SKIN HEALTH INSTITUTE

Consumer and Community Participation Framework

Consumer engagement is the process for incorporating consumer and community aspirations and needs into governance, decision making, service planning, delivering and evaluation of our health services systems and processes.

Contributions from consumers are unique and essential to ensuring quality, patient centred care and continuous growth and improvement. The Skin Health Institute staff are thankful and grateful for the time and dedication of our consumers.

Introduction

The Australian Commission on Safety and Quality in Health care has identified consumer centred care as a core dimension of the Australian Safety and Quality Framework for Health care. Partnership with consumers and the community has been identified as a core standard of the National Safety and Quality Health Service Standards.

Partnerships with consumers are critical to achieving safe and high-quality care. There is not one single way of partnering with consumers, there are many strategies. Partnerships are not what about what we do or how we do it but rather how we conduct our business daily.

What is partnering with consumers?

Partnering with consumers is a broad concept that covers a wide range of strategies, approaches and terms. Partnerships exist when consumers are treated with dignity and respect, when information is shared with them, and when participation and collaboration in healthcare processes are encouraged and supported to the extent that consumers choose.

The purpose of these partnerships is to improve the outcomes, experiences and the delivery of care by drawing on the knowledge, skills and experiences of people who are using, have used or may use our health facilities.

The Skin Health Institute values consumer participation throughout the organisation. The Skin Health Institute as an organisation, sees consumer participation at all levels, including seeing the consumer as an active partner in care as key components of the quality improvement and risk management framework.

One of The Skin Health Institute core values is “People First” this provides a foundation for the context for consumer rights and participation and guides the principles and features of good practice, our patients are at the centre of everything we do.

The following document outlines The Skin Health Institute Consumer and Community framework, it defines who is our consumer, the benefits of consumer participation, and how consumers can be involved within the organisation at various levels. The purpose of this framework is to assist consumers, carers and The Skin Health Institute staff to work in a genuine collaboration in order to:

- Increase consumer and carer participation in the health care
- Facilitate joint decision making
- Improve the development, delivery and evaluation of the care that we provide
- Partner with consumers in their own care

What is a consumer?

We broadly use the term ‘consumer’ to refer to people, families, carers and communities who are current or potential users of our health care services. We work with and provide culturally aware and safe care to people who identify as Aboriginal and / or Torres Strait Islander and we are welcoming of difference and cater to diverse needs by working with and providing care to people who:

- are Culturally and Linguistically Diverse (CALD)
- live with a disability
- have different spiritual or religious beliefs
- are from different socio-economic backgrounds
- have different health needs
- have varying levels of education and literacy
- are of all ages
- identify as gender diverse
- identify as LGBTIQ+ (Lesbian, Gay, Bisexual, Transsexual, Intersex, Queer)

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

What are the benefits of Consumer Participation?

A 2015 literature review conducted by the Consumers Health Forum of Australia concluded that there is a substantial body of research supporting the involvement of consumers in health decision-making, and consumer engagement can add value to the healthcare system by improving quality of care, efficiency of resource use, and community support for programs or services.

Consumer partnerships add value to healthcare decision-making. Consumer involvement in the development, implementation and evaluation of health care contributes to:

- Appropriately targeted initiatives
- Efficient use of resources
- Improvement in the quality of care provided by our services.

There is growing acceptance that practices supporting partnerships at the level of the individual – from communication and structured listening, through to shared decision making, self-management support and care planning – can improve the safety and quality of health care, improve patient outcomes and experience, and improve the performance of our healthcare facilities.

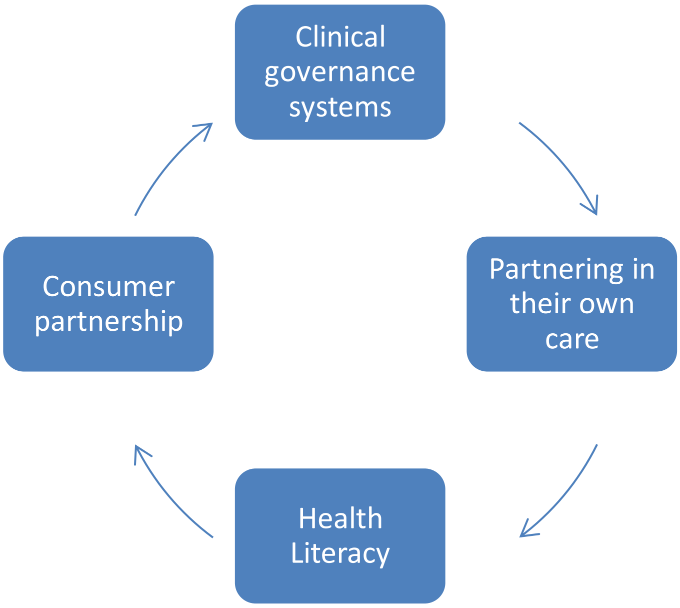
Partnering with Consumers Model

The Skin Health Institute partners with consumers in many ways, and at all levels of engagement throughout the organisation, from the Boardroom to the bedside. The intention of National Standard 2: Partnering with Consumers is to create an organisation where:

- consumers are partners in planning, design, delivery, measurement and evaluation of systems and services
- patients are partners in their own care to the extent that they choose

The four criteria detailed under National Standard 2 state that these intentions should be achieved through organisations having in place:

- Clinical governance and quality improvement systems to support partnering with consumers
- Partnering with patients in their own care
- Health literacy
- Partnering with consumers in organisational design and governance



Based on the direction above from the National Standards (second edition), The Skin Health Institute provides opportunities to partner with consumers in the following ways:

National Standard 2 criteria	Methodology and Approach
Clinical governance systems	• Robust systems are in place for effective consumers partnerships, such as: orientation and training for consumers; and a thorough recruitment and selection process which ensures our consumers are well prepared and supported to participate in Committee and other quality activities. • Policies and procedures are in place to support partnering with consumers • Partnering with consumers in planning, design, delivery, measurement and evaluation at the committee level is actively embraced from the Senior Management to operational staff level • We actively encourage consumers to provide feedback about their partnering experiences and improvements are made based on this. “You said, We did program” • Safety bulletins displayed in hospital
Partnering in their own care	• The Charter of Healthcare Rights is available to patients through brochures and displayed throughout the hospitals • All patients are required to give informed consent prior to procedures being performed. Compliance is closely monitored and feedback sought. • Patients are supported to participate in shared decision making at the point of care including during the development of their comprehensive care plan • When a medical treatment decision maker is appointed, this is documented in the patient’s history and alerts available within our hospitals systems. • Ensuring consumers understand the risks and benefits of procedures, medications and therapies to give informed consent

National Standard 2 criteria	Methodology and Approach
Health Literacy (communicating effectively)	• We have undertaken a health literacy gap analysis and developed a health Literacy Framework and education plan to ensure universal precautions are taken to ensure patients can understand risks and benefits and make inform decision making about their healthcare goals and involvement • We strive to communicate by openly and transparently sharing information between staff and consumers to empower patients and their carers to participate in shared decision making • We explain care and treatment in plain language and ensure that patients and their carers can ask questions to clarify their understanding • We provide information to patients and carers in a way they can understand: ○ through interpreters ○ using plain English ○ ensuring accessibility ○ Practice Call back processes • Patient information factsheets are regularly reviewed and developed with consumer input/ endorsement • Our systems invite consumers to provide feedback • We use consumer feedback to inform improvement activities • Staff have training in cultural awareness • Cue cards available online to assist consumers and staff
Consumer partnership	• Consumers partner at the committee level through their membership on our Quality, Risk and Clinical Leadership governance committee • Staff undertake training on patient centred care and understanding patient experiences (Corrective Action Reports (CARs) on Feedback, Audits and Incident Management. • Consumer feedback for new designs or redesign • Welcoming environment for all inclusive of Aboriginal and Torres Strait Islanders and diverse communities

Levels of Consumer Engagement

Partnering with consumers is relevant in many different ways across the health system. Different types of partnerships are not mutually exclusive. Partnering with consumers at all levels of the health service organisation is necessary to ensure that our service is responsive to consumer input and needs.

The Skin Health Institute has identified three levels at which partnerships can be implemented:

- The individual level: is where there are interactions between patients and healthcare providers. At this level a partnership involves the provision of care that is respectful, sharing and information provided is useful and continuous. It involves working with patients, family and carers to make decisions and plan care. Consumers participate in their own healthcare, treatment, as do their family and carers. Our health facilities enable and support consumers to be equal partners in their care, including through shared decision-making.

- The Service level: is where consumer and carer participation is focused on contributing to service delivery such as guidelines and procedures and quality improvements. At this level a partnership would involve the participation of consumers in the overall design of the service, or program changes. Consumers provide feedback, ideas and personal experiences to drive change.

- The organisation level: is where participation is focused on broader strategic and operational development activity. At this level, partnerships relate to the involvement of consumers as members of organisational governance committees for subjects such as patient safety, facility design and quality projects (design and redesign).

Facilitating quality consumer participation is a continual process that requires commitment and understanding from all parties - from consumers and carers, health professionals, other support staff and senior leaders. The level of commitment and understanding that all parties bring will determine whether the participation process is meaningful and delivers the desired health outcomes. Consumer participation must be supported at all levels in the workplace culture, policies, scheduling and allocation of resources.

Types of consumer roles

The role of a consumer is to provide an individual perspective primarily based on their own knowledge, areas of interest, experience and skills as an individual consumer of health services; or as someone supporting a consumer of health services.

Individual consumers are motivated to become involved in partnerships for a variety of reasons, including positive and negative experiences within the system. A consumer representative provides a consumer perspective, but their input is often informed by feedback and the views of other consumers as well as their own experience and opinions. The role of the consumer representative involves liaison between the committee or other governance mechanisms that they may be interested in consumers.

At The Skin Health Institute we have four types of consumer engagement:

This diagram represents the four types of consumer engagement at The Skin Health Institute.

Patients/Families/Carers/e-participation:

Patients and families are encouraged and supported to make informed decisions about their care, treatment and discharge planning. Patients are seen as active participants in their care and not passive recipients. They can participate in their everyday care planning and delivery, decision making about advanced care directives (limitation of treatment programs), nutrition, personal care needs and ongoing care issues and management. A major part of Consumer participation may include decisions support tool or aids to set meaningful health orientated goals i.e. Goals of care for the patient's specific wants and goals of treatment for medical outcomes. Consumers are encouraged to ask questions and to provide feedback on their experience of health care. This information is used to evaluate the service and care provided and make appropriate changes. Patient feedback may be used to inform changes across the hospital such as but not limited to changes in policy and procedure, patient information, hospital design, work flows, models of care and personnel. Patient feedback via CARs and surveys enabling the health care facility to connect with a wider range of consumers. Consumer participation in handover and escalation of care is another way of ensuring patient, family and carer/ consumer participation.

Governance

Consumers are supported and encouraged to be involved in the governance of The Skin Health Institute throughout the committee structure. The Skin Health Institute has a commitment to partner with consumers for planning, policy development, training and care delivery. By encouraging consumer through clinical governance processes, it ensures an effective partnership between consumers and the healthcare facilities at all levels. The Skin Health Institute aims for improvements to be made, to build safe, effective, patient centred, timely, efficient and equitable healthcare. This can only be achieved through effective partnerships with consumers at a governance level. The Skin Health Institute staff believe the role of the consumer in governance is evident through participation in the Quality, Risk and Clinical Leadership Governance Committee which oversees quality and safety improvements and partnering in governance, planning and policy. Consumers may participate by e-participation i.e. via teams, zoom, face time or email. Consumers also have the role of being an active advocate for patient safety. Consumers are supported by a buddy system with the Director of Nursing giving briefings and debriefs post meetings to ensure consumer understand fully discussion points, terminology and objectives for improvement and so they feel confident and one of the team to speak up during the governance meeting.

Strategic Planning

It is The Skin Health Institute's goal to have consumer involvement in service planning and delivery as well as strategic planning. Consumer engagement is supported across all levels at The Skin Health Institute. Strategic planning involvement occurs through the Consumer Participation Discussion Group. The hospital involves consumers in decision making, consumer feedback is used to plan, design and evaluate services. The Skin Health Institute's strategic and quality plans have a strong, patient centred care focus.

Consumer Participation Discussion Group

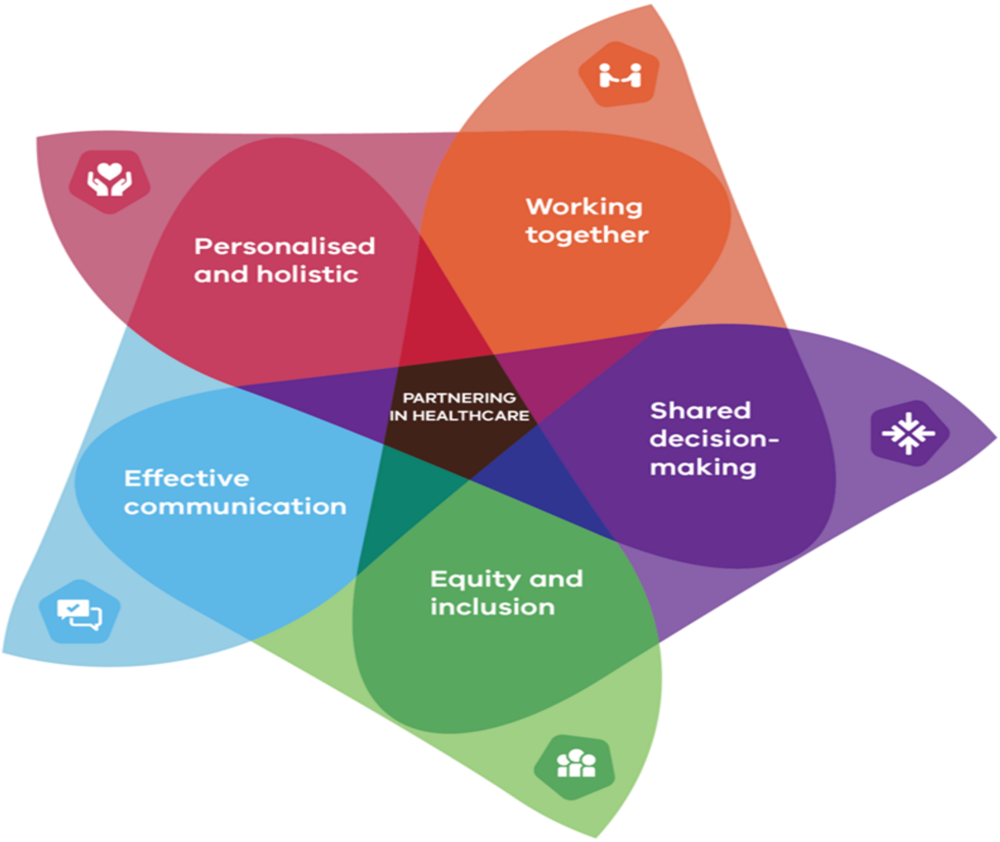
The Skin Health Institute has a formal Consumer Participation Discussion Group that reports to the Medical Advisory Committee.

Representative consumers should be able to reflect the perspectives of the communities they belong to and may also be able to present perspectives form independent community groups.

The role of any member is to provide direction and leadership in relation to the integration of consumer, carer and community views across all levels of the service. They also have a role to play in safety and quality; by participating in review of safety and quality data provided and providing comment to influence change in practice and/ or policy.

Partnering in healthcare (Safer Care Victoria)

Figure 1: Five domains of Partnering in healthcare



1. Personalised and holistic

This domain includes what people can do for their own health and wellbeing, as well as what is done with and for people in a healthcare setting. This domain pivots on considering the whole person (or family). This means understanding their physical, cultural and social context, to identify what makes a difference to a person's health, wellbeing and safety. It also recognises that people have rights to be at the 'centre' of care being provided to them by healthcare professionals.

The Skin Health Institute has identified the following actions to ensure best practice is achieved in relation to this domain:

- Treating consumers as a whole person and provide more individualized care
- Provide training to staff on person-centred care and cultural diversity
- Spend time with consumers to understand their needs
- Include family and carers in care planning
- Ensure ease of access to services and preparation required for procedures
- Build a support network of consumers
- Provide access for consumers and healthcare workers regarding legislative compliance adhering to the Australian Charter of Healthcare Rights.

2. Working together

Personalised and holistic care is possible when people work together in strong teams, partnerships and share knowledge. Knowledge transfer is a two-way street. Teams of health professionals should be connected and well informed about diagnostic techniques, the causes of disease, prognosis and health strategies. The consumer knows about his or her experience of the illness, social circumstances, values and culture. Without exchanging this information, the knowledge of each party may be limited, and the resulting care may be compromised.

The Skin Health Institute has identified the following actions to ensure best practice is achieved in relation to this domain:

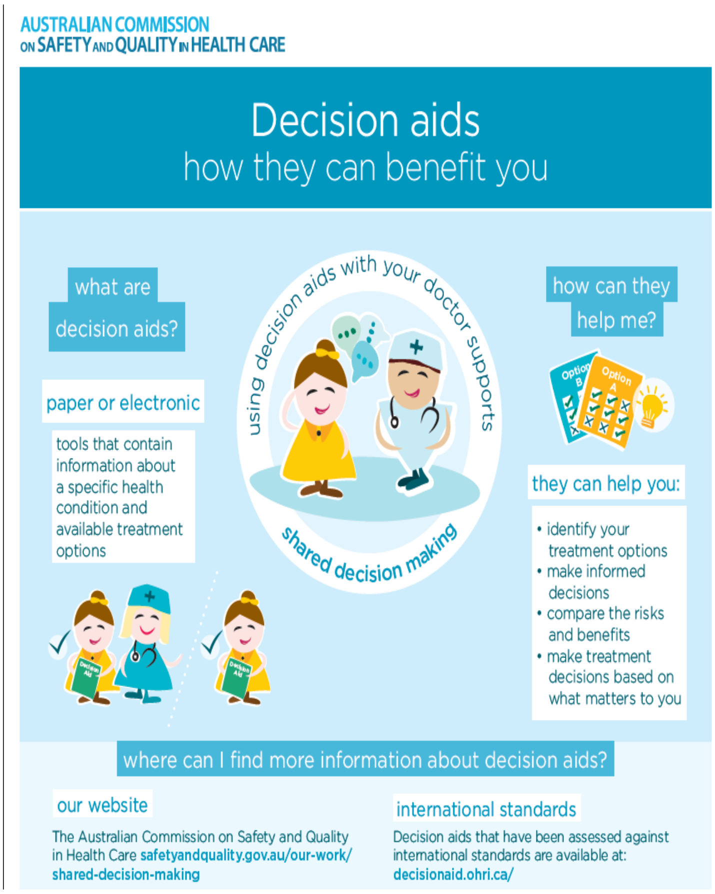
- Promotes clinical and multi-disciplinary teamwork
- Comprehensive discharge communication and processes for consumers
- Support clinician, consumer and family interactions as required
- Use feedback from consumers for quality improvement and effective risk management
- Measure and report on quality, safety, consumer experience and outcomes data
- Include consumers in staff training
- Training for consumers involved in governance
- Share patient stories and incidents as learnings

3. Shared decision-making

Shared decision-making includes the process by which health decisions are made by consumers and health professionals, using the best available evidence and discussion of consumers' preferences (Stacey et al., 2016). Key tools to support shared decision-making include decision aids and decision coaching.

The Skin Health Institute has identified the following actions to ensure best practice is achieved in relation to this domain:

- Record, communicate and implement consumer's preferences through comprehensive care planning.
- Involve consumers at the service design, policy and governance levels
- Development of a Shared decision-making policy
- Decision making aids are
  a) Tools to provide high quality information about particular conditions
  b) Explain the risks and benefits of treatment options
  c) Clarify what matters most- make a shared decision about what is the best option



AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

Decision aids
how they can benefit you

what are decision aids?

paper or electronic

tools that contain information about a specific health condition and available treatment options

how can they help me?

they can help you:

- identify your treatment options
- make informed decisions
- compare the risks and benefits
- make treatment decisions based on what matters to you

where can I find more information about decision aids?

our website

The Australian Commission on Safety and Quality in Health Care **safetyandquality.gov.au/our-work/shared-decision-making**

international standards

Decision aids that have been assessed against international standards are available at: **decisionaid.ohri.ca/**

4. Equity and inclusion

Responding to diverse needs is complex. People want to be engaged and empowered in their healthcare experience and journey. Some groups and communities are often under-represented in healthcare participation opportunities and structures and over-represented in clinical risk. Informed by a definition of equity provided by the World Health Organization, equity is the absence of avoidable or remediable differences among groups of people, whether they are defined socially, culturally, linguistically, economically, demographically or geographically (HPH Task Force, 2014). Equity in healthcare means that all people receive care of equal quality that is safe, effective and person-centred. An equitable approach does not mean that everyone receives the same care, but that all people have their healthcare needs equally well met, including through removing differences in the quality, safety and accessibility of opportunities, services and rights between groups of people.

The Skin Health Institute has identified the following actions to ensure best practice is achieved in relation to this domain:

- It has a culturally diverse consumers representative on the Quality, Risk and Clinical Leadership committee
- Ensure access to accredited interpreters is provided when needed
- Provide cultural safety and cultural responsive training for staff
- Ensure information can be provided in various languages

5. Effective communication

Health communication refers to interactions that occur during the process of improving health and healthcare. Effective health communication is essential for public health strategy and practices. Poor quality communication, and the mistakes associated with it, are a major cause of error in diagnosis and treatment. Heath literacy is an enabler of communication and participation in healthcare. It is also the product of good communication between health professionals and consumers, and of health systems that are responsive to consumer needs (Phillips, 2016).

The Skin Health Institute has identified the following actions to ensure best practice is achieved in relation to this domain:

- Health literacy Framework developed to support staff and patients
- Facilitate open and timely communication with consumers
- Develop clear written communication (for example discharge information)
- Enable consumers to provide feedback
- Ensures Open Disclosure training is undertaken

Patient and family centred care

There are many definitions of patient or consumer-centred care, but at heart these all describe “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”.

Drawing on the work of the Picker Foundation it is generally accepted that the most important aspects of patient or consumer-centre care include:

- Respect for patients’ preferences and values;
- Emotional support;
- Physical comfort;
- Information, communication and education;
- Continuity and transition;
- Coordination of care;
- The involvement of family and friends; and
- Access to care.

For the International Association of Patients’ Organisations (IAPO), the essence of consumer or patient-centred healthcare is that the healthcare system should be designed and delivered to address the healthcare needs and preference of patients, so that healthcare delivers better health and wellbeing, and is cost-effective and appropriate.

IAPO identifies five principles that underpin patient-centred healthcare:

1. **Respect:** Patients and carers have a fundamental right to patient-centred healthcare that meets their unique needs, preferences and values, as well as their autonomy and independence.

2. **Choice and empowerment:** Patients have a right and responsibility to participate, to their level of ability and preference, as a partners in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organisations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

3. **Patient involvement in health policy:** Patients and patients' organisations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives.

Australian Charter of Health Care Rights

Respecting consumer and carers rights is fundamental to ensuring their participation in their health care. The Skin Health Institute is committed to upholding and implementing the *Australian Charter of Health Care Rights.* Everyone who is seeking or receiving care in the Australian health system has certain rights regarding the nature of that care. These are described in the Australian Charter of Healthcare Rights.

My healthcare rights

This is the second edition of the **Australian Charter of Healthcare Rights.**

These rights apply to all people in all places where health care is provided in Australia.

The Charter describes what you, or someone you care for, can expect when receiving health care.

I have a right to:

Access

- Healthcare services and treatment that meets my needs

Safety

- Receive safe and high quality health care that meets national standards
- Be cared for in an environment that makes me feel safe

Respect

- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

Partnership

- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to
- Include the people that I want in planning and decision-making

Information

- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Request access to my health information
- Be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe

Privacy

- Have my personal privacy respected
- Have information about me and my health kept secure and confidential

Give feedback

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services

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For more information, ask a member of staff or visit
safetyandquality.gov.au/your-rights

Table 4: The Australian Charter of Health Care Rights

The Skin Health Institute, our organisation, recognises that patients, consumers, healthcare providers and our health service organisations all have an important part to play in achieving these healthcare rights and contributing to a safe and high quality healthcare system.

Evaluation of the Effectiveness of Partnering with the Community and Consumers Framework

Hospital accreditation has been defined as a self-assessment and external peer assessment process used by health care organisations to accurately assess their level of performance in relation to established standards and to implement ways to continuously improve

The Skin Health Institute uses an external, independent company to access our quality and safety systems and standards. The Australian Commission on Safety and Quality Healthcare Standards has 8 National Safety and Quality Health Service (NSQHS) Standards to provide a nationally consistent statement of the level of care consumers can expect from any health service organisation in Australia. The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health care provision. They provide a quality assurance mechanism that tests whether relevant systems are in place to ensure expected standards of safety and quality are met. Governance and Partnering with Consumers are major components of the full 8 NSQHS Standards and vital to a successful hospital accreditation being awarded. For the purpose of this framework governance includes the following:

- Monitoring, leadership and culture
- Patient safety and quality systems
- Clinical performance and effectiveness
- Safe environment for the delivery of care

The 8 NSQHS Standards are as follows:

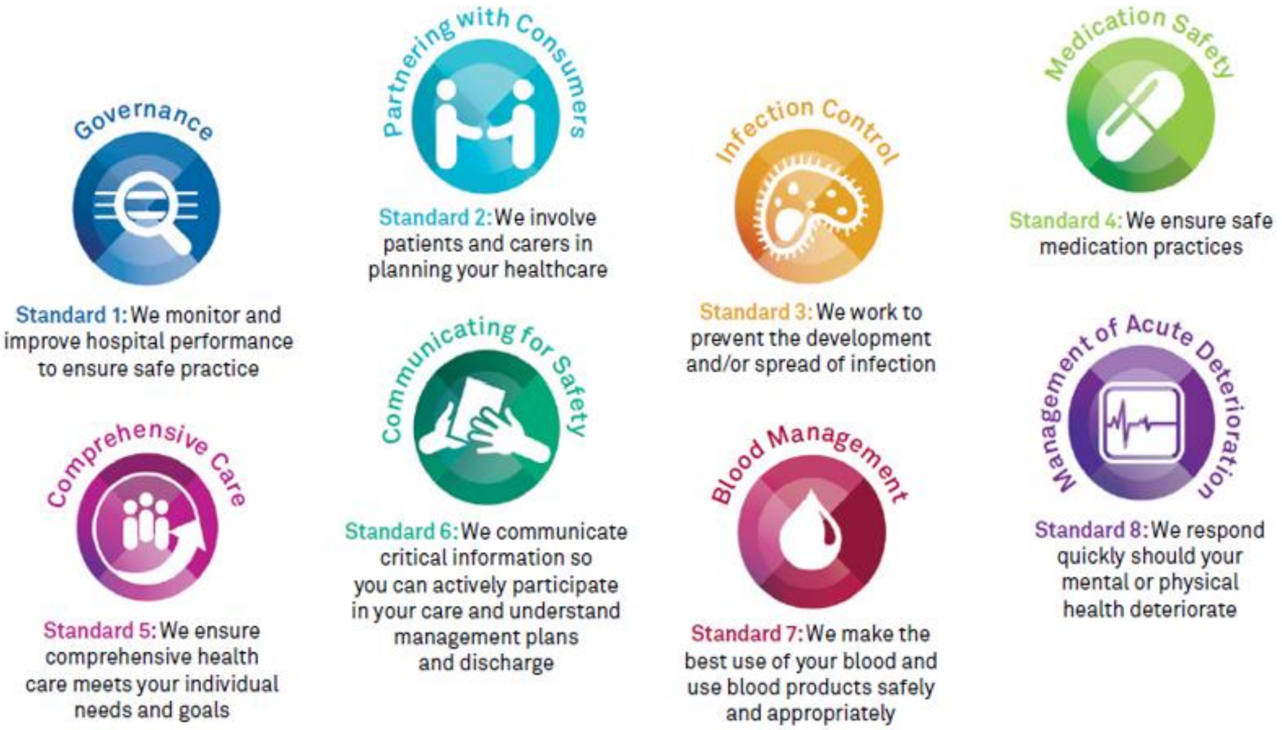
1. Governance
2. Partnering with Consumers
3. Infection Control
4. Medication safety
5. Comprehensive Care
6. Communicating for Safety
7. Blood management (N/A at the Skin Health Institute)
8. Management of acute deterioration (Mentally and physiologically)

The Skin Health Institute also has a number of other measures to monitor the success of Partnering with Consumers and the Community Framework including:

- An established Quality plan with action items to support partnering with Consumers
- A Partnering with Consumers and Community Action plan
- A Consumer contribution tracker detailing implemented and sustained actions that have occurred as a result of consumer suggestions and
- An audit schedule that monitors action items- surveys, consent satisfaction, wayfinding audits, consumer led cleaning audits etc.

National Standards – keeping you safe

At the Skin Health Institute we are accredited so that you can be confident that you are receiving quality care. Here's how:



Standard 1: We monitor and improve hospital performance to ensure safe practice

Standard 2: We involve patients and carers in planning your healthcare

Standard 3: We work to prevent the development and/or spread of infection

Standard 4: We ensure safe medication practices

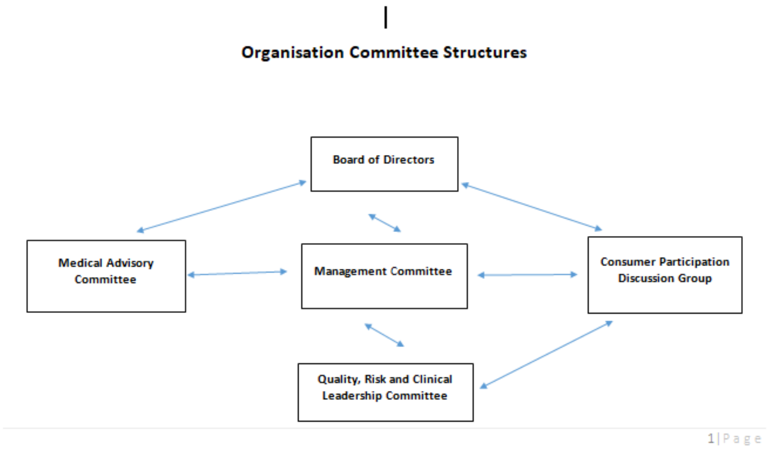
Standard 5: We ensure comprehensive health care meets your individual needs and goals

Standard 6: We communicate critical information so you can actively participate in your care and understand management plans and discharge

Standard 7: We make the best use of your blood and use blood products safely and appropriately

Standard 8: We respond quickly should your mental or physical health deteriorate

The Skin Health Institute Organisational Structure



Definitions

This Framework utilises the following definitions of key terms:

Consumers

Consumers are people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

Carers

A carer as an individual who provides, in a non-contractual and unpaid capacity, ongoing care or assistance to another person who, because of disability, frailty, chronic illness or pain, requires assistance with everyday tasks.

Consumer engagement

Consumer engagement is more than participation, conveying the idea that a person or group of people are occupied, focused, and committed to an issue and ready to take ownership of the outcomes. It is a dynamic process.

Consumer Participation

The term *participation* is broadly defined as the involvement of individuals and their significant others in decisions that affect their lives. Participation is about being part of the decision making process, with active involvement in developing additional options or actions, and not merely observing and commenting on these processes.

Governance

Encompasses the system by which an organisation is controlled and operates, and the mechanisms by which it and its people are held to account. Ethics, risk management, compliance and administration are all elements of governance

Patient and Family Centred Care

Patient and family centred care refers to a collaborative approach to care-giving and decision-making which is fundamental to facilitating quality consumer and carer participation and which is respectful of and responsive to individual patient preferences, needs and values.

Patient Journey/experience

Patient journey describes the touch points or areas of care encountered by a patient.
Patient experience is their interpretation of their journey

Note: This document is to be read in conjunction with the Skin Health Institute's Clinical Governance Framework

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