



Health
Hunter New England
Local Health District

A Framework for Partnering with Consumers 2019



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Hunter New England Local Health District (HNE Health) respectfully acknowledges Aboriginal people as the traditional owners and custodians of the land in which our health facilities are located.

We pay respect to the Elders, community members and the community-controlled sector who partner with us to improve health outcomes for Aboriginal and Torres Strait Islander people in our District.



Foreword

Achieving Hunter New England Health's (HNE Health's) vision of healthy people now and in the future can only be accomplished in partnership with the people we serve - patients, clients, their families, carers and our wider communities.

There is good evidence that active partnerships between health professionals and consumers increases the quality and safety of care and offers the respect and dignity that all patients deserve.

Our healthcare consumers consistently advocate for 'nothing about us without us'.

Implementing the Excellence - Patient Care Essentials tools has helped HNE Health staff systematically involve patients more in their own care. But now we need to go further.

The Australian Commission on Safety and Quality in Health Care is challenging Australian health services to take a quality improvement approach to consumer partnerships.

As an organisation, we are asked to partner with consumers in our governance, monitor processes for partnering with consumers, and report on our partnerships.

At the level of a service, department or program of care, we are asked to involve consumers in designing (or redesigning) services and participating in planning, implementing and evaluating change.

At the level of the individual patient, the Commission is asking us to more effectively share decision making with patients, to be more deliberate about communicating the rights of patients, exploring options for care in partnership with patients and their families, and ensuring truly informed consent for the preferred course of treatment. All of us are expected to take into account the often misunderstood

concept of health literacy in our interactions with patients and families.

HNE Health has a proud history of involving consumers in healthcare in HNE Health. We partnered with the Ministry to conduct the first state-wide patient survey years ago and were one of the first public health services in NSW to pilot experience-based co-design. Services such as our mental health service are exemplars for meaningful partnership with consumers. Partnering with consumers transcends the tokenism of inviting a lone consumer onto a committee. Genuine partnership brings so much rich learning for everyone. So we urge you to take up the challenge to work creatively and respectfully with members of the community we serve.

Our services will continue to be challenged by growing community expectations, health needs, demographic shifts and finite resources. Involving patients, their families and carers and the community in individual patient care; in planning and delivering services, programs or facilities; in the decisions and deliberations of the organisation can help us meet the challenges.

This document outlines our commitment to partner with our patients, their families, carers and our communities. It provides a conceptual framework for how we meet the Commission's standards and move forward towards achieving excellence in consumer partnership.




Mr Michael DiRienzo,
Chief Executive




Associate Professor Lyn Fragar,
AO Board Chair



Introduction

Partnering with consumers involves working in collaboration with consumers, to improve patient experience and outcomes.

Partnering with consumers recognises the value of the consumer voice and the need for effective partnerships between:

- individual patients and their healthcare providers
- consumers, and a service department or program of care
- consumers and the HNE Health organisation.

This framework outlines:

- the reasons for and benefits of partnering with consumers
- our approach to partnering with consumers
- links to further information, practical guidance, resources, tools and examples of good practice
- information about the HNE Health clinical governance and quality improvement systems that support partnering with consumers
- an overview of policies, procedures, guidelines and plans at national and state level that align with this framework.

Whilst the framework is written predominantly for HNE Health employees, it will also help consumers understand what they can expect when they engage with HNE Health and support them to develop effective partnerships and a common understanding of their possible roles.



A note on terminology²

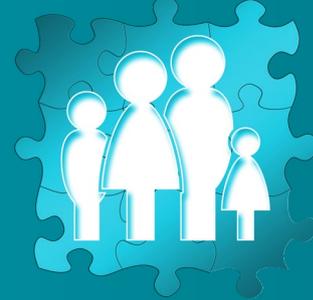
We use the term 'consumer' to refer to people, families, carers and communities who are current or potential users of HNE Health services. This includes: children, women and men; people living with a disability; people from diverse cultural, linguistic and religious backgrounds, socioeconomic status and social circumstances, sexual orientation, genders and gender identities, health and illness conditions.

The term also includes: people who choose to be involved in decision making; carers who often have an important role in healthcare decision making and care giving and health consumer representatives who provide advice on behalf of consumers with the aim of improving health care.

This is a living document and will be updated as we progress.

To ask questions or provide feedback, please email:

HNELHD-Participate@health.nsw.gov.au



Why partnering with consumers is important

There is a growing body of national and international evidence of the benefits of partnering with consumers in individual patient care and in the planning, design and ongoing development of health services.

Partnering with consumers is now embedded in a range of local, state, national and international frameworks, standards and policies.

Effective partnership embraces the approach of 'working with' people, rather than 'doing to' people. Effective partnership is genuine and meaningful.

Partnering with patients, their carers, families and consumers gives our communities a greater sense of empowerment, wellbeing and belonging. It also:

- Creates health systems that are responsive and accountable to the people they serve²
- Provides services that are more accessible and appropriate for users³
- Delivers effective services that are closely targeted to people's needs²
- Provides high quality patient and community information materials²
- Makes better use of scarce financial resources and reduces waste in our health services.

Evidence is continuing to build about the link between effective partnerships, consumer experience and high quality health care. Effective partnerships benefit patients, clinicians, services and organisations.

For patients, effective partnerships have been shown to be associated with:

- better health outcomes²
- improved functional status²
- provision of high quality patient information materials²
- improved health literacy resulting in a better understanding of health issues and services²
- effective services that are targeted to their needs²
- accessible and appropriate services³.

Clinicians and services also benefit from effective partnerships through:

- improved patient adherence to treatment regimes²
- improved patients outcomes²
- decreased rates of patient healthcare complications²
- decreased patient re-admission rates²

For health service organisations effective partnerships also result in:

- systems that are responsive and accountable to the people they serve²
- better use of scarce financial resources and reduced waste².

Health service organisations will be assessed against the National Safety and Quality in Health Service (NSQHS) Standards, second edition. National Standard 2 – Partnering with consumers⁴, describes the minimum requirements for partnering with consumers. This framework aims to assist services to meet their accreditation requirements and to move the organisation forward towards achieving excellence in consumer partnership.



Our approach to partnering with consumers

Partnerships with consumers come in many different forms in HNE Health. There is no single correct approach. However, our overall approach to partnering with consumers is underpinned by:

- HNE Health Principles for Partnering with consumers
- The Spectrum of Public Participation (IAP2)
- Health Literacy Universal Precautions

HNE Health Principles for Partnering with Consumers

HNE Health acknowledges that consumers have views that provide a unique perspective on health matters.

We embrace a respectful and responsive attitude that builds upon our CORE Values of Collaboration, Openness, Respect and Empowerment. The following principles have been developed in consultation with consumers.

Respect and Trust

- We show respect to consumers.
- We earn the respect of consumers.
- We build trust through partnerships.

Transparency

- We are accountable to our consumers.
- We partner with patients in their care.
- We have open and clear partnership processes.

Inclusiveness

- We value involvement of consumers.
- We work together to overcome barriers to being involved.
- We make sure there is equal access to opportunities for all consumers including:
 - Aboriginal and Torres Strait Islander people;
 - people from culturally and linguistically diverse backgrounds;
 - people living with disabilities;
 - people experiencing disadvantage.
- We recognise and respect the diverse backgrounds of people within our communities.

Responsiveness

- We listen to the valuable information provided through consumer partnerships.
- When necessary, we will explain why an issue may not be fixed in the way that consumers have suggested.
- We appreciate and acknowledge the time and feedback consumers give us.

Commitment to Improvement

- We are open to new ideas.
- We use evidence to improve our practices and contribute to new evidence for continuing improvements in the future.
- We collect and include feedback from consumers when designing our health services.
- We thank those who have contributed to the improvement.
- We share what has been learned throughout our organisation.

Communication

- We make sure that consumers have access to information.
- We seek feedback from consumers to make sure our communication is effective.
- We make sure that the information is relevant, timely, accurate and easy to understand.
- We make sure that consumers who partner with us are informed of outcomes.

Spectrum of public participation (IAP2)

The Spectrum of Public Participation (IAP2)⁵ is widely used by health and other organisations as a guiding framework for partnering with consumers.

The spectrum sets out a continuum of five levels of engagement - Inform, Consult, Involve, Collaborate, Empower.

When partnering with consumers on any given issue, project or initiative, those involved must first decide what level of engagement is appropriate.

There is no one right answer – this will vary depending on many different factors. Differing levels are legitimate depending on the goals, timeframes, resources and levels of concern/interest in the process, issue or decision to be made.

The spectrum sets out the promise being made at each level. Delivering on our promises is vital to achieving effective and genuine partnership.

Consideration of the IAP2 spectrum is particularly relevant to partnering with consumers at the level of a service, department or program and at the level of the health service.



Forster Health Committee members bundle copies of the group's health and support information booklets for distribution to local residents and visitors.

Increasing level of patient/community impact

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Public/ Patient Participation Goal	To provide the public with balanced, objective information to assist them in understanding the problems, alternatives and/or solutions.	To obtain public feedback on analysis, alternatives and/or decision.	To work directly with the public throughout the process to ensure that public issues and concerns are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and identification of the preferred solution.	To place final decision-making in the hands of the public.
Promise To The Public/ Patient/Carer	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and issues are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.
Possible Tools/ Methods	Fact sheets Brochures Hospital Tours Websites Media releases & pitches Social media Corporate Documents Health Committees	Public meetings and workshops Focus groups Surveys In-depth interviews Health Committees	Multi-stakeholder forums Advisory panels Workshops Consultative committees Health Committees	Consumer advisory groups Consensus-building processes Planning groups Co-design Health Committees	Integration of stakeholders into clinical governance Consumer juries REACH

Health Literacy Universal Precautions

Health literacy is an important consideration when partnering with consumers.

Health literacy is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it⁶.

Health literacy has two major components^{7,8}:

Individual health literacy. This is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action. Low health literacy can lead to poor health outcomes, reduced access to service and poor management of illnesses and chronic conditions.

The health literacy environment. This is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way that people access, understand, appraise and apply health-related information and services.

HNE Health's approach to health literacy aligns with the Clinical Excellence Commission's (NSW Health) [Health Literacy Framework](#)⁹.

HNE Health takes a universal precautions approach to health literacy⁶. This approach assumes that:

- It is not possible to know a person's level of health literacy by looking at them.
- Health literacy is a dynamic state and changes depending on the situation.
- All patients and consumers may have difficulty understanding health information and accessing health services.

It involves simplifying information and ensuring it is in plain English¹⁰, checking that information has been understood, making it easier for people to self-manage their health, access services and find their way around.

This approach plays an important role in facilitating communication and enabling effective partnerships with consumers. For partnerships to work, everyone involved needs to be able to give, receive, interpret and act on information⁷.

Partnering with consumers to deliver care and services that are safe, high quality and person-centred must include consideration of health literacy at an individual, service/facility and HNE Health (organisation) level.



A Mental Health manager and consumer review a consumer-developed wallet communication card tool.



The three key levels of partnership

To achieve the best possible outcomes for patients, families, carers and our communities, effective partnerships are needed at three key levels²:

1

Partnerships between individual patients and their healthcare provider(s)

The **aim** is to improve the patient's own care.

This could involve patients being involved in shared decision making processes, developing advance care plans and identifying people they want to be involved in their care.

See pages 12-14 for details

2

Partnerships between consumers and a service, department or program of care

The **aim** is to improve local programs or services for care.

This could involve consumers being engaged as members of quality improvement and redesign teams, including participating in planning, implementing and evaluating change.

See page 15 for details

3

Partnerships between consumers and the HNE Health organisation

The **aim** is to improve overall systems and processes for care.

This could involve consumers being engaged as members of key organisational and governance committees in areas such as patient safety, quality improvement, patient or family education, ethics and research.

See page 16 for details

HNE Health Partnering with Consumers Hub

The [Partnering with Consumers Hub](#) provides links to a range of resources including:

- relevant policies, procedures and guidelines
- tools and resources
- education

The Hub uses icons to denote the levels of partnership relevant to each section:

- I** Partnerships between individual patients and their healthcare provider/s
- S** Partnerships between consumers and a service, department or program of care.
- O** Partnerships between consumers and the HNE Health organisation
- G** Governance and quality improvement

1

Partnership at individual level

In HNE Health we strive to deliver Excellence to every patient, every time¹¹. Excellence means delivering the best possible care to each patient in a safe and compassionate environment.

Person-centred care

Person-centred care is the foundation of Excellence and a core component of value-based health care. It requires clinicians and our services to understand what matters to each patient. It involves treating the individual as a person and putting the person, their family and carers at the centre of care rather than 'fitting them into' services. Care is individualised, taking into account culture, language, mental state, patient preferences, physical health, age, cognitive capacity and disabilities^{12,13}.

Person-centered care enhances the experience of healthcare. It ensures people retain control, and supports partnership between individuals, families and their healthcare provider(s).

Patient Reported Measures (PRMs) will be used to better understand the patient's perspective about their experience of care and how illness or care impacts on their physical, mental, emotional health and wellbeing.

Patient Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs) are surveys that are conducted regularly to provide direct feedback from patients and carers to:

- Understand and enhance interactions between patients and clinicians
- Help patients and carers to decide their choice of treatment, provider or facility, and to improve their ability to manage the quality of care received as relevant to their health care needs
- Increase the level of engagement between clinicians and patients, helping to deliver personalised, appropriate and integrated care in a timely manner
- Support evidence-based care by using real-time patient-reported measures at the point of care
- Evaluate and research to understand patient needs, preferences and the impact of treatment and care
- Improve health literacy across the population.

Person-centred care involves many interwoven practices including but not limited to:

- Communication
- Sharing decisions and planning care
- Informed consent.



1

Communication

Actively communicating, engaging and seeking input from our patients, their carers and families about what matters to them is crucial, whether it is at the bedside, point of care and treatment, discharge planning, or in follow-up calls and actions.

Communication should be open and respectful.

Health literacy must be considered in communicating with patients, their carers and families. A universal precautions approach⁶ should be used. This means that all communication, written and spoken should be in plain English¹⁰ with a check to make sure the person has understood⁶. Staff are expected to:

- Confirm they understand the patient and the patient understands them by using a tool such as Teach-back¹⁴.
- Use interpreter services to assist communication and understanding with patients who are deaf or for whom English is a second language.
- Be aware of the cultural background of patients, families and carers that may influence communication and communicate in a culturally appropriate way.
- Ask patients with disabilities about any aids they normally use (eg: a communication board) and use them.
- Provide patient information resources (print, audiovisual, web) that are in plain English¹⁰, tested by consumers, available in priority community languages and in accessible formats.
- Inform patients, their carers and families of their [patient rights and responsibilities](#) at relevant points throughout their health care journey.
- Inform patients, carers and families of HNE Health's procedure for providing feedback, including [complaints](#).

The HNE Health '[Patient Care Essentials](#)'¹¹ suite of tools (part of the Excellence framework), supports person-centred care by facilitating communication and active and meaningful partnership with patients, families and carers. These tools include:

- Hourly patient rounding
- Patient care boards
- HAIDET (Hand Hygiene; Acknowledgment, Introduction, Duration, Explanation, Thank You)
- Bedside clinical handover
- Follow-up phone calls.



1

Sharing decisions and planning care

Patients, carers and families should be involved in discussions and decisions about care and treatment to the extent the patient wishes¹⁵.

Shared decision making is a consultation process where a clinician and patient jointly participate in making a health decision or by:

- Discussing the options and their benefits and harms
- Considering the patient's values, preferences and circumstances.

Decision aids are a key tool in supporting shared decision making¹⁶.

The extent of involvement in shared decision making will vary between individuals and between consultations, and according to the patient's preferences and the context in which the decision is occurring.

HNE Health has processes in place to identify patients who do not have capacity to make decisions about their health care as well as processes for identifying substitute decision makers.

Informed consent

Informed consent is a person's voluntary decision about their health care that is made with knowledge and understanding of the benefits and risks involved⁷. It is a minimum legal standard. HNE Health has informed consent processes that comply with legislation and best practice.



Links to policies, procedures and guidelines, resources, tools and education can be found in the [Partnering with Consumers Hub](#).

The relevant sections of the hub are labelled with 

Partnerships between patients and their healthcare provider/s links to the following elements of National Standard 2:

Criterion: Partnering with patients in their own care

Healthcare rights and informed consent:
Actions 2.3, 2.4 and 2.5

Sharing decisions and planning care:
Actions 2.6 and 2.7

Criterion: Health Literacy

Communication that supports effective partnerships: Actions 2.8 and 2.10

2

Partnership at service, department, program level

Partnerships between consumers and services, departments or programs of care focus on engaging with consumers to input into how programs, services or facilities are planned, designed, delivered, evaluated and improved⁷.

When partnering with consumers on any given issue, project or initiative, it is important to decide on the level and methods of engagement that are appropriate. The IAP2 Spectrum of Participation⁵ can be used as a framework to consider this.

A universal health literacy precautions approach⁶ must be adopted where all communication, written and spoken, is in plain English¹⁰. This will help facilitate effective partnerships where everyone involved is able to give, receive, interpret and act on information⁷.

Some examples of partnering at this level include consumer involvement in:

- Health Committees and other advisory committees
- Developing and reviewing patient information
- Measuring patients' experience of care
- Quality improvement projects
- Evaluating of existing services
- Planning and implementing changes to an existing facility, service or model of care
- Planning for new services or facilities
- Research
- Staff recruitment and orientation
- Staff training.

In addition, information and data that is routinely collected from patients can be collated and used at this level. This may include, but is not limited to, Patient Reported Measures, follow-up phone call data, information from rounding.

Patient reported measures of experience and outcomes can be used by services to:

- Understand factors that influence health outcomes
- Monitor effectiveness and impact of intervention and care over time
- Understand patient needs, preferences and adherence or impact of treatment and care
- Benchmark between services and interventions for continuous quality improvement in health care service delivery.

Links to policies, procedures and guidelines, resources, tools and education can be found in the [Partnering with Consumers Hub](#).

The relevant sections of the hub are labelled with 

Partnerships between consumers and a service, department or program of care links to following elements of National Standard 2:

Criterion: Clinical governance and quality improvement systems to support partnering with consumers

Integrating clinical governance: Action 2.1
Applying quality improvement systems: Action 2.2

Criterion: Health Literacy

Communication that supports effective partnerships: Actions 2.8 and 2.9

Criterion: Partnering with consumers in organisation design and governance

Partnerships in healthcare governance planning, design, measurement and evaluation: Actions 2.11, 2.12, 2.13 and 2.14

3

Partnership at organisational level

HNE Health, led by Hunter New England Local Health District Board, is supported by a range of formal and structured district committees that provide avenues for partnership, and enable consumer input into overall systems and processes for care. These include:

- Community and Patient Partnership Committee (a committee of the Board)
- Aboriginal Health Partnership Committee (a committee of the Board)
- District Partnering with Consumers Committee
- District Clinical Quality and Patient Care Committee
- District Human Research Ethics Committee
- Mental Health Consumer Advisory Committee
- The Children Young People and Families Family Advisory Council
- Clinical Network and Streams committees

The appropriate level and methods of engagement will depend on the specific context. The IAP2 Spectrum of participation⁵ can be used as a framework to consider this.

A universal health literacy precautions approach⁶ must be adopted where all communication, written and spoken, is in plain English¹⁰. This will help facilitate effective partnerships where everyone involved is able to give, receive, interpret and act on information⁷.

At the HNE Health organisation level, patient reported measures of experience and outcome can be used to:

- Help decision makers within the broader system to establish and evaluate policies to benefit whole populations
- Ensure care is more appropriate and value-based
- Improve integration and continuity of care across the health system
- Improve health literacy across the population.

Links to policies, procedures and guidelines, resources, tools and education can be found in the [Partnering with Consumers Hub](#).

The relevant sections of the hub are labelled with 

Partnerships between consumers and the HNE health organisation links to following elements of National Standard 2:

Criterion: Clinical governance and quality improvement systems to support partnering with consumers

Integrating clinical governance: Action 2.1
Applying quality improvement systems: Action 2.2

Criterion: Health Literacy

Communication that supports effective partnerships: Actions 2.8 and 2.9

Criterion: Partnering with consumers in organisation design and governance

Partnerships in healthcare governance planning, design, measurement and evaluation: Actions 2.11, 2.12, 2.13 and 2.14



Dungog Health Committee



Governance and quality improvement

Roles and responsibilities

Partnering with consumers is a key component of clinical governance in HNE Health. Patients and consumers, clinicians, managers and the HNE Health Executive Leadership Team and Board all have important responsibilities in relation to the way in which patients and consumers are involved in partnerships in their own care and in organisational design and governance. These are outlined below:¹⁷

Role	Responsibilities
Patients and consumers	<ul style="list-style-type: none"> • Are involved in planning and sharing decisions about individual health care • Ask for more information, information in different formats or an interpreter, if required • Let the workforce know who should be involved in sharing decisions about their care • Provide feedback about care experiences • Consider being involved in the governance of HNE Health, when opportunities exist • Consider being involved in the development and review of health information for consumers, when opportunities exist
Clinicians	<ul style="list-style-type: none"> • Understand the evidence on consumer engagement, and its contribution to the safety and quality of health care • Understand how health literacy might affect the way a consumer gains access to, understands and uses health information • Support patients to have access to, and use, high-quality, easy-to-understand information about health care • Support patients to share decision-making about their own health care, to the extent that they choose • Work with consumer groups to ensure that systems of care are designed to encourage consumer engagement in decision-making • Assist consumers to access to their own health information, and complaints and feedback systems • Implement and fully take part in the HNE Health's open disclosure policy compliance procedure
Managers	<ul style="list-style-type: none"> • Understand the barriers for patients and consumers to understand and use health services, and develop strategies to improve the health literacy environment of the health service organisation • Ensure that patients and consumers have access to high-quality, easy-to-understand information about health care • Set up organisational systems to enable consumers to fully engage in <ul style="list-style-type: none"> ▶ planning and sharing decisions about their own health care ▶ planning, designing, reviewing and evaluating clinical systems, and safety and quality of care • Collect and review patient experience information as part of quality improvement processes • Create opportunities for consumer involvement in relevant operational committees • When appropriate, set up specific consumer advisory committees

Role	Responsibilities
Executive Leadership Team and the Board	<ul style="list-style-type: none"> • Show leadership and commitment to partnerships with consumers • Set up high-level policies and procedures that support partnerships with consumers • Ensure that HNE Health has effective systems for consumer complaints and open disclosure, and monitor performance of these systems • Ensure consumer input to decisions • Create opportunities for consumer involvement in district level committees • Ensure that organisational systems support consumer engagement in decision-making

Committee Structure

HNE Health's established committee structure supports governance and quality improvement in partnering with consumers. The committee structure that provides governance of partnering with consumers includes:

Community and Patient Partnerships Committee

This committee provides strategic advice to the Board, Chief Executive and Executive Leadership Team (ELT) to ensure systems are designed and used to support patients, carers, families and consumers to be partners in healthcare planning, design, delivery and measurement. The committee has consumer members.

The Committee's responsibilities include:

- Establish high-level policies and procedures that support partnerships with consumers
- Monitor progress and quality improvement of strategies and actions that support the District in partnering with consumers.

The Committee reports at least quarterly to the Hunter New England District Health Board and the Chief Executive on its operation and activities during the reporting period.

District Clinical Quality & Patient Care Committee

The Clinical Quality and Patient Care Committee has predominately clinical membership and is an advisory committee with an operational focus, including such roles as coordination, monitoring and evaluation of the Hunter New England Health Patient Safety and Clinical Quality initiatives in accordance with the HNE LHD 'Framework for Quality and Patient Safety' and in alignment with the following documents:

1. NSW Ministry of Health Performance Agreement
2. HNE LHD Operational Plan
3. Australian Safety and Quality Framework for Health Care
4. National Safety and Quality Health Service Standards
5. NSW Patient Safety and Clinical Quality Program

The Clinical Quality and Patient Care Committee has the delegated authority to:

- Provide clinical and managerial advice, review and feedback about HNE LHD clinical quality and patient care functions
- Provide overarching systems approach to minimising clinical risk and improving safety of care which includes the identification, monitoring and responding to incidents and adverse events
- Provide oversight of initiatives to continuously improve the quality of health care services, and

- Safeguard high standards of care by promoting an environment of excellence in patient care and service delivery
- The committee has consumer members.

District Partnering with Consumers Operational Committee

The Committee reports to the Community and Patient Partnerships Committee of the Board, and to the District Clinical Quality and Patient Care Committee in line with the Clinical Governance Framework. The committee has consumer members.

This committee supports HNE Health to partner with consumers in line with the National Safety and Quality Health Service Standards (Second Edition). The committee's scope of activities includes integrating clinical governance systems and applying quality improvement systems to support partnering with consumers.

The relationship between committees can be seen below in Figure 1.

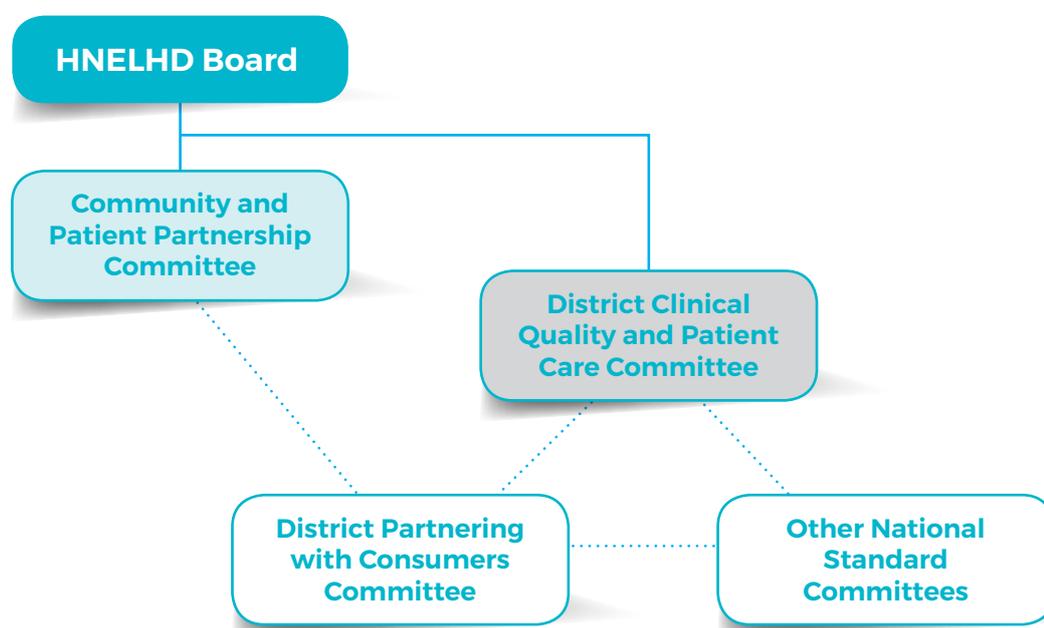


Figure 1 – Committee structure for governance of partnering with consumers.

Policies, procedures and guidelines

The HNE Health policy, procedure and guideline framework is used for the development, implementation and monitoring of policies, procedures and guidelines related to partnering with consumers.

A suite of policies, procedures and guidelines for partnering with consumers is currently in place or under development. These include:

- Partnering with Consumers Framework
- Guideline for partnering and working with consumers
- Health Literacy Framework
- Development, Approval and Publishing of Consumer Information Resources
- Healthcare rights
- Consent for clinical treatment and care
- Shared decision making and planning care
- Patient Reported Measures

Risk management

The HNE Health Risk Management Framework is used to manage risks associated with partnering with consumers. The framework provides clear guidance and instructions on how to manage risk; outlining how risks are identified, assessed, treated and reported through governance and operational committees. This framework is applied to any risk, regardless of severity.

HNE Health utilises the Planning & Accountability Framework supported by the Excellence tool as the primary mechanism to manage and monitor risk. Risks are identified, monitored and managed through the Excellence processes, including:

- Monthly Accountability Meeting (MAM)
- Key Performance Indicators reported on SMaRTA Viewer
- 90 Day Action Plan (90DAP)
- Traffic Light Reports
- Patient and Staff Rounding

Training for partnering with consumers

Development and implementation of training for partnering with consumers is guided by the HNE Health Education Framework. This framework provides structured district level governance of education.

The framework encourages and supports educators to develop education in collaboration with relevant stakeholders and other educators, share resources, reduce duplication and waste and improve the quality of education. The framework has 5 key elements:

- Learning aligned to strategic priorities and operational initiatives
- Needs analysis informs resource deployment
- Education design is fit for purpose
- Assessment of participant
- Evaluation of program.



A consumer sharing ideas during a REACH patient and family activated escalation workshop.

Links to policies, procedures and guidelines, resources, tools and education can be found in the [Partnering with Consumers Hub](#).

The relevant sections of the hub are labelled with 

Governance and Quality Improvement

Criterion: Clinical governance and quality improvement systems to support partnering with consumers

Integrating clinical governance:
Actions 2.1 and 2.2



Glossary

Capacity: A person's ability to make a decision. The ability to use information about an illness and proposed treatment options to make a choice that is in line with one's own values and preferences¹⁸.

Carers: People who provide unpaid care and support to family members or friends who have a disability, mental illness, chronic condition, terminal illness or general frailty. Carers include parents and guardians caring for children. In some services the term 'care giver' is used¹⁹.

Community: community refers to groups of people with diverse characteristics who are connected through common location, attitudes, cultures or interests. Individuals can be considered to be members of multiple communities at once. In the health context, it can be used to describe the population of the area serviced by an organisation, a cultural group or a group of people who all experience a particular health condition²⁰.

Decision aids: these are specifically designed to help clinicians and patients draw on available evidence together when making clinical decisions. The aim is to help patients weigh up the risks and benefits for them. They contain clear, easy to understand language that explains each option and the benefits and risks of each option. They may also include questions that help patients clarify what is most important to them¹¹.

Empower: placing final decision-making in the hands of the community/patients.

Health literacy: is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it.⁷

Health literacy universal precautions: The steps that are taken when it is assumed that all patients may have difficulty understanding health information and accessing services, this includes simplifying information, making it easier for people to find their way around and supporting people to self-manage their health⁶.

Informed consent: is a person's voluntary decision about their health care that is made with knowledge and understanding of the benefits and risks involved. Under Australian legislation, all adults are presumed to have the capacity to decide whether they wish to receive health care, except when it can be shown that they lack the capacity to do so. A person has the capacity to make a decision about their care if they can⁷:

- Understand and retain the information needed to make a decision
- Use the information to make a judgement about the decision
- Communicate the decision in some way, including by speech, gestures or other means.

Participation or public participation: any process that involves the public (those stakeholders who are not typically part of the decision-making entity or entities) in problem-solving or decision-making and that uses public input to make better decisions⁵.

Patient: a person receiving health care. It is acknowledged that in some settings, client, is the preferred term. In this document, patient encompassed all persons receiving health care.

Patient Reported Measures (PRMs): are any report that comes directly from a patient about their health or experience of care without interpretation by anyone else. PRMs should be repeated by patients at regular intervals over a whole journey in order to highlight changes in health and experiences.

Patient Reported Experience Measures (PREMs): provide direct feedback from patients and carers about the experience of receiving care. Surveys are completed anonymously with questions such as “Were you or your carer involved as much as you wanted to be in decisions about your care and treatment?”

Patient Reported Outcome Measures (PROMs): capture the patient’s perspective about how illness or care impacts on their physical, mental, emotional health and wellbeing. PROMs can be general quality of life surveys asking questions like: “In general, how would you rate your physical health?”, or they can be surveys about a specific condition such as: “How would you describe the pain you usually have in your hip?”

Person-centred care: health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. It is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families ^{12,13}.

For some health settings, the term patient-centred may be used instead of person-centred care.

The widely accepted dimensions of patient – or person-centred care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care ^{12,13}.

Stakeholders: any individual, group of individuals, organisation or political entity with an interest or stake in the outcome of a decision or action⁵.

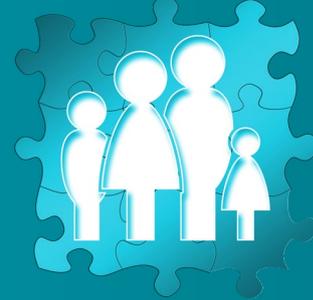
Shared decision making: a consultation process where a clinician and patient jointly participate in making a health decision by discussing the options and their benefits and harms as well as considering the patient’s values, preferences and circumstances¹⁵.

Substitute decision maker: a person appointed to make decisions about a patient’s care if the patient does not have capacity to make their own health care decisions.

Teach-back: a simple but effective communication tool used to check understanding¹⁴.



Shamirah with her carer awaits surgery at John Hunter Children’s Hospital.



Appendix A

About HNE Health Communities

There are a large number of communities within HNE Health's geographic boundaries. These communities incorporate a rich and growing diversity.

HNE Health covers a large geographic area (more than 130,000 square kilometres or 16 per cent of the area of NSW) spanning almost 700 kilometres from north to south, and about 500 kilometres from east to west. It incorporates the major metropolitan centre of Newcastle and Lake Macquarie, several large regional centres such as Maitland, Taree, Tamworth and Armidale, and many smaller rural centres and remote communities.

Demand for health services is growing, including an increasing demand for chronic disease services among our ageing population. Community expectations of health services are also growing.

We provide health services to approximately 920,370 people. Hunter New England is home to approximately 52,990 Aboriginal people, which equates to 5.5% of the total Hunter New England population, 20% of the NSW Aboriginal population and 6.6% of Australia's total Aboriginal population. Providing culturally appropriate care and closing the unacceptable gap in life expectancy and health disparity between Aboriginal and non-Aboriginal Australians remains an important strategic and operational focus for HNE Health.

About 28% of the population is born overseas, with 47% of our population having one or both parent born overseas. Across Hunter New England, 5% of our population speak a language other than English at home. Newcastle, has the largest concentration of residents from a non-English speaking background with 10% speaking a language other than English at home. The HNE Healthcare interpreter service provides up to 90 different languages to support patient and clinicians. The top five languages used are Mandarin, Arabic, Macedonian, Dari and Vietnamese. Added to skilled migration, HNE Health supports refugee settlements in Newcastle and Armidale, with the majority of arrivals coming from Democratic Republic of Congo, Syria, Iraq, Afghanistan and Tibet.

Many people in Hunter New England are living with long-term disability/disabilities. Given that approximately 18% of the Australian population has a disability, the number of people with a disability in HNE LHD is estimated to be approximately 162 000. HNE Health is committed to addressing the barriers experienced by people with a disability/disabilities and adopting a coordinated approach to improve access to and participation in health services.

There are areas of affluence in many of our communities where health levels are generally good and health literacy is relatively high. However, HNE Health also has significant areas of disadvantage. These include many Aboriginal communities, people on low incomes, and people living in rural or remote areas, all of whom suffer poorer health than the rest of the population and are likely to also have poorer health literacy. Many of these groups are difficult to reach or experience barriers to accessing health care that need to be considered if we are to achieve effective and meaningful partnership with our communities.

Important stakeholder groups may vary from place to place. Every community is different. Individual services and facilities should develop an understanding of the key groups in their respective communities and consider them in any community partnerships when planning for services, designing care and evaluating services or programs.



Appendix B

Relevant national and state plans policies, procedures, guidelines

National

[The Australian Commission on Safety and Quality in HealthCare Standards - Standard 2: Partnering with Consumers](#)

A nationally consistent standard to create health services that are responsive to patient, carer and consumer input and needs.

[The Australian Charter of Healthcare Rights](#)

Patient's rights are known and respected to ensure safe and high quality care.

NSW

[NSW State Health Plan: Towards 2021](#)

Direction Three: Delivering Truly Integrated Care - Empower patients to be partners in their care

[NSW Plan for Healthy Culturally and Linguistically Diverse Communities: 2019-2023](#)

Outcome 2: NSW Health supports people from culturally and linguistically diverse backgrounds to build their health literacy so they can be actively involved in decisions about their health.

[Clinical Excellence Commission - NSW Health Literacy Framework](#)

The CEC has developed a Health Literacy Framework as a guide to action. There are four priorities outlined in the framework. The priorities aim to create sustainable system level change, and improve safety and quality of care.

[Your Healthcare Rights and Responsibilities: A Guide for NSW Health Staff](#)

The rights and responsibilities of health services staff, patients and carers. In particular, the right to participation, to be included in decisions and choices about health care.



A consumer and staff at Cessnock sharing ideas about what patients need and want to know when they are going home from hospital.



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