makers and shapers'** of services and policy, as well as the 'users and choosers'

- embrace **value-based healthcare**, which includes providing high-quality care, experiences and outcomes that matter to patients and carers

- care for the **whole person**, considering their culture and educational background, social and economic circumstances, and support networks

- use **timely feedback and data** to measure progress and continue to understand what is working well, and what could be done differently or where there are opportunities to do it better.

Achieving the NSW Health vision by embracing the human experience and value-based healthcare

The vision for the future state of our NSW health system is achieved by successful implementation of not just this *Guide to action*, but also supporting works such as the Strategic Framework for Integrating Care, Value Based Health Care, Future State Plan, and collaborative commissioning.

Like many health systems around the world, NSW is facing challenges from a growing and rapidly ageing population, rising costs (including purchase of new technology) and, more recently, COVID-19. This is against a backdrop of changing needs and expectations of patients, carers, clinicians and the community – patients and carers are more vocal in expressing what they expect and would like to receive for their healthcare journey. To continue delivering excellent healthcare in a changing environment, we need the system and our people to maximise value, where value is defined in terms of the outcomes and experiences that matter most to the people receiving care relative to the costs of achieving those outcomes.

For example, value-based healthcare focuses on how to ensure sustainability of the system to meet these challenges while recognising that a focus on efficiency alone is insufficient. The changes in emphasis, from volume to value, challenges the system to better understand the patient experience and to critically review how and where care is delivered. It involves working to develop, validate and spread successful models that improve health outcomes for patients and value for the health system. In NSW, the definition of value-based healthcare considers what value means for patients, clinicians and the health system across four domains:

- health outcomes that matter to patients
- experiences of receiving care
- experiences of providing care
- effectiveness and efficiency of care.

The goal is to use health resources optimally, delivering the right care in the right setting and at the right time.

Our **Guide to action** on a page

Human experience is defined as the sum of all interactions, shaped by our culture, that influence patient perceptions across the continuum of care.

Adapted from the Beryl Institute

OUR VISION

A sustainable health system that delivers outcomes that matter most to patients and the community, is personalised, invests in wellness, and is digitally enabled.

PURPOSE OF THIS GUIDE

This *Guide to action* outlines what the NSW health system can do together, in partnership with patients, families, carers and caregivers, to consistently create positive, personalised experiences.

OUR ASPIRATIONS ARE FOR OUR HEALTH SYSTEM...

To be designed collaboratively, in **partnership** with patients, carers, caregivers and the wider community to deliver care that meets needs, expectations and preferences of patients, families and carers.

Evolve to view **consumers as 'makers and shapers'** of services and policy, as well as the 'users and choosers'.

Embrace **value-based healthcare** which includes providing high quality care, experiences, and outcomes that matter to patients, families and carers.

Care for the **whole person**, considering their culture and educational background, social and economic circumstances, and support networks.

Use **timely feedback and data** to measure progress and continue to understand what is working well, and what could be done differently or where there are opportunities to do it better.

WHICH WE WILL CHANGE BY INVESTING IN...

01   **Leadership, accountability and governance**

02   **Culture and staff experience**

03   **Collaborative partnerships**

04   **Innovation and technology**

05   **Information and communication**

06   **Measurement, feedback and response**

07   **Environment and hospitality**

SO THAT OUR PATIENTS, FAMILIES, CARERS AND STAFF...

Are shown compassion, respect and kindness

Have trust and confidence in their care providers and the quality of their care

Are involved in shared decisions and receive care and treatment that is personalised

Receive clear information and effective communication

Have timely access to coordinated care and smooth transitions

Receive healthcare in clean, safe, comfortable, culturally-appropriate environments

2 Outcomes

Outcomes for patients, families, carers and caregivers

How will we know we are successful?

The success of this *Guide to action* is about how patients and staff describe their care and experience when they interact with the NSW health system. Equally, through many years of partnering with patients, we know that the following six outcomes reflect what patients have told us matters most. The needs of our staff are not dissimailar. They also wish to be valued, to be treated with respect and kindness, and to have the time to care. They wish to work in environments that are clean, safe, comfortable and culturally-appropriate environments. We aspire to be agile and flexible, and to adopt new ways of measuring what success looks like. These outcomes align to the Australian National Safety and Quality Health Service (NSQHS) Standards, the Australian Charter of Healthcare Rights, the Australian Hospital Patient Experience Question Set and the NSW Government customer commitments. Ultimately, we will know we are successful when we get the things that matter most to patients, families, carers and caregivers right.

We define success when patients, their families and carers:

- **Are shown compassion, respect and kindness**

   'Our needs are respected, my healthcare team are kind and courteous.'

   Experiences are enhanced when care teams listen to and honour patient and carer perspectives, preferences and choices, and respond to the emotional needs of patients and carers with kindness, empathy and courtesy.

- **Have trust and confidence in their care providers and the quality of their care**

   'We trust our healthcare team because they have demonstrated professionalism and competence.'

   Patients often come to the health system in a state of vulnerability. It is critical that patients and carers can trust and have confidence in the professionals delivering their care. Trust is influenced by staff members' knowledge and capability, their interpersonal style (ability to listen, comfort and care), their approach to care and the quality of the time they spend with patients. When there is trust, patients are more likely to be engaged in decision-making, which can lead to better adherence to treatment and improved outcomes. Trust increases when care is coordinated across their healthcare team.

- **Are involved in shared decisions and receive treatment and care which is personalised and of the highest quality**

   'We are involved in decisions about my care and I get the treatments that are right for me.'

   Shared decision-making and personalised treatment mean having patient and carer preferences and needs heard, respected and responded to, including cultural and religious needs and other

preferences. This fosters trust and confidence in the relationship between patients and clinical staff. We also know that shared decision-making can improve partnerships with patients and their carers and improve clinical outcomes. Safety of patients is improved if patients and carers are better informed about their care and treatments.

- ## Receive clear information and effective communication

    'We know what's going on and when we have questions, we can get an answer we can understand.'

    Clear, accurate and transparent information and tailored communication empowers patients to exercise independence and autonomy. This improves self-care and contributes to trust in healthcare providers. Information must be appropriate to a patient's cultural, linguistic and health literacy needs.

- ## Have timely access to coordinated care and smooth transitions

    'My care is seamless, we understand what's next and we have the support we need when we move between healthcare providers.'

    Patient experience is influenced by timely access to appropriate healthcare. This includes the extent to which patients can access smooth, consistent and coordinated care throughout their journey. It means patients and carers do not have to provide the same information to many different staff members. The care the patient needs is integrated across all relevant services and tailored to the particular needs of individuals. Patients and carers are included by health professionals in the care team.

- ## Receive healthcare in clean, safe, comfortable, culturally appropriate environments

    'We are comfortable and feel safe when receiving care. The setting is accessible, clean and makes me feel welcome.'

    Patients, families, carers, volunteers and staff should view the healthcare environments as clean, safe, welcoming places. Cleanliness is universally synonymous with hygiene and health – patients feel less safe in environments that are badly worn or not cleaned well. Patients are often at hospital for long periods of time and should be made as comfortable as possible. Integral to this is being able to easily navigate their way around the hospital to the locations they need. Culturally appropriate care builds trust with patients; it means patients are welcomed and supported, particularly in an environment that may have historically felt hostile or traumatic. Delivering culturally appropriate care requires caregivers to examine their own behaviours and practices to ensure that the care provided is considered to be safe and appropriate by the patient.

'Patients and those who love and care for them are likely to be the first to raise the alarm about the quality of care at a hospital or other provider, if only they are listened to and the significance of what they are saying is properly appreciated.'

Robert Francis QC (2013), Mid Staffordshire NHS Foundation Trust Public Inquiry (Final Report, Vol.1. p.585.)

Spotlight on carers

Working in partnership with carers is an important policy objective as well as a key principle in understanding person-centred care (Institute for Patient- and Family-Centered Care, 2018). Carers and the support they provide are incredibly diverse but evidence suggests that many are not receiving support they need. In a recent Australian study, results showed that carers perceived they worked in isolation rather than in a partnership with staff. This perceived lack of support is associated with negative outcomes for carers. Solutions to this lack of partnership in safety require a greater emphasis on human-centred care, which is respectful and inclusive of the views and experiences of patients and carers.[12,13] In 2020, NSW Health will expand collection of patient experience information to include the experiences of carers, including experiences of caring for those at end of life.

Carers and the support they provide are incredibly diverse but evidence suggests that many are not receiving support they need.

NSW Carers Charter, Schedule 1 of the NSW Carers (Recognition) Act 2010, states:

1. Carers make a valuable contribution to the community

    (c) Carers' unique knowledge and experience should be acknowledged and recognised.

    (d) The relationship between carers and the people they care for should be respected.

2. Carers' health and well-being is important

3. Carers are diverse and have individual needs within and beyond their caring role

4. Carers are partners in care

    (a) The choices, views and needs of carers and of the people they care for should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.

    (b) Carers should be referred to, and assisted to access, appropriate supports and services.

    (c) Support for carers should be timely, responsive, appropriate and accessible.

(Source: *NSW Carers (Recognition) Act 2010* No 20 Schedule 1, Section 6)

View: legislation.nsw.gov.au/view/whole/html/inforce/current/act-2010-020

Carers are entitled to the same rights, choices and opportunities as all Australians so:

- find out what support and services carers need and refer them to those services

- make support for carers easy to access and available when needed

- take into account the additional difficulties faced by carers in rural and remote areas

- recognise that young carers have the same rights as all children and young people, so help them overcome any disadvantage they face

- acknowledge that carers have needs and interests beyond their caring role.

Download: www.health.nsw.gov.au/carers/Publications/Rec-Act-Summary-Charter-Poster.pdf

Example best practice

New tool gives carers a voice in hospital discharge planning

Carers have unique insights, which can play a valuable part in a patient's effective discharge from hospital. Central Coast Local Health District's (CCLHD) Carer Readiness Tool (CRT) gives carers a voice in the process, so they can flag concerns to the clinical team before the patient goes home.

"The CRT is NSW Health's first tool for carers that's been specifically developed in an inpatient setting," says Sîan White, Manager Carer Support Unit and Carer Retreat. "It's been driven by feedback from community and inpatient carers and adds the carer perspective to the discharge planning process."

The tool is easy to use and is integrated into the patient electronic medical record, so all clinicians are aware of carer concerns and so carers don't have to repeat the same information multiple times.

Wyong Hospital's M1 Ward Nursing Unit Manager Aimee Plamer, and Allied Health Assistant Karen House have been trialling the tool for the last few months and report good results in gaining a better picture of what support carers need post-discharge.

The project team is currently assessing the CRT's transferability across surgical, acute, medical and rehab inpatient wards at the hospital.

The importance of measuring, monitoring and improving

Measurement is critical to understanding, tracking and taking action on our progress to improve human experience. The benefits are twofold. Measurement of the current status helps us understand how we are doing in achieving human-centred health systems, i.e. where we are now. This allows us to identify and celebrate aspects of patient experience that we are doing well at, and therefore where to focus efforts and investments to improve aspects that need to be better. Measurement of change helps us understand which initiatives are effective and should be shared and expanded.

To do this well, we rely on good data and reliable feedback. These help us make decisions about where to put more resources and to track improvements over time. Over the past decade, the NSW Bureau of Health Information has been publishing information about the experience of patients in NSW public hospitals. These results have made us better informed, allowed greater transparency, and made staff and hospitals more accountable for the patient experience. Since 2015 mental health services in NSW have been routinely offering the Your Experience of Service (YES) questionnaire to consumers. The information from the more than 20,000 questionnaires returned every year is reported back to health services, the Ministry of Health and the Commonwealth to compare to other states and territories. The Agency for Clinical Innovation (ACI) pioneered the first real-time collections of patient experience in NSW, and LHDs introduced innovative ways to collect and analyse data. This has helped us in building a health system dedicated to excellence in care. We are committed to pursuing other mechanisms for obtaining patient feedback, such as patient and family advisory councils, focus groups, phone calls, patient shadowing, online platforms and social media. These are all important tools for eliciting essential feedback and perspectives of patients and carers.

NSW Health is committed to collecting information on what matters most to patients, families, carers and staff, and to having fewer but more relevant and important measures of patient experience.

3 Enablers

Enablers

Considering people, process and place

Evidence and input from stakeholders has shown that there are seven key enablers of experience. These enablers collectively support positive experiences across the health system, distributed across people, process and place. This means that isolated activities under any one enabler alone will not deliver the aspirational vision NSW Health has to transform experiences.

As suggested in the diagram below, we know that an organisation's people are the key success factor in providing exceptional patient experiences. We also know that the processes we use and the environment in which they take place are critical components in how patients perceive their healthcare experience. But for change to occur, we know that the processes for delivering exceptional patient experiences need to be thought through and designed for, they cannot develop organically beyond what is already in place. Cultural evolution and commitment underpinned by investment in change and communications are essential.

Figure 2: Lens of people, process and place

This lens has helped guide the way in which we have considered our priority initiatives. Experience encompasses all individual encounters and the expectations they have for safe, quality, reliable and effective care focused on positively impacting health and wellbeing
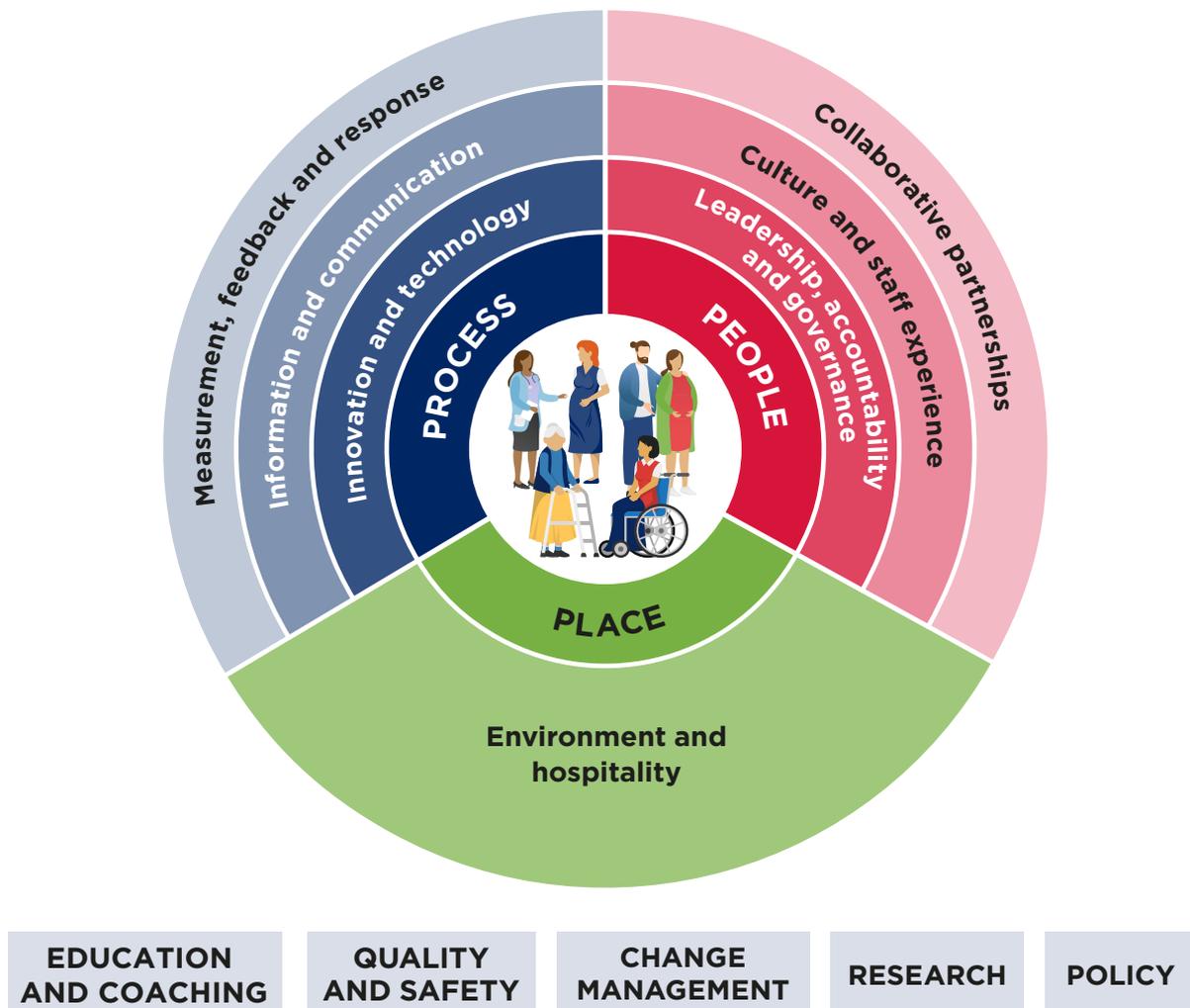
👥 People

We know that people are the key to receiving and delivering exceptional patient and caregiver experiences.

01 Leadership, accountability and governance

Leadership is essential to guide the direction of and commitment to patient and caregiver experience across NSW Health. The growth and development of Patient Leaders is critical, and a sign of a mature organisation. Effective corporate and clinical governance structures help ensure that people across NSW Health understand and are committed to excellence in patient and carer experience. Quality leadership and governance result in constructive accountability, through which staff are encouraged to share responsibility for change and improvement.

02 Culture and staff experience

The foundation of any successful experience is based on the organisation vision and values. Evidence shows that a strong, positive workplace culture is directly related to positive patient and carer outcomes and experience. The way staff relate and interact with each other can significantly influence patient and carer experiences. All staff, not just clinicians, shape the patient experience.

03 Collaborative partnerships

Patients are the only constant in every healthcare journey. Their insights help us see the care we provide from a different perspective and contribute ideas to what we can do to improve care, innovate services and deliver experiences that matter to people. The health system cannot achieve excellence in patient and carer experience without partnering with patients, carers and health professionals from other parts of the health continuum.

The NSQHS Standards elevate the importance of partnering with consumers. The Partnering with Consumers Standard aims to foster health service organisations that benefit from having consumers as partners in planning, design, delivery, measurement and evaluation of systems and services, in addition to being partners in their own care, to the extent that they choose.

The Partnering with Consumers Standard recognises the importance of involving patients in their own care and providing clear communication to patients. This Standard, together with the Clinical Governance Standard, underpins all the other Standards.

Wellness is our goal, Excellence is our passion.

Process

The delivery of exceptional patient experiences needs to be thought through and designed for. It cannot be expected to develop organically – cultural evolution and commitment are needed with a systematic approach to how we communicate, measure success, innovate and improve services.

04 Innovation and technology

It helps to think about innovation in patient experience as fulfilling the needs of our patients, families and carers. Innovation offers new ways to accomplish goals or make lives or jobs easier, better, happier, satisfying or more productive. It is not a once-off initiative, and the creation of a workplace that encourages a culture of continuous innovation is equally important.

05 Information and communication

Communication is the provision of information in a way that can be understood by the recipient. Technology offer many new ways of providing information but, most importantly, it must be tailored to the patient's and their carer's capabilities to understand. Open access to information about previous medical encounters facilitates active partnering of staff with patients and carers.

06 Measurement, feedback and response

Measurement is critical to understanding and tracking progress and improvements in human experiences. For patient experience to be effective, we must design the right measures, for the right moments and the right purpose, while working to ensure consistency and comparability of results. We must evolve measurement systems to meet the needs of patients and staff to interpret and act on the findings.

Place

We know that the place in which our people and our processes take place is a critical component in setting the tone for both patients and caregivers.

07 Environment and hospitality

For a physical environment to enhance patient and caregiver experiences, it must be comfortable, safe, clean and culturally appropriate, with amenities such as food and Wi-Fi that can support patient and caregiver emotional and physical wellbeing.

4 Getting started

Where might we begin?

Elevating the human experience is not the responsibility of one person alone it takes the entire ecosystem of those receiving the care and those delivering it.

In order to deliver on our ambition, at a system and local level, we have developed outcome focused priorities.

Principles that guide the priorities

1 — The patient, their family and carers, our volunteers and staff are at the centre of everything we do.

2 — All levels of healthcare are to be considered – from the individual to the service and system levels.

3 — Cultural change evolution and change management are key to achieving systems change.

4 — Exploration and planning in partnership with patients, families, carers and caregivers will be needed.

5 — These priorities allow for flexibility when it comes to delivery and execution.

6 — Quality, safety and clinical excellence underpin everything.

7 — All organisations will have varying levels of maturity on their patient experience journey.

Imagining an exceptional patient and carer experience

Follow 'Zara's journey' for what integrated, human-centred care might look like in the future at www.health.nsw.gov.au/Performance/Pages/experience.aspx

Support in getting started

Patients and carers

Patients, families and their carers can support the *Guide to action* by:

- partnering with their LHD as a consumer advisor or representative to contributing to improving services

- joining the NSW Health Patient Experience Strategy Committee

- providing feedback to their caregivers on the quality of care and experiences

- providing feedback on what we could do better.

Health services and NSW Ambulance

LHDs, SHNs and NSW Ambulance can support the *Guide to action* by:

- promoting the *Guide to action* across the health service including tabling at board meetings and peak consumer groups

- conducting a maturity assessment of patient experience efforts across the service

- developing LHD/SHN *Guide to action* improvement plans and integrating them into National Standards governance structures

- participating in Communities of Practice (CoPs) and joining the Beryl Institute

- participating in the *Guide to action* enabler working parties

- identifying at least two key initiatives to focus on over the next 12–18 months

- participating in key human experience events, for example Patient Experience Week, World Kindness Day and the Patient Experience Outcomes Symposium.

The Ministry of Health, pillars and other NSW Health organisations

The Ministry, the pillars and other NSW Health organisations can support the *Guide to action* by:

- taking the lead in setting policy and guidelines, and funding statewide initiatives

- promoting consumer partnerships and the role of patients and carers in NSW Health service design and delivery

- continuing to drive system-wide strategies such as the approach to value-based healthcare

- collaborating with LHDs and SHNs to analyse and interpret data and apply this evidence to local improvement initiatives and projects

- building systems to benchmark LHD and SHN performance, and sharing examples of existing good work and continued best practice around the world

- creating and supporting Communities of Practice

- integrating *Guide to action* improvement plans into quarterly LHD performance meetings.

Consumers as partners: the role of consumers in making priorities succeed

The following sections describe the seven enablers and each of their associated priorities. Each section also lists suggested actions that can be undertaken at either the system level or at the LHD and SHN levels.

Integral to each of these suggestions is the need to involve patients, families, consumer representatives and carers in developing these actions. While each organisation should already have guidance about how to interact with consumers, the following list offers best practice for engaging with consumers and carers.

- Respect the consumer's contributions and acknowledge that their experience of health is often very different from the clinicians or health managers in the group.

- Respect the consumer's time. They are often attending the group as an unpaid member but with the expectation that their contribution can improve services for all patients.

- Consumers and carers may need education and coaching to maximise their contribution. This includes education about the topic area, how the group will be managed, encouragement to participate, and agreeing on a strategy for how the Chair will provide opportunity for consumers to advise.

- Have more than one consumer on any committee or working group. This provides support for the consumer in a situation that can be intimidating but also acknowledges that each person has a different experience and therefore different insights to contribute.

- Recognise and employ skills and knowledge that the consumer has from outside their health experience. For example, a consumer who is an accountant may offer to review costings or a builder may have advice on optimising access.

- Consider the many ways of finding out what consumers think about the issues – this could come from patient survey data, comments or complaints made to the organisations, interviews, small working groups and formal committees.

- There are people in every organisation who specialise in how to engage with patients in the most constructive ways – seek their advice and support.

- Acknowledge consumer and carer contributions, time and effort.

The following section contains many ideas on where to start improving the patient experience. As you read these, think about how you could be working with those who have lived experience to improve the quality of care for all.

01
Leadership, accountability and governance

How might we continue to create a human-centred culture at the leadership and governance level so that all caregivers are supported in their commitment to excellence in patient and carer experience?

People Process Place

Positive, committed leadership drives us to achieve exceptional human-centred care. Leadership for elevating the human experience in NSW comes from the Secretary of NSW Health and the Deputy Secretary of Patient Experience and System Performance. This vision for improved patient care and experience is shared with the chief executives of NSW's health organisations and out to all levels of the system. As a system, we must ensure that:

- every person at every level is safe and empowered to champion the importance of human experience
- there are clear accountabilities relating to human experience for individuals and teams at every level of the organisation
- management decisions, including resource allocation, explicitly consider and prioritise human experiences
- we are committed to supporting and developing Patient Leaders.

Priority initiatives

1a. Champion and develop 'kind and compassionate leadership'

Leadership is considered pivotal for enabling the development and preservation of kind, compassionate healthcare organisations. Strategies for developing compassionate healthcare leadership will require abandoning individualistic, heroic models of leadership for a model of shared, distributive and adaptive leadership. Ensuring our workforce is valued, respected, engaged, supported and encouraged to their full potential will be fundamental to delivering an exceptional experience.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Provide patient experience leadership and support for the development, implementation and evaluation of this *Guide to action* across NSW Health.

- Align patient experience work plans and resources across NSW Health, the Ministry, pillars and other NSW Health organisations.
- Establish governance to oversee the implementation of the *Guide to action*, enshrining co-design and ensuring balanced partnership with consumers.
- Develop a register of all patient experience innovation under way, accessible to all staff.
- Create and support the development of an Emerging Patient Experience Leaders program.
- Develop compassionate leadership programs which can be piloted and scaled across LHDs and SHNs; for example, the Emergency Department Good to Great program
- Establish and promote Human Experience Hero Awards.
- Enhance and support the 'kindness movement' resources.

At a local level, health services may seek to:

- Celebrate and reward kind leadership.
- Establish a system for the Chief Executive to promote and sponsor patient experience.
- Bring together feedback, patient experience, consumer partnerships and volunteers.
- Build patient experience capabilities into staff job descriptions, coordination of attributes and selection criteria.
- Create processes to assist leaders in developing skills and leadership competencies necessary to attain desired results.
- Integrate a module on compassionate leadership into existing leadership programs.
- Encourage formal 'champions of human-centred care'.

> ' The challenge for us is that sometimes when we are focused on the task at hand, we can lose touch with the human element. For patients, it's the small acts of kindness that make the difference.'
>
> Susan Pearce, Deputy Director Patient Experience and System Purchasing, NSW Ministry of Health

1b. Recruit, and support patient and consumer leaders and include them in all levels of governance

Patient leadership and involvement in the design of initiatives cannot be seen as a one-time initiative. In order to create a truly human-centred system, it is important that we always and systematically embed the voice of the patient in everyday ways of working in order to mitigate the risk of the consumer voice getting lost. Adopting such principles and techniques in our day-to-day work is crucial in ensuring effective, fit-for-purpose, sustainable, high-impact approaches to improve patient and carer experiences.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Foster a learning and partnering culture that includes listening to consumers and partnering with them to deliver services that provide the best possible outcomes.

- Strengthen consumer engagement across the Ministry, pillars and other NSW Health organisations.

- Develop organisational templates (for example, terms of reference) that assume inclusion of consumers in all groups or states the reason why. The guiding principle should be 'if not, why not?'.

- Support the development of an overarching NSW Health consumer and community partnership framework.

- Identify best practices across LHDs and SHNs and share widely.

- Develop interactive tools and educational materials for the coaching of staff partnering with consumer advisors.

- Develop organisational processes and resources to educate and empower consumers and carers sitting on any groups or committees.

- Develop social listening tools that allow early identification of human experience issues, e.g. access to healthcare, safety concerns.

At a local level, health services may seek to:

- Integrate patient and carer stories into all levels of governance.

- Instigate leader rounding in hospitals where the patient, their family and carers have an integral role.

- Partner with patients and carers in the training of staff at orientation.

- Partner with patients and carers to engage meaningfully in the outcomes of complaints investigations.

- Create paid consumer-led lived experience roles within the LHD Patient Experience Teams.

- Actively recruit volunteers that represent the diversity of the community served by the health service, for example, increased proportion of people with lived experience of disability, Aboriginal people or younger people.

Example best practice

Peer Workforce Program

Mental Health Peer Workers use their own lived experience of mental distress and recovery to provide peer support and advocacy to mental health consumers. Peer workers are often employed at inpatient or community mental health services as part of the multidisciplinary team. They encourage recovery-oriented and trauma-informed care and practice and are an integral part of contemporary mental health services.

The Peer Supported Transfer of Care Initiative is funded to provide LHDs and SHNs with mental health peer workers to support consumers in their transition from mental health inpatient care to the community over a period of six weeks. Using a contemporary peer-support model, this initiative has delivered additional resources to health services to provide enhanced seven-day follow-up, and to reduce 28-day re-admission rates. This program has increased the peer workforce by 28 full-time equivalent staff across NSW since 2017.

1c. Assess the maturity of your organisation's patient experience strategy and develop robust and transparent plans to improve

Depending on where you are in your human experience journey, there may be different priorities to consider. Understanding your starting point can help develop a more effective plan for delivering human-centred experiences.

Creating foundational experience capability requires clarity on who will lead the key initiatives. These include developing a coordinated approach to leveraging existing work; establishing a governance and resource model to support the patient experience; and considering a platform to share methods, tools and successful examples of patient and carer experience initiatives for appropriate scale up.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Develop a human experience maturity assessment tool and supporting toolkits that allows health services to better understand and benchmark their current maturity.

- Engage and advise health services on the roadmap to maturity and next steps.

At a local level, health services may seek to:

- Better understand their current state maturity of human experience.

- Identify their level of maturity of human experience against the maturity tool.

- Identify clear priority improvement areas and responsibility and incorporate into 90-day action plans.

- Ensure the Partnering with Consumers Committee, or equivalent, is involved in planning, monitoring and tracking the local patient experience strategy and programs.

- Encourage membership of the Beryl Institute and participate in CoPs.

- Promote the importance of research into patient experience.

Example best practice

Leadership at Sydney LHD

Members of the workforce at all levels are clear about expectations and accountabilities. At Sydney LHD, the Chief Executive Officer takes the time to meet with all members of the workforce (including engineers, security and cleaning) to ensure they understand how integral they are to patient and carer experience. It is important that members of the workforce at every level understand their accountabilities, and that this is appropriately managed. This includes having difficult performance discussions when needed and ensuring that the workforce is supported to learn and do better.

1d. Establish and encourage participation in Human Experience Communities of Practice (CoPs)

CoPs are a group of people who share a passion or concern for something they do or would like to learn to do better. Establishing Patient Experience CoPs is fundamental to how decisions and initiatives can remain contemporary and driven by best-practice research in patient experience. CoPs also create a practical way to share knowledge across organisations nationally and globally, allowing staff to remain informed in best practice.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

• Establish a Patient Experience Leaders CoP.

• Fund a statewide membership of the Beryl Institute.

• Provide leadership and support for ongoing education in patient experience for health organisation staff.

• Support regional and rural events based around the CoP.

At a local level, health services may seek to:

• Support Patient Experience Leaders to participate in CoPs.

• Host Patient Experience CoPs.

• Celebrate Patient Experience Week in April each year.

• Celebrate World Kindness Day on 13 November each year.

• Encourage and promote attendance at Annual Patient Experience conferences and symposiums.

• Encourage knowledge sharing, for example by encouraging staff to participate and present in patient experience webinars and presentations.

Example best practice

Champions of human-centred care

In high-performing human-centred organisations, the Chair of the Board and the Chief Executive are seen as champions of patient, family, carer and caregiver experience. Champions can be individuals, teams or support services, appointed to guide implementation of human-centred care activities across clinical and nonclinical areas. In 2019, the Deputy Secretary of System Performance took on the additional responsibilities of patient experience, the first time NSW has had a Deputy Secretary leading on patient experience. NSW Health also appointed its inaugural Chief Patient Experience Officer. The establishment of these two senior leadership positions are an important signal to NSW of the importance and relevance of patient experience.

NSQHS Standards
This enabler aligns to Standards 1 and 2.

02
Culture and
staff experience

How might we create a positive culture for all
staff, so that the experience they have is one of
compassion, kindness and respect?

Evidence suggests that a positive workplace culture contributes towards a positive patient experience. The way staff relate and interact with each other can significantly influence patient and carer perception of the care that is provided. All staff, not just clinical staff, are integral to creating exceptional patient experiences. Whilst setting the right leadership, accountability and governance is a foundational start to improving culture and staff experience – it is just a start. There are also a number of critical priorities relating to culture and staff experience.

Priority initiatives

2a. Embed and encourage patient experience initiatives in existing ways of working

We know that most people that join the healthcare profession do so because they care deeply about people. Growing and nurturing a more empathetic culture involves strategically incorporating practices in our day-to-day work that put patient experiences at the heart of the way we operate.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

• Develop a repository of evidence-based best practice for local health services to consider a range of initiatives, from small improvements and quick wins through to large scale change and transformation.

At a local level, health services may seek to:

• Create an 'ideas fund' to generate ideas for improvement in the way things occur day to day.

• Celebrate incremental improvements by communicating initiatives, changes and successes across the organisation.

• Promote improvement work to consumers through tools such as the mental health service Hotboards.

Example best practice

Schwartz Rounds program

The Schwartz Centre for Compassionate Healthcare is a leader in the movement to strengthen and sustain the human connection at the heart of healthcare. It was founded in 1995 on the belief that greater compassion and more meaningful collaboration are fundamental to the kind of care clinicians want to deliver and patients want to receive.

The Schwartz Centre is an independent, nonprofit organisation with more than 425 healthcare members in the US, Canada, Australia and New Zealand supporting 200 000 healthcare professionals each year. In partnership with the Point of Care Foundation, more than 150 organisations conduct the innovative Schwartz Rounds program in the UK and Ireland. The program unites caregivers from a range of disciplines to share experiences, learn from each other and focus on the human dimension of care.

2b. Promote and prioritise staff safety, health and wellbeing

High-performing, person-centred organisations look beyond workforce satisfaction and focus on supporting the overall safety, wellbeing and morale of its workforce. Staff who are well and resilient can provide better patient-centred care.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Pilot Schwartz Rounds into three LHDs in 2020.
- Explore the SEED program implemented in Illawarra Shoalhaven LHD.
- Create and fund a Small Acts of Kindness (Sequel) video and develop materials to support it.
- Support the extension of the Improving the Patient Experience in the Emergency Department Program.
- Provide tools to support growing resilience in caregivers, for example a 'pandemic kindness' movement.

At a local level, health services may seek to:

- Create a stronger focus on workforce wellbeing, recognising that members of the workforce who are well and resilient are able to deliver better human-centred care.
- Support staff health and wellbeing programs.
- Consider the appointment of a Chief Wellbeing Officer.
- Promote Kindness Works Here and Pandemic Kindness movement.
- Consider technological solutions to reducing staff isolation in outer rural locations or if working remotely
- Investigate establishing staff 'resus trolleys'.
- Invest in and support staff to attend mindfulness programs (for example, laughing yoga).
- Implement face-to-face recognition and delivery of a 'thank you' by the manager to a staff member directly.

- Consider Chief Executives writing a personalised 'thank you' note to a staff member recognised by a peer or by patients.
- Display staff recognition information on a notice board.
- Review opportunities to implement the Daisy Program.
- Investigate the Code Lavender program.

Example best practice
Staff mental health and wellbeing

The MDOK program is a Sydney LHD initiative aiming to drive cultural and systemic change, to reduce the stress and burnout for junior medical staff. The MDOK program teaches all medical staff the skills to care for their own health, manage traumatic events and mentor younger staff. The program includes workshops and sessions on goal-setting, relaxation, stress management, clinical debriefing, nutrition and exercise.

2c. Build and cultivate a service culture through mindset shifts, skills and training, and continuous capacity building in human-centred service delivery

Culture is not a one-time initiative; it happens as an evolution. For that evolution to succeed, we must have an overarching strategy, leadership and commitments. The development and ownership of a cultural improvement strategy allows for this commitment across the organisation and puts human experience on the agenda.

Creating the intention to be more human-centred, and evolving the culture of a workplace to encourage it, is critical to changing mindsets and behaviours. However, there is often a gap in practical skills and knowledge of staff to act on that intention.

There are core communication skills needed for human-centred care. These include eliciting the patient's needs using open-ended questions, not interrupting the patient, and engaging in focused active listening. Understanding the patient's perspective of their illness and expressing empathy are key features of human-centred communication. Also key are exploring the patient's feelings, ideas, concerns and experience regarding the impact of the illness and what they expect from the clinicians. These communication skills require training and development so that staff are consistent and confident in the way they practise human-centredness.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Develop a customer service, skills and capabilities framework, aligned to signature moments.

- Create a Patient Experience Academy that provides certification-based learning and development in patient experience.

- Develop a patient experience 'playbook' with easy-to-use resources that provide practical ways to be more human-centred.

At a local level, health services may seek to:

- Identify and support staff to participate in patient experience certification programs.

- Promote the playbook or integrate it into existing resources.

- Review position descriptions and recruitment criteria to ensure human-centred care is built into position descriptions, to clearly articulate the position's responsibilities in this area.

- Consider including consumers on interview panels to ensure consumer perspectives inform recruitment decisions (as per National Standards 2).

- Provide multiple training opportunities for the workforce across the organisation to increase staff capacity to deliver human-centred care, provide high levels of customer service, and cater to diverse patient cohorts.

- Support a culture of respect for others and appreciation of diversity, including by gender, sexuality, language, ancestry and life experiences.

- Introduce routine customer service training for all staff. Focus on frontline staff but include security, cleaning, catering and switchboard staff, as these people have regular contact with patients and carers.

- Provide training in complaint management, including open disclosure, the improvement cycle and service resumption.

- Review switchboard protocols to ensure the highest levels of service and courtesy are provided to all callers.

Example best practice

Team Stripes

In 2018, the Clinical Excellence Commission (CEC) began work with the Moruya Renal Dialysis Unit using the Team Stripes framework to improve multidisciplinary team communication. As the renal unit operates as a satellite unit of Canberra Hospital, the CEC team worked across the health systems of two jurisdictions. The team was seeking new ways to overcome physical distance to improve team connection and enhance patient and carer experience.

The Team Stripes framework involved engaging with leadership and point-of-care teams, on-site visits and observations, formal presentations and facilitated conversations. A range of changes were implemented and have led to more robust multidisciplinary coordination. Over 2018–19, the CEC continued to support this team with coaching and identifying further opportunities for improvement.

Example best practice

Customer service culture

The Hunter New England LHD have implemented several initiatives to promote a culture of excellence. They include an emphasis on customer service in recruitment, customer service training for its workforce, and rewards for members of the workforce who display strong customer service..

Example best practice

Workforce-led initiatives to improve service delivery

Under the NSW Health Essentials of Care program, Nurse Unit Managers and the nursing workforce have received guidance and support to develop programs for their wards to improve care delivery. These programs not only improve workforce capacity but also empower the workforce to develop and implement their own patient experience initiatives. The results of these programs are closely monitored through clinical data, patient surveys and other measures.

NSQHS Standards

This enabler aligns to Standard 1.

03
Collaborative partnerships

How might we shift our regard for consumers as 'users and choosers' to also be the 'makers and shapers' of services and policy by making involvement systemic, authentic, meaningful and part of usual business?

Patients are the only constant throughout every healthcare journey. They have so many insights to offer that can help us think differently about how we can improve care, innovate services and ensure experiences that matter to people. The health system cannot achieve excellence in patient and carer experience without collaboration with patients, carers, health professionals and other staff.

Partnerships with other providers are also critical to coordinate services for the needs and preferences of individuals and to ensure human-centredness. Partnering with patients, and carers in the planning, design, implementation and evaluation of services is a core enabler of human-centred care. In high-performing human-centred healthcare organisations, patients, carers and consumers are integrated as active partners in governance at multiple levels throughout the organisation.

Broader linkages across the community provide the mechanism for change at the population health level. For example, LHDs may partner with other community organisations (such as housing authorities, religious institutions, law enforcement agencies, schools and social services) to address social determinants that may affect individuals' access to care, health and wellbeing. The local community should play a critical role in driving and supporting these intersectoral linkages and optimising local use of resources.

The National Partnering with Consumers Standard focuses on supporting patients, carers and consumers to be actively involved in decisions about their care. This is supported by evidence that effective partnerships help promote a positive consumer experience, as well as high-quality healthcare and improved safety. Meeting and exceeding the National Standards is a key outcome of this guide.

SPOTLIGHT ON HUMAN-CENTRED PARTNERSHIPS

Human-centred partnerships at the organisational level

In high-performing human-centred organisations, boards and management lead by practising and promoting a human-centred perspective. They explicitly identify human-centred care principles in their strategic statements, in their personal and group behaviours, and in their meeting practices. They ensure governance systems embrace a human-centred approach and that resources are allocated to sustaining human-centred care principles and practices. Clinical governance and quality and safety processes include partnerships with patients, carers and consumers, including several key components:

- meaningful roles for consumers in partnerships
- addressing issues arising from complaints and including the voice of the patient
- partnering in investigations into adverse events or mistakes
- requiring boards to consider person-centred outcome and experience measures equitably alongside financial performance, and make decisions on resource allocation that encourage person-centred care.

3a. Develop a NSW Health framework for consumer and community partnerships

Consumer and community partnerships are planned, two-way relationships in which patients, carers and the broader health ecosystem are given the opportunity to lead and provide input. This input enhances decision-making processes on issues that affect their wellbeing and interests. These partnerships demonstrate a shift away from the mindset of engaging consumers as simply 'users and choosers' of services and policy to the 'makers and shapers' of them.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Develop an overarching NSW Health consumer and community partnerships framework.

- Create a repository of patient, family, carer and caregiver stories which can be shared widely across the state.

- Sponsor the Consumers Health Forum of Australia 2021 conference.

- Sponsor and facilitate an **Elevating the Human Experience** outcomes summit every two years.

- Support the continuing development of the PARVAN Good Engagement Guide and the Agency for Clinical Innovation codesign programs.

- Support and sponsor learning opportunities for managers of consumer partnerships, consumer advisors, and consumer advisors and representatives.

At a local level, health services may seek to:

- Identify opportunities to align patient experience and consumer partnership teams under one governance model.

- Contribute to the development of a NSW Health consumer and community partnerships framework.

- Contribute patient, family, carer and caregiver stories to the statewide repository.

Example best practice

REACH

REACH is a system for patients, their families and carers to raise their worries with staff about changes in a patient's condition. In June 2019, the Nyngan Health Service was recognised for its innovative REACH program, winning a CEC Patient Safety First award. 'We acknowledge family members and friends know patients better than us, and we need them to raise a hand and let us know' said Nyngan Health Service Manager, Jenny Griffiths. The Western NSW LHD acknowledged the Nyngan program as the first to use the services of a virtual team in the family-escalated response process. The Nyngan Health Service partnered with the Patient Flow Unit and Patient Transport Services for Western NSW LHD in Dubbo to access clinical experts for an independent review of a patient using telehealth technology. We know that the work experiences of staff can directly affect patient experience.

Example best practice

South Eastern Sydney Primary Health Care Network and Patient Activation Measures

One priority in the South Eastern Sydney LHD Integrated Care Strategy is 'to engage with people and communities.' One of the two actions under this priority area is 'to test use of patient activation, outcome, experience measures and sharing of outcomes across all providers as a tool to improve quality of care.' There are several activities using the patient activation measure (PAM) that have already been undertaken in the LHD. These include the PAM to measure patient engagement and as a pre and post measure of rehabilitation and self-management programs. The findings from this project will be used to design a program of work to increase the use of PAM across SESLHD to improve the quality of care provided to patients with chronic conditions.

3b. Recruit and support Patient Leaders to actively participate across all levels of engagement

High-performing human-centred organisations recognise it is not enough to just include a consumer in a committee. Consumers must be engaged in a meaningful way in governance decision-making processes, quality and safety, accreditation, recruitment and education.

Consumers and carers should not be expected to arrive with the skills or confidence necessary to interact with LHD staff clinicians. Education, coaching and ongoing support are essential for consumers to be able to meaningfully contribute. Education is also required for the health workforce to understand how to facilitate these interactions and to understand the benefit of working with consumer representatives.

High-performing organisations respect and value the role of the consumer representative. They ensure they have recruitment processes in place that identify the skills and perspectives of potential consumer representatives, and can suggest where the representative can most effectively contribute to the organisation. They seek representation from the full spectrum of the community they serve.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

• Review recommendations of the Health Consumers NSW report commissioned by the Ministry of Health in 2019.

• Identify best practices for continuously incorporating the consumer voice into all planned improvements.

• Support the development of a NSW-wide health consumer advisory panel to provide greater access to consumers for engagement and co-design purposes.

• Encourage the embedding of consumers into the core business of NSW Health, the pillars and other NSW Health organisations.

At a local level, health services may seek to:

• Invest in the training of health services staff in working with consumers.

• Ensure consumer representatives are provided with orientation, training and ongoing support regarding their role within the organisation.

• Ensure the consumer perspective is incorporated into workforce training, including how to recognise, engage and support partnerships with patients, carers and consumers in the governance and design of the organisation.

Example best practice

The YES and CES initiatives

These surveys of patient and carer experience are a partnership between the Ministry of Health and the two peak mental health consumer and carer organisations; Being and Mental Healthcarers NSW. The YES and CES Advisory Committees were established to support the implementation and ongoing use of the questionnaires. These committees have representatives from all LHDs and SHN, along with consumers and carers. The meetings are jointly chaired by staff from the Ministry of Health, Being and Mental Healthcarers NSW. The findings of these surveys are used to support service improvement.

3c. Better understand volunteer needs, and embrace their contribution to patient experience

Partnering with volunteers plays an important role in improving patient experience, addressing health inequalities, and building a closer relationship between services and communities. Volunteers have multiple roles within healthcare organisations, including assisting with activities. Volunteers make a significant positive contribution to the patient experience and receive consistent positive feedback from patients. High-performing healthcare organisations do not just wait for volunteers to approach, but actively support and enhance the role of volunteers through active recruitment and reward systems.

Acknowledging and encouraging the contribution of a volunteer workforce requires conscious thought, planning and, ultimately, leadership.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

• Develop a White Paper to guide incorporation of volunteers into patient experience.

• Create a statewide appreciation program for volunteers and consumer representatives.

At a local level, health services may seek to:

• Review current volunteer strategies to ensure patient-centredness is at the heart of recruitment and selection.

• Review volunteer governance to align with consumer advisors.

• Rewrite position descriptions for volunteer recruitment to ensure candidates selected value and promote exceptional patient experiences.

• Reward volunteers for positive contributions to patient-centredness.

• Engage with the community to actively recruit volunteers from diverse backgrounds and from under represented cohorts.

• Recruit volunteers with lived experience as peer support to other patients and their families.

• Support volunteers to organise themselves into formal structures.

• Provide training, resources and other supports to help volunteers in their role.

• Offer dedicated spaces for volunteers to rest in the hospital (for example, tea rooms).

• Openly acknowledge the importance of volunteers, including through volunteer-appreciation events, awards and newsletters.

Example best practice
Mid North Coast LHD

The Mid North Coast LHD Action and Change working party identified peer support as an area for improvement using the YES mental health survey.

As a result, a strategy was developed to employ mental health peer workers at Coffs Harbour Community Mental Health Service. The responsibilities of this role were agreed and included in the strategy, and two peer workers were employed. They provide advice and support to consumers and their carers, help them in their navigation and understanding of the health system, and can take the role of advocate for consumers.

The strategy was promoted on the YES Hotboard, with the slogan 'You Said, So We Did', featuring a photograph of the two new peer workers.

SPOTLIGHT ON BEST PRACTICE IMPROVEMENTS

Communication boards (which are identified by different names). Electronic screens or whiteboards are situated near the patient's bed. Depending on the setting, they will have different content but the same base level of information including the patient's preferred name, the name of their clinician, the changing names of people who are providing daily care, the anticipated date of discharge, and appointment times. Patients and carers can contribute to the boards. This may include, but is not limited to, asking a question that they do not want forgotten or sharing something about themselves. Some systems can provide families and carers with real-time information about the patient's progress through procedures or surgery, or to state the outcome criteria required to be discharged.

Bedside journals. A complimentary journal is provided to the patient or carer to write down questions and symptoms to discuss with the care team. They can also write down information received from the care team.

Open Notes. This program shares the patient's complete medical record with the patient on request. Family and carers may also review the record if authorised by patient. If the patient has questions about his or her record, the clinician or other care provider can discuss them at the next visit with the patient, usually during the patient's stay. This helps patients take an active role in their health. Sharing notes can help improve communication with your patients, build stronger, more trusting relationships and enhance patient safety.

Care partner programs. Families and carers are a vital part of a patient's healing and support. Once admitted, the staff ask the patient if they want to designate someone as their carer – someone who will assist the patient with their care during the hospital stay. If so, the carer is included in discussions with the patient and the care team. The carer receives a carer badge and is oriented to the clinical area.

Collaborative Pairs: leading collaboratively with patients and communities.

This program builds and enables a different type of relationship between health consumers and health staff. As a pair, they break down communication barriers and build a safe and supportive relationship. The pair explores different ways to actively listen, to challenge each other's views, and to successfully influence the direction of reform in the health system.

This internationally established program uses a joint project as the platform for service improvement and personal development of both the consumer leader and the health worker.

The *Collaborative Pairs* program is currently being evaluated for the Australian context by several national health organisations.

Carer lounges. This is a comfortable area, separate from the patient's room and the other areas of the hospital floor, where family and carers can take time for themselves. The area has comfortable chairs, drinks and snacks.

Visiting hours. Evidence supports that removing visiting times provides increased flexibility for family and carers to see a patient at a time convenient for them. This can include staying with a patient overnight (at the discretion of the patient).

Complementary holistic care. Introduce integrated services for the whole-person needs of patients, such as aromatherapy, massage therapy, healing touch, and pet visits from certified pet therapy dogs.

Nurse leader rounding. Nurse leader rounds are processes in which nurse leaders make daily visits to check in with patients and carers in order to build relationships, verify consistency of care, gather real-time feedback, perform immediate service recovery if needed, and follow up with staff on complaints or opportunities for improvement.

NSQHS Standards
This enabler aligns to Standards 1 and 2.

04
Innovation and technology

How might we challenge the way we have always done things by doing them differently, and leveraging digital technology to help us, in a way that is caring, inclusive and delightful?

In healthcare, innovation has been an essential focus in creating safer, higher-quality, more reliable, rewarding experiences. It has driven the capacity to ensure better care and have a positive impact on the lives of people served by healthcare. In innovation, there is an opportunity to consider technology and how it might benefit the patient experience.

Priority initiatives

4a. Consider and design new models of care

Evidence suggests that patients benefit when their care is managed outside the hospital whenever possible. Innovation in healthcare is beyond simply digital technology. It includes redesigning the way we use technology to be smarter, faster and, most importantly, more valuable for our patients, families, carers and caregivers. It is important to consider alternative care settings that enhance patient experience – such as care at home, using virtual care and telehealth.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Identify and share best practices in new models of care delivery.

- Investigate clinical and patient experience outcomes of the acceleration of virtual care during the COVID-19 pandemic.

- Encourage and support the pilot testing of Care Navigation programs.

- Encourage and support the use of virtual reality.

- Investigate alignment of initiatives identified in key strategic guidelines and frameworks such as first 2000 days, HIV strategy, outcomes of inquiries into Aged Care, Mental Health, Disabilities and Domestic Violence.

- Investigate the establishment of a patient experience innovation fund.

- Keep a registry of patient experience innovation in development to prevent duplication and connect projects together across LHDs.

- Create 'innovation champion' roles that encourage innovation and identify opportunities for improvement across the Ministry.

At a local level, health services may seek to:

- Create innovation champion roles that encourage innovation and identify opportunities for improvement.

- Ensure all major program-evaluation criteria include one relating to positive impact on patient and staff experiences.

- Establish an incentive scheme to recognise and reward staff for successful innovations.

- Provide advice and assistance for staff to apply for grants and funding from outside the health service.

- Connect innovators in the health service to clinicians or researchers who could help develop new initiatives.

Example best practice

Virtual reality to alleviate stress for patients receiving chemotherapy

Chris O'Brien Lifehouse is trialling the use of virtual reality for patients undergoing cancer treatment. For many patients, treatment can be as stressful as diagnosis. Virtual reality technology is used to take them out of the moment and distract them from stress and anxiety. The oncology patients can select from a range of virtual reality experiences – including jumping from an aeroplane in a skydiving simulation, taking a boat ride through Sydney Harbour and petting koalas at a zoo – as they undergo challenging treatments.

Example best practice

Sydney LHD RPA Virtual Hospital

Sydney LHD has launched a trial of 24-hour virtual care for patients in the community from Royal Prince Alfred Hospital, **rpa**virtual. It provides care by phone, video calling and remote monitoring of patient data. Patients are lent an iPad which allows them to view their health data, sync medical device and health app data using Apple Health, and communicate with their remote care team. According to Sydney LHD, patients who accept an invitation to enrol with **rpa**virtual have access to a registered nurse through the **rpa**virtual care centre. The nurse can arrange for home visits or refer patients to their hospital care team if needed. During the COVID-19 pandemic, **rpa**virtual ramped up to provide virtual care services to patients testing positive to COVID-19 and not requiring inpatient care.

4b. Consider ways digital technology can improve access to information and services

Healthcare is deeply personal and requires a human touch, so we need to strike the right balance between high-tech self-service and high-touch human service.

We are shifting to think about being digital-first and creating a self-service customer environment. It is not about just digitising products and services; we need to rethink the entire experience to be proactive, personal, seamless and logical from a patient and carer perspective.

Meeting with a clinician using telehealth for a minor ailment is a good example – it is convenient and affordable but still allows a personal interaction with a doctor from the comfort of a patient's home. From being a rarely offered option, it has become the norm during the COVID-19 pandemic, ensuring continuity for patients.

We know that our patients and carers want a health system which puts people first – giving them more choice, agency and transparency. They want better access to mobile digital health services for the whole community, not just those who are experienced users of new technology.

The benefits of improved digital information are many. Some of the systems that patients could directly use include online booking systems; automated reminders for appointments, medications or treatment; electronic wayfinding around hospitals; live updates on waiting times; booking and paying for parking; telehealth appointments; and remote monitoring of patients after discharge.

Technology also offers many operational benefits, such as better medication management resulting in fewer adverse drug events, reduced duplication of tests, better coordination of care and greater transparency of the system.

The case is compelling but advances must always offer improvements to staff and patient experiences and outcomes. High-performing organisations understand the opportunities and limitations of technology – technology is used to increase the efficiency and safety of tasks, allowing more time to be spent caring for patients. This is the objective of this priority.

While digital technology has the ability to improve access and connect individuals and communities, there also remain significant barriers to ensuring digital technology is inclusive for all. It is important that we consider how digital technology can be made more accessible, through physical products or removing language and communication barriers such as low digital literacy. Digital health solutions may focus on (but are not limited to) improving home-based clinical care, managing care pathways, and supporting community members to engage with coordinated mental health and wellbeing plans.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Support the development of a common patient-engagement platform that provides a single digital 'front door'.

- Partner with Service NSW to identify opportunities to simplify registration and consent processes.

- Establish a single patient record – a holistic statewide view of a patient's healthcare information that will support safe, high-quality care.

- Review patient and staff apps used across health settings and identify opportunities to consolidate or leverage.

- Support the digitisation of outpatient referrals and simplify appointment bookings (linked to outpatient strategy).

- Support the extension of electronic check-in at all stages of the patient journey.

- Support the development of electronic request for admissions (RFA's)

- Ensure free patient Wi-Fi is available in all hospitals and community facilities.

- Review the strategies to provide interactive, personalised entertainment, education, care plans and virtual connections in all care settings, and transition to a patient portal.

- Provide telehealth and virtual care solutions and work with other organisations to evaluate the outcomes of virtual care projects on patient and staff experience.

- Review the opportunities to integrate multilingual text messaging services into patient engagement platforms and call centres.

At a local level, health services may seek to:

- Identify 'pain points' for patients and consumers accessing services.

- Identify priority use cases (working with the Ministry, pillars and other NSW Health organisations) where technology can be used to improve access to information and services aligned to key 'moments that matter', for example real-time language translation for wayfinding in physical spaces, live streaming from neonatal intensive care for the family, or tracking a patient's progress during a hospital stay.

- Implement the Outpatient Services Framework.

Example best practice

Esther, the virtual patient and real-life educator

Jönköping Healthcare Service (Sweden) has developed a virtual patient called Esther to improve organisational processes and educate the workforce about the needs and preferences of patients. By following Esther's patient journey, Jönköping has been able to better educate the workforce and substantially improve practices and process. During the initial three-year Esther project, there was a significant reduction in hospital admissions, waiting times for referral appointments and hospital days in hospital for certain conditions.

Example best practice

GoShare

As a part of the NSW Health Emergency Department Patient Experience project, GoShare is used to send a Welcome to the Emergency Department pack to the mobile devices of patients or families in their preferred language when they present. With engaging animations available in 10 languages for both adults and children, the digital bundle is also being accessed via posters with quick-reader (QR) codes displayed in hospital waiting areas. GoShare survey functionality is also being used to capture valuable feedback from patients about the pack. When a patient leaves the emergency department, clinicians can also send relevant resources about self-care and local treatment options or support services. In 2019, the program received the NSW Premier's Award for World Class Customer Service. Commenting on the award at the time, participating hospitals said that patients were much better informed while waiting for treatment as a result of the program and that it helped to reduce stress and anxiety.

4c. Develop digital literacy programs to educate and empower patients and staff

As digital technology and its uses in our places of work improve and are enhanced, it is important that our patients and staff are brought along on that journey. Digital technology will only be good at improving patient experiences if our patients are empowered and enjoy using them. It is important to consider digital literacy programs to educate, empower and uplift patient and staff digital capability – particularly as new products, processes and ventures are launched.

The use of technology can also have unintended negative consequences on patient experience and operate as a barrier to personal connection between patients and clinicians. Further, organisations need to be aware of the need to build workforce willingness and capability in use of new technologies. Communicating better human-centred care as the driver or rationale for change (for example, implementation of electronic medical records and changes to visiting protocols) can be an effective way to build workforce buy-in and willingness to adapt to new technologies and processes.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Develop a statewide digital literacy plan that includes best practice on how to improve digital literacy among patients and staff, and provides local health services with clear next steps on how to take action.

At a local level, health services may seek to:

- Integrate digital literacy into staff learning curriculums.
- Introduce 'digital champions' into teams who can upskill, educate and support staff who have lower digital literacy.
- Establish digital-assisted channels, where patients can be guided through digital platforms by a staff member so they can be educated to use the tool independently in the future.

4d. Foster a culture of continuous innovation and improvement

Innovation is often misunderstood, and used as a buzzword, with few knowing what tactical action to take to drive it. But innovation is as strategic as it can be tactical, with clear and measurable ways to implement it – from organisational innovation through to product and process innovation. Innovative ideas are rarely born in closed labs, but rather thrive and rise in cultures that are consumer-focused and collaborative, with the right supporting processes. In order to foster a culture of continuous innovation, we must consider building a shared responsibility for innovative thinking, practices and implementation, creating a culture that prioritises an innovative way of working, and encourages the generation of ideas, collaboration and co-design.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

• Establish a shared culture and responsibility for innovative thinking, practices and implementation driven and owned by NSW Health across the Ministry, pillars and LHDs.

At a local level, health services may seek to:

• Establish innovative idea management by creating ways to crowdsource innovative ideas from across the organisation and create a culture of innovation in which innovation is organically encouraged and cultivated.

• Establish innovative project-management practices whenever initiatives are being launched, for example using iterative project management methodologies such as Agile for fast testing, and incentives such as venture funds to encourage the development of ideas.

Example best practice

Blacktown Hospital digital prescriptions

Blacktown Hospital in Sydney has set up a portal within its electronic medical record that allows prescriptions for discharge medications to be sent electronically to the hospital pharmacy, meaning a paper prescription no longer has to be physically signed and delivered. The new workflow is part of Blacktown's electronic medications management (eMeds) program, which has seen the Cerner medications system rolled out across the Western Sydney LHD hospitals, along with most other LHDs in the state. This system automates manual tasks to improve consistency and free up time for staff to provide patient care.

Example best practice

St John of God tracking of surgical patients

Live tracking of patient journeys at St John of God allows families to follow an electronic patient journey. A 'patient finder' for patients in surgery allows the family to track when an individual is going into and coming out of surgery. This initiative has reduced family anxiety and resulted in fewer enquiries (and hence fewer disruptions).

Examples of existing innovation initiatives at LHDs in NSW

- Northern Sydney LHD has introduced a web platform for the public to directly contact the Board members.

- South Western Sydney and Western Sydney LHD are building the My Experience Matters and Transforming your Experience surveys into day-to-day practices. This is an electronic system that gives immediate real-time feedback on patient and carer experience.

- The Ministry and eHealth have made important changes to the NSW Health Patient Administration System and electronic medical record to identify at registration if a patient has or is a carer. Involving the carer can ensure a better outcome for the patient and reduce the risk of avoidable admissions and a longer stay in hospital.

- ACI has developed the Consumer Enablement Guide, a comprehensive web resource that brings together concepts, evidence and resources to inform and support the use of enablement approaches in clinical practices.

- ACI implemented the Music and Memory program in 21 metropolitan and rural healthcare settings in NSW. The use of personalised playlists was a novel, low-cost music intervention to improve how patients perceived and experienced their healthcare.

05
Information and communication

How might we be better at creating dialogue and communicating clearly with our patients, carers and caregivers so that they are informed, empowered and at ease with their experience?

At the heart of a better patient experience is how patients understand and engage with the information provided to them during their journey. Clear information, communication and engagement during decision-making supports independence, autonomy and greater self-care for patients. Through effective communication, patients and their families know that they are important partners in planning and decision-making for their care.

Acknowledgment and integration of a patient's expertise about their situation, their priorities and desired health outcomes into care-planning is seen as a hallmark of high-performing, human-centred organisations and is frequently referred to in the literature. It is a key part of establishing a shared understanding and formulating goals of care with the patient and carer. Shared decision-making is a practical, core requirement of human-centred care. While it is a structural component of care, it requires a person-centred attitude and culture to be truly effective.

Priority initiatives

5a. Develop human-centred communications aligned to known 'moments that matter'

Failures in communication are the most common primary cause of errors and adverse events in healthcare, as well as a significant factor in patient satisfaction and complaints about care. Communication plays an integral role in service quality in all service professions by providing the right information, to the right people, at the right time – making patients empowered and informed, and reducing operational burden on our staff.

Communication should be tailored to the needs, preferences and capabilities of the patient and their carer. Providing useful information and supporting patients' health literacy are prerequisites for encouraging meaningful partnerships with patients and their carers. Information and knowledge allow patients and their carers to make informed decisions, navigate the system, and manage and share in their care – the essence of human-centred care.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Review and revise NSW Health intranet and internet capabilities to ensure they meet accessibility standards.
- Identify and communicate key moments that matter in the patient journey, for NSW health services to use as a guide to identify areas for improvement.

- Develop and share a best-practice guide and principles for patient–caregiver communication.

At a local level, health services may seek to:

- Identify and communicate key moments that matter in the patient journey, and assess the quality of existing communications, for example, how patients and carers raise issues such as uncontrolled pain with staff, information about personalised admission or discharge instructions and after-care plans, available through a patient's channel of choice.
- Conduct a baseline assessment of all patient information and develop a method for introducing improvements to ensure that patient information meets health literacy best practice guidelines, including identifying review and revision dates.
- Support patients to participate in communications about their care, including through inclusive bedside handovers and communication boards.
- Translate materials to the language status on a patient's request for admission that also accommodates a patient's accessibility needs.
- Develop a post-operative helpline available for any patient to contact for questions, concerns and support.
- Provide patients access to their own medical records and information in a way that is accessible to them and in their preferred channel (for example, Open Notes, My Health Record).

5b. Implement initiatives to improve health literacy for patients, carers and caregivers

Health literacy is a significant issue for NSW and across the world. Health information and systems have become increasingly complex and harder to understand. Health literacy is important for patients because it affects their capacity to make decisions and take action to manage their health and healthcare. It is important for caregivers because it affects the way they manage their relationships with patients and deliver healthcare. It is important for managers and policy makers because the complexity of their systems and services can affect the ability of patients to use those services effectively. It is also important for the broader society because health literacy contributes to people's overall health, and consequently their capacity to participate and contribute productively to society. Addressing health literacy can also contribute to reducing health disparities and increasing equity.

Partnerships with consumers are essential for the development of better healthcare systems. Improving health literacy ensures that consumers can fully participate in these partnerships, and that the health system and healthcare organisations are oriented to support such partnerships.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Progress the development of a statewide communications portal, including patient survey results, health literacy, shared decision-making, wayfinding, patient information, webinars, podcasts and access to formal education.

At a local level, health services may seek to:

- Create 'health literacy ambassadors'.
- Implement the NSW Health Literacy Guide.
- Identify incremental opportunities to improve patient health literacy.
- Promote the ACI Consumer Enablement guide and Spotlight series.
- Add, promote and support programs to increase access to interpreter services for non-English speaking patients.
- Integrate the 'teach-back' concept into all interactions.
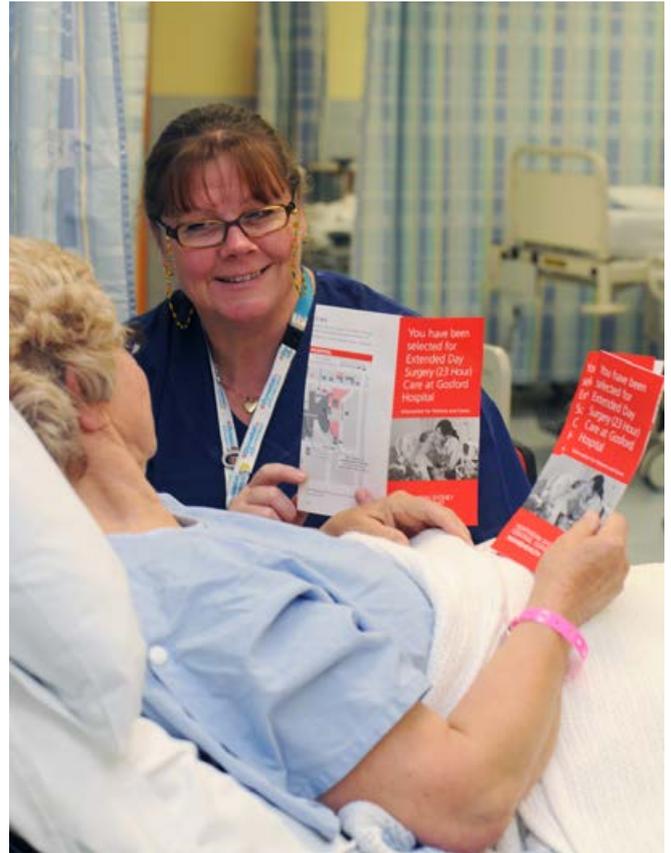
Example best practice

Sydney LHD Aboriginal Mental Health Unit

The YES survey identified that results for Sydney LHD relating to 'providing Information and support' needed to be improved. The Sydney LHD Aboriginal Mental Health Unit met with indigenous consumers about what might help. Together, they began to develop specialised mental health information sheets aimed at their local Aboriginal community. Five information sheets were developed; 'the Aboriginal Mental Health Unit', 'Grief, loss and trauma', 'Substance misuse', 'Getting better and healing', and 'Mental health problems in our communities'. All sheets were developed in partnership with Aboriginal mental health consumers before endorsement from the Mental Health Service Lived Experience Advisory Panel and the Sydney LHD Aboriginal Health Unit. These information sheets are now used improve the health literacy of local consumers.

Example best practice

Teachback.org

Teach-back is a way to confirm what the consumer understands, using their own words. It is a method that creates an opportunity for communication in which the health professional gives information, and then asks the consumer to respond and confirm their understanding before adding any new information. Teachback.org was developed as a collaboration between the Community Partnerships Unit, Directorate of Planning, Population Health and Equity, South Eastern Sydney LHD and the Health Systems Improvement Unit, Deakin University. While teach-back is not a new concept, it is often not routinely used across health services. The aim of the project is to clearly demonstrate the value of teach-back and to provide a greater understanding of how to use it in everyday practice. The module has been piloted-tested with health professionals and consumers to inform its usability and accessibility. It is a free resource.

Example best practice

Health literacy

There are four priorities outlined in the CEC NSW Health Literacy Framework. The priorities aim to create sustainable system-level change, and improve safety and quality of care.

1. Patients, families and carers are active partners in their healthcare.

2. Staff communicate with patients, families and carers in ways they understand.

3. Our health systems are built to be sustainable and reliable for every person, every time.

4. Health facilities and centres are easy to access and navigate.

Northern NSW LHD Health Literacy Officer works with the LHD and Primary Health Network. The aim is to advise staff on how to provide more accessible information and to improve health literacy of the community members. More than 1000 health professionals have received this training in the past two years.

Western Sydney LHD Health Literacy Hub provides access to a wide range of educational materials and programs, practical tools and advice on health literacy.

Illawarra Shoalhaven LHD partners with staff and consumers to improve health literacy in their facilities. They have helped staff develop consumer-friendly information that meets the principles of good health literacy. Their Health Literacy Ambassadors help local staff develop information brochures and maintain an inventory of patient information resources in plain English. Illawarra Shoalhaven LHD provides their health literacy framework and resources (including an implementation toolkit) on request to health organisations who want to duplicate their work.

5c. Continuously improve patient communication to be easy to understand and engage with

Communication preferences change and evolve over time, and ways of doing things better, faster, and in more human-centred ways will continue to emerge. Practising continuous improvement in humanising our communication with patients, carers and caregivers may begin with identifying the critical moments that matter to patients and carers and working with them, and caregivers, to identify ways we could do better.

For example, that might be through clearer and simpler language used, greater involvement in decision-making at the right times, or communicating the names and roles of a care team early and notifying patients when that changes. These needs and opportunities to be more patient-centred are ever evolving, and our considerations and improvements should be too.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Develop guidelines, principles and tools for best-practice patient–clinician communication.

- Implement the Improving the Rural Patient Journey initiative.

- Review and update policies and procedures related to transitions of care which could include the development of transition-care business rules.

At a local level, health services may seek to:

- Identify incremental opportunities to improve patient and caregiver communications.

- Ensure information and communication are tailored to the needs of culturally and linguistically diverse patients, families and carers.

- Ensure consumers are actively engaged in the development of patient information.

- Implement procedures that require cultural and language considerations to be incorporated into all communication strategies.

- Implement a plain-language policy that makes written information easier to understand.

- Educate the workforce about the diversity of the consumers who use the organisation's services.

- Consider accessing cultural competency training for people who regularly use the service and are from culturally and linguistically diverse communities, or from Aboriginal and Torres Strait Islander communities.

- Engage consumers in developing and reviewing health communications.

- Improve access to interpreting services (policy, procedure and technology)

Example best practice

The Western NSW Living Well Together Aboriginal Yarning tool

This tool helps clinical leaders to have culturally appropriate conversations with Aboriginal patients and carers. The Living Well Together Aboriginal Yarning tool is a collaborative approach to healthcare and means patients:

- are empowered with a better understanding of clinical care and their illness
- are supported by staff and engaged in shared decision-making
- feel their values and needs are considered through culturally appropriate conversations
- have an increased knowledge of their treatment, medications and discharge plans.

The Aboriginal Yarning approach:

- improves Aboriginal patient experience
- improves delivery of culturally appropriate services to Aboriginal patients
- identifies barriers Aboriginal people face when accessing services
- builds stronger relationships with Aboriginal patients and carers.

Example best practice

EnableNSW

EnableNSW provide equipment and services to people in NSW with chronic health conditions or disability to assist them with mobility, communication and self-care. Their website allows people with health needs to directly apply for support, such as wheelchairs, ventilators and prosthetics. The service allows consumers to check the status of their request(s), update personal and delivery details, reorder consumable products and request repairs to equipment. The website includes an online catalogue and shopping cart function to provides users with an easy way to view and request equipment.

Example best practice

Communicate with H.E.A.R.T.

Communicate with H.E.A.R.T. (hear, empathise, apologise, respond, thank) is Cleveland Clinic's foundational communication model for delivering a culture of service excellence. The program empowers caregivers to provide outstanding service to patients, visitors and fellow caregivers, and includes interactive activities to support the learning process. The program includes interactive training sessions and learning activities that focus on Cleveland Clinic's expected service behaviours.

NSQHS Standards

This enabler aligns to Standards 1, 2, 5, 6 and 8.

06
Measurement, feedback and response

How might we introduce and embed clear, robust ways of capturing, tracking and analysing data that reflects patient and caregiver experiences so we can continue to evolve, grow and invest in being better each day?

Measurement is critical to understanding, tracking and taking action on our progress and improvements in patient and carer experience. The benefits are twofold. Measurement of the current status helps us understand how we are doing in achieving human-centred health systems, i.e. where we are now. This allows us to identify and celebrate aspects of patient experience that we are doing well at, and therefore where to focus efforts and investments to improve aspects that need improving. Measurement of change helps us understand which initiatives are effective and should be shared and expanded.

Measurement needs clear objectives to be useful in influencing decisions and changing practice. High-performing person-centred healthcare organisations emphasise the need to collect data that can be acted on to improve patient experiences and outcomes and reflect what is important to patients and communities. High-performing organisations also embrace and foster learning, evaluation, and continuous improvement as core to their culture. Part of being a learning organisation and embracing a culture of continuous improvement is information transparency.

Understanding, measuring and improving key moments that matter is a foundational start to scaling a broader measurement methodology and embedding a broader culture of patient experience measurement. This includes defining the key moments that matter to patients and carers, and defining a core set of questions to ask in those moments, as well as mechanisms to gather that feedback in real- time. The benefits of continuous monitoring, evaluation and reporting on patient experiences enable us to learn and understand, so that we can act and respond to evolving patient needs in faster and more nimble ways.

Priority initiatives

6a. Design and apply consistent methodology for patient experience feedback capture (including right measures, right time, right purpose)

Evaluating the effectiveness of communication, monitoring progress, collecting feedback and measuring outcomes are core to the success of patient and carer experience. Feedback should be sought on the planning, design and execution of initiatives. When we close the loop by feeding back to the patient, we establish a continuous improvement cycle. This can lead to greater satisfaction and trust, and an overall increase in how patients and carers connect with and care about their healthcare. However, a culture of measurement, and methodology to measure, must occur at all levels – from the strategic to the tactical. To do this, it will be critical to make sure everyone understands why patient experience is being measured, what they are expected to do with the feedback, and how this feedback will be used.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Build on the existing patient reported measures (PRMs) framework to define more clearly the purpose of, and relationship between, statewide and local patient experience measurement and feedback collection mechanisms, i.e. the NSW Patient Survey Program (PSP). This program provides facility, LHD and state-level comparisons and trends for both improvement and accountability purposes. Local real-time measurement provides local (including ward and service-level) information to drive local response, improvement programs and local accountability.

- Provide guidance and resources on good practice in using and reporting patient experience measures and feedback, and incorporating into existing improvement and accountability processes.

6b. Strengthen the consistency and quality of patient experience data capture, storage, reporting and use

A critical component of an overarching *Guide to action* is measuring impact during the critical moments that matter to patients. While the intent to measure and take action on patient and carer experiences is a critical starting point, the quality of information depends on the quality of the data captured, and the mechanisms by which the data is stored, linked, analysed, used and reported. Critical to this is building analytical capability at the local and system-wide levels. Having centralised guidance, tools and support systems will enable us to monitor our progress to deliver the vision and outcomes we have set for patient, family, carer and caregiver experiences.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Strengthen analytical capability and provide guidance on how to make better use of patient and caregiver experience data captured at system-wide and local levels to drive decision-making.

- Identify and better integrate and expand key sources of data on patient and carer experiences to provide a more coherent and comprehensive understanding for those working in healthcare settings (for example, PSP and administration data).

- Develop a best-practice playbook with guidelines for how to use the linked data, develop appropriate KPIs to measure success and report on progress (for example, via a dashboard using NSW PSP).

At a local level, health services may seek to:

- Establish clear processes and procedures for data capture and storage that meet NSW Health best-practice guidelines.

- Pilot-test cases of reporting on key patient experience indicators and identify the best actions to improve on them.

- Develop an ongoing strategy for how patient experience measures will be tracked, reported and communicated, and how action will be taken to improve on them.

- Ensure that there is clear governance for analysing and responding to patient experience data and sharing information across the organisation.

- Set up 'Knowing how we're doing' boards on public display in wards and departments, with information on how wards and departments are performing along with measuring patient experience.

Example best practice

Real-time feedback at Western Sydney LHD

Real-time feedback from patients, carers and their families staying in some of Western Sydney's busiest hospitals can now be offered and addressed in real time using a new Australian-first digital platform. Western Sydney LHD now runs a My Experience Matters survey using cutting-edge feedback technology, allowing staff to instantly analyse patient experiences in their hospitals. The survey, which was officially launched at Westmead Hospital on 17 January 2017, has been rolled out to Blacktown, Mount Druitt and Auburn hospitals, allowing patients to provide their feedback through a hospital iPad or online.

6c. Improve complaint handling, including guidelines and practices for consistent actioning of feedback and closing the loop in improvements

Complaints are a valuable source of data for several reasons. Unlike other patient feedback mechanisms (for example, patient satisfaction surveys, focus groups), complaints are unsolicited and represent the care issues that breach a threshold of concern and compel patients and carers to take action. This includes safety incidents and poor experiences that are not always identified in internal systems of healthcare monitoring (for example, incident reports and retrospective case reviews).

Complaints contain data on difficult-to-monitor areas of practice, such as care access or continuity, systemic problems and care omissions. However, in contrast to standard feedback and incident-reporting mechanisms, complaints systems are not primarily designed for quality monitoring and improvement, but rather to provide individual complainants with a formal response; that is, complaint handling. Developing and practising a consistent approach to complaint handling is important for a better patient and caregiver experience, and for instilling community trust and confidence in the health system. Therefore, it must be embedded from a policy level through to the processes which enable us to better handle complaints – from how we receive them through to how we act and report on them.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Develop overarching guidelines for consistent and quality management of feedback (complaints and compliments).

- Review and revise existing policies and guidelines related to managing complaints and compliments.

- Review roles and responsibilities for complaints management across the Ministry, pillars and other NSW Health organisations.

- Identify best practices in education and coaching in service recovery.

- Investigate the use of a single platform to interrogate text comments.

- Establish a CoP to support staff working in complaints management.

- Partner with three LHDs or SHNs to trial Care Opinion, an online platform for driving service improvement and addressing patient issues.

At a local level, health services may seek to:

- Provide consistent education and coaching for staff dealing with complaints.

- Develop communication skills and training programs for staff (for example, expression of listening; empathy) to provide exceptional responses to complainants.

- Set and monitor local targets.

- Ensure Board agendas focus on and respond to patient feedback, such as complaints.

- Develop practices that are transparent and accountable when dealing with complaint handling to encourage other patients and carers to provide feedback.

- Embed quality monitoring and improvement in existing complaint handling practice.

- Investigate the need for better policy, tools and guidance to establish a quality monitoring and improvement pathway that is distinct from immediate, case-by-case practice.

- Encourage a culture among staff that supports patients and carers providing feedback and staff receiving and responding.

6d. Develop human-centred performance targets that encourage staff to deliver positive experiences

The ways we measure the success of teams encourage certain behaviours and cement particular mindsets of success. A critical component of creating change towards a human-centred organisation is to encourage the right behaviours among staff to do so. Embedding performance targets for measurement of patient experiences creates an environment that allows staff to prioritise patient and carer care, and rewards them when they excel in doing so.

Currently, patient experience is included in all LHD service level agreements with the Ministry, for admitted patients, emergency department patients and mental health patients. These are regularly reported to and discussed at LHD Senior Executive and Board meetings.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Review in conjunction with patients and families all current patient experience KPIs and recommend new indicators for 2021–2022.

At a local level, health services may seek to:

- Identify existing local process outcome measures and link to the Bureau of Health Information and real-time feedback results.

- Use information from statewide performance measures that reflect patient priorities locally to establish targets for individual health services.

Example best practice

South Eastern Sydney LHD and Care Opinion Australia

Care Opinion Australia provides a platform for health services to learn from their patients' experiences, through listening to patient stories, both positive and negative, and encouraging changes and improvements within health service organisations. South Eastern Sydney commenced a pilot of Patient Opinion at Sydney and Sydney Eye Hospital in 2018. Following positive feedback from patients and staff, the program has now been rolled out to all facilities across the LHD. Hundreds of patient stories have been collected, read and improvements made available for all to see online.

Examples of existing initiatives

- **South Western Sydney LHD** uses strategic indicators to measure progress towards a learning and mentoring culture; recruiting and retaining the best talent; engaging staff in decision-making; celebrating staff achievement; and communicating respectfully from leadership.

- **YES surveys** were developed for national collection of mental health consumers' experiences of care. In NSW, more than 20,000 surveys are returned every year, providing essential insights into the quality of care provided and the level of support needed by consumers, carers and staff. Since 2018, NSW has also collected carer experiences using the Mental Health CES. Information collected is used locally to improve services but also reported at a national level.

- **The Register of Outcomes, Value and Experience (ROVE)** brings together data from across the health system to provide greater insight into how we manage serious acute and chronic conditions. As part of NSW Health's Leading Better Value Care work, data about patient experiences, outcomes, services used and cost are linked in ROVE. In 2020–21, the Ministry will release an interactive app for health staff to use to better understand what happens to their patients during and after treatment.

- **St Vincent's Hospital** uses Qualtrics to capture feedback from patients and families, and provides those results to ward dashboards in real time.

- **The Cancer Institute NSW** has funded the patient-reported outcome measures for personalised treatment and care (PROMPT-Care) pilot in South Western Sydney and Illawarra Shoalhaven LHDs, helping to support people living with cancer both during and after treatment. The project captures information about a patient's symptoms, distress, quality of life and unmet needs to inform and provide self-management tools and resources.

- The **Agency for Clinical Innovation** is leading on establishing an integrated collection of patient experiences and outcomes across NSW. This IT platform will support the systematic collection and use of PRMs across the state. Internationally validated outcome measures will ask the patient about their health, quality of life and function, comparing this to past ratings and to other patients. Experience measures will be collected asking patients to recall their health encounters and the degree to which they were informed, involved and respected by health staff.

NSQHS Standards
This enabler aligns to Standards 1, 2 and 6.

07
Environment and hospitality

How might we create places for our patients and staff that make them feel welcome, safe, comfortable and at ease during their interactions with us?

People Process **Place**

Placemaking in healthcare is the art and science of creating welcoming, functional spaces. We know that the design and layout of patient spaces are vital for ensuring the comfort, wellbeing and recovery of the patient. Dark, messy, unkempt spaces can negatively affect a patient's perception of not only the healthcare facility itself but also their speed of recovery. Old, badly worn or ill-repaired facilities adversely affect staff satisfaction, which can also affect patient experiences.

Priority initiatives

7a. Create a physical environment that is warm, clean, welcoming and conducive to wellbeing and care

By providing a space in which people are safe, comfortable and confident in the care they receive, hospitals and health systems become a positive environment for patients. Simple aesthetic design elements such as pops of colour, attractive feature walls and areas with natural sunlight can have a large impact on patients, visitors and staff perceptions of their environment. Beyond the aesthetic, and critical to this experience, is ensuring the functional design of a space meets the needs of our patients and carers. Design elements such as wayfinding in a hospital can have a significant impact on the experience.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Improve guidelines and requirements for wayfinding in physical spaces.
- Encourage and support the Health and the Arts program.
- Investigate the provision of entertainment platforms at the bedside to keep patients informed, educated and connected.
- Share the finding of the Emergency Department Patient Experience amenities checklist with all health services.
- Investigate opportunities to reduce isolation and loneliness in hospitals.
- Investigate the creation of sensory-friendly spaces within emergency departments and other areas where adults or children require safe and quiet spaces.

At a local level, health services may seek to:

- Integrate the learnings from the Health and the Arts program into all new building projects and refurbishments.
- Consult with local population groups to find out what would be perceived as welcoming and acknowledge the diversity of responses.
- Create dedicated carer spaces.
- Ensure clinical staff are provided with safe, comfortable spaces to retreat to, adequate food and drink, and appropriate places to rest.
- Improve wayfinding with consideration for both physical and digital wayfinding.
- Integrate music and time out into ward routines.

Example best practice

Westmead Hospital redevelopment

As Westmead Hospital underwent redevelopment, it ensured that hundreds of meetings and workshops with consumers took place to inform the decisions. Consumers' personal experiences have ensured person-centred design has occurred at all stages of the planning process. Their personal experiences and insights, as carers and patients, have shaped the design of the entrance to the new hospital building. Consumer experience has also resulted in the inclusion of patient rooms (including carer zones, waiting areas and patient lounges on each floor), a parent's retreat, an arts and culture strategy, and a cultural gathering place.

7b. Optimise amenities and food experiences that support a better patient, family, carer and caregiver experience

Patients expect that places that provide healthcare to them will be clean and safe. It is also becoming increasingly important to patients and carers that hospitals and health services are environments that are comfortable and minimise the disruption to day-to-day life.

The people that spend time in our hospital spaces – patients, carers and caregivers – must be more than passive users of the environment they are in. The time they spend in the physical locations of healthcare must be designed to meet their needs. Providing amenities such as better food and cleaning services, Wi-Fi and charging stations (amenities now the norm in public areas) can create spaces that are like an extension of life beyond the hospital.

Food satisfaction in hospitals is an evaluation process that depends on more than the nutritional content of meals. The expectations of the patient have a significant impact on how satisfied patients are with their meals. Patient perception of meal quality is impacted by many considerations, such as food taste, temperature, range of alternatives offered, reliability of food service in terms of time and providing the meal the patient selected, attitude of the catering staff when providing menus and the meals, support provided to open packages or eat, and catering to personal, religious and dietary needs. The literature recognises that, whatever the methods of food service and the environment, every patient makes an implicit comparison with their own home when answering questions about satisfaction with hospital food service.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

- Co-design guidelines on the minimum amenities that meet the expectations of patients, families, carers and caregivers today.

- Enable access to food in out-of-hours periods and support short-order service delivery, to allow patients to eat when they are hungry.

- Develop a patient-transport system with real-time updates of vehicle locations for patients and their carers, with estimated times of arrival and warnings of delays sent directly to a patient's mobile or email address.

At a local level, health services may seek to:

- Support and implement improved food experiences.

- Enhance the hospital and community environment by offering a broad range of performance, music and visual arts activities that support patient recovery and promote the health and wellbeing of all.

- Identify and implement strategies for reducing noise, particularly at night.

- Identify the roles of volunteers in meal-assistance programs.

- Identify and implement strategies to ensure privacy is paramount during ward rounds and sensitive conversations.

Example best practice

Targeted cleaning at Liverpool Hospital

NSW PSP results identified that the cleanliness of some areas at Liverpool Hospital needed improving. Liverpool Hospital used this information to target this issue using their real-time patient feedback devices. The information was then provided to the relevant general service managers, allowing them to take the necessary action to ensure cleaning processes could be enhanced. Some key actions included amending cleaning staff rostering schedules to ensure appropriate coverage, and ensuring those staff had the necessary equipment to do their jobs effectively. Patients reported improvements in cleanliness, for example, the Cardiac Catheterisation Laboratory bathrooms consistently improved during 2019, rising to the 95% mark. Also during 2019, ratings for cleanliness of the bathrooms in the hospital's children's ward improved by 15% in a one-month period following the introduction of a rotating cleaning roster and enhanced inspections. This is one way that timely patient feedback can improve services for patients and others.

Example best practice

Carer zones at Blacktown Hospital

As part of the Blacktown and Mount Druitt Hospitals Expansion Project, 40 unique carer zones were commissioned in single rooms across the new clinical services building. In single rooms, a visitor lounge near the window converts to a bed for carers to stay overnight with an adult patient. The patient bed curtain draws across the zone at night to maintain privacy for the carer without restricting nursing access to the patient. The concept is well established in children's hospitals but new to adult hospitals. The design is unique, having been developed by architects Jacobs to use existing space while maintaining access, privacy, comfort and spaciousness.

Example best practice

Finger food menu on the specialised dementia and delirium ward

Malnutrition (undernutrition) is a serious and debilitating condition that is highly prevalent in the hospital setting. At Hornsby Ku-ring-gai Hospital in the Northern Sydney LHD, the introduction of a finger food menu to Ward 2D has provided increased opportunities for independence and self-esteem at mealtimes, with the patient less reliant on assistance from staff. Patients also maintain control of what they eat and the time it takes to eat. Finger foods are easy to eat either at, or away from, a table. This can be helpful for those who wander or tend to leave the table in the middle of mealtimes.

7c. Consider cultural appropriateness in the design of physical space

When thinking about placemaking, it is important that we consider the role of culture in creating spaces that are accessible and appropriate for our patients, carers and staff. Acknowledging and embedding cultural considerations in the design of a space can have a significant impact on the access, outlook and outcomes of our services. Aboriginal culture should be acknowledged and respected in all NSW facilities, with culturally appropriate spaces available.

At a system-wide level, the Ministry, pillars and other NSW Health organisations will seek to:

• Promote and support the guidelines supporting equity and inclusion in design and redesign of health facilities.

At a local level, health services may seek to:

• Promote and support the guidelines supporting equity and inclusion in design and redesign of health facilities.

• Partner with patients and carers from diverse cultural backgrounds in the design and redesign of health facilities.

• Create culturally and religiously appropriate spaces that are easy to find and may be booked in advance.

Example best practice

Project Chef

The patient-food system in NSW public hospitals has recently undergone a period of continuous reform, underpinned by the centralisation of food services operations. There are opportunities to further innovate the patient food model, in line with advances made in other jurisdictions, which would significantly improve patient experience. Project Chef will:

• improve menu design by realigning nutrition standards and food safety policy so that menus match patient expectations

• enable access to food in out-of-hours periods and outside of common ward areas

• align tableware design with modern dining and sustainability expectations

• support short-order service delivery to allow patients to eat when they are hungry

• employ digital patient experience feedback to inform 'agile' system redesign.

NSQHS Standards
This enabler aligns to Standards 1, 2 and 5.

5 **Next steps**

Delivering on our commitment

The purpose of this *Guide to action* is to set out what it means to deliver human-centred care and to state our commitment to improving patient, family, carer and caregiver experience. The work that comes next is to empower consumers to partner with our teams.

The organisations that make up NSW Health have different levels of patient experience maturity, with many delivering care and experiences that are comparable to any facility in the world.

Through understanding the maturity of our organisations, what patients have told us about the service (through surveys, comments and complaints) and working with local people (both patients and caregivers), we can work to elevate the human experience for everyone.

Next, we will actively coordinate and work in partnership at a systems level and co-design solutions with patients, carers and staff at the local level. In this way, we will continue to listen to and reflect on the real needs of patients, carers, family, staff and local communities.

Opportunities to align, strengthen, consolidate and share successes and lessons will be explored further in the early work plan activities.

Once priorities are identified for Year 1, we will conduct an alignment workshop to agree on roles and responsibilities and plan the priority programs as work streams.

This *Guide to action* will be complemented by an annually refreshed work plan that determines the priorities under the enablers.

The immediate next steps for the Ministry are to:

– Establish the NSW Elevating the Human Experience Steering Committee, which will provide oversight and strategic direction for this work.

– Develop and consult on the governance structure to support Elevating the Human Experience program by September 2020.

– Execute the Change and Communications Plan, with an emphasis on raising awareness of the *Guide to action* which will include the design and delivery of a dedicated intranet page and fostering the growth of Communities of Practice from August 2020 onwards.

– Coordinate the staged establishment of enabler working groups to recommend the prioritisation of initiatives to the Steering Committee, including scheduling and outcomes for patients, carers and caregivers. Committees to be established from October 2020 to March 2021.

– Develop the maturity assessment tools (individual and organisational) for implementation in late 2020.

The future of human experience

Extensive research and consultation occurred for the development of this *Guide to action*. Throughout the process, the fundamentals of communication and accessibility, quality and safety, and dignity and respect were universally enshrined as the basis of good patient experience. The next steps for NSW Health are to follow the recommendations of this *Guide to action* and to implement and measure the change it effects.

What then lies in the future for patient experience in NSW? In 2019, the Beryl Institute offered five thoughts when looking at the future of patient experience:

1. Patient experience will change as it evolves to include the realities people face in their lives, such as equity of access, poverty issues and sustainability of the system.

2. An expanding global conversation will shift the centres of excellence in experience.

3. Measurement will move away from static and lagging points of data.

4. Consumer voice will influence policy direction and ultimately leadership action.

5. A focus on human experience will root itself at healthcare's core.

This paper identified evolving patient experience leadership from countries such as Australia, greater respect and consideration for the patient voice (individual and as a group), and modernisation of measurement and engagement using technology.

The COVID-19 pandemic has spurred rapid innovation and policy change at speeds many believe was not possible. Consultations by teleconference have increased significantly, with many face-to-face outpatient visits transitioned to virtual appointments. In NSW and internationally, health has become the number one issue for people and their communities. In some ways, the COVID-19 crisis has accelerated human-centredness in healthcare.

Because of this, we can be reassured that we know what human experience will look like in the post-COVID world: the continued importance of individuals to be treated as human beings, with dignity and respect; inclusion of family and carers as integral to the health and wellbeing of patient; and the need for trusted information and involvement in decisions. In essence, it will be a partnership built on mutual respect and trust.

In response to physical distancing and isolation, we will need to reconsider our assumptions that human-centred care relies on the proximity of people. We must innovate to ensure that our patients can keep meaningful family and carer support throughout their health journey. Technology can offer us choices and increased flexibility in how we provide the human touch in our interactions. But for consumers across Australia, this work reinforces that experience matters greatly to patients and significantly influences their healthcare decisions.

We will be called on to think about how we address our new reality and new issues, such as addressing the needs and fears of consumers and their carers, retaining the improvements in care and experience we have seen in recent years and considering the health and needs of carers as we provide truly holistic care to our community.

References

1 Bureau of Health Information, 2020. Adult Admitted Patient Survey 2019. Available at www.bhi.nsw.gov.au/BHI_reports/patient_survey_results.

2 NSW Government Department of Premier and Cabinet, 2019. Customer Experience Unit, Customer Commitments. Available at www.dpc.nsw.gov.au/programs-and-services/nsw-customer-service-commissioner/customer-commitments.

3   Source: NSW Carers (Recognition) Act 2010 No 20 Schedule 1, Section 5) https://legislation.nsw.gov.au/view/whole/html/inforce/current/act-2010-020

4 Kemp KA, Quan, H, Santana, M, 2017. Lack of patient involvement in care decisions and not receiving written discharge instructions are associated with unplanned readmissions up to one year. *Patient Exp J*; 4(2), Article 4. Available at https://pxjournal.org/journal/vol4/iss2/4

5 Senot C, Chandrasekaran, A, Ward, PT, Tucker, AL, Moffatt-Bruce, SD, 2015. The impact of combining conformance and experiential quality on hospitals' Readmissions and Cost Performance. *Manage Sci*; 62(3). Available at https://pubsonline.informs.org/doi/10.1287/mnsc.2014.2141

6 Greaves F, Pape UJ, King D, Darzi A, Majeed A, Wachter RM, Millett C, 2012. Associations between internet-based patient ratings and conventional surveys of patient experience in the English NHS: an observational study. *BMJ Qual Saf*; 21:600–5. Available at https://qualitysafety.bmj.com/content/21/7/600.long

7 Charmel PA and Frampton SB, 2008. Building the business case for patient-centered care. *Healthc Financ Manage*; 62:80–5.

8 Isaac T, Zaslavsky AM, Cleary PD, Landon BE, 2010. The relationship between patients' perception of care and measures of hospital quality and safety. *Health Serv Res*; 45(4):1024–40. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2910567/

9 Fortuna RJ, Nagel AK, Rocco TA, Legette-Sobers S, Quigley DD, 2018. Patient experience with care and its association with adherence to hypertension medications. *Am J Hypertens*. 31(3):340–5. Available at https://academic.oup.com/ajh/article/31/3/340/4742742

10 Doyle C, Lennox L and Bell D, 2013. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*; 3:e001570. doi: 10.1136/bmjopen-2012-001570. Available at bmjopen.bmj.com/content/3/1/e001570.

11 Bureau of Health Information, 2020. Healthcare in Focus – People's experiences of hospital care: Insights from five years of patient feedback. Sydney (NSW).Available at http://bhi.nsw.gov.au/BHI_reports/healthcare_in_focus.

12 Entwistle VA, 2007. Differing perspectives on patient involvement in patient safety. *Qual Saf Health Care*; 16(2):82–3. doi:10.1136/qshc.2006.02036. Available at qualitysafety.bmj.com/content/16/2/82.1.

13 Hovey RB, Morck A, Nettleton S, et al., 2010. Partners in our care: patient safety from a patient perspective. *Qual Saf Health Care*; 19(6):e59. doi:10.1136/qshc.2008.030908. Available at qualitysafety.bmj.com/content/19/6/e59.

Foundational references

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Adapted from: Clinical Excellence Commission, person-centred care definition; and Australian Commission on Safety and Quality in Heath Care, 2018, Review of key attributes of high-performing person-centred healthcare organisations. Sydney. ACSQHC.

Agency for Clinical Innovation, 2015. Patient experience and consumer engagement: a framework for action, NSW.

Agency for Clinical Innovation, 2019. Patient reports measures: outcomes that matter to patients. Accessed at www.aci.health.nsw.gov.au/make-it-happen/prms (accessed 3 October 2019).

Agency for Healthcare Research and Quality, 2016. What is patient experience? Accessed at www.ahrq.gov/cahps/about-cahps/patient-experience/index.html.

Australian Commission on Safety and Quality in Healthcare, 2010. Australian Safety and Quality Framework for Healthcare. Accessed at www.safetyandquality.gov.au/sites/default/files/migrated/Australian-SandQ-Framework1.pdf (accessed 4 October 2019).

Australian Commission on Safety and Quality in Healthcare, 2019. The National Safety and Quality Health Service Standards. Accessed at www.safetyandquality.gov.au/standards/nsqhs-standards (accessed 3 October 2019).

Australian Commission on Safety and Quality in Healthcare, 2019. Australian Charter of Healthcare Rights: second edition. Accessed at www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-charter-healthcare-rights-second-edition-a4-accessible (accessed 4 October 2019).

Australian Commission on Safety and Quality in Healthcare. The Australian hospital patient experience question set. Accessed at www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/patient-experience/about-ahpeqs/why-ahpeqs-needed.

Balik B, Conway J, Zipperer L, Watson J, 2011. Achieving an exceptional patient and family experience of inpatient hospital care. Institute for Healthcare Improvement, Innovation Series white paper. Cambridge, Massachusetts: IHI. Accessed at app.ihi.org/Events/Attachments/Event-2346/Document-2437/IHI_Patient_Family_Experience_of_Hospital_Care_Whi.pdf.

Beryl Institute. Defining patient experience. Accessed at https://www.theberylinstitute.org/page/DefiningPatientExp.

Bureau of Health Information, 2018. Measurement matters: development of patient experience key performance indicators for local health districts in NSW.

Bureau of Health Information, 2018. Snapshot results from the 2017 patient survey: adults admitted to hospital. Bureau of Health Information: Sydney.

Bureau of Health Information, 2019. BHI patient surveys. Accessed at www.bhi.nsw.gov.au/nsw_patient_survey_program (accessed 3 October 2019).

Bureau of Health Information, 2019. Snapshot Aboriginal people's experiences of hospital care. Bureau of Health Information: Sydney.

Bureau of Health Information, 2019. Snapshot results from the 2017–2018 patient survey: Emergency department. Bureau of Health Information: Sydney.

Clark PA, Drain M and Malone MP, 2003. Addressing patients' emotional and spiritual needs. Joint Commission on Accreditation of Healthcare Organizations, 29;12:659–70.

Doody O, Butler MP, Lyons R and Newman D, 2017. Families' experiences of involvement in care planning in mental health services: an integrative literature review.

Dwyer D, Liu H and Rizzo J, 2012. Does patient trust promote better care? *Appl Econ*, 44(18): 2283–95.

Haggerty J, et al., 2003. Continuity of care: a multidisciplinary review. *BMJ*; 327:1219.

Henderson A, Caplan G and Daniel A, 2004. Patient satisfaction: the Australian patient perspective. *Aust Health Rev*; 27(1):73–83.

Jackson M, 2018. An exploration of factors affecting healthcare decision making: a patient's perspective [thesis]. London School of Economics, London.

Jorm C, Dunbar N, Sudano L and Travaglia J, 2009. Should patient safety be more patient-centred? *Aust Health Rev* 33(3):390-9.

Kenney L and Martin D, 2016. Improving the patient experience through the healthcare physical environment. American Hospital Association.

Kuluski K, et al., 2019. Twelve principles to support caregiver engagement in healthcare systems and health research. *Patient Exp J*; 6(1):141–8.

Multicultural Health Information Awards 2019 Winners and Finalists. Accessed at www.mhcs.health.nsw.gov.au/services/award/Winners_Finalists_MHCS_Awards_2019.pdf (accessed 25 October 2019).

National Health Service. Patient experience improvement framework. Accessed at improvement.nhs.uk/documents/2885/Patient_experience_improvement_framework_full_publication.pdf.

National Safety and Quality Health Service. Partnering with Consumers Standard. Accessed at www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard.

NSW Government Department of Premier and Cabinet, 2019. Customer commitments. Accessed at www.dpc.nsw.gov.au/programs-and-services/nsw-customer-service-commissioner/customer-commitments (accessed 4 October 2019).

NSW Government Public Service Commission, 2019. People matter employee survey. Accessed at www.psc.nsw.gov.au/reports---data/people-matter-employee-survey/previous-surveys/people-matter-employee-survey-2019 (accessed 3 October 2019).

NSW Health, 2017. Shared decision making, trust and respect are core elements of a patient-centred culture that values and promotes a mutually beneficial partnership between staff, patients and carers and responds to patient needs and values. System Purchasing and Performance Safety and Quality Framework 1 July 2018 – 30 June 2019.

NSW Health, 2018. Leading better value care. Accessed at https://www.health.nsw.gov.au/Value/Pages/leading-better-value-care.aspx.

NSW Health, 2018. Strategic framework for integrating care. Accessed at www.health.nsw.gov.au/integratedcare/Publications/strategic-framework-for-integrating-care.pdf.

NSW Health, 2019. Leading better value care. Accessed at eih.health.nsw.gov.au/bvh (accessed 4 October 2019).

NSW Premier's Priorities. Accessed at www.nsw.gov.au/improving-nsw/premiers-priorities (accessed 25 October 2019).

Picker Institute Europe, 2008. Patient experience surveys: the rationale. Picker Institute Europe, Oxford. Accessed at www.picker.org/working-with-us/surveys.

Productivity Commission, 2017. Shifting the dial: 5 year productivity review.

Schoen C, et al., 2011. New 2011 survey of patients with complex care needs in eleven countries finds that care is often poorly coordinated. *Health Aff*; 30(12):2437–48.

Shaller D, 2007. Patient-centred care: what does it take? Report for the Picker Institute and the Commonwealth Fund. Commonwealth Fund. Accessed at www.commonwealthfund.org/publications/fund-reports/2007/oct/patient-centered-care-what-does-it-take.

Sizmur S and Redding D, 2009. Core domains for measuring inpatients experiences of care. Picker Institute Europe. Accessed at www.picker.org/wp-content/uploads/2014/10/Core-domains-for-measuring-inpatient-experience-of-care.pdf.

Sloan DA, 2014. Wayfinding in healthcare facilities: contributions from environmental psychology. *Behav Sci*; 4(4):423–36.

The Institute for Patient and Family Centered Care. Core concepts of patient and family centered care. Accessed at www.ipfcc.org/about/pfcc.html.

Van de Ven A, 2014. What matters most to patients? Participative provider care and staff courtesy. *Patient Exp*; 1(1):131–9.

van Walraven C, Oake N, Jennings A and Forster AJ, 2010. The association between continuity of care and outcomes: a systematic and critical review. *J Eval Clin Pract*, 16:947–56.

Wolf J, Niederhauser V, Marshburn D and LaVela S, 2014. Defining patient experience. *Patient Exp J*; 1(1):7–19.

' I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.'

Maya Angelou