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What is the Link to Consumer and Community Participation?.........................................................................29
The Sydney Local Health District (SLHD) Consumer and Community Participation Framework provides a vehicle for ensuring a strong and vital relationship between the District, its consumers and communities. The Consumer and Community Framework is one of the key enabling documents that have been developed to inform the overall SLHD strategy. Its purpose is to articulate and strengthen the bonds and consultation processes between consumers, communities and the SLHD. The Framework is built on the strong foundation established under the previous administration, the Sydney South West Area Health Service. The Framework provides an important philosophical approach to undertaking healthcare business. That is, all activities whether they are policy, planning, service delivery, research or evaluation will seek to positively include consumers and relevant communities. As well, the Framework provides a set of structures and processes which will promote enhanced consumer and community engagement.

Key structural aspects of the Framework include the establishment of a SLHD Consumer and Community Council (CCC), a peak committee dedicated to ensuring community and consumer input into all aspects of the District’s business. In addition, hospital based community participation representative networks have been established across the District with a role in providing input and constructive feedback about our hospital care so as to promote more accessible and appropriate service delivery, policies and structures.

The SLHD provides healthcare to a very wide range of consumer and community groups. We have a growing population of people who are elderly and who have chronic illnesses or conditions. We have a large and vibrant Aboriginal community. The community is rich culturally and linguistically with over 170 languages spoken in our District. We have a growing birth rate. This diversity can pose some challenges in providing healthcare. It is imperative that we build structures and processes capable of capturing the views, concerns, issues and ideas of these diverse communities. This will help ensure that our healthcare dollar is expended in ways that positively impact on health and wellbeing and more importantly that our health services meet the needs of those they are designed to assist.

This Framework is an important guiding document for the District. Both the SLHD Board and Executive wish to thank all those who have contributed to the development of this Framework, particularly the many consumers and community members.

Chairperson          Hon. Ron Phillips
SLHD        Chairperson
Consumer and Community Council  SLHD Board
Introduction

This Consumer and Community Participation Framework provides a blueprint for the way the SLHD will do its business in partnership with our consumers and communities. The Framework provides an invigorated approach to investing in and developing our relationships with our communities.

Consumer and Community Participation is the process of involving consumers and community members in decision making about their own health care, health service planning, policy development, setting priorities and addressing quality issues in the delivery of the health services. This can be achieved via a variety of means including participation in forums, committees, projects, working groups or peak state and national health agencies.

The term ‘community’ within this Framework is a term that refers to consumers of health services, such as patients or clients, families, friends, carers and the broader community at large. The community is made up of many smaller communities or groups of individuals with shared qualities, ideas, characteristics and interests which bring groups and individuals together such as culture, language, religion, beliefs, geographic location, gender, profession and certain interests etc. Individuals may associate with a number of groups or communities and may represent a variety of interests.

The term Consumers within this Framework is a term that refers to any actual or potential recipient of health care, such as a patient in a hospital, a client who visits a community health centre, or a person who goes to their doctor for treatment. This may include a person’s family, friends or carers who are also regarded as consumers. For the purpose of this framework, Consumers and Communities are not mutually exclusive terms.
Background

The idea of community participation in health first appeared in the early 1970s when it became clear that the basic health needs of many countries could only be met through the greater involvement of local communities. Self-help and consumer groups were founded at this time and concepts of self-management and participatory democracy also developed. The community health program began to grow as a programmatic response to community needs for healthcare. The World Health Organisation (WHO) articulated this at the Alma-Ata conference in 1978 and consequently a campaign was launched by the WHO along with several member governments to promote wellness and the prevention of disease through public empowerment.

Physician centred care and hospital based programmes were identified as being insufficient in achieving global health. It was thought that the attainment of good health centred on health promotion and the empowerment of local communities through collective action. As a result, the concept of community participation became integrated into international health policy and formed the cornerstone for strategic planning to achieve health for all (David, Zakus & Lysack 1998).

The development of consumer and community participation has also been a means to address health problems through social policy, legislation and engagement of the public in health planning (Primary Health Care Reform in Australia - Report to Support Australia’s First National Primary Health Care, 2009). Such active participation may occur in a variety of ways, including research, focus groups, use of interactive media, forums and community development projects.

Australia along with other countries such as Canada, the UK and US have been encouraged and assisted by the WHO and the Organisation for Economic Cooperation and Development (OECD) to create various forms of community participation. At a national and state level, a variety of models for community participation have been developed in Australia ranging from incorporating individuals into existing organisational committees such as advisory committees and community health councils to formalised public partnerships and citizen juries (David, Zakus & Lysack 1998).

Community participation has been adopted in Australia by such organisations as the Australian Commission on Safety and Quality in Health Care, Consumers Health Forum of Australia, NSW Agency for Clinical Innovation, NSW Clinical Excellence Commission and Health Consumers NSW.

The Australian Commission on Safety and Quality in Health Care have developed The Charter of Healthcare Rights for Consumers. One right specified in this charter concerns communication, and states that “communication is enhanced if healthcare providers ensure that the patient or consumer understands the information being provided to them” Additional detail concerning the importance of health literacy is contained in Appendix 2. In addition The Australian Commission on Safety and Quality in Health Care have released a set of national safety and quality health care standards one of which addresses consumer and community participation (CCP). Both documents aim to improve patient outcomes and people’s experience of the health system and health services. They underpin all activities within the health service.
CONSUMER AND COMMUNITY PARTICIPATION FRAMEWORK

Sydney Local Health District and Community Participation

The Sydney Local Health District through its Strategic Plan 2012-2017 clearly states its commitment to consumer and community participation. The Plan outlines a set of goals and activities developed following a series of community consultations in 2011. These include partnerships with relevant community organisations and the use of a wide variety of tools to engage and communicate with consumers and local communities. The commitment to a Community Participation Framework is highlighted.

The involvement of communities and consumers in all aspects of the business of the District is a strongly held goal. This may include health service planning, service development, service evaluation and policy making. It is clear that consumer involvement results in more accessible service delivery approaches and more appropriate service models.

Sydney Local Health District is committed to involving consumers and the community in a number of ways. Examples include community representation on hospital boards, supporting hospital auxiliaries, providing volunteer programs, facilitating consumer and community involvement in local health advisory groups and committees, and providing community development programs.
The Sydney Local Health District (SLHD) is located centrally in the Sydney metropolitan area and in the inner west region of Sydney. The District comprises 8 local government areas: Ashfield, Burwood, Canada Bay, City of Sydney (part), Leichhardt, Marrickville and Strathfield and encompasses a total land area of 126 square kilometres with a population density 4,210 residents per square kilometre (ABS 2006). The Sydney Local Health District provides healthcare to over 530,000 residents with a population expected to reach 642,000 by 2021.

The District is culturally, linguistically and socially diverse. Almost half of the SLHD population speak a language other than English at home including significant numbers of refugees, asylum seekers and special humanitarian entrants. The major languages spoken include Chinese languages, Arabic, Greek, Korean, Italian and Vietnamese. However there is great variation in the Culturally and Linguistically Diverse (CALD) population mixes across the Sydney LHD. Canterbury Local Government Area (LGA) has the largest CALD communities with 46.9% of people born overseas and 70% speaking a language other than English. Between 2005-2011 9% of the refugee and humanitarian entrants across NSW initially settled in the Sydney Local Health District (2,335 people), Sydney was the third largest place of initial settlement for newly arrived humanitarian entrants. A wide range of countries of origin were represented including Sierra Leone, Sudan (and other parts of Africa), Iraq, Pakistan, Burma, China and Sri Lanka. 60% of SLHD’s entrants initially settled in the Canterbury LGA.
A significant Aboriginal population resides in SLHD especially around the Redfern/Waterloo area, in the City of Sydney and in Marrickville LGA’s. There are approximately 4,407 Aboriginal residents identifying as Aboriginal or Torres Strait Islander background. Aboriginal people are widely recognised as having poorer health and poorer access to appropriate health services.

SLHD is characterised by socio-economic diversity with pockets of extreme advantage and extreme disadvantage. The LGAs with the highest proportion of the population being unemployed include Canterbury, Marrickville and Ashfield. The mean taxable income is lowest in the Canterbury LGA which has a higher index of disadvantage than the rest of the State.

This diversity is also reflected in educational attainment, employment, unemployment and housing-related statistics. SLHD has a high proportion of lone person households and people pay relatively high rental rates in the District.

Sydney Local Health District’s broader community

As well as a local resident population, SLHD provides health care to a large population of people from other health districts, from interstate and overseas.

These populations of consumers use the tertiary and quaternary services at SLHD such as tertiary level surgical services, cancer services, cardiology, burns etc. Some of these consumers spend short periods of time using the SLHD services while others may spend long periods of time depending on their health care needs. The various perspectives of these consumers are very valuable as well as those of our local residents.
Purpose of the Consumer and Community Participation Framework

There is growing evidence which indicates that consumer and community participation (CCP) results in improved health care and promotes a more transparent, accessible accountable and appropriate health service. Through participation consumers and community members can make a valuable contribution to the health system and strengthen links between health services and their local communities.

Community participation embraces a philosophy of ‘working with’ rather than ‘doing to’ people. Community participation is the involvement of consumers and carers in decisions about individual health care, as well as the involvement of consumers and communities in decisions about the planning, provision and evaluation of health care services.

The Sydney Local Health District Consumer and Community Participation Framework identifies a range of partnerships between the SLHD, its services and communities. The flexible yet formal structure provides guidance to all health services and consumer and community representatives within SLHD.

The Framework is a living document, designed to evolve along with the further growth and development of consumer and community participation in the Sydney Local Health District. It aims to provide guidance to all people in the District involved in consumer and community participation including the Board, the Chief Executive, Facility General Managers, Clinical Directors, the Community Participation Manager and Community Participation Coordinators and Consumer/Community Representatives.

While the Framework suggests community groups that are considered important for community participation, it acknowledges that each facility and its community groups differ. The Framework encourages flexible structures and activities that meet the specific needs of each facility/service and its community groups.

Some sections of the Framework will be more relevant to some consumer and community members than others, however, it is intended that the Framework provides enough detail for each member to understand each other’s roles and responsibilities.
Aims of Consumer and Community Participation

The aims of Consumer and Community Participation (CCP) in the Sydney Local Health District (SLHD) are to ensure that:

• the health service involves consumers, carers and the community in planning, delivery and evaluation of services;

• local communities are well informed about local and District health service issues and priorities; and

• there is transparency and accountability in the health service decision-making and evaluation.

SLHD is committed to involving consumers, carers and community members at all levels of the organisation through a range of processes to enable an empowered and coordinated voice to be included in decision-making.

SLHD will achieve this by:

• working in partnership with consumers and communities;

• building the capacity of staff and the organisation to undertake consumer, carer, and community participation - from the level of individual care to the level of system changes;

• providing and integrating structures and processes for participation in all aspects of policy development, health service planning and evaluation and in quality improvement processes;

• providing resources to ensure that CCP occurs equitably throughout the District;

• providing information to our communities in an appropriate manner;

• promoting, supporting and developing the capacity of community members to participate in health service planning, delivery and evaluation;

• ensuring those involved in participation reflect the diversity of the SLHD population;

• encouraging innovative approaches to participation;

• training and supporting staff to undertake CCP; and

• creating an open, transparent and accountable healthcare organisation.
Core values and principles that underpin Consumer and Community Participation

Table 2: The core values and principles that underpin consumer and community participation (Community Participation Working Party).

<table>
<thead>
<tr>
<th>Respect</th>
<th>Accountability</th>
<th>Communication</th>
<th>Teamwork</th>
<th>Commitment</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Promotes a culture of collaboration by listening, involving and responding to community concerns</td>
<td>• Works to ensure that outcomes of consumer and community participation are fed back to communities and health services</td>
<td>• Ensures that consumers, carers and community members have relevant information about their own health and health care services in order to make their own decisions, and that the information is provided in appropriate ways</td>
<td>• Works in partnership with consumers, carers and communities</td>
<td>• Is willing to negotiate on key decisions</td>
<td>• Provides resources and support to consumer and community participation activities and staff</td>
</tr>
<tr>
<td>• Is committed to including community views and concerns in decision making</td>
<td>• Is committed to developing services based on our communities identified needs and ensuring they are understood and acted upon</td>
<td>• Creating an open, transparent and accountable organisation</td>
<td>• Ensures that consultation and participation processes are inclusive and provide equity of access for consumers, carers and community members</td>
<td>• Is committed to building the capacity of the organisation to enable effective consumer and community participation at all levels</td>
<td>• Trains and supports staff to undertake consumer and community participation</td>
</tr>
<tr>
<td>• That there is mutual agreement of the processes and assessment of issues under consideration as developed through productive working relationships</td>
<td>• Providing information to consumers, carers and community members</td>
<td>• Values and recognises the diversity of communities within the health system</td>
<td>• Builds trust and credibility throughout the participation process</td>
<td>• Values, welcomes and recognises consumers, carers and community experience(s) and expertise within the health district</td>
<td>• Is committed to involving communities in making decisions about how they will participate</td>
</tr>
</tbody>
</table>
Levels of Consumer and Community Participation

The following figure represents the various levels of consumer and community participation. This ranges from involvement in decision making about the care of individuals and families, to involvement in hospital and facility services, contributing to District level debates, planning and development, to system-wide levels of involvement.

Figure 1: Levels of Consumer and Community Participation
Sydney Local Health District (SLHD) Structure of Consumer and Community Participation

Figure 2: The structure of consumer and community participation in the SLHD

Partnership Consultations – Population Health Groups
- Young people
- People who are Aboriginal or Torres Strait Islanders
- People with Culturally & Linguistically Diverse backgrounds
- People with Disabilities
- Mental Health Consumers
- Carers

SLHD Consumer & Community Networks:
Representation to be determined

Proposed SLHD Consumer and Community Council
Proposed membership to be determined

SLHD Clinical Networks

SLHD Facilities
Community Participation Coordinators

Proposed SLHD Consumer and Community Participation Council

SLHD Consumer and Community Participation Manager

SLHD Chief Executive

Sydney Local Health District Board
CONSUMER AND COMMUNITY PARTICIPATION FRAMEWORK

SLHD Structure for Consumer and Community Participation

Introduction

SLHD’s structure for consumer and community participation is outlined in Figure 2 on page 13. This includes a proposed SLHD Consumer and Community Council, facility-based consumer and community networks and consultations with priority populations.

Figure 1 on page 12, outlines various levels of engagement for consumer and community participation in the SLHD.

1. Individual Level:
At an individual level consumers and community members may be involved in decisions about their individual treatment and healthcare. This would involve strong engagement between health providers and patients. An important document that promotes the rights of patients, carers and their families produced by NSW Health is ‘Your Healthcare Rights and Responsibilities: A guide for patients, carers and families’. Another similar document has been produced for staff, ‘Healthcare Rights and Responsibilities: A guide for NSW Health staff’.

2. Facility or Service Level:
Consumers and community members may choose to become involved in patient experience programs, participate in patient surveys, or complaint and compliment processes where patients are encouraged and empowered to become actively involved in their health care.

At a Local Health District facility or service level consumers and community members may be involved with an individual health service or facility, such as a hospital or community health centre or cluster of facilities, such as mental health services.

Consumers and community members may elect to actively participate in service delivery changes within a specific Department or ward within hospital, or in areas that directly interface with the public such as emergency departments or outpatient clinics. They may also be involved in the consumer and community representative council or hospital network.

3. District Level:
SLHD’s Board undertakes consumer and community engagement activities as part of its overall role. However there are opportunities outside this formal structure for consumers and the community to become involved with SLHD at a District wide level. This may include involvement in District-wide quality and safety programs, being a community representative on a District-wide service planning initiative or a review of systems issues arising from consumer and carer feedback and complaints. Consumer and community representatives may be involved in aspects of the Local Health District’s organisational planning and development or be involved in the evaluation and monitoring of engagement activities across the District.

4. State and National Level
Consumers and community representatives may be involved in State and National policy development or strategic frameworks. They may also be involved with state and national health care advisory committees or other advisory committees or councils.
Sydney Local Health District Board and Chief Executive

As part of the National Health Reform, Local Health Districts commenced operation on the 1st January 2011. The former Area Health Services ceased and a more decentralised and localised approach to health care began with the formation of geographically smaller Districts across NSW. Effectively Sydney South West Area Health Service became Sydney Local Health District and South Western Sydney Local Health District. This included the formation of District Boards to oversee the governance and management of the new Local Health Districts. The Chief Executive reports to the Board and to the NSW Ministry of Health.

Sydney Local Health District (SLHD) provides health care services to the Sydney metropolitan and inner west region of Sydney as well as to patients from other parts of NSW, Australia and overseas.

Proposed Sydney Local Health District, Consumer and Community Council

The proposed SLHD Consumer and Community Council will act as a key consultative and advisory group to the Board of the SLHD on consumer and community issues relating to all aspects of health care delivery. The Council will be a high-level strategic committee comprising of consumers and community members as well as representatives of the SLHD.

The Consumer and Community Council’s proposed role is:
- to act as a representative body of SLHD health CCP;
- to implement the ‘Business Plan’ of the Consumer and Community Council (CCC);
- to encourage involvement of health consumers and community representatives in all aspects of the health district;
- to be a strategic link between SLHD communities and the Board;
- to monitor and enhance the SLHD commitment to consumers, carers and community;
- to ensure community participation is included in health planning by the SLHD;
- to present the views and recommendations of the SLHD Consumer and Community Representative Network (CCRN) to the SLHD and the Board; and
- to provide feedback from the Board and the SLHD to the SLHD CCRN.

Consumer and Community Representative Networks

Consumer and Community Representative Networks comprise of local members who meet at the health facilities listed above. They meet on a regular basis and provide valuable feedback to local health services on improving patient care, consumer and community engagement and participation.

The Consumer and Community Representative Networks’ key roles are:
- to advocate for CCP within the health facility;
- to enhance the understanding of SLHD health services;
- to research and discuss, and where needed raise issues to their facility General Manager and make recommendations to the SLHD CCC;
- to facilitate the sharing of information between stakeholders; and
- maintain an accessible structure that supports and sustains health consumer and community representatives.
Who can be Consumer and Community Participation Representatives?

Representatives may live within the boundaries of the Local Health District/health facility or may be consumers who have a connection to our local health facilities. Residents who have used or are using the health service are particularly valued and welcomed.

Representatives can also include organisations that act on behalf of the diverse communities and population groups within the District (for example, people with a disability, specific cultural groups or a particular age group). They are appointed to a formal structure or through other processes to represent consumer interests.

Information related to the recruitment process for consumer and community members is outlined in Appendix 1.

What does a Consumer and Community Participation Representative do?

Consumer and Community Participation Representatives (members), work alongside health staff at all levels of the organisation providing a voice for their community. The purpose is to improve the accessibility, quality and safety of care at the local hospital or health facility or across the health system. Participation can include attendance at meetings with staff, contributing to forums or implementing projects. Consumer and Community Participation Representatives are members of committees, boards, reference groups, working groups and District wide committees and networks. They may also be involved in peak state and national health agencies. Involvement can range from a few hours a month to contributing an intensive period of time on a particular project.

Representatives can, if they choose, have a nominated support person, mentor or ‘buddy’ to provide them with information and support. The support person can also act as a contact point for Consumer and Community Participation activities.

Consumer and Community Participation Manager

The Consumer and Community Participation Manager (CCPM) holds a District wide position and is responsible for developing, implementing, marketing, monitoring and evaluating health Consumer and Community Participation (CCP) across SLHD. Internally to health, the Consumer and Community Participation Manager will work closely with the Chief Executive, SLHD Board, Facility General Managers, Clinical Directors, SLHD Executives and most especially, the CCP Coordinators and the Consumer Representatives.

Externally, the Manager will work with a range of related stakeholders such as service groups, the non government sector, peak agencies such as Health Consumers NSW, Agency for Clinical Innovation, Clinical Excellence Commission, Consumers Health Forum, NSW Commission of Social Services and other state and federal peak bodies to ensure proper support and advocacy for SLHD.
Facility Consumer and Community Participation Coordinators

Facility Consumer and Community Participation Coordinators are based in health facilities across SLHD and are responsible for recruiting, supporting and coordinating health consumer and community participation within their local network. Currently there are Coordinators based at Royal Prince Alfred and Balmain Hospitals, Concord Hospital and Canterbury Hospital.

Generally, Coordinators are required to:
- work closely with both staff and community to increase knowledge and skills in the value of health consumer and community participation;
- promote, recruit and support consumer and community representatives;
- advocate for and manage resources allocated to CCP at the facility level;
- build capacity of both representatives and staff; and
- provide on-going support for a positive culture of participation.

Coordinators report directly to a Hospital General Manager or other designated Director/Senior Manager within the Hospital and they are supported by the District CCP Manager.
Conclusion

The SLHD is committed to working in close partnership with our communities in our joint endeavours of achieving healthcare excellence for all and in our accompanying mission of ensuring the community has access to high quality patient-centred care.

Our commitment to community and consumer involvement is two-fold:

1. To enable participation of consumers and communities into the core business of the District by purposefully engaging consumers and communities in our planning, delivery and evaluation of our health services. This engagement will require some degree of change in some of our processes. This change will reap benefits for both consumers, communities and for the healthcare services of our District.

2. To develop and evaluate a flexible structure for community participation. This includes the development of a new SLHD Consumer and Community Council, community participation networks in all facilities and an investment in developing community participation staffing across the District.

SLHD is committed to developing a stronger engagement with our consumers, communities and our community organisations. This Framework provides a flexible framework for the achievement of this important ideal.
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Acronyms

AHAC   Area Health Advisory Council
ACSQH  Australian Commission on Safety and Quality in Healthcare
CCC    Consumer and Community Council
CCP    Consumer and Community Participation
CCPU   Consumer and Community Participation Unit
CCRN   Consumer and Community Representatives Networks
CE     Chief Executive
CP     Community Participation
CPU    Community Participation Unit
CR     Community Representative
CRC    Criminal Record Check
CRN    Community Representative Network
CSAHS  Central Sydney Area Health Service
EQuIP  Evaluation and Quality Improvement Program
EOI    Expression of Interest
GM     General Manager
IAP2   International Association for Public Participation
LHD    Local Health District
MOU    Memorandum of Understanding
NGO    Non-Government Organisation
SLHD   Sydney Local Health District
SSW    Sydney South West
SSWAHS Sydney South West Area Health Service
SWS    South Western Sydney
SWSLHD South Western Sydney Local Health District
Definition of Terms

Capacity Building
An approach to the development of sustainable skills, organisational structures, resources and commitment to health improvement in health and other sectors, to prolong and multiply health gains many times over (Hawe et al, 1999).

Carer
A Carer is someone who cares for a family member or friend who has an ongoing illness, disability or condition. The Carer does this in an unwaged capacity.

Carer Representative
A person appointed to a formal structure or other process to represent Carers or Carer interests. A Carer representative will be a Carer as defined in this Framework.

Citizens Juries
A process randomly selected and demographically representative panel of citizens to carefully examine an issue for four to five days.

Community
For the purposes of this document the Community includes individuals who live within the boundaries of SLHD, and organisations that represent the diversity of community groups such as people with a disability or a specific cultural background.

Community Development
The process of supporting communities to identify their health issues and to plan, develop and implement strategies to address inequalities or injustices for social action or social change. A result of these activities is increased self-reliance and decision-making power.

Community Engagement
An informed dialogue between an organisation and consumers, carers and the community which encourages participants to share ideas or opinions and undertake collaborative decision making, sometimes as partners.

Community Participation
The process of involving community members in decision making about their own health care, the health service planning, policy development, setting priorities and addressing quality issues in the delivery of the health services.

Community Representative
A person who becomes a member of their local network registered on the database of the Community Participation Unit. Once registered are able to choose their involvement through activities, formal processes or a combination of both.

Confidentiality
An undertaking that information provided from one person to another will not be disclosed.

Consultation
The ways used to gain community input or feedback around a specific issue or topic. These are usually one-off or short term.

Consumer
A person that uses or is a potential user of health services together with family and carers of recipients’ and clients.

Consumer Advocate
A person or organisation appointed to speak or act on behalf of a consumer or group of consumers.

Consumer Representative
A person appointed to a formal structure or other process to represent consumers or consumer interests.
Evaluation and Quality Improvement Program (EQUIP)
EQUIP has been designed by the Australian Council of Health Standards, and the Australian health care industry, to assist organisations to establish an effective continuous improvement program.

Facilities
SLHD is managed under a system of five facility Health Services. Each facility has a General Manager and an Executive team. The facilities are Balmain, Canterbury, Concord, RPA, Sydney Dental Hospital.

Observer
A community representative only attends a committee or forum by invitation of the Chairperson. This person has no formal voting rights. Invitees can speak at the discretion of the Chairperson.

Participation
The involvement of consumers, carers and communities in decision making about their own health care and health care services.

Partnerships
The process where joint decision making, planning, accountability and responsibility occur between the community and the health service.

Sydney Local Health District
SLHD is one of eight metropolitan Local Health Districts and one of 15 across NSW. It is directly accountable to the NSW Minister for Health. SLHD encompasses RPA, Concord, Canterbury, Balmain, Sydney Dental hospitals. The local government areas covered in this catchment include Ashfield, Burwood, Canada Bay, Canterbury, Leichhardt, Marrickville, Strathfield, and the City of Sydney.

Volunteer
A person working within SLHD in a voluntary capacity and not receiving salary or wages.
Appendix 1: Recruitment of Consumer and Community Representatives

Recruitment methods
Recruitment of potential community representatives is a joint responsibility between the CCPM, CCP Coordinators, health staff and community representatives.

This may involve:

- Word of mouth;
- Placing advertisements in local newspapers;
- Placing community service announcements with local radio stations;
- Distributing information flyers;
- Internet / electronic media;
- Writing to local community organisations;
- Writing to consumers of the service;
- Placing posters on notice boards; and
- Promoting and conducting presentations to appropriate services and groups.

Each CCP Coordinator has flyers available for distribution to interested parties. See Introduction on page 6, 14 & page 16 for more information defining Community Participation and the role of Consumer and Community Participation Representatives.

If the interested parties wish to proceed, they are given an application form and an informal interview with the CCP Coordinator is organised.

Informal Interview
The CCP Coordinator will meet with the applicant to ensure the criteria are met and that they understand their role and responsibilities.

Some key points to discuss may include – code of conduct, confidentiality, grievance process, annual review and conflict of interest.

Consumer and Community Representatives application and selection
Once the applicant is interviewed they are given a recruitment pack which consists of:

- Application to join the CCPU;
- National Criminal Record Consent Form – Non Child Related Position;
- NSW Health Code of Conduct;
- Consumer and Community Representative Agreement;
- 100 Point Identification Check; and
- A list of the roles and responsibilities of the Representative.

Acceptance as a Consumer and Community Participation Representative
Once the applicant has completed the forms and passed the criminal record check, they can undergo orientation.

Orientation involves familiarising the Representative with the Consumer and Community Participation Framework and participating in a facility orientation. It may also involve applying for an identification badge, parking and being vaccinated. Vaccination is not mandatory, but may be necessary if working in certain areas of the hospital.
Interested Consumer or Community Member

 Completes Expression of Interest Form

 Informal Interview with Consumer and Community Participation Coordinator

 Completes Paperwork Package that includes National Criminal Check Form – Non Child Related, NSW Health Code of Conduct, Consumer and Community Representative Agreement and Confidentiality Agreements and Identification Check

 Acceptance as a Consumer and Community Representative

 Joins Facility Network and undergoes orientation

**PLEASE NOTE that all paperwork and orientation must be completed before a consumer and community representative is accepted and their participation can commence. This includes attendance at any health service meetings.**
Appendix 2: Understanding Health Literacy and Community Participation

What is Health Literacy?
Health literacy is the ‘ability of individuals to gain access to, understand and use information in ways which promote and maintain good health’ (Nutbeam 2008). It refers to a person’s knowledge or competency in the subject of health. Health literacy is a fundamental requirement if people are to successfully manage their own health and make critical health decisions (Keleher & Hagger 2007).

Health literacy levels are low in Australia. Although a person may be knowledgeable in many areas, they may be unfamiliar with the language used by healthcare workers and used in health information literature. Health has specific concepts and words for particular diseases that consumers need to understand to manage their care and navigate the health system. The Australian Bureau of Statistics (ABS) reports that 59 per cent of the Australian population aged 15–74 did not achieve health literacy skill level 3 (out of 5) or above which is the minimum required to effectively engage with the health system and manage their own self-care.

HEALTH LITERACY SKILL LEVELS (a) - 2006

![Chart showing health literacy skill levels]

(a) Skill levels 3, 4 and 5 represent adequate or better health literacy.
Source: Health Literacy, Australia (ABS cat. no. 4233.0)

What does this mean?
Low health literacy makes it harder for a person to take care of their own health, or participate in their own healthcare decision making. It has been found that about 60% of Australians have difficulty in understanding the information on a bottle of medicine regarding the maximum number of days the medicine can be taken (ABS 2008. Health Literacy, Australia).

Why is health literacy important?
Low levels of health literacy have implications for patient centred care. It makes it harder for a person to participate in their own health care if they do not fully understand their health condition. For example, people with low health literacy are less likely to ask questions, understand medical terminology, or effectively manage chronic and complex conditions. (Keleher & Hagger 2007)
People with low health literacy levels:

- Have difficulties understanding what clinicians are saying to them;
- Find it difficult to read and understand signs posted in hospitals or clinics;
- Are often unable to fill out patient forms including informed consent forms;
- Can’t read prescription bottles;
- Can’t take medications appropriately;
- Find it difficult to read and understand patient education materials; and
- Often don’t understand public health messages.

(Barrett 2010)
What is the link to Consumer and Community Participation?

Health literacy is critical to empower health consumers to be able to take care of their own health, in partnership with health professionals and also to be able to make broader decisions about the health system. By improving people’s access to information and their capacity to use it effectively (Nutbeam 2008) consumers can speak up about health issues which affect them as individuals and advocate on community health concerns.

The SLHD supports health literacy by employing Coordinators at hospitals to educate the local community and support community representatives. The Coordinators support staff to adopt practices that increase health literacy for all health consumers. For example, encouraging clinicians to use the teach back method and by reviewing patient support material for literacy levels.

Improving the health literacy of the population is part of the nation health reform agenda. Increased health literacy will increase the ability of people to: participate in health care decisions, understand the benefits of preventive measures, detect illness and disease early and manage chronic disease (Primary Health Care Reform in Australia - Report to Support Australia’s First National Primary Health Care).

Health staff, consumers, carers and community representatives can work together to develop health literacy initiatives at the local level to increase consumer participation in health care.
it’s your local health district
Consumer and Community Participation Framework