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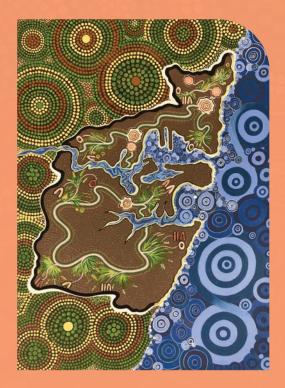
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# Acknowledgement of Country

South Eastern Sydney Local Health District would like to acknowledge the Traditional Custodians on whose land we stand, and the lands our facilities are located on; the lands of the Dharawal, Gadigal, Wangal, Gweagal and Bidjigal peoples.

We would like to pay our respects to the Elders past, present and those of the future.

Artwork by Brenden Broadbent
Originally commissioned by SESLHD District Mental Health

### **Foreword**

This Framework clearly articulates the absolute commitment of South Eastern Sydney Local Health District to engage with consumers at all levels and to work in partnership to achieve the highest levels of patient safety. It defines the roles, responsibilities and expectations for the health system, organisation and consumers as we move towards a future where consumer partnerships and participation are the norm.

From the Chief Executive all the way to the staff providing clinical care and support staff the focus is on the goal of great patient outcomes. And those outcomes can best be shaped through the input of the people using the services. Partnerships with consumers are vital in our health service today and in all future health systems.

As consumers, we have unique insights into how care is delivered – insights that can be used to guide and improve on healthcare delivery. It is only by listening to the voices of consumers that we can be sure that our health services are fit for the future. This Consumer Partnership Framework is the guide for the District to plan for a future built on consumer empowerment and engagement.

Malcolm Ricker and Harris Mihailidis SESLHD Consumers

# Message from our Chief Executive



What matters to people is central to how our health and care services are designed, delivered and improved. The South Eastern Sydney Local Health District (SESLHD) and its Board are committed to engaging with consumers and the community in decision making for planning, design, delivery, measurement and evaluation of health systems and services.

Increasing engagement through effective partnerships leads to improved health outcomes for individuals and more rewarding work environments for healthcare professionals. Engaging with our consumers adds additional expertise into the system that supports decision making and enables staff to be more confident that we are delivering services that are needed into the community. True human centered care can only be delivered if services have been developed in partnership with consumers.

Our SESLHD Strategy 2022-2025 and 2031 Statement of Intent outlines the organisation's ambition for the next ten years. Our strategy lays the foundation for our ambition to work with consumers to transform the way we deliver care. This Framework will drive a more consistent and coordinated partnering approach aligned with the national Safety and Quality Health Service (NSQHS) Standard 2 – Partnering with Consumers. Consumer partnership initiatives are already being undertaken in SESLHD by many services and departments. This Framework builds on these initial efforts and sets out a consistent approach to how we partner with our consumers supported by infrastructure and governance.

Broader links across our consumers provide the mechanism to enable change at the population health level and assist our district to design programs to take patient care beyond the boundaries of our facilities. We look to our consumers to partner with us, and to be the driving force to support our initiatives. I encourage all of our staff to build relationships and partner with consumers to design the best possible health service for the community we serve.

I would like to thank all the stakeholders who have contributed to this Framework and to acknowledge the important role our consumers, carers and community members have made. This Framework represents a step towards improving health care service quality, equity and access across our health district.

### **Tobi Wilson**

**Chief Executive** 

### Introduction

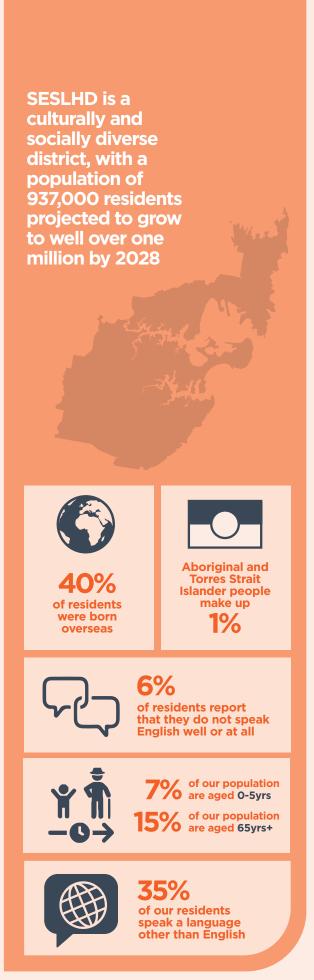
Partnership with consumers in the delivery of healthcare enables health services to use information gained at both the individual and collective level to inform service planning, design, delivery and evaluation. This results in better, more responsive services that address the needs of the local population.

Effective consumer engagement begins with health services working with consumers as equal partners in their own care, to deliver better health outcomes. SESLHD is committed to partnering with consumers and has well established networks of consumers that have helped us shape our services for many years, contributing to the better health and wellbeing of our community. As we have grown as an organisation, so too has our capacity to engage and partner with our consumers and community. We have adopted flexible methods of engagement, allowing our clinicians to directly partner with those receiving care, and gathering feedback from across a variety of platforms.

This Consumer Partnership Framework will ensure that we effectively and meaningfully partner with consumers, carers and the community to improve the quality of health care services and better meet patient needs and preferences. It will also outline the responsibilities of our services to strengthen and improve the practice of consumer, carer and community engagement. It details our core values and goals around the importance of partnering with consumers. The framework supports our requirements to meet national, state and legislative responsibilities and aligns with SESLHDs Journey to Excellence 2018-2021 and SESLHD 2031 Statement of Intent.

At the heart of everything we do is a set of values -

Collaboration, Openness, Respect, and Empowerment.





# **Principles of engagement**

Consumer engagement and partnership is underpinned by the NSW Health's CORE set of values; Collaboration, Openness, Respect and Empowerment. These support the philosophy, approach, processes, priorities and structure of participation and engagement in all aspects of our work. SESLHD's vision "Exceptional Care, Healthier Lives" supports the foundation for health services to partner with consumers, carers and community members.

Principles of engagement based on our CORE values are an important foundation for our District's engagement processes. These principles should be evident in daily work from our policies and processes to the activities we complete every day to show true partnership with our consumers. The table on the next page highlights our District's principles of engagement, how we can embed these into our practice to bring these to life and how they support the criteria under National Standard 2 – Partnering with Consumers. These principles have been adopted with permission from Health Consumers Queensland, Consumer and Community Engagement Framework, for health Organisations and Consumers (2017).

### **Collaboration**

Working relationships between engagement partners are built on transparent and accountable processes. The purpose of consumer and community partnership is to shape service delivery to better meet consumer and community needs. Engagement takes place at all levels of the service: planning, design, delivery, evaluation and monitoring

### National Standard 2 Criteria

- Clinical Governance
- Partnering with patient in their own care
- Partnering with consumers in organisational design and governance

### **Openness**

Engagement partners value each other's perspectives, knowledge and beliefs and develop relationships based on clear and open communication and shared goals. Partnerships focus on solutions and support the participation of consumers and community

### National Standard 2 Criteria

- Clinical Governance
- Partnering with consumers in organisational design and governance

### Respect

Engagement processes are accessible, flexible and designed to promote partnerships with populations that reflect the diversity of their communities and identified health needs. The health service engages through outreach and is respectful of existing community resources and expertise

### National Standard 2 Criteria

- Partnering with patients in their own care
- Health Literacy

### **Empowerment**

All engagement activities are evaluated by health staff and consumers and findings implemented for continuous improvement. Ongoing training and development opportunities are provided to support the capability building of all engagement partners

### National Standard 2 Criteria

- Clinical Governance
- Partnering with patients in their own care
- Health Literacy
- Partnering with consumers in organisational design and governance

### **Collaboration**

### PRINCIPLES IN PRACTICE

### How do we know we are working to our principles?

Guidelines, policies and procedures are in place to guide transparent, accountable and creative processes that support staff to create meaningful and equal partnerships within their health organisation and communities

Consumers and the community we serve are engaged at the planning phase of projects to maximise their opportunity to contribute to and shape the outcome

Consumers and staff are provided with clear information about the engagement activities they participate in, including the scope and responsibilities of their roles (e.g. in Terms of Reference) and the outcomes and progress of their partnerships

### **KEY ACTIONS**

#### What action do we need to take?

- Streamline and simplify onboarding process for formal committees
- Develop standardised terms of reference, position descriptions
- Review and update existing engagement documents to be more accessible, appropriate for a range of literacy levels, and consistent across facilities

Early engagement to involve consumers from project initiation, including membership of steering committees

Develop a consumer community network to facilitate connections and cross facility collaboration between consumers

### **Openness**

### PRINCIPLES IN PRACTICE

### How do we know we are working to our principles?

All SESLHD staff and consumers are provided with training on consumer and community engagement how to partner effectively, and effective communication and facilitation

SESLHD engagement partners have opportunities for professional development e.g. attending conferences, forums and external training

Evaluation of engagement activities is built into all project plans and undertaken to assess the quality of the partnerships and encourage continuous improvement. Both health staff and consumer feedback on activities is sought

### **KEY ACTIONS**

### What action do we need to take?

- Develop a toolkit of engagement resources to allow flexibility in consumer engagement processes
- Include feedback on successful engagement strategies

Opportunities for engagement partners to showcase work undertaken in SESLHD

Evaluation of projects is built into all project plans with measureable KPI's

### Respect

### **PRINCIPLES IN PRACTICE**

### How do we know we are working to our principles?

Remuneration and reimbursement processes are in place to ensure consumers are not out of pocket and are remunerated for their time

SESLHD culture supports a sound understanding of, and respect for consumer engagement and values the benefits of partnering with consumers to enhance shared decision making

### **KEY ACTIONS**

#### What action do we need to take?

Education sessions for the community are led by consumers

Review and revise paid participation procedure in line with the MoH policy

SESLHD has a consumer partnership profile that reflects the diversity of our District

### **Empowerment**

### **PRINCIPLES IN PRACTICE**

### How do we know we are working to our principles?

SESLHD partners with external agencies (e.g. multicultural, youth agencies) and where appropriate externa staff lead culturally appropriate processes and projects

Creative engagement methods are explored to ensure that activities are appropriate for all parts of the community e.g. people with low literacy children and young people

### **KEY ACTIONS**

### What action do we need to take?

Consumers feel culturally safe and their beliefs incorporated

SESLHD identify when it is appropriate to partner directly with consumers and when it is appropriate to engage intermediaries

Development of methods of engagement to reach all parts of the community including web-based platforms and social media

# A spectrum of participation

Promoting engagement opportunities and inviting the broadest range of consumers encourages meaningful collaboration.

Consumer engagement activities vary across a continuum according to the level of influence that consumers have over the process and outcome. The level of influence is usually defined by the health care organisation.

This Framework will assist services to determine and develop the level of participation which defines the involvement of consumers, carers and community members based on the International Association for Public Participation (IAP2 Spectrum of Public Participation). <sup>4,10</sup> The level of participation depends on the goals, time frames, resources and the level of decision to be made. The Spectrum most importantly sets out the promise being made by the health service to consumers, carers and community members at each participation level.

The following table brings the spectrum of engagement to life for our District. This Engagement Spectrum has been adopted for use in SESLHD from and with the permission of the International Association of Public Participation (IAP2) (2016).



INFORM	CONSULT	INVOLVE	COLLABORATE	CONSUMER LED
Information giving	Information seeking	Information sharing and joint planning	Participatory decision making	Stakeholder leadership
We will keep you informed	We will keep you informed, listen to you, acknowledge your views and provide feedback	We will work with you, consider your views and provide feedback on how your input influenced outcomes	We will look to you for advice and innovation in the formulation of solutions and incorporate your advice to maximum extent	
One way communication	One way communication	Two way communication	Two way communication	Two way communication
Common methods	Common methods	Common methods	Common methods	Common methods
Fact sheets Written information Patient information Web based information Social media Pop-up stalls Open days Web pages	Public meetings Online forums Focus groups Surveys Public comment – web based Workshops Suggestion box Information sessions	Focus groups Participatory workshops Reference groups Committees Working parties	Consumer advisory Committee  Consumer representation on governance committees  Key stakeholder and interagency	Consumer led models of care projects support by hospital staff Steering committees
Recruitment	Recruitment	Recruitment	Recruitment	Recruitment
Public consultation Print media Online media	General recruitment  Can be engaged at the service level	Targetted recruitment Orientation Commitment to Code of Conduct	Specific recruitment  Mandatory checks  Orientation  Mandatory training	Formal recruitment Mandatory checks Orientation Mandatory training
Level of influence	Level of influence	Level of influence	Level of influence	Level of influence
Low	Low	Moderate	High	Control
SESLHD Commitment	SESLHD Commitment	SESLHD Commitment	SESLHD Commitment	SESLHD Commitment
We will keep you informed and provide you with an opportunity to get in touch if you have any questions	We will listen to and acknowledge your input and provide feedback on how your input has informed the outcome	We will support consumers to ensure feedback informs the outcome and decision-making process	We will work with you to identify and include collaborative outcomes, and consider collaboration as part of the decision making process	We will empower consumers to develop and deliver solutions
Key Performance Indicators	Key Performance Indicators	Key Performance Indicators	Key Performance Indicators	Key Performance Indicators
Number of publications with consumer input  Web based information is evaluated by consumers  Shared decision making is evaluated through patient surveys	Consumer perspectives are included in a wide range of presentations and workshops  Publications and campaigns have been developed jointly with members where there is a common interest	Consumers are visible as part of major campaigns on health initiatives or issues relating to service needs  Consumer perspectives are included in a wide range of presentations and workshops	Consumers are visible as part of major campaigns on health initiatives or issues relating to health  Consumer satisfaction and perceptions of Consumer Advisory Committee (CAC) will be regularly measured	Demonstrated consumer led projects  Consumers as key members and project partners with key alliances, and act as spokespersons for the alliances where
	Consumer voice is recognised in decision-making	Staff accept and consider consumer input as business as usual, and useful for identifying how to improve the patient experience Initiatives relating to consumer perspective including "you said we did"	Evaluations and reviews of performance are predominately positive and constructive or negative feedback is acted upon and actions reported back  Staff accept and consider consumer input as business as usual, and useful for identifying how to improve the patient	appropriate  Staff accept and consumer-led projects as business as usual, and participate on projects to improve the patient experience  Consumers deliver education sessions in partnership with SESLHD staff
		Page 11	experience  There are consumer representatives on governance and/or high-level committees	

# The Four Levels of Engagement

Operationalising and implementing this Framework requires a commitment from all levels of the organisation. It requires strategic leadership, designated responsibilities, monitoring, reporting and evaluation mechanisms, and alignment of business processes. Capability and capacity development across all levels of the organisation, together with appropriate tools and resources will support our staff to develop the confidence and skills to meet and partner with consumers in a more meaningful way. This Framework sets out the responsibilities for SESLHD to strengthen, improve and promote partnerships with health consumers through the different levels of engagement.

### The four levels of engagement are:



Provides a nationally consistent statement about the level of care consumers can expect from health service organisations. Standard 1 Clinical Governance and Standard 2 Partnering with Consumers underpin all of the other standards. The Partnering with Consumers standard aims to support health service organisations to involve consumers as partners in planning, design, delivery, measurement and evaluation of systems and services, in addition to partnering with patients in their own care, to the extent that they choose.



Consumers can partner in governance, planning, policy and system level strategy and feedback. This partnership may include community organisations and members of the local community. At the health service level, partnerships may be demonstrated through the participation of consumers on governance committees, for example patient safety, redesign, redevelopment and facility design or quality improvement. Members of local community groups and organisations may also be engaged in partnership more broadly about future community health needs.



Partnerships develop to support the organisation and delivery of care in a specific area. Overall service or program design can be enhanced through the participation and partnership of patients, families and carers. Valuable feedback about experiences of care can be gained from those who have a lived experience of the service. This involves patient's carers, families and consumers providing direct feedback about a service and also including consumer participation in the design, monitoring and evaluation of services, departments or programs.



Partnerships are formed between clinicians and the patients where care is delivered. These partnerships support the provision of care that is respectful. They allow for the sharing of information suitable to the individual patient, and ensure that patients and their carers or family are engaged in care planning and decision making, and are supported in the management of their own care.

# **Monitoring and Evaluation**

Consistent with obligations to oversee, monitor and promote partnering with consumers for safety and quality improvements in health care services, the SESLHD Board will receive reports that evaluate the impact of initiatives to measure consumer partnerships activities. These activities will be evaluated to consider how they can be improved to meet the strategic aims of their health service. Monitoring and evaluation processes will vary within each health facility and program, depending on local circumstances.

## **Measuring success**

We will measure partnering with consumers outcomes in accordance with this Framework and the National Safety and Quality Health Services Standards. This framework supports excellence and compliance against the following standards:

- National Safety and Quality Health Standards (NSQHSS), in particular the Clinical Governance Standard, Partnering with Consumers Standard, and other consumer-centred items across the eight Standards
- NSQHS Standards Six Actions for Aboriginal Health

The NSQHS Standards include six defined actions that specifically address the needs of Aboriginal and Torres Strait Islander people. Implementing these actions will support the provision of culturally appropriate care to Aboriginal and Torres Strait Islander people across the health system. One of these six actions is related to the Partnering with Consumers Standard.

Partnering with Consumers Standard – Action 2.13. The health service organisation works in partnership with Aboriginal and Torres Strait Islander communities to meet their healthcare needs.

Australian Safety and Quality Framework for Health Care, which specifies three core principles for safe and high quality care including

- 1. Consumer-centred;
- 2. Driven by information and
- 3. Organised for safety



# Legislation

This framework is consistent with the:

- Aged Care Act 1997
- Australian Charter of Healthcare Rights 2020
- Healthcare Complaints Act 1993
- Health Services Act 1997
- Mental Health Act 2007
- NSW Carers (Recognition) Act 2010
- Public Health Act 2010

# **Guiding policies and plans**

- NSW Ministry of Health CORE Values
- NSW Ministry of Health, Evaluating the Human Experience
- SESLHD Journey to Excellence 2018 2021
- ACSQHC Australian Charter on Health Care Rights
- ACSQHC National Safety and Quality Health Service (NSQHS) Standards second edition
- ACSQHC NSQHS Standard 2 Partnering with Consumers



# Responsibilities

All responsibilities are in accordance with the Framework. Strategic leadership, designated responsibilities, monitoring, reporting and evaluation mechanisms, and alignment of business processes are essential.

### **SESLHD Governing Board will:**

Ensure mechanisms are in place to effectively implement a consumer engagement framework strategy to promote consultation with health consumers about the provision of health services.

### **SESLHD Chief Executive will:**

- Ensure the District is committed to partnering
  with its consumers through open communication
  on committees, focus groups and through the
  development of models of care and service
  development. Our consumers participate in the
  highest levels of governance, making a valuable
  contribution from the Board level through to
  strategic planning initiatives and service redesign
- Build workforce capabilities to proactively engage with consumers in accordance with this Framework
- Allocate appropriate resources and support to implement a sustainable consumer engagement system
- Monitor and evaluate to ensure consumer participation is evident in engagement strategies, safety and quality process, service planning and design, complaints management processes and service outcomes evaluation

# **SESLHD Board Strategic Community Partnerships Committee (BSCPC) is:**

An inter-sectoral committee reporting to the SESLHD Board. It is focussed on legislation that governs Local Health District (LHD) Boards, Commonwealth, State and local strategic priorities, and National Safety and Quality Health Service (NSQHS) Second Edition. The BSCPC provides advice and recommendations to the Board, and Chief Executive and other staff as required.

The purpose of this committee is:

- To seek assurance that a strategic, coordinated and integrated strategic community partnership approach is undertaken with community members and agencies to deliver better physical health, emotional and social well-being outcomes
- To seek assurance that there is a strong focus on promoting health equity \* and best possible return on investment via robust cross-agency approaches in areas where collaboration will provide the greatest impact
- To support and seek assurance that effective two-way communication is in place with the community and with agencies

<sup>\*</sup> Equity in health is usually understood to be about ensuring equal access to health services for people with equal need, irrespective of personal characteristics such as gender, cultural background or place of residence. While equity in health certainly includes equity of access, it is ultimately about improving equity in health outcomes for those people with the poorest health in our society NSW Health NSW Health and Equity Statement, May 2004.

### **SESLHD Community Partnerships Alliance (Alliance):**

Reports to the SESLHD Board Strategic Community Partnerships Committee (BSCPC). A coordinated and integrated strategic and community partnership approach is undertaken with community members and agencies to deliver better physical health, emotional and social well-being outcomes for the community. The Alliance provides reports, advice and recommendations to the BSCPC. The Alliance creates working groups as required to address specific issues or focus on specific topics

### **Facility and Service Commitment:**

All sites and services in our District are committed to partnering with consumers to strengthen their involvement and influence in health service provision. Local Consumer Advisory Committees or consumer advisory groups exist across the district to support the commitment to partnering with consumers in organisational design, governance measurement and evaluation reflecting the diversity of consumers and the local community

### **Consumer Advisory Committee:**

The role of the Consumer Advisory Committees (CAC) is in service level engagement focusing on partnerships that influence quality improvement, planning, delivery and evaluation and monitoring of projects, programs and services at a facility level. The CAC will achieve this by ensuring a clear and diverse consumer voice and the integration of consumer perspective into services, projects and programs provided by Hospitals and Health Services

### Operational and departmental services will:

Develop and implement new models of care, design material for patient use or have specific projects to implement. A tailored approach to Consumer engagement for these activities should be undertaken using the IAP2 framework and the Principles of Engagement to guide participation using the principles of co-design



## **Consumer and Carer Rights**

This Framework, in acknowledging the rights of consumers and carers is underpinned by the Australian Charter of Healthcare Rights (2020) and the NSW Carers (Recognition) Act 2010.

### **Consumer Rights**

All consumers within SESLHD have the right to:

### Access

healthcare services and treatment that meets

### Safety

receive safe and high quality healthcare and be cared for in an environment that makes them

### Respect

be treated as an individual with dignity and have their culture, identity, beliefs and choices recognised and respected

### Partnership

be involved in open and honest communication; make decisions about their health with their provider and include the people that they want in planning and decision-making

### Information

right to be informed about their condition, receive information about services, costs, waiting times and be given assistance when needed to help them understand and use the health information

### ■ Privacy

right to privacy and confidentiality

### Give feedback

right to comment or complain and share their experience and participate to improve the quality of care and health services

### **Carer Rights**

This Framework supports the NSW Carers (Recognition) Act 2010 and its four main pillars of the Charter:

- 1 Carers make a valuable contribution to the community
- Carers' health and well-being is importan
- **3** Carers are diverse and have individual needs within and beyond their caring Role
- 4 Carers are partners in care



# **Appendix I - Policy Context**

# **South Eastern Sydney Local Health District Journey to Excellence, 2018 - 2021**

South Eastern Sydney Local Health District Journey to Excellence, 2018 - 2021 outlines the organisations purpose for the next ten years. The strategy lays the foundation for SESLHDs ambition to work with consumers to transform the way care is delivered.



#### Safe, person-centred and integrated care

Everyone in our community will have access to safe, compassionate and high quality healthcare. That care will be provided either at home, or as close to home as possible



#### Better value

We will deliver value to our patients through maintaining financial sustainability and using our resources in a way that is consistent with our priorities



### Community wellbeing and health equity

We will work together with our partners to achieve health, wellbeing and equity for our shared communities



### Workforce wellbeing

We will create an environment where our people can be accountable, happy and well, and supported to reach their



#### Fostering research and innovation

We will focus on translating research and innovation into clinical service models that deliver positive health outcomes

### **NSW Health CORE Values**

This Framework is underpinned by the NSW Health CORE Values and the SESLHD vision "Exceptional Care, Healthier Lives"

We will work together as a The decisions we make are team to provide the best health transparent and we accept care for our community. accountability for our actions. Our patients and their carers have a right to know how and **Collaboration Openness** why decisions are made and who is making them. We will work with our We respect and acknowledge patients and their carers the contribution made by each member of our team in to enable them to take **Empowerment** Respect greater control of their own providing the best possible health care. We acknowledge healthcare for our patients. that for empowerment to work there must be trust between our patients and all staff involved in the provision of health care.

### **A Spectrum of Participation**

The Spectrum has been used to help guide SESLHD to drive stronger engagement.

# IAP2 Spectrum of Public Participation



IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

	INCREASING IMPACT ON THE DECISION				
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for 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.

**Source:** IAP2 Federation

# Appendix II - Definitions

Term	Definition			
Carer	A carer is a person who provides ongoing unpaid support to people who are frail aged, those living with lifelong disabilities, mental health conditions, alcohol or drug dependency, dementia, terminal illness, HIV or with a chronic illness			
Co-design	Co-design is a process that enables those who deliver services and those who receive services to create improvemen together. Healthcare workers and consumers are considered equal partners in the planning and decision making proc			
Community	A group of people with diverse characteristics who are connected through a common location, culture, interest or attitude. In a healthcare context community can be used to define the population of the area, a cultural group or a group of people who are all experiencing a certain health condition.			
Consumer and Community Engagement	Consumer and community engagement refers to the activities and processes through which consumers and their communities partner with health organisations around policy development, service design, delivery, evaluation and monitoring of their services. <sup>1</sup> The most effective way for health organisations to best meet their community's needs and preferences is to work in partnership with the community to develop and plan care.			
	Community engagement takes place with 'broader' groups of consumers and community members who are able to speak about the types of healthcare they would like and contribute to addressing issues such as access, health literacy and strategic priorities.			
Consumer	Consumers are people who use, or are potential users of health organisations including their family and carers.  Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities. <sup>1</sup>			
Consumer Advisory Committee	The role of the Consumer and/or Community Advisory Committee is to provide consumer advice, direction and advocacy for the planning and delivery of health care provided by the organisation.  The Committee provides a structured partnership between consumers, carers and the health care service on safety and quality issues, patient experiences, consumer-centred care and other issues such as co-design of health and medical research, as identified in its terms of reference.			
Consumer Advisory Member / Representative	A person recruited to an advisory committee by an organisation to represent and advocate for the community they see The representative will voice the collective perspective and take part in decision making as a representative of those consumers and communities.  In the SESLHD context, this refers to a consumer, carer or community member who has been engaged through format processes to this specific role.			
Diversity	In the context of this Framework, diversity refers to the inclusion of the numerous voices and experiences of the broadest range of individuals and groups which include but not limited to:  Aboriginal and Torres Strait Islander peoples and communities and the diversity within Aboriginal cultures  People from Culturally and Linguistically Diverse backgrounds  People living with disability (such as people with physical, sensory, intellectual and cognitive disability)  People who have lived or living experience of mental illness  LGBTQIA+ communities  Family structures and roles  Older Australians  Children and Young people  Health and illness conditions (such as people who may be long term users of the service, chronic health conditions)  People experiencing homelessness  People in prison  Trauma affected persons  Religious and spiritual groups and belief systems  Emerging communities (such as new migrant communities, refugees including those who have experienced torture, trauma, grief and loss)			
Engagement	Engagement refers to a range of activities and processes that involve consumers or communities participating in health service decision making, policy development service and service design, delivery and evaluation.  Effective and active partnerships exist when:  • people are treated with respect  • information is shared and explored with them  • participation and collaboration in healthcare processes are encouraged and supported			

#### Governance

Is a set of responsibilities and relationships between the organisation; being the executive team, healthcare workers and consumers, carers and community members of a health service. It incorporates the laws, policy directives, and processes affecting the way an organisation is directed, administered and controlled. Governance arrangements provide the structure for setting the corporate objectives (social, fiscal, legal, human resources) of the organisation and the means to achieve the objectives. (National Safety & Quality Health Service Standards - 2nd edition, 2017)

### Health Literacy

The Australian Commission on Safety and Quality in Health Care separates health literacy into two components – individual health literacy and the health literacy environment.

Individual health literacy is the skills, knowledge, motivation and capacity of a consumer to access, understand, appraise and apply information to make effective decisions about health and health care, and take appropriate action.

The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the health system, and it affects the ways in which consumers access, understand, appraise and apply health information. (National Safety & Quality Health Service Standards - 2nd edition, 2017)

### Lived Experience

A lived experience is the understanding and knowledge you get when you have lived through something. For example a person who has a lived experience of mental illness brings their understanding and knowledge gained from their direct experience living and recovering from a mental illness.

### National Safety and Quality Health Service (NSQHS) Standards

The National Safety and Quality Health Service (NSQHS) Standards were developed by the Australian Commission on Safety and Quality in Health Care (the Commission) in collaboration with the Australian Government, states and territories, the private sector, clinical experts, patients and carers. The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health service provision. (National Safety & Quality Health Service Standards - 2nd edition, 2017)

### National Safety and Quality Health Service (NSQHS) Standard Partnering with Consumers

The Standard Partnering with Consumers describes the systems and strategies to create a person-centred health system by including patients in shared decision making, to ensure that patients are partners in their own care, and that consumers are involved in the development and design of quality health care. (National Safety & Quality Health Service Standards - 2nd edition, 2017)

### **Partnership**

Effective partnership exists when consumers are treated with dignity and respect, when information is shared, and when participation and collaboration in healthcare processes are encouraged and supported to the extent that consumers choose.

### Person Centred Care

An approach to the planning, delivery and evaluation of health care that is grounded on mutually beneficial partnerships among clinicians and patients. Key dimensions of person centred care include respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of carers and family and access to care. Also known as patient centred care or consumer centred care. (National Safety & Quality Health Service Standards - 2nd edition, 2017)

### Safety and Quality Improvement

Safety and Quality Improvement is the framework we use to systematically improve the way care is delivered to patients. Processes have characteristics that can be measured, analysed, improved, and controlled. Quality Improvement (QI) entails continuous efforts to achieve stable and predictable process results, that is, to reduce process variation and improve the outcomes of these processes both for patients and the health care organization and system. Achieving sustained QI requires commitment from the entire organization, particularly from top-level management. (Agency for Healthcare Research and Quality, n.d.)

# Shared decision making

Shared decision making and personalised care planning are important ways in which patients can partner in their own care. This process can support conversations that lead to better-informed decisions aligned with what matters most to patients.

Shared decision making is a collaboration and discussion between a consumer and their healthcare provider. It joins together the consumer's values, goals and preferences with the appropriate evidence regarding the benefits, risks and uncertainties of treatment, in order to determine the most appropriate healthcare decisions for the patient. The benefits of shared decision making are many and include:

- improved satisfaction with care and better quality care decisions
- Consumers using evidence-based decision aids have improved knowledge of the options, more accurate expectations of possible benefits and harms, and feel that they had greater participation in decision making than people receiving usual care
- Better-informed consumers make different, often more conservative, less costly choices about treatment as the
  information provides a realistic appreciation of likely benefits and risks of treatment and enables decisions about
  the potential outcomes in a more considered way.

### **Reference List**

- 1. Australian Bureau of Statistics, Census of Population and Housing 2016
- 2. Health Consumers Queensland. Consumer and Community Engagement Framework. Brisbane, February 2012
- 3. Sarrami-Foroushani, P., Travaglia, J., Debono, Deborah and Braithwaite, J. Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review. BMC Health Services Research 2014, 14: 402. Available from: http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-402
- 4. Tasmanian Council of Social Service Inc. Consumer Engagement Handbook for HACC Services in Tasmania. Hobart, 2012. Adapted from definition of community.

#### Available from:

http://www.tascoss.org.au/Portals/0/Documents/ Strengthening%20 Our%20Sector/Consumer%20Engagement/HACC%20 Handbook%20Sept%202012.pdf.

- International Association of Public Participation (2016). IAP2 Public Participation Spectrum.
   Available from: www.iap2.org.au/Resources/IAP2-Published-Resources
- 6. An Introduction to improving health literacy in your organisation. A fact sheet for quality managers. **Downloaded from:** www.safetyandquality.gov.au
- 7. Australian Commission on Safety and Quality in Health Care. (2018) National Safety and Quality Health Standards. User Guide for Measuring and Evaluating Partnering with Consumers.
- 8. SESLHD CORE Values. Downloaded from: SESLHD Core Values (nsw.gov.au)
- 9. Consumer and Community Engagement Model. An outcome of the WentWest Health Consumers NSW Joint Consumer Engagement Project. June 2015.
- 10. Stakeholder Engagement Framework. (2012). Aboriginal Policy & Stakeholder Engagement Branch.
- Six tips on Co-design.
   Downloaded from: https://koawatea.countiesmanukau.health.nz/knowledge-hub/expert-views/six-tips-on-co-design



