Consumer and Community Engagement in Health Services: A Literature Review to Support the Development of an Evidence Based Consumer and Community Engagement Strategy for the Women’s and Children’s Health Network, South Australia

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Executive Summary

Introduction
The Women’s and Children’s Health Network (WCHN) in South Australia has commissioned this literature review. This is for the purpose of informing the development of their Consumer and Community Engagement Strategy. The aim is to base decision making about the development of the Strategy on best available evidence and insights into effectiveness of consumer and community engagement strategies in health services.

Consumer and community engagement in health services has been a priority in international and national policy for several decades. Consumer and community engagement offers a promising pathway toward better quality health care, more efficient health care and service provision, and improved population health (1).

Consumer and community engagement involves bringing the voice of consumers and the community into various aspects of a health service’s work (1).

There is an underlying assumption that through engaging with consumers and the community that there will be at least some level of power transfer and contribution to decision-making processes.

Various commentators in their deliberations about the complexities of consumer and community engagement in practice have discussed the different range of factors for health services to consider when developing approaches to consumer and community engagement activities. They represent the multiple contexts in which engagement activities take place (2).

- Unstructured — Structured
- Informal — Formal
- Passive — Active
- Individual — Collective
- One-off — Ongoing
- Unpaid — Paid
- Reactive — Proactive
- Self-interested — Altruistic
- Resisting social change — Driving Social Change

Gregory (2008) states that there is no ‘one size fits all’ approach to consumer and community engagement (1). Methods and techniques should be selected in response to the issues being addressed. Different methods and techniques will be needed at different stages and multiple approaches to engagement will be necessary for health services to be effective in their engagement strategies (1).

Two overarching conceptual models appear to interact and underpin consumer and community engagement within health services. These are ‘Patient and Family-Centred Care’ and ‘Health Literacy’.
Search Strategy
A structured literature search was used to search widely across different sources of published literature. The search was conducted in January 2015. It examined relevant Australian and international studies and reports. The literature search was not intended to be systematic; it was structured to provide an account of the current evidence related to the search questions.

There were two parts to the search strategy. Part 1 was to locate examples of Australian health service consumer and community engagement strategies and plans, and Part 2 was to locate evidence for consumer and community engagement in health services and the methods used.

The search strategy had five stages:
1. The search engine Google was used to identify grey literature not traditionally published in the biomedical bibliographic databases.
2. The electronic Library data bases Scopus, Science Direct, and ProQuest were used to search the academic literature.
3. Reference lists of key publications identified in stage 1 and 2 were searched for key publications which required further examination.
4. A Literature Map was developed.
5. Where gaps were identified, more specific searches were conducted in the electronic library databases and search engine Google.

Thematic analysis was undertaken and key themes and sub themes were determined. A Literature Map was developed to organise the literature and build a visual picture of the themes as they emerged. Once the complexity of the scope of the emerging themes was determined, the decision was made to utilise a higher order structure for presenting the findings about methods of engagement based on a synthesis of the National Safety and Quality Health Service Standards (3). Additional references were sought to contribute to the depth of evidence and examples provided. A total of 161 references were included in the literature review.

Findings
The literature review revealed that there are complex and inter-related concepts, approaches and methods related to consumer and community engagement in health services that are relevant to WCHN as they consider the development of a Consumer and Community Engagement Strategy.

The following themes and sub-themes emerged from the thematic analysis of the literature:
1. Need for conceptual clarity
   - Principles of Engagement
   - Levels of Engagement
   - Organisational Domain of Engagement
   - Clarity about Terminology
2. Barriers to active consumer and community engagement in health services

Due to the complexity and diversity of literature about the evidence and methods relevant to health services, a higher order structure was developed. This higher order structure is based on a synthesis of the National Safety and Quality Health Service Standards and was used as the framework to present the findings (3):
- Partnerships in direct care
- Partnerships in organisational design and governance
A third theme of ‘Organisational requirements to support consumer and community engagement’ was identified. There are a number of sub themes which the Australian Commission on Safety and Quality in Health Care have identified as foundational organisational requirements to support partnerships with consumers and the broader community (3).

- Leadership and strategic vision
- Governance framework
- Skilled and informed workforce
- Environment (physical and policy)
- Evaluation and monitoring
- Access to records.

It was beyond the scope to address each of these organisational requirements in this literature review. Skilled and informed workforce will be the focus of a separate scoping paper to be developed further into the WCHN project. This will inform the staff training program to be developed.

However, some relevant points were raised to support the need for developing these organisational requirements to sustain and support consumer and community engagement. Many health services fail to adequately attend to these foundational issues and consumer and community engagement can result in a series of ad hoc, unauthentic, and disconnected activities.

Due to the complexity and detail provided in the findings, only the key themes and sub-themes will be identified in the Executive Summary for Partnerships in Direct Care and Partnerships in Organisational Design and Governance.

**Partnerships in Direct Care**

There is strong evidence on the effectiveness for methods of engagement at the direct care level. These are methods that enable the individual consumer and their carers/family to be involved in shared decision making processes around direct care.

Based on the synthesis of the NSQHS Standards, the following key themes and sub themes were identified and used to provide the framework to discuss the evidence and methods of engagement for Partnerships in Direct Care:

- **Shared decision making**
- **Participation in communication processes and open disclosure**
  - Communication and ward rounds
  - Communication and bedside handover
  - Communication and open disclosure
- **Information provision**
  - Printed information
  - Electronic media (including social media)
  - Interpersonal Communication

**Partnerships in Organisational Design and Governance**

It is strongly argued that consumers and community have a role to play in shaping the strategic direction, operational planning and organisational processes in health services. There is strong evidence showing that the involvement of consumers in planning, delivery, monitoring and evaluation can make a positive impact in these areas, as well as on the attitudes of health professionals and managers (4-6).
There is also strong evidence that demonstrates that consumer and community engagement has contributed to changes in the provision of health services through involvement in planning and development, and shows how consumers and community members can effectively contribute to decision making to shape the strategic direction, operational planning and organisational processes of health services through various methods (4, 5).

Key themes and sub themes identified in Partnerships in Organisational Design and Governance are:

- **Organisational Governance**
  - The nine sub themes addressed in this section are:
    - Functional Organisational Chart mapping
    - Formal Organisational Committee Structures
    - Partnering for Hospital Design and Building Initiatives
    - Determining and Embedding Consumer Centred Values
    - Experience-Based Co-Design Method
    - Open Access Board Meetings
    - Community Collaborative – Implementing Policy-Relevant Programs
    - Community Level Methods
    - Consumer Engagement Population-Level Interventions.

- **Safety and Quality Improvement**
  - The six sub themes addressed in this section are:
    - Methods to engage children and young people in safety and quality improvements
    - Consumer Feedback and Complaints Management
    - Consumer Stories
    - Real Time Feedback
    - Quality of Care Reports to the Community
    - Consumers Involvement in Staff Selection.

- **Review and Development of Information**
  - The three sub themes addressed in this section are:
    - Need for Strategic and Coordinated Approach
    - Good Practice Guidelines
    - Methods for Engaging Consumers.

- **Partnerships which Reflect the Community and Support People from Diverse Groups and Vulnerable Populations**
  - The three sub themes addressed in this section are:
    - Strategic Approach
    - Cultural Safety and Formalising Links with Community Groups and Organisations
    - Community Development Approach.

- **Supporting and Informing Consumers who Partner with the Health Service**
  - The three sub-themes addressed in this section are:
    - Consumer Training
    - Support and Capacity Building
      - Strategic Leadership
      - Facilitator/Coordinator Support
      - Mentoring
      - Reimbursement.
- Communicating with Consumers
  - Develop a Database
  - Develop and Implement a Communication Plan.

## Conclusion

The literature on consumer and community engagement in health services is extensive. There were complex and inter-related concepts, approaches and methods identified in the literature review. The challenge was to identify the best evidence to support the development of a Consumer and Community Engagement Strategy, which would meet NSQHS Standards and enable meaningful and authentic engagement of consumers and community in partnerships in direct care and partnerships in organisational design and governance.

Whereas the evidence to support consumer and community engagement in direct care and organisational design and governance is compelling, there were few comparative studies and evaluations of consumer and community engagement methods that would be transferable to all health service contexts. Whilst valuable and informative, much of the literature about methods of consumer and community engagement in health services did not provide the level of evidence required to conclusively and definitively provide a strong evidence base for the development of the WCHN Strategy. Instead there are a range of options for WCHN to consider, some of which have a strong evidence base, some are evaluated and may be transferable, others are descriptions of what other health services have found useful and published an account of, and others are guidelines to guide practice. A key finding is that consumer and community engagement methods are often context specific and there is no ‘one size fits all’ approach to consumer and community engagement.

An exciting opportunity exists for WCHN to utilise this literature review as a spring board for ideas as they move forward to strengthen consumer and community engagement. However, this is underpinned by another key finding, which is that effective, meaningful, and sustainable consumer and community engagement will only be achieved if the appropriate organisational attributes and processes are in place.
Introduction
The Women’s and Children’s Health Network (WCHN) in South Australia has commissioned this literature review. This is for the purpose of informing the development of their Consumer and Community Engagement Strategy. The aim is to base decision making about the development of the Strategy on best available evidence and insights into effectiveness of consumer and community engagement strategies in health services.

Consumer and community engagement in health services has been a priority in international and national policy for several decades. Consumer and community engagement offers a promising pathway toward better quality health care, more efficient health care and service provision, and improved population health (1).

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Various commentators in their deliberations about the complexities of consumer and community engagement in practice have discussed the different range of factors for health services to consider when developing approaches to consumer and community engagement activities. They represent the multiple contexts in which engagement activities take place (2).

- Unstructured      Structured
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Gregory (2008) states that there is no ‘one size fits all’ approach to consumer and community engagement (1). Methods and techniques should be selected in response to the issues being addressed. Different methods and techniques will be needed at different stages and multiple approaches to engagement will be necessary for health services to be effective in their engagement strategies (1).

Two overarching conceptual models appear to interact and underpin consumer and community engagement within health services. These are ‘Patient and Family-Centred Care’ and ‘Health Literacy’.

Patient and Family Centred Care
Consumer and community engagement in health services is based on a model of care and service delivery that is responsive to the perspectives, needs and values of the consumers and communities served by the health service. It is an approach to care and service delivery where ‘the needs of the patient come first’ (7).
The various models identified in the literature were, ‘person-centred care’, ‘patient-centred care’, ‘consumer-centred care’, ‘family-centred care’, ‘partnership-in-care’, ‘patient and family-centred care’. These are often used interchangeably in different health care settings and underpin contemporary health care policy, management and clinical care. These models of care are described as both a method of care delivery and a philosophy that value the vital role the patient and family play (8).

In Australia, a patient and family-centred approach is supported by the Australian Charter of Healthcare Rights, the Australian Safety and Quality Framework for Health care, and National Safety and Quality Health Service Standards (9). In South Australia patient and family-centred approach is supported by a Policy Directive: Framework for Active Partnerships with Consumers and Community (10).

From a medical ethics perspective, patient and family-centred care fulfils health care professionals’ and the health services’ obligations to place the interest of the patient within the family context above all else (11). Families are seen as a vital part of the care experience, especially in the care of children, young people, and maternity care. Families can have a profound influence on the individual patients health and well-being and should be viewed by health professionals, policy makers and health service managers as essential partners in care and co-designers of care, rather than having less important perspectives, or being hindrances or nonentities (11, 12).

Patient and family-centred models require health professionals and health service managers to shift from a position of ‘care-prescriber’ and ‘we know best, we are the experts’ to one of ‘collaborator’ and working in partnership with the patient and family (8, 13). In addition, Luxford (2013) argues that these models of care are a shift from provider-focused ‘paternalism’, to ‘patient empowerment’ (14). These models also require patients and families to change from being passive recipients of care, to be more actively involved in care, and decision making around that care (13).

Models of care, such as of ‘family-centred care’ and ‘partnership-in-care’ began to underpin paediatric care up to four to five decades ago, with varying degrees of commitment to application in health services over that time (8, 15). Lack of clarity and a common understanding of the concepts such as partnership-in-care and family-centred care have resulted in the varying extent to which these models have consistently been applied in practice (8, 16).

Key attributes of family-centred and partnership-in-care are:
- valuing the patient and family’s knowledge and experiences;
- supporting the family in their role as care-giver; and
- incorporating the patient and family’s expertise into clinical and psychosocial care (8).

Key strategies for building patient and family centred care into a health service include:
- regular monitoring and reporting of patient feedback data
- engaging patients, families and carers as partners
- demonstrating committed senior leadership
- building staff capacity and a supportive work environment
- establishing performance accountability
- supporting a learning organisation culture (17).

A synthesis of studies by Curtis-Tyler (2011) identified that the key ‘levers’ to patient-centred care with children include (15):
- engaging with children’s expertise about their own lives; their personal and social experiences in their care, including how these are affected by their relative lack of power in some settings;
- exploring children’s understandings and preferences in terms of their physical sensations and day-to-day experiences;
- willingness to find resources to engage with even the youngest children; and
- avoiding age-based assumptions about children’s contributions to their care.

Curtis-Tyler concludes that action by health professionals on these ‘levers’ may present a range of challenges as they represent a shift away from the historical focus of children developing competencies to engage, to a focus on children’s social realities from the earliest ages (15).

Patient and family-centred care is one of the six quality aims for improving care. It is recognised as a dimension of high quality care in its own right (17). Studies have found that patient and family-centred care improves clinical outcomes, decreases costs, and provides the opportunity for shared decision-making (11).

Shields et al. (2012) report on their Cochrane systematic review that assessed the effects of family-centred models of care for hospitalised children. They identified that there was a lack of randomised trials on which to compare results. However, the studies that met the inclusion criteria suggest some benefits of a family-centred care, such as higher standard of care provided, lower costs, and increased parental satisfaction. There was no evidence of harms (18).

**Health Literacy**

Health literacy of consumers is integral to the effectiveness of consumer and community engagement, especially in the delivery of high quality and appropriate care and improving the safety and quality of health services and the health system (19, 20). Health literacy involves the ability to read, understand, evaluate and use health information to make appropriate decisions about health and health care. Low health literacy is associated with health inequalities, and people with low health literacy tend to have poorer health and a greater risk of hospitalization (21).

The need for health consumers and the community to be ‘health literate’ in today’s society is greater than ever before. Health consumers are required to participate in more complicated preventative health care and self-care regimes, understand more complex health information to make decisions and take action, navigate more complex health systems, and have input into improving the safety and quality of health services (22). The Australian Commission on Safety and Quality in Health Care separates health literacy into two areas (23).

- **Individual health literacy** is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action (23).

- **Health literacy environment** is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way that people access, understand, appraise and apply health-related information and services (23).

Health literacy is the junction between general literacy, health, and health care but also can incorporate aspects of the other types of literacies (such as traditional (general) literacy, media literacy, information literacy, computer literacy, and scientific literacy) to varying degrees (22).
Health literacy is important for consumers as it affects their capacity to make decisions and take action to manage their health and access health services (24).

Health literacy is a significant issue for Australia. The Australian Bureau of Statistics (2008) identified that nearly 60% of adult Australians have low individual health literacy (25). Low individual health literacy is associated with higher use of health services, low levels of knowledge among consumers and poorer health outcomes (21). Strong international evidence shows the negative relationship between health literacy and a health consumer’s ability to function within health care settings, as well as the ability to understand prescriptions and diagnoses, chronic disease management and provide informed consent (24).

There is a need for health services to consider ways to improve health literacy of consumers and the community as part of a consumer and community engagement strategy (24). Health literacy is linked integrally to the National Safety and Quality Health Service Standards (NSQHS). There are a range of actions that require health services to working closely with consumers in the delivery, planning and evaluation of health care and services to ensure that the health service delivers care and services in a way that is understandable and that meets the needs and preferences of consumers and the community (24).

To address health literacy in a coordinated way, it is necessary for health services to:
- Embed health literacy into high-level organisational policies and practices.
- Ensure that health information is clear, focused and useable, and that interpersonal communication is effective.
- Integrate health literacy into education for consumers and health professionals (24).

Health literacy interventions have three key objectives:
- to provide information and education,
- to encourage appropriate and effective use of health care resources, and
- to tackle health inequalities (26).
Search Strategy
A structured literature search was used to search widely across different sources of published literature. The search was conducted in January 2015. It examined relevant Australian and international studies and reports. The literature search was not intended to be systematic; it was structured to provide an account of the current evidence related to the following range of search questions.

There were two parts to the search strategy. Part 1 was to locate examples of Australian health service consumer and community engagement strategies and plans, and Part 2 was to locate evidence for consumer and community engagement in health services and the methods used.

Part 1: Consumer and community engagement strategies and plans

Search Question 1
What Australian health service consumer and community engagement strategies and plans are publically available, how are they structured, and how do they relate to National Accreditation Standards?

Type of information required
Examples of consumer and community engagement strategies developed in the past three years by Australian health services.

Resources to Search
Search engine - Google
Children’s Health Care Australasia (CHA)

Review Process
Strategy documents were compared and contrasted for structure, conceptual frameworks used and content. A separate summary document was prepared for the Project Management Group and the Project Advisory Group. Information about conceptual frameworks has been integrated into the literature review in the findings section. This is part of the discussion about the ‘Need for Conceptual Clarity’.

Part 2: Evidence for consumer and community engagement in health services and the methods used

Search Question 1
What internationally published strategies for consumer and community engagement in have been effective for involvement in:

- Health service governance?
- Health service planning and design?
- Health service evaluation/monitoring?
- Health service safety and quality?

Search Question 2
Are social media and web-based strategies effective for consumer engagement by health services?
Search Question 3
What practices increase engagement at point of care?

Search Question 4
What are effective strategies for engaging children and young people?

Stages of the Search Strategy
The search strategy had five stages:
1. The search engine Google was used to identify grey literature not traditionally published in the biomedical bibliographic databases.
2. The electronic Library data bases Scopus, Science Direct, and ProQuest were used to search the academic literature.
3. Reference lists of key publications identified in stage 1 and 2 were searched for key publications which required further examination.
4. A Literature Map was developed.
5. Where gaps were identified, more specific searches were conducted in the electronic library databases and search engine Google.

Search Terms
The review utilised the following concepts to guide the search strategy. Combinations of concepts were used as search terms for the structured literature review.

<table>
<thead>
<tr>
<th>Concept 1 - Population</th>
<th>Concept 2 – Issue</th>
<th>Concept 3 – Organisational Setting/strategies</th>
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<tbody>
<tr>
<td>Consumer</td>
<td>Participation</td>
<td>Health service governance</td>
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<td>Community</td>
<td>Engagement</td>
<td>Health service planning and design</td>
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<td>Patient</td>
<td>Involvement</td>
<td>Health service evaluation/monitoring</td>
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<td>Women</td>
<td>Experience</td>
<td>Health service safety and quality</td>
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<td>Parent</td>
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<td>Web-based strategies</td>
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Definitions
When conducting the literature search, the following definitions were used from SA Health Policy: A Framework for Active Partnerships with Consumers and Community (10):

- **Consumers:** patients and potential patients, carers and organisations representing consumers’ interests. When referring to consumers, SA Health is referring to patients, consumers, families, carers and other support people.
- **Carer:** a family carer is someone who provides care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness.
- **Consumer advocate**: a person who advocates the consumer perspective and has the requisite experience to speak as an informed consumer.

- **Community**: Refers to groups of people or organisations with a common interest, including nongovernment organisations who represent the interests of health consumers. While some communities may connect through a local or regional interest in health, others may share a cultural background, religion or language. Some communities may be geographically dispersed but linked through an interest in a specific health issue by the internet, or some other means.

- **Consumer engagement**: informs broader community engagement. Health consumers actively participate in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels.

- **Community engagement**: refers to the connections between government, communities and citizens in the development and implementation of policies programs, services and projects. It encompasses a wide variety of government-community interactions ranging from information sharing to community consultation and, in some instances, active participation in government decision making. It incorporates public participation, with people being empowered to contribute to decisions affecting their lives, through the acquisition of skills, knowledge and experience.

- **Consumer Advisory Group**: an advisory group established by a health care service which compromises of consumers and / or carers including those from diverse and hard-to-reach groups who use the organisation’s services. The consumer advisory group provides a structured partnership between consumers and / or carers and the health care service on safety and quality issues, patient experiences, consumer centred care and other issues identified in its terms of reference.

- **Consumer group**: group of consumers, carers and / or healthcare providers with experience and / or expertise relevant to your health care service. The group is convened to provide advice and feedback to your healthcare organisation on specific issues, including safety and quality improvement activities, patient experience and consumer centred care.

- **Consumer nominee**: a person nominated by a consumer organisation or group for consideration for appointment by the requesting body.

- **Consumer representative**: a person who represents a consumer organisation or group and is authorised to speak on behalf of that organisation or group, making them accountable to and responsible for reporting back to that organisation or group.

- **Consultation**: a method to engage early with consumers and/or community to obtain feedback on issues, analysis, alternatives and decisions being considered by SA Health. It should be considered as part of an engagement process.

**Inclusion Criteria**
- Relevant to search questions
- Available in English language
- Years 2007 – 2015 (except if deemed important to include)
- Full text available
- From a credible source (refereed journal preferred and Government websites)
- Journal articles reporting original research and/or conceptual frameworks/models
- Non-original or summarised literature (systematic and non- systematic literature reviews, critiques and commentaries)
- Research reports
- Evaluations of participation methods and activities.

**Management of Information**
References were entered into EndNote and e-publications saved to an electronic database in a specific Folder.
Rationale for the approach used
A structured literature review was utilised. Literature was searched for across different sources of published literature. A structured literature review differs from a systematic review in that there were no judgements made of the grade or quality of the evidence, or to assess if the results were generalisable (except where comments were made by the original authors). The reasons for taking this approach were in part due to the nature of the evidence, and to respond to the search questions.

Identifying potentially relevant publications
Initially 10,008 potentially relevant articles were identified. Titles and abstracts of published journal articles, or the executive summary of reports, were visually scanned to ascertain if they contained information that would meet the inclusion criteria.

Review and Analysis Process
When the information outlined in the abstract or executive summary appeared to be relevant to the search questions, the full text of the publication was sourced, downloaded, printed and reviewed. A total of 204 references were downloaded, printed and reference details entered into EndNote. Further examination of the full text of each publication was conducted.

Thematic analysis was undertaken and key themes were determined. A Literature Map was developed to organise the literature and build a visual picture of the key themes as they emerged as the literature was reviewed. Once the complexity of the scope of the emerging themes was determined, the decision was made to utilise a higher order structure for presenting the findings about methods of engagement based on a synthesis of the National Safety and Quality Health Service Standards (3). Additional references were sought to contribute to the depth of evidence and examples provided. A total of 161 references were included in the literature review.

Limitations
There were a number of limitations to the literature review:

1. The extensive literature on consumer and community engagement is dispersed across a wide range of publications types.
2. The concepts identified above do not tend to sit easily with MeSH terms, which are used for searching in many of the academic library databases. When initial attempts were made to search by matching the concepts to MeSH terms the search revealed massive amounts of references but very few relevant articles. Only academic library databases which enabled searching for the above search terms could be used (e.g. Scopus, Science Direct, and ProQuest). This was on the advice of the Health Specialist Librarian at Flinders University Library.
3. There were few published evaluations of consumer and community engagement methods and activities. The evaluations that were found were mainly process evaluation or descriptive in nature. Comparative studies were hampered by lack of consistent evaluation frameworks. This was due to contextual issues such as variations in:
   - Terminology used
   - Conceptual frameworks used
   - Methodologies used.
4. Much of the literature identified was ‘grey literature’ which was found through the search engine Google. These consisted of government publications which were either guidelines for health services, or were literature reviews to support policy directions.
Terms Used in the Findings of the Literature Review
The terms ‘consumer’ and ‘community’ will be used throughout the report on the findings of the literature review to refer to:

- People
- Patients
- Users, service users or potential service users
- Public
- Citizen
- Lay people
- Carers
- Survivors
- Clients
- Informants and key informants

The use of the terms ‘consumer and community’ in the report is to aid the flow of the literature review and to avoid the potential of confusing the reader by using different terminology. Where direct quotes have been included, the terms used by the original authors will be used.

In addition the term ‘engagement’ will be used throughout the report on the findings of the literature review to refer to ‘activation’, ‘experience’, ‘involvement’ and ‘participation’. Where direct quotes have been included, the terms used by the original authors will be used.
Findings

The literature review revealed that there are complex and inter-related concepts, approaches and methods related to consumer and community engagement in health services that are relevant to WCHN as they consider the development of a Consumer and Community Engagement Strategy.

The following themes and sub-themes emerged from the thematic analysis of the literature:

1. Need for conceptual clarity
   - Principles of Engagement
   - Levels of Engagement
   - Organisational Domain of Engagement
   - Clarity about Terminology

2. Barriers to active consumer and community engagement in health services.

Due to the complexity and diversity of literature about the evidence and methods relevant to health services, a higher order structure was developed. This higher order structure is based on a synthesis of the National Safety and Quality Health Service Standards and these themes are used as the framework to present the findings (3):

- Partnerships in direct care
- Partnerships in organisational design and governance
- Organisational requirements to support consumer and community engagement

Need for Conceptual Clarity

The literature, and the examples of Australian health service consumer and community engagement strategy documents, revealed that many different terms and concepts are used as part of conceptual frameworks for consumer and community engagement strategies in health services. There was a lack of clarity. Clarity of conceptual framework is important as it provides the overarching structure for the understanding and practice of consumer and community engagement in health services.

The concepts that made up the most comprehensive frameworks in the literature related to:

- Principles of Engagement
- Levels of Engagement
- Organisational Domain of Engagement

Different terminology was used to describe these concepts, so for clarity and consistency the above headings will be utilised in presenting the findings in the Literature Review. These will be each discussed separately to provide insights into the range of options available for WCHN to consider. In addition a new Engagement Cycle is presented for consideration.

Principles of Engagement underpin the conceptual framework and will be presented first.

Principles of Engagement

Principles of consumer and community engagement underpinned several health services frameworks for consumer and community engagement strategy, and the SA Health policy. The principles underpin consumer and community engagement practices and are a way of holding health services accountable for the way they approach consumer and community engagement. There appeared to be several ways of utilising principles to underpin frameworks. Some health services
(27) utilised the IAP2 Code of Ethics (28) as their principles of their ‘Promise to the Community’. A health service (29) developed their own principles to meet the Convention on the Rights of the Child (30). Other health services have adapted existing principles such as those from the OECD (31). SA Health (10) have included principles in their Policy directive based on the Australian Safety and Quality Framework for Healthcare (32).

Deitz discusses transforming health care for children and their families (33). He argues strongly for the number one principle to be ‘Empathy’ when engaging with people in health services, especially with children and families. Empathy is not incorporated in any of the examples of Principles of Engagement identified in the literature search.

Sarrami Foroushani (2012) identified in their meta-analysis of the literature that ‘shared decision making’ was an underlying principle of consumer and community engagement and that it relates to all domains of engagement. However, shared decision making, was not incorporated as a stated principle in any of the examples of Principles of Engagement identified in the literature search (34). In some examples, shared decision making is incorporated as a component of patient-centred care.

The Lucian Leape Institute (2015) strongly support ‘transparency’ as a fundamental principle of health care provision and consumer engagement (35). Transparency was not incorporated in any of the examples provided, but ‘openness’ was included in one of the examples.

The following provide a range of examples of the Principles of Engagement from SA Health, Children’s Health Queensland Hospital and Health Service, OECD and IAP2. There are similarities between some examples, such as the inclusion of the principles ‘Partnership’, ‘Patient Centred Care’, ‘Engagement/Participation’, ‘Support’, ‘Diversity’, ‘Rights’, and ‘Continuous Improvement’. However, most of the documents contain many different and varied principles of engagement.

There was no research literature located that could provide evidence that having Principles of Engagement had an impact on the way consumer and community engagement was enacted within health services. Nor was there any evidence to determine which set of principles of engagement would provide the most effective principles to underpin a conceptual framework.

**SA Health Framework Principles**

The Principles in the SA Health Policy Framework (2012) (10) are based on the Australian Safety and Quality Framework for Healthcare (32). SA Health emphasise that these principles are consumer centred, driven by information and organised for safety.

<table>
<thead>
<tr>
<th>Principle 1 – Partnership</th>
<th>Principle 7 – Access and information</th>
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<tbody>
<tr>
<td>Partnering with consumers and the community to design the way care is delivered to better meet patient needs and preferences. Consumers and the community engage with the health care service organisations in the strategic and/or operational planning for the organisation, as equal partners.</td>
<td>Consumers and the community have a right to access and receive information and education about their health and wellbeing in a way that meets their individual needs, and is a form that the consumer understands.</td>
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<tr>
<th>Principle 2 – Engagement</th>
<th>Principle 8 – Support</th>
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<td>Consumers and the community are actively encouraged in decision making about improving the consumer experience, safety and quality and service improvement.</td>
<td>Consumers and the community are provided with support they need to engage with the healthcare system. This requires a workforce with expertise in</td>
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**Principle 3 – Patient and consumer centred care**

Patient and consumer centred care is healthcare that is respectful of, and responsive to the preferences, needs and values of patients, consumers and the community, with dimensions including respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care. This means:

- treating patients, consumers, carers, families and the community with dignity and respect
- encouraging and supporting engagement in decision making by patients, consumers, carers, families and the community
- communicating and sharing information
- fostering collaboration with patients, consumers, carers, families, the community and health professionals in program and policy development, and in health service design, delivery and evaluation.

**Principle 9 – Charter of Health and Community Services Rights**

Consumers and the community are aware of their rights and:

- that a person should be entitled to participate effectively in decisions about his or her health, well-being and welfare;
- that a person should be entitled to take an active role in his or her health care and in decisions about the provision of health or community services to the person;
- that a person should be entitled to be provided with appropriate health or community services in a considerate way that takes into account his or her background and any requirements that are reasonably necessary to ensure that he or she receives such services;
- that both professional and non-professional providers of health and community services should be given consideration and recognition for their contribution to health care and the well-being and welfare of individuals’
- that a person should be entitled to obtain reasonable access to records concerning his or her health or other personal information relating to the person (taking into account what is appropriate and reasonable in the circumstances of a particular case), but that otherwise the confidentiality of such information should be maintained
- that a person should be entitled to have access to procedures for dealing with complaints about the provision of health or community services.

**Principle 4 – Diversity**

Partnerships are reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people who do not usually provide feedback. The

**Principle 10 – Continuous improvement, measuring and evaluation**

Consumers and the community participate in continuous improvement activities, including the collection, analysis and reporting of safety and
health service engages with individuals and groups including Aboriginal and Torres Strait Islander people, people with a disability, older adults, young people, people with a mental illness and people from cultural and linguistically diverse backgrounds.

**Quality and other performance measures, the results of which are interpreted and communicated in plain language and design.**

**Principle 5 – Feedback and consumer experience**
Consumers and the community provide feedback about their experience and participate in the evaluation of patient information data and develop action plans. Consumers and the community are engaged in the planning and implementation of quality improvements.

**Principle 11 – Consumers and the community, and research and evaluation**
Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind.

**Principle 6 – Empower consumers and the community to be equal partners in care and treatment**
Consumers and the community are empowered to improve the safety and quality of health care and partner with healthcare professionals.

**Children’s Health Queensland Hospital and Health Services Principles of Engagement**
Children’s Health Queensland Hospital and Health Services (2012) have 9 principles included in their consumer and community engagement strategy (29). They aim to undertake community engagement activities that:

- encourage and respect consumer and community engagement
- are meaningful to consumers/community according to directions established by the CHQHHS
- empower staff through training and education to enable effective dialogue
- establish engagement systems and processes that are sustainable
- collaborate with a shared vision and mutual trust among all people involved
- evaluate outcomes against goals.

Children’s Health Queensland Hospital and Health Services state that ‘this approach acknowledges the United Nations Convention on the Rights of the Child: Children have the right to the best possible care, to be listened to, to have their thoughts and feelings understood and to be loved and cared for by others’ (30). The 9 Principles of Engagement are:

<table>
<thead>
<tr>
<th>Principle 1: Participation</th>
<th>Principle 6: Mutual respect and value</th>
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<tr>
<td>Consumers and community participate and are involved in decision making about the health care system.</td>
<td>Engagement is undertaken with mutual respect and valuing of each other’s experiences and contributions.</td>
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<tr>
<th>Principle 2: Person-centred</th>
<th>Principle 7: Support</th>
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<tbody>
<tr>
<td>Engagement processes are consumer and community centred</td>
<td>Consumers and community are provided with the support they need to engage meaningfully with the health care system.</td>
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<th>Principle 3: Accessible and inclusive</th>
<th>Principle 8: Influence</th>
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<tbody>
<tr>
<td>Needs are considered to enhance accessibility</td>
<td>Consumer and community engagement</td>
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and inclusion of consumers and community who may experience barriers to engage effectively. influences health policy, planning and system reform, and feedback is provided about how the engagement has influenced outcomes.

### Principle 4: Partnership
Consumers, community and health service organisations work in partnership.

### Principle 9: Continuous improvement
Consumer and community engagement is reviewed and evaluated to drive continuous improvement.

### Principle 5: Diversity
The engagement process values and supports diversity of consumers and community.

### OECD Principles of Public Engagement
The OECD (2009) recommend 10 principles to underpin consumer and community engagement practice (31). Their focus is on policy and services. These principles have been widely used within the literature and adapted to the relevant setting.

| Principle 1: Commitment: Leadership and strong commitment to open and inclusive policy making is needed at all levels – politicians, senior managers and public officials. |
| Principle 6: Resources: Adequate financial, human and technical resources are needed for effective public information, consultation and participation. Government officials must have access to appropriate skills, guidance and training as well as an organisational culture that supports both traditional and online tools. |
| Principle 2: Rights: Citizens’ rights to information, consultation and public participation in policy making and service delivery must be firmly grounded in law or policy. Government obligations to respond to citizens must be clearly stated. Independent oversight arrangements are essential to enforcing these rights. |
| Principle 7: Co–ordination: Initiatives to inform, consult and engage civil society should be coordinated within and across levels of government to ensure policy coherence, avoid duplication and reduce the risk of “consultation fatigue.” Co-ordination efforts should not stifle initiative and innovation but should leverage the power of knowledge networks and communities of practice within and beyond government. |
| Principle 3: Clarity: Objectives for, and limits to, information, consultation and public participation should be well defined from the outset. The roles and responsibilities of all parties must be clear. Government information should be complete, objective, reliable, relevant, easy to find and understand. |
| Principle 8: Accountability: Governments have an obligation to inform participants how they use inputs received through public consultation and participation. Measures to ensure that the policy-making process is open, transparent and amenable to external scrutiny can help increase accountability of, and trust in, government. |
| Principle 4: Time: Public engagement should be undertaken as early in the policy process as possible to allow a greater range of solutions and to raise the chances of successful implementation. Adequate time must be available for consultation and participation to be effective. |
| Principle 9: Evaluation: Governments need to evaluate their own performance. To do so effectively will require efforts to build the demand, capacity, culture and tools for evaluating public participation. |
| Principle 5: Inclusion: All citizens should have equal opportunities and multiple channels to | Principle 10: Active citizenship: Societies benefit from dynamic civil society, and |
access information, be consulted and participate. Every reasonable effort should be made to engage with as wide a variety of people as possible

governments can facilitate access to information, encourage participation, raise awareness, strengthen citizens’ civic education and skills, as well as to support capacity-building among civil society organisations. Governments need to explore new roles to effectively support autonomous problem-solving by citizens, CSOs and businesses.

IAP2 Code of Ethics

IAP2 Code of Ethics is a set of 10 principles which guides the practice of enhancing the integrity of the public participation process (28). Some health services utilised these as the principles for their ‘Promise to the Community’, others utilised them as the Principles of Engagement in their strategy.

1. Purpose. We support public participation as a process to make better decisions that incorporate the interests and concerns of all affected stakeholders and meet the needs of the decision-making body.

6. Access to the Process. We will ensure that stakeholders have fair and equal access to the public participation process and the opportunity to influence decisions.

2. Role of Practitioner. We will enhance the public's participation in the decision-making process and assist decision-makers in being responsive to the public's concerns and suggestions.

7. Respect for Communities. We will avoid strategies that risk polarising community interests or that appears to "divide and conquer."

3. Trust. We will undertake and encourage actions that build trust and credibility for the process among all the participants.

8. Advocacy. We will advocate for the public participation process and will not advocate for interest, party, or project outcome.

4. Defining the Public's Role. We will carefully consider and accurately portray the public's role in the decision-making process.

9. Commitments. We ensure that all commitments made to the public, including those by the decision-maker, are made in good faith.

5. Openness. We will encourage the disclosure of all information relevant to the public's understanding and evaluation of a decision.

10. Support of the Practice. We will mentor new practitioners in the field and educate decision-makers and the public about the value and use of public participation.

Levels of Engagement

This concept was represented by different terminology in the publications reviewed. However, the common theme was that there are different ways of engaging with consumer and communities and there are increasing opportunities for engagement along the spectrum or continuum. To enhance clarity of the concept in this Literature Review these examples will be categorised under the heading of 'Levels of Engagement'.

Arnstein’s Ladder of Participation (1969) is the original conceptual model that classified participation, which has inspired other models to be developed (36). Arnstein’s Ladder is still widely used in the consumer and community engagement literature, and consumer and community engagement strategies by some health services. However, Bishop and Davis (2002) state that such a model is problematic as it is based on power relationships alone, and as such makes value
judgements (37). Several commentators argue that this type of hierarchical model over-simplifies engagement in terms of the power relationship held between two parties e.g. health professionals and consumers/community. Moreover, some commentators state a hierarchical model does not sit well with many health professionals whose expertise appears to be downgraded (37-39).

Since Arnstein’s Ladder of Participation was published, many different models have been developed which approach participation as a continuum of management techniques and as a discontinuous interaction. Shand and Arnberg’s Participation Continuum was one of the first models of this genre, and has since been adapted and further developed by other researchers and practitioners (37). A critique by Bishop and Davis (37) states that the continuum of management technique model and the model of discontinuous interactions both offer a set of choices for engagement with each having its own purpose and set of practices for that level of engagement.

The four most common models referred to in the literature, which can be categorised as a continuum of management technique or discontinuous interactions, will be briefly described. These will provide insight into the range of Levels of Engagement models which can be considered. There was no research literature located that could provide evidence that one model was more effective than another.

**IAP2 Spectrum**

The International Association for Public Participation (IAP2) spectrum of levels of participation is commonly referred to in the literature (2007). The IAP2 spectrum goes from lowest to highest level of impact (40).

- **Inform** – to provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or structures.
- **Consult** – to obtain public feedback on analysis, alternatives and/or decisions.
- **Involve** – working directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.
- **Collaborate** – to partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.
- **Empower** – to place final decision-making in the hands of the public.

One of the differences and strengths of the IAP2 spectrum is that it includes the need to identify the ‘Promise’ to the participants/community.

**Three Levels of Engagement**

Gregory (2008) describes three levels of engagement and structures them into levels of low, medium and high levels of engagement (1).

- **Information**: one-way relationship. Active, where information is disseminated, and passive, where consumers and community members can access it upon demand.
- **Consultation**: two-way relationship. An issue is defined by decision makers and consumers and others are invited and consulted.
- **Participation**: consumers and community members are more actively engaged to define the issues and parameters of the issue(s) and how the participation is to occur. Input can be in setting the agenda, proposing options and sharing the overall dialogue.
Continuum of Engagement as part of a multidimensional framework for patient and family engagement in health and health care

Carman et al. (2013) propose three types of engagement in a continuum of engagement as part of a multidimensional framework for patient and family engagement in health and health care (41). These are:

- Consultation
- Involvement
- Partnership and Shared Leadership.

Carman et al. state that patient engagement can be characterised by how much information flows between consumer/community and health care provider/health service, how active a role the consumer/community has in care decisions, and how involved the consumer/community becomes in the decision making in the health service (41).

Continuum of Community Engagement

Bowen et al. (2010) analysed different types of community engagement strategies and developed a model which depicts a continuum of increasing community engagement (42).

The three levels on the continuum are categorised as:
- **Transactional** – is a passive role of receiving information (e.g. charitable donations, employee volunteering, and information sessions)
- **Transitional** – is a more active role where there is two-way communication, but the community is more a recipient than an equal partner (e.g. stakeholder dialogues, public consultations, and meetings).
- **Transformational** – there is shared decision making and the community has equal position (e.g. joint management, joint decision making, and co-ownership).

Organisational Domain of Engagement

Another concept, which forms an integral component to understanding consumer and community engagement in health services, is to distinguish the levels and type of engagement in health services/systems. This concept relates to the organisational domain in which consumers and communities can engage. There were six main models identified in the literature. Again the terminology differs in each example. For the purpose of clarity around this concept the examples will be grouped under the heading of ‘Organisational Domain of Engagement’. There was no research literature identified that could provide evidence that using one model for structuring consumer and community engagement in a health service was more effective than other.

Three Organisational Levels

Three levels of consumer and community engagement were described in the literature review by Sarrami Foroushani et al. (2012 p. 16) (34).

The three organisational domains are: Micro, Meso and Macro.

- **Micro**: consumer to clinician, direct where consumers are seen as experts/equal partners in the delivery of care: where consumers have an active role in assessing and directing the
quality and safety of their own or their family member’s care; and or where consumers directly participate in research.

- **Meso:** consumer an community engagement in service and information planning and delivery; in designing, directing or governing research including through ethics committees, in evaluating the effectiveness of services; and or in developing or direction information about health care issues.

- **Macro:** consumers are engaged as part of health system consumer councils; in state or country wide ethics committees and review mechanisms; in patient safety inquiries; on professional boards and bodies; in setting professional and service standards; and accreditation boards.

**Five Levels of Engagement**

Bruce et al. (2008) identified in their literature review that the five main levels of consumer and community engagement with the health system were (43):

- The individual care level
- Ward/program level
- Organisational level
- Government, predominately the health department level
- Community level.

**Scales of Participation**

SA Health (2012) identified four levels that consumers can engage within the health system (10). This was also utilised by Health Consumers Queensland (2012) in their guidelines for health services on developing a consumer and community engagement strategy (44).

- Individual
- Service Group Level/Work Unit Level
- Network
- System.

**Organisational Levels of Engagement**

Carman et al. (2012) identified three levels of engagement as part of their Multidimensional Framework for Patient and Family Engagement in Health and Health Care (41). The three levels of engagement are:

- Direct Care
- Organisational Design and Governance
- Policy Making.

**Three Domains of Engagement**

These three domains of engagement are based on the conceptual framework developed by Health Consumers Queensland (2012) (44, 45).

- **Consumer partnership in service planning** - Governance structures are in place to form partnership with consumers and/or carers.

- **Consumer partnership in designing care** - Consumers and/or carers are supported by the health service organisation to actively participate in the improvement of the patient experience and patient health outcomes.
Consumer partnership service measurement and evaluation - Consumers and/or carers receive information on the health service organisation's performance and contribute to ongoing monitoring, measurement and evaluation of performance for continuous quality improvement.

Synthesis of the National Safety and Quality Health Standards

The following model is a synthesis of the review of the 2011 National Safety and Quality Health Service (NSQHS) Standards, specifically Standard 2: Partnering with Consumers, and other standards which refer to aspects of consumer engagement (3). This model provides a useful segmentation of organisational activities/programs to consider for the Organisational Domains of Engagement. It was not identified in the literature search as being a model used for a consumer and community engagement strategy for a health service before, though all Australian health services with a consumer and community engagement strategy state that they aim to meet the NSQHS Standards.

The strengths of this model are:

1. that it will align with the revised NSQHS Standards, and
2. it includes the organisational requirements to support consumer engagement which are fundamental to the effectiveness and sustainability of consumers and community engagement in health services.

The organisational requirements, or foundational requirements, is a component missing from other domains of engagement models. It was evident in the literature that an organisational approach and mindset is required for consumer and community engagement to be effectively implemented and sustained in health services (1, 3, 6, 14, 34, 46, 47). In addition, it fits with ‘Health Literate Care Model’ with its focus on clarity and usability of information as part of direct care, engaging consumers and community in the review and development of information, and ensuring environmental factors are in place to support consumers to navigate the health service (48).

The three Organisational Domains of Engagement themes are identified below along with the areas of engagement from the relevant NSQHS Standards. These have been categorised under each of the Organisational Domains of Engagement.

- **Partnerships in Direct Care**
  - Shared decision making
  - Participation in communication processes and open disclosure
  - Information provision.

- **Partnerships in Organisational Design and Governance**
  - Organisational governance
  - Safety and quality improvement
  - Review and development of information
  - Partnerships which reflect the community and support people from diverse groups and vulnerable populations
  - Supporting and informing consumers who partner with the health service.

- **Organisational Requirements to Support Consumer and Community Engagement**
  - Leadership and strategic vision
  - Governance framework
  - Skilled and informed workforce
  - Environment (physical and policy)
A New Consumer and Community Engagement Framework – The Engagement Cycle

The Engagement Cycle is a new framework that can assist health services undertake meaningful consumer and community engagement for maximum impact. It has been developed by InHealth Associates in the UK (2013) (49).

Figure 1 The Engagement Cycle (49)

The Engagement Cycle is a different way of conceptualising consumer and community engagement. It identifies five purposes of engagement, represented as five different stages when people can be engaged in decisions:

- Working with communities (of geography and of interest) to identify needs and aspirations.
- Working with the public (as citizens and taxpayers) to plan and transform services.
- Working with patients and carers to design services and improve quality and safety.
- Working with patients and the public to procure and contract services.
- Working with patients and carers to monitor services and share learning.
For each of these five purposes, The Engagement Cycle provides simple advice on what to do in order to undertake high quality consumer and community engagement that will enhance and support the decisions of health services. Each stage of the cycle provides useful intelligence for the next. In order for the Engagement Cycle to work effectively, the hub of The Engagement Cycle focuses on developing the engagement strategy, culture and systems that turns engagement into everyday practice (49).

Clarity about Terminology
There were three areas identified in the literature which require clarity as a health service embarks on developing a consumer and community engagement strategy. These were the use of the terms: consumer and community, engagement, and the need for clarity about the role of consumer and community in health services.

Consumer and Community
In Australian academic literature and policy documents there appears to be a fairly consistent use of the terms consumer and community participation in health services. These terms have consistently been used in the health service policy documents and academic literature since the Consumer Focus Collaboration program, which was implemented by the Commonwealth Government in late 1990’s and early 2000 (50). However, there are many different terms used in the international literature. For example, service user, user, patient, public, and citizen. There is also concern about the interchanging of the terms consumer and community as they are different conceptually and pragmatically (51). Taylor et al. (2006) state that the notion of representative community verses individual consumer perspectives are often interchanged and lead to confusion and are barriers to participation for consumers and the community (51). The SA Health definitions referred to earlier in the Search Strategy section provide insight into the difference.

Consumer and Community Engagement
‘Engagement’ is a relatively new term used within the health literature. In Australia the term participation has been the main term used for about two decades. Consumer engagement informs broader community engagement. Health consumers actively engage as participants in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels (10, 44).

SA Health state that community engagement refers to the connections between government, communities and citizens in the development and implementation of policies, programs, services and projects. It encompasses a wide variety of government-community interactions ranging from information sharing to community consultation and, in some instances, active participation in government decision making. It incorporates public participation, with people being empowered to contribute to decisions affecting their lives, through the acquisition of skills, knowledge and experience (10).

Role of Consumers and Community
The use, or more specifically misuse, of the term consumer and community representatives and the issues of consumer perspectives, and representativeness of consumers and community members engaging within health services are frequently debated and contested issues within the literature.
It has been suggested that the tensions surrounding ‘representation’ have contributed to the delay in the evolution of consumer and community engagement in health services (52-54).

‘Representativeness’ has been criticised on the grounds that the consumer or community member who takes part in a health service cannot, and will not, be representative of all consumers or the community. In addition there is a concern commonly expressed that the more a consumer or community member takes part in engaging with health services, the more the consumer will become ‘professionalised’ and not be able to represent the views of consumers or the community. This is where consumers and community members see issues from the viewpoint of health professionals or health service managers, and not the consumer or community perspective (55). Hogg and Williamson’s (2001) observational study of ‘lay people’ involved in health service committees supports these assertions (56). They state that it is generally assumed that ‘lay members’ on committees are working for patients’ interests, but their observations identified that some lay people tend to support professionals’ or managers’ interests rather than patients’ interests.

Hogg and Williamson (2001) observed three broad categories of lay person’s representation:

- supporters of dominant (professional) interests
- supporters of challenging (managerial) interests
- supporters of repressed (patient) interests (56).

They argue that the different roles that ‘lay people’ play need to be explicitly defined in order for their contributions to be realised.

Beresford (2007) states that the issue of ‘representativeness’ is commonly confused with the need to address diversity in consumer and community engagement (57). He argues that other stakeholders are not expected to be ‘representative’ and generally they have no special mandate, so he questions why raise this particular argument in relation to the constituency that is most liable to be excluded (57). This view is also supported by Happell (2010) (53). Consumer and community perspectives, rather than consumer or community representativeness is advocated as a more suitable approach (58). Beresford et al. (1994) argue for the importance of health services seeking to be inclusive and address diversity in consumer and community engagement (59). Boote et al. (2002) and Happell (2010) also argue that ‘representativeness’ is not a one-sided issue and that a health professional is not necessarily representative of other health professionals in their field (53, 55). Hanley et al. (2000) argue that ‘it might be helpful to think about seeking consumer or community perspectives rather than consumer or community representativeness’ (60).

Boote et al. (2010) state that concerns about representativeness betrays to some extent health professionals’ epistemological, quantitative leanings; a viewpoint whereby consumers or community members engaging with health services ought to share similar characteristics to the ‘average’ demographic makeup of potential participants (61).

Robinson et al. (2010) state that providing a statistically representative sample of a target population is a concept traditionally associated with the positivist paradigm. They argue that such methods do not necessarily guarantee accurate representation (54).

Morrow et al. (2012) suggest that debates about consumer and community representation are very common in the literature, but the meaning of the term is rarely considered (62). Morrow et al. describe different forms of representation and stress that it is important to understand that representation and representativeness have different meanings. Morrow et al. (62) stress the importance of clarity about the different terminology used to depict the different forms of
representation. They have provided the following descriptions of the different forms of representation as a guide to health services and health researchers (see Box 1).

**Box 1 Forms of Representation** (62) p. 23

- **Democratic representation** – ‘One person one vote’, equally weighted voting
- **Proportional representation** – The use of shared or weighted votes to represent different groups
- **Statistical representation** – Could include selection, randomisation or controlled samples.
- **Representational membership** – Nominated or elected individuals represent the views of their candidacy
- **Representation by someone who is ‘typical’ of others** – An individual is nominated or identified because they are thought to share similar experiences or characteristics as others
- **Dispositional representation** – Individuals become or adopt representative roles by virtue of their job/organisational membership
- **Representation of shared interests** – Self-nominated representatives from groups on the basis of their shared interests
- **Representation of self** – Personal image, interests and decisions

A commonly used definition of a consumer representative in Australia is: a person who represents a consumer organisation or group and is authorised to speak on behalf of that organisation or group, making them accountable to and responsible for reporting back to that organisation or group (10, 63).

In Aboriginal and Torres Strait communities, and culturally and linguistically diverse communities, the issue of community representation is critical to respect the cultural and social practices (64, 65). When engaging with these communities, it is important to identify and work with community elders and leaders and develop relationships to enable different points of view to be heard and valued (66). Community elders and leaders are often formally recognised and designated spokespersons and the representative for a particular community. For individual health consumers from Aboriginal and Torres Strait communities, and culturally and linguistically diverse communities, to be asked to be a ‘consumer representative’ can be a barrier to participation as it can be seen as in conflict with their cultural and social practices around interpretations of representation (66).

Whereas it is widely acknowledged in the literature that consumer and community representatives have a significant role to play within health services, especially on committees, not all consumers or community members who participate in health services are representing a consumer organisation or a constituency, and as such should not be called representatives (67). Consumers or community members can be involved as individuals to provide their perspective, and at times provide advice on how health services can further engage with people from diverse backgrounds.

There are alternatives to the use of the terms consumer and community representatives provided by consumer organisations to health services (68). For example, Cancer Australia provides the following descriptions for health services to understand more clearly the different types of consumer roles. This provides a context for the appropriate engagement of consumer representatives, and the other types of roles that consumers can take on:

- **Partner**: Consumers are considered equal partners with essential knowledge for health reform, research and policy development and system change.
• **Expert**: Consumers participate on organisational boards or in high-level advisory committees or major projects and are invited for their high-level expertise as a consumer.

• **Advisor**: Consumers participate in government policy or health services to provide advice and to influence final decisions.

• **Advocate**: Consumers represent the broad views and experiences of a range of people affected by a disease/condition/issue.

• **Personal engagement**: Consumers actively participate from their personal perspective and provide feedback to services through sharing stories and participating in focus groups and targeted working groups.

It is important for health services to consider the purpose and role of consumers and community members and be clear about the type of role consumers or community members are required to play and the skills required to be able to engage effectively within the health service (68).

**Barriers to Active Consumer and Community Engagement in Health Services**

Many studies have identified a range of barriers to active consumer and community engagement in health services. The benefits of identifying barriers in the literature is that they can provide valuable lessons, and inform ways to avoid, address, or overcome these when implementing consumer and community engagement strategies in health services.

The most significant barriers identified in the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry by Francis (2013) that are relevant to the focus of this literature review are:

- An organisational culture focused on doing the system’s business – not that of the patients.
- There is no culture of listening to patients. The health service does not value feedback from consumers and does not act on negative feedback or complaints.
- Patients and family members feel excluded from effective participation in care.
- The concept of patient and public involvement in health service provision is not part of the culture.
- There are failings of the leadership to give sufficient explicit priority to the protection of patients and to ensuring that patient safety and quality standards are observed (69).

Sarrami Foroushani et al. (2012) in their meta-analysis of the literature report on gaps and barriers to consumer and community engagement in Australia (34). These are:

- Lack of infrastructure support of health services
- Lack of skill and confidence in health services
- Lack of skills in consumers
- Insufficient opportunity for vulnerable groups for input
- Disseminating information without consumer input
- Stigma of mental illness
- Language and cultural differences
- Time factors (for consumers and community members, as well as for health professionals)
- Geographical distance, especially for rural and remote consumers and community members to engage with state-wide, metropolitan based health services
- Transportation problems for consumers and community members
- Consumer literacy – low health and general literacy complicates the process
- Physical and psychological exhaustion of involvement for some people with disabilities
Different perspectives on what consumer and community engagement is, or should be, can operate within and across health services, and between consumers and health providers, and between members of different professions at any one time.

The Department of Human Services, Victoria (2009 p. 18) identified the following barriers to effective consumer and community engagement and state that it is critical for strategies to be developed to reduce and counter them (70):

- Lack of clarity on the type and purpose of participation, e.g. where members of a process are not sure about their roles and functions, role strain can occur.
- Insufficient resources available or allocated for participation, e.g. for ongoing support, education and training.
- Attitudes, understanding and competency among staff on consumer participation.
- Lack of integration of consumer participation mechanisms within the formal service planning, delivery and evaluation processes.
- Adequacy of consumer representation is likely to impact on effective participation and the achievement of anticipated goals.
- Poor communication and non-collegial approaches between staff and consumers, including unequal power relationships, e.g. lack of shared decision-making power.
- Consumers may have support requirements that, if not provided, may prevent participation, e.g. young people or culturally and linguistically diverse people.
- Information not presented in a way that was easy to read, understand and use.
- Conflict resolution processes not managed in a proactive way.

The Victorian Auditor-General’s Report (2012) on the audit into consumer engagement in some Victoria health services identified inadequate understanding of, and lack of support for, consumer participation by the executive sponsor as a barrier to consumer engagement (6). In addition board members and senior executives at one health service reported cost as a significant barrier to consumer engagement and questioned the economic benefit of their investment (6).

A South Australian study by Johnson et al. (2006) identified that a lack of education, training and support were the main barriers to consumers being able to effectively engage with health services (71).

Sarrami Foroushani et al. (2012) report that the health of consumers and general literacy are also barriers in consumer and community engagement (34).

Happell (2010) reviewed the literature about barriers that exist to genuine and active consumer and community engagement in mental health care (53). The barriers include:

- Reluctance of health professionals to engage with consumers in a more equal way.
- Despite the rhetoric being adopted regarding consumer and community engagement, health professionals practice did not tend to reflect the espoused ideals and frequently contributed to the barriers to effective participation.
- Health professionals stated they did not have sufficient time, as well as inadequate knowledge.
- Having difficulties relinquishing power and establishing more equal relationships with consumers.
- Lack of resources to help consumers understand and negotiate complex health care issues and services.
- A tendency for health services to engage consumers in a tokenistic way and therefore prevent the opportunity for genuine engagement.
Lack of clarity about how to engage with consumers and community members, and who are the ‘right’ consumers and community members to engage with.

In addition, other studies have found divergent views in the way health professionals and consumers construct ‘representativeness’. The divergent views were identified as undermining the legitimacy and power of consumer and community engagement in health services. Martin (2008) argued that the issue of consumer or community ‘representativeness’ is often used as a ploy to defend existing power relationships and control over decision-making processes in the face of the ‘challenge’ from consumers and community members (72).

Lack of clarity about the role of consumer and community members engaging with health services was seen as problematic and a barrier (52, 53). This was also identified by Nathan et al. (2014) who identified that many health professionals did not understand the role of consumers on committees and how to work with them in an open manner, despite clear structures and processes to support participation being in place for many years (52). Role ambiguity and failure to harness consumers’ skills was seen as a barrier to effectiveness of engagement (52).

Happell (2010) stated that lack of clarity about defining the roles that consumers and community members can have in health services, and attitudes of some health professionals about needing to ‘finding the right consumer’ presents major barriers to creating an environment where consumer engagement flourishes (53).

Martin (2008) in his review of the literature noted that health services often relied on self-selection or the selection of ‘appropriate’ or acquiescent individuals. This can result in exclusion and elitism, with the reliance on a few consumers and community members ‘representing’ the interests of all (72). Nathan (2014) reported that by becoming confident and powerful, consumers were often called ‘unrepresentative’ by the staff that they hoped to influence, as they were seen as ‘atypical’ of consumers who used the health service (52).

Gagliardi et al. (73) identified in their research that lack of patient interest, health professionals’ attitudes, and a lack of insight on appropriate methods were the barriers which limited consumer engagement in health service planning and evaluation.

### Methods for Effective Consumer and Community Participation in Health Services

A purpose of this literature search is to examine the literature for the best available evidence and insights into effectiveness of consumer and community engagement methods and to identify innovation, especially in the area of child and youth participation. Whereas a significant number of publications were identified that provided strong support for the importance of consumer and community engagement, there was limited literature located through this search that provides a strong evidence base on the effectiveness of specific methods of engagement.

One area of this review where strong evidence was found in the literature was in the domain of Partnerships in Direct Care. This was also a finding by Bruce et al. (2008) who conducted a literature review of methods for engaging consumers and community in the different domains of the health system (43). Bruce et al. identified that overall evaluations of consumer and community engagement methods were generally ad hoc and internal, especially at the ward/program level, and organisational and health system.
Gregory (2008) also found in her review of consumer engagement that the evaluations were often descriptive with very few evaluations exploring impact and outcomes measures (1). In addition Sarrami Foroushani et al. (2012) state in their meta analysis of the literature that the evidence is mixed; meaning that the impact of consumer and community engagement is not always clear, and that it is in many instances due to methods and activities being context dependent and not always transferable (34).

This literature review for WCHN aims to include consumer and community engagement methods that have been evaluated. However, throughout the analysis of the literature, and writing of the literature review, there were tensions about which articles, publications and examples to include, as many articles and publications were either descriptive of the engagement methods, and did not include a critique or evaluation, or reported on evaluation without any mention of the impact or outcomes of the methods used. There was also the issue of how transferable some of the results of evaluations were, considering that the results were often determined to be context dependent. In some instances where research articles could not be found on specific areas, relevant and credible websites and reports/guidelines were accessed.

The review by Sarrami Foroushani et al. (2012) identified a complex set of inter-related concepts, strategies and approaches relating to community engagement. They developed a thematic map of consumer and community engagement in health care. It is presented in Figure 2. The map represents the five major, inter-related themes associated with consumer and community engagement in health care (34). These are:

1. Community engagement
2. Patient centeredness
3. Clinician-consumer communication and interaction
4. Shared decision making

Linked to each of these themes are a series of smaller concepts and themes. These include:

- community based research
- research
- policy
- consumer evaluation of services
- electronic systems
- virtual consumer held information
- informed decision making
- decision aids
- consumer education
- outcome evaluation
- management
- informal care givers
- virtual communities
- self management
- shared management.
Within the literature review they address each of the key themes and sub-themes. The thematic map is conceptually informative for health services, and the findings provide the evidence base for consumer and community engagement through their meta-analysis (34). Where relevant, the evidence from this meta-analysis will be integrated into the WCHN literature review.

As mentioned previously the structure to be used to present the findings for the WCHN literature review on the methods for effective consumer and community participation in health services will be that of the synthesis of the review of the 2011 NSQHS Standards. These are:

1. Partnerships in Direct Care
2. Partnerships in Organisational Design and Governance
3. Organisational Requirements to Support Consumer and Community Engagement.

However, the scope and focus of this literature review will be on ‘Partnerships in Direct Care’ and ‘Partnerships in Organisational Design and Governance’. With regards to ‘Organisational Requirements to Support Consumer and Community Engagement’, the area of ‘Leadership’ will be the only area briefly discussed.
**Partnerships in Direct Care**

There is strong evidence on the effectiveness for methods of engagement at the direct care level. These are methods that enable the individual consumer and their carers/family to be involved in shared decision making processes around direct care.

Based on the synthesis of the NSQHS Standards, the following themes of engagement will be used to provide the framework to discuss the evidence and methods of engagement for Partnerships in Direct Care:

- Shared Decision Making
- Participation in Communication Processes and Open Disclosure
- Information Provision

**Shared Decision Making**

One of the most common sources of consumer dissatisfaction is not feeling properly informed about their care and treatment and involved in decision making. Shared decision making, where consumers are involved as active partners with the health professional in care and treatment decisions, can be an effective way to address this issue. Health professionals and consumers work together as active partners to clarify acceptable care options and choose appropriate treatments. While not all consumers desire to play an active role in decision making about care and treatment most want health professionals to inform them about their care and treatment options and take their preferences into account (26).

Shared decision making is a collaborative process between a consumer and their health professional. It is a process that enables the consumer and health professional to make decisions together, taking into account the best evidence available as well as the consumer’s values and preferences. They discuss options, and the risks and benefits, and after taking all the information into account they negotiate a care pathway. Shared decision making relies on the consumer’s individual health literacy and the health professionals ability to apply a patient and family-centred approach to care (24).

Shared decision making is widely reported in the literature both in Australia and internationally. Sarrami Foroushani et al. (2012) identified that in Australia shared decision making is linked to the commitment made by the Australian Health Ministers and the Australian Commission on Safety and Quality in Health Care to consumer engagement (34). It is associated with the re-distribution and recalibration of power between health professionals and consumers (34).

Sarrami Foroushani et al. (34) in their meta-analysis identified that shared decision making refers to the style of communication and tools that places patients’ preferences and values beside clinical information. It is directly promoting consumer involvement in health related decisions and makes the communication between health professional and patient more satisfying and assists in the selection of better treatment options. Bruce et al. (2008) identified in their literature review that consumers who reported a role in shared decision making were most satisfied with the consultation and the information about treatment and the emotional support provided (43).

Coulter et al. (2011) suggest a range of prerequisites that should be put in place in order to make shared decision making the norm in clinical practice (74). These include: appropriate policies, regulation and standards, availability of tools and information, tools for monitoring progress, training, clinical and patient champions, evidence of effectiveness, incentives and implementation plans (57).
Legare et al. (2011) identified in their systematic review that there were a number of methods of educating and providing learning materials for health professionals to be more effective in shared decision. These include giving the health professionals feedback and decision aids (75). However, Curtis et al. (2010) found that implementing shared decision making by changing long-established communication styles to be a challenge, even for motivated and well educated health professionals (76).

Fine et al. (2010, p. 601) concluded in their systematic review of the literature that health professionals may need to learn to ‘speak less, listen more’ (77). Ensuring effective two-way communication is a fundamental requirement for shared decision making, and safe and high-quality health care. As emphasised by the Australian Commission on Safety and Quality in Health Care (2014), communication failures between health professionals, health services and consumers are one of the most commonly cited underlying causes of adverse events and complaints about the health care system (24).

Moore and Kirke (2010) identified in their literature review on children and young peoples’ participation in health care decisions, that health professionals need guidance to assist children and young people to participate in decision making (78).

Simmons et al. (2012) in their review of the evidence determined that there is little research investigating the decisional capacity of young people diagnosed with mental disorders specifically. However, there may be the opportunity for future research for young people (particularly those aged 14 years and older) to be deemed competent to provide informed consent for participation in research studies. Decision making for young people diagnosed with mental disorders is likely to be complex, and the point at which adult input is required needs to be assessed on an individual basis (79).

Alderson and Montgomery (cited in Franklin and Sloper 2005) define four levels at which children can participate in health care and health services (80):

- Being informed
- Expressing a view
- Influencing a decision
- Being the main decider.

However, Franklin and Sloper conclude in their literature review that it would appear that participation practice is limited and patchy and, particularly within service development, may only be occurring at relatively lower levels of decision-making of Alderson and Montgomery’s model (80).

A UK study by Hemmingway et al. (2011) examined children and young people’s participation in health care consultations in an Emergency Department (81). They found that child and young people’s participation within the ED consultations were low. They identified some of the barriers to child and young people’s active participation in consultations in ED as; noise, child and parental anxiety and distress, professional time pressure, and severity of child illness or injury add to the inherent complexity of triadic communication (parent, child health professional). Hemmingway et al. provide practical suggestions for health professionals to encourage active participation of children and young people in consultations (p. 195). They also provide a checklist to guide parents in considering how to encourage their child’s participation in consultations. This is seen as a way of empowering a child to participate with the parent’s support (p. 196) (81).

Coyne (2008) conducted a literature review on child participation in consultations. Her findings support the work of Hemmingway et al. in that there was little evidence that children’s views were
rarely sought nor acknowledged within the health care setting. The research evidence shows that children usually appear to occupy a marginal role in the information-exchange process. She argues that health professionals and parents play a significant influence on whether children’s efforts to participate are facilitated and supported in the hospital setting (82). The evidence suggests that children and young people may want to participate, but there is not enough information on children’s preferences and what role children want to play in consultations and decision making. Barriers that children identified as constraining their active participation include: not knowing health professionals; not wanting to hear bad news; fear of causing ‘trouble’ by asking questions; lack of time with health professionals; being ignored; being disbelieved; health professionals not listening; difficulty understanding medical terminology and parents’ actions (p. 1687).

Decision aids are commonly used as tools by health professionals to assist consumers make decisions about health care options during shared decision making processes. Sarrami Foroushani et al. state that these could be tools such as pamphlets and videos which provide structured information about health options, and assist consumers’ participate in their own health care and make an informed decision (34). These have been found to increase consumers’ knowledge about options and their risks and benefits, and enhance their participation in the process (83). However, the design of decision aids and patient information is a complex process and should be prepared carefully with active involvement of consumers (84). Sarrami Foroushani et al. (34) prove a summary of tools related to shared decision making which have been categorised by Scholl et al. (2011) (85).

Shared decision making in paediatrics is unique because it often involves active participation of both the child or young person and his or her parents in the decision making process with the health professional. However, little is known about the nature of paediatric-specific shared decision making interventions and their impact. Wyatt et al. (2013) have registered a systematic review protocol to summarise the nature of shared decision making practices, tools, techniques and technologies in the paediatric setting, as well as their effects (86).

A narrative review by Lipstein et al. (2012) identified that although parents’ preferences for their degree of participation in paediatric decision making vary, most are interested in sharing the decision with the health professional. In addition to the health professional, parents are influenced in their decision making by changes in their child’s health status, other community members, prior knowledge, and personal factors, such as emotions and faith. Most parents appear to struggle to balance these influences as well as to know when to include their child in decision making (87).

There were many different decision aids reported in the literature but many were published in the mid 1990’s and early 2000. These following websites provide an insight into the wide range of current decision aids for use in paediatric health care settings with parents of young children and women.

- Children’s Hospital Eastern Ontario, Ottawa Canada have an inventory of all family and paediatric decision aids see [http://www.cheo.on.ca/en/decisionaids](http://www.cheo.on.ca/en/decisionaids);
Participation in Communication Processes and Open Disclosure

An organisational commitment to the principle of transparency between health professionals and consumers is fundamental to the participation in communication processes such as ward rounds and hand-over’s and open disclosure. The Lucian Leape Institute (2015) report offers “sweeping recommendations to bring greater transparency in four domains: between clinicians and patients; among clinicians within an organization; between organisations; and between organisations and the public.” The report argues strongly that true transparency will result in improved outcomes, fewer medical errors, more satisfied patients, and lowered costs of care (35). One key insight was the degree to which these four domains are interrelated. The report makes key recommendations and actions to improve transparency between clinicians and patients. These include:

1. Provide every patient with a full description of all of the alternatives for tests and treatments, as well as the pros and cons for each.
2. Provide patients with relevant, neutral, third-party information (e.g., patient videos, checklists) and expand the availability of such resources.
3. Provide patients with full information about all planned tests and treatments in a form they can understand.
4. Include patients in inter-professional and change-of-shift bedside rounds.
5. Promptly provide patients and families with full information about any harm resulting from treatment, followed by apology and fair resolution (35).

Consumer participation goes beyond providing information. It also requires a two-way communication process, where the consumer provides input to decisions, and feedback on their experiences. Effective communication is critical through all stages of the consumer experience, from hospital admission, through to discharge and follow-up. Communication issues make up a substantial proportion of complaints made to health services (SA Health 2013 p. 29)(88). Frontline staff including nurses, doctors and allied health staff, have a major role in communicating with, and seeking feedback from consumers. Some of the effective means of communication seen at the health services audited as part of the Victorian Auditor-Generals report into consumer participation in Victorian health services included:

- hourly nursing rounds, providing more opportunity for interaction between nurses and patients
- use of whiteboards and communication books to facilitate two-way communication between patients, family members and clinical staff
- a strong culture of empowering staff to resolve complaints directly and encouraging open disclosure of errors
- a personalised post-discharge information pack to assist ongoing treatment and recovery, including the individual’s health record, personal care plan, information about their health condition or medications, and relevant local support services and groups (6).

The sub themes identified in this area which will be discussed in more detail are:

- Communication and ward rounds
- Communication and bedside handover
- Communication and open disclosure

Communication and Ward Rounds

Stickney et al. (2014) state the concept of patient and family-centred ward rounds has experienced a burgeoning popularity in paediatrics in recent years, which is supported by national and international organisations (89). They report on studies in the literature that have shown a broad base of parental enthusiasm for the practice. One study they discuss is a qualitative study of parents who participated in patient and family-centred ward rounds on a hospital’s general paediatrics unit.
This study revealed strong themes from the parents’ perspective about the importance of communication via rounds, parental inclusion in rounds, and of seeing teamwork in the care of their child (89).

Stickney et al. (2014) conducted their own study into the process of involving parents in ward rounds in a neonatal intensive care unit. There was agreement between health professionals and parents in the study that the goal is to help parents achieve an understanding of the child’s current status and plan of care. Professionals and parents disagreed, however, about the nature of opportunities to ask questions. Parents wanted to be able to ask questions but health professionals discouraged this as it prolonged ward rounds. Parents additionally reported a strong desire to provide expert advice about their child and expected transparency from the care team, while professionals stated that parental presence sometimes hindered frank discussions and education of trainee staff. Stickney et al. offer solutions to address some of the barriers identified. Solutions may involve a protocol for orienting parents to morning ward rounds, focusing on improving communication with parents outside of morning ward rounds, and the preservation of a forum for professionals to have private discussions as a team (89).

No studies could be found on the inclusion of children and young people in ward rounds.

**Communication and Bedside Handover**

Accurate and effective communication transfer during patient handovers is critical in ensuring safe care (90). Handover has been defined as the transfer of responsibility and/or accountability for patient care from one professional or team of professionals to another (90). This can be at shift change over, or transfer of a patient to another ward/service. Inadequate handovers between health professionals are key contributors to adverse events (91). With a patient and family-centred approach, the patient and family are partners in care with the expectation that their participation may lead to better outcomes (92). Bedside handover, where the outgoing nurse provides a report to the incoming nurse at the patient’s bedside, is strongly being advocated for by the Australian Commission on Safety and Quality in Health Care as a way to move toward a more patient and family-centred approach, and to enhance the safety and quality of care.

Chaboyer et al. (2009) describe practice guidelines for bedside handover that were developed by an Australian health service (90). The guidelines are structured under three headings: Preparation, Content, and Safety Scan. In addition Chaboyer et al. report on the development of nursing competencies with accompanying performance indicators. The first evaluation of the handover project was conducted, and overwhelmingly consumers perceived the bedside handover positively. The second evaluation was a survey of staff. The three benefits identified by staff were: support from shift coordinators and team leaders; improved patient safety; and improved patient outcomes through discharge planning. They reported that in one ward (the rehabilitation ward) consumers lead handover, with nurses adding information as required. One improvement reported has been the development of a computerised handover sheet to assist with consistent and accurate information. Another improvement was the introduction of SBAR (situation, background, assessment, recommendations) when a patient’s condition has changed or when staff are unfamiliar with the patient (90). In SA Health ISBAR would be used (88).

Key benefits for health professionals to conduct bedside handovers are (92):
- Clarify issues and ask questions to enhance the accuracy of the handover
- Visualise the patient and priorities care
- Engage patients and family members in care.
Key benefits to for patients are (92):

- Patients report greater satisfaction with care
- Have improved perceptions of safety during handovers related to the patient being able to correct inaccuracies in care
- Are informed of their plan of care
- Experience fewer patient falls at shift change and fewer medication errors
- Have increased risk assessment for pressure ulcers completed by nurses.

Jeffs et al. (2014) identified three emergent themes in their study of consumers’ views on bedside nursing handover. These were:

1. creating a space where they could connect and bond with nurses in a more personal manner;
2. enabling them to be kept up to date on their care and being aware of what was going on; and
3. varying preferences on their level of engagement and what information they want to be disclosed or discussed at the handover, especially between long-term and short-term patients (92).

No studies could be found on the inclusion of children or young people in handover communications.

**Communication and Open Disclosure**

Open disclosure is the open discussion, between health professionals and the patient and family, of adverse events that result in harm to a patient while receiving health care. It is an important aspect of transparent engagement with consumers at the direct care level.

A key recommendation of the Francis Inquiry (69) was for:

- Openness: enabling concerns to be raised and disclosed freely without fear, and for questions to be answered;
- Transparency: allowing true information about performance and outcomes to be shared with staff, patients and the public;
- Candour: ensuring that patients harmed by a healthcare service are informed of the fact and that an appropriate remedy is offered, whether or not a complaint has been made or a question asked about it (p. 75).

The Australian Commission on Safety and Quality in Health Care (2013) have published an Australian Framework on Open Disclosure (93). The Framework provides a nationally consistent basis for communication following unexpected healthcare outcomes and harm. It is designed so that patients are treated respectfully after adverse events.

The elements of open disclosure are:

- an apology or expression of regret, which should include the words ‘I am sorry’ or ‘we are sorry’
- a factual explanation of what happened
- an opportunity for the patient, their family and carers to relate their experience
- a discussion of the potential consequences of the adverse event
- an explanation of the steps being taken to manage the adverse event and prevent recurrence.

The Australian Commission on Safety and Quality in Health Care (93) states that it is important to note that open disclosure is a discussion between two parties and an exchange of information that may take place in several meetings over a period of time.
The Australian Commission on Safety and Quality in Health Care provide an extensive range of information and resources for clinical staff and consumers (see http://www.safetyandquality.gov.au/our-work/open-disclosure/).


Iedmea et al. (2008) provide consumer perspective recommendations, from their Australian study about how open disclosure should be enacted. They state that staff must become more attuned in their disclosure communication to the consumer’s perceptions and experience of adverse events, to offer an appropriate apology, to support consumers long-term as well as short-term, and to consider using consumers’ insights into adverse events for the purpose of service improvement (95).

A study into Australian rural consumers’ experiences of the open disclosure by Piper et al. (2014) provides insights into the additional challenges in their experiences of health care incidents. The additional challenges include: delays in diagnosis and transfer, distance between services, and lack of communication between providers. These impact not only upon how consumers and their families experience incidents, but also how open disclosure is implemented. The paper provides guidance to health services on how to conduct open disclosure with rural consumers; taking into consideration the personal relationships between health professionals and patients in rural communities, situations where multiple health services are involved, and where incident trajectories may need to be reconstructed through careful collaboration across organisations (96).

Iedema et al. (2009) report on findings of their Australian study about the impact of open disclosure on clinicians’ practices. It situates open disclosure in the context that health professionals are increasingly expected to do ‘emotional labour’ with patients and their families, and are required to practise ‘reflexive listening’ as a means of managing patients’ and family members’ emotions in response to adverse events. The intensity of the interactions introduces many clinicians to a new way of communicating and working with consumers. The research identifies the tensions of the open disclosure processes and the implications (97). Pratt and Jachna (2015) discuss strategies to support clinicians after the open disclosure process, who they describe as the ‘second victims’. These strategies include formal peer support programs in which clinicians are trained to act as peer supporter for emotional recovery after adverse events. Other formal emotional support systems might be needed by some clinicians, including employee assistance programs, hospital clergy or psychological and psychiatric services developed formal peer support programs in which clinicians are trained to act as peer supporter for emotional recovery after adverse events. Finally, more formal emotional support systems might be needed by some clinicians, including employee assistance programs, hospital clergy or psychological and psychiatric services(98).

No studies could be found that explored how to involve children and young people in the open disclosure process.

**Information Provision**

Easy access to understandable and relevant quality information is a fundamental component of patient and family-centred care and is an intervention to improve health literacy. There is strong evidence that shows that providing information that is accessible, understandable, and relevant can improve consumers’ knowledge, understanding and recall about their health and care. It can also
increase consumers’ feeling of empowerment, improve their ability to manage and cope, increase satisfaction and reduce anxiety (99).

Consumers need such information in order to:
- understand what is wrong
- gain a realistic idea of prognosis
- make the most of consultations
- understand the processes and likely outcomes of possible tests and treatments
- assist in self-care
- learn about available services and sources of help
- provide reassurance and help to cope
- help others understand
- legitimise seeking help and their concerns
- learn how to prevent further illness
- identify further information and self-help groups
- identify the ‘best’ healthcare professionals (20).

Studies indicate that patients want more information than they currently receive. In addition, health professionals frequently overestimate the amount of information they supply. In order to overcome this gap in the provision of consumer health information, five key issues need to be taken into consideration (20). These are:
- Information needs
- Accessibility
- Quality
- Readability and comprehensibility
- Usefulness.

Health information can be communicated through:
- Printed information e.g. written and visual formats such as consent forms, fact sheets, posters, brochures, written instructions and medication information.
- Electronic media e.g. visual formats such as web sites, email, podcasts, Facebook, DVDs, blogs, twitter feeds, apps.
- Interpersonal communication e.g. exchange of information in a combination of written, oral and visual formats from person to person (24).

These sub themes will be discussed separately.

**Printed Information**

Written health information tailored to an individual’s needs and can be helpful in reinforcing professionals’ explanations of health problems. The provision of timely, well written health information, which supports consumers to gain knowledge and participate in decision making, is one strategy to enable the sharing of information and power. Coulter et al (2008) state that information and education addressed specifically to people with low levels of health literacy can be effective as an aid to communicating health information and complex care needs (26).

The Cochrane Collaboration has undertaken several systematic reviews that examine the effectiveness of printed information used as consumer engagement tools at the level of care and treatment. The Cochrane Review by Kinnersley et al. (2007) found that interventions which assist consumers to address their information needs in consultations increased the number of questions
asked during the consultation, and may increase consumer engagement in the consultation process and improve patient satisfaction (100).

Butow et al. (2004) undertook several studies to examine the impact of consumer engagement in the use of question prompt lists and shared decision making. The cancer consultation preparation package contained a question prompt sheets, booklets on clinical decision making and patient rights, and an introduction to the service. The evaluation concluded that patients who received the package asked significantly more questions, tended to interrupt the clinician more, and challenged the information more often (101).

The Cochrane Systematic Review by Johnson et al. (2003) concluded that printed discharge information, when combined with verbal information by health professionals, was more effective in improving consumer knowledge and satisfaction, than just the provision of printed information alone or verbal information alone (102).

**Electronic Media (including Social Media)**

Coulter and Ellins (2006) conducted a review of the evidence to examine interventions that would mitigate the effects of low health literacy. They found that alternative format resources, such as the internet, audiotapes, virtual health communities and support groups improved health knowledge and resulted in higher satisfaction. There was also some evidence of beneficial effects on health behaviour, particularly with web-based educational interventions (20).

Coulter et al (2008) state that computer-based information may be more effective than paper-based information, as it can be more easily tailored to needs. Interactive television, audio tapes and web-based interventions have mixed results for improving knowledge, but can have beneficial effects on patients’ confidence and ability to be involved in decisions. They may also improve clinical outcomes and health behaviour (26). Well-designed education programmes can make a difference, and some evidence shows that people from disadvantaged groups benefit more from computer-based support than do people from affluent groups if access barriers can be overcome (26).

Thackeray et al. (2012) argue that social media has enhanced the communication between individuals and organisations and has the potential to augment health service communication. They state that use of social media by health services is in the early adoption stage (103). They conclude in their study that health services use social media as a channel to distribute information rather than capitalising on the interactivity available to create conversations and engage consumers and the community (103). Social media is defined as the collection of digital channels and tools such as Facebook, Twitter, and YouTube (104).

Aase & Timimi (2013) discuss health care and social media and consumer engagement and state it can be difficult for health services to grasp the transition that is occurring within society with regard to social media and social networking (105). Social media and social networking represents a profound shift in the ability of health services to engage with consumers and the community. They conclude that before exploring opportunities for social media and social networking, health services must develop and communicate a social media policy and guidelines. In addition training of staff in the effective use of social media and social networking tools is essential.

Heldman et al. (2013) argue that social media is often used by health services for mass information dissemination rather than engaging consumers and the community in true multi-way conversations and interactions (104). They state that it is the interactive potential that defines social media engagement: lack of interaction is simply the health service broadcasting information to consumers.
and the community. They examine principles of social media management, different levels of engagement for health communication and consider the potential risks, benefits, and challenges of a health service truly embracing the social media as a forum for consumer and community engagement (104).

There is growing evidence that peer-to-peer healthcare is an important source of information and support for patients. The empowerment and information exchange among patients and families already occurs in online support groups and forums. A range of studies have found that a high percentage of young people see social media as an essential method of communication. Wong et al. (2014) focus on the potential for social media as a way to engage young people and young adults in their health (106). They provide examples of how social media has been used to increase young adults engagement with health reform, and how a youth advocacy organisation and a health organisation collaborated to host an online crowd-sourced video contest which had over 100 submitted videos and more than half a million votes and video views to raise awareness about health insurance (106).

Willis (2014) reports on a study into the role of online health communities in arthritis self-management (107). The findings show that online health communities facilitate self-management behaviours through the exchange of health information and disease experience. The online health communities are peer led with peers with the same chronic disease working to improve members’ health literacy related to arthritis (107).

Logsdon et al. (2015) report on a study they conducted with adolescent mothers who lived in rural communities to determine the use of social media and Internet to obtain health information. They found that all the adolescent mothers accessed social media and the Internet via mobile phones or computers. They concluded that communication of health information using social media and the Internet may be an effective way to assist young mothers living in rural communities access health information (108).

A systematic integrative review into Internet-based peer support for parents found that mothers were more active users of Internet-based peer support. For mothers it provided emotional support, information and membership of a social community. For fathers it provided support for the transition to fatherhood, information and humorous communication. They found that the evidence of the effectiveness of Internet-based peer support was inconclusive but no harmful effects were reported in the studies reviewed. Niela-Vilen et al. (2014) conclude that Internet-based peer support provided informational support for parents and was accessible despite geographic distance or time constraints. It was identified as a unique form of parental support, and supplemented support offered by health professionals (109).

Park (2012) discuss the issue of digital media literacy and the relationship with social exclusion (110). Newman et al. (2012) present research findings on access to, and use of, digital information and communication technologies by Australians from lower income and disadvantaged backgrounds to determine implications for equitable consumer access to digitally-mediated health services and information. They conclude that there is considerable variation in access and use within lower income and disadvantaged groups. If health services require consumers to participate in a digitally-mediated communication exchange, then they suggest that health services might support skills and technology acquisition, or provide non-digital information technology alternatives in order to avoid exacerbating health inequalities (111).
As mentioned previously, access to quality health information is a significant issue for consumers. High performing health services in the US such as the Mayo Clinic and Cleveland Clinic utilise the online experience for consumer’s easy access to:

- An extensive range of high quality health information written using health literacy principles (healthy lifestyle, symptoms, diseases and conditions, tests and procedures, medications and supplements)
- Medical records
- Manage their appointments on-line
- Pay their bills (112, 113).

Both health services have very informative Facebook sites which provide extensive up-to-date information to the community through postings and also promotion of webinars and podcasts for community members to access. The Mayo Clinic provides workshops on how health services can utilise social media as a community engagement strategy.

**Interpersonal Communication**

Health literacy awareness and improved communication have been identified as key factors that can improve interpersonal communication between health professionals and consumers. The goal of interpersonal communication is to support greater understanding of health information and empower consumers to share in health care decision making to the extent that they choose.

Effective interpersonal communication is based on trust, understanding, empathy and cooperation. A patient and family centred approach to interpersonal communication is used to build relationships and improve the quality of care based on the principles of dignity, respect, sharing information, collaboration and partnership (24).

Effective interpersonal communication requires that health professionals understand health literacy concepts. This is in order to tailor health information so it is delivered in a manner that is understandable and considers the consumers needs and preferences, especially cultural needs and preferences, and the lived experience and expertise of the consumer (24). Thomacos et al. (2007) provides evidence based recommendations for communicating with people from different cultural backgrounds and vulnerable population groups, based on health literacy principles (114).

Berkman et al. (2011) conducted a systematic review to examine communication interventions that would mitigate the effects of low health literacy (21). Findings include:

- Using plain language to communicate health information, instructions and choices.
- Using essential information first and by itself.
- Using consistent denominators for presenting risk and benefit information.
- Adding video to verbal information
- Providing written information with verbal information.

Educative and recall strategies such as Teach-Back, Show-Me, Encouraging Questions, Teach-to-Goal, and Ask-tell-ask have been proven to be effective (21, 24, 102, 115, 116). Specifically Teach-to-Goal is effective with communicating complex health information (116). Teach-Back and Show-Me are easy techniques to teach health professionals and are effective strategies for engaging all consumers, including children and young people, in clarifying information and correcting misunderstandings. These techniques have been proven to be effective for clarifying care instructions, medication administration, and discharge processes (117). The Health Literacy Universal Precautions Toolkit is one of the most commonly utilised toolkits that includes an extensive range of techniques to improve interpersonal communication and health literacy (118).
Partnerships in Organisational Design and Governance

It is strongly argued that consumers and community members have a role to play in shaping the strategic direction, operational planning and organisational processes in health services. There is strong evidence showing that the involvement of consumers in planning, delivery, monitoring and evaluation can make a positive impact in these areas, as well as on the attitudes of health professionals and managers (4-6).

Sarrami Foroushani et al. (2012 p. 28) examined the evidence for consumer and community engagement in health services in a meta-analysis of existing systematic reviews. They identified a number of factors that contributed to the success of consumer and community engagement in health services. These included: adequate financial and logistical support; adequate communications; collaboration with consumer organisations; and keeping the project at a small scale.

Examples of where consumer and community engagement in health service planning and development have had an impact are outlined in the systematic review by Mockford et al. (2012). These include:

- The design of new healthcare buildings and their environment.
- The location of and access to services, such as relocation of existing services and the provision of transport and car parking.
- The provision of additional services.
- Re-organisation of existing services such as improved booking service, changes to appointment systems and a review of day services.
- Improved communication between health professionals and consumers through an interactive web site co-designed by consumers.
- Improve communication between consumers (5).

Key themes identified in Partnerships in Organisational Design and Governance which relate to NSQHS Standards are:

- Organisational Governance
- Safety and Quality Improvement
- Review and Development of Information
- Partnerships which Reflect the Community and Support People from Diverse Groups and Vulnerable Populations;
- Supporting and Informing Consumers who Partner with the Health Service.

Organisational Governance

Governance is defined as the process of decision-making, and the process by which decisions are implemented, or not implemented (119).

SA Health states that

Governance is the set of relationships and responsibilities established by a health service organisation between its executive, workforce and stakeholders including consumers. Governance incorporates the set of processes, customs, policy directives, laws, and conventions affecting the way an organisation is directed, administered, or controlled. Governance arrangements provide the structure through which the objectives (clinical, social, fiscal, legal, human resources) of the organisation are set, and the means by which the objectives are to be achieved. They also specify the mechanisms for monitoring performance. Effective governance provides a clear statement of individual accountabilities within the organisation to help in aligning the roles, interests and actions of different...
participants in the organisation in order to achieve the organisation’s objectives. SA Health’s definition of governance includes both corporate and clinical governance and where possible promotes the integration of governance functions (10).

There is strong evidence that demonstrates that consumer and community engagement has contributed to changes in the provision of health services through involvement in planning and development, and shows how consumers and community members can effectively contribute to decision making to shape the strategic direction, operational planning and organisational processes of health services through various methods (4, 5).

This section outlines the evidence for, evaluations of consumer and community engagement methods, and some practical activities which have proven to be effective for other health services (including health service networks) in the area involving consumers and community members in organisational governance and decision making. Areas covered in this section include:

- Functional Organisational Chart mapping
- Formal Organisational Committee Structures
- Partnering for Hospital Design and Building Initiatives
- Determining and Embedding Consumer Centred Values
- Experience-Based Co-Design Method
- Open Access Board Meetings
- Community Collaborative – Implementing Policy-Relevant Programs
- Community Level Methods
- Consumer Engagement Population-Level Interventions

**Functional Organisational Chart – Mapping for Opportunities and Synergies**

Functional Organisational Structure mapping is a practical activity, which has proven effective for complex health services to plan for consumer and community engagement in decision making through an appraisal of opportunities to participate in formal structures and processes. Figure 3 and 4 show how a health service have prepared a visual map of the health service’s functional organisational chart and then conducted an analysis of that chart to identify opportunities for consumer and community engagement and identify synergies between programs. The example provided is from Domiciliary Care SA when they were preparing their Consumer Participation Strategy in 2006 (120).
Figure 3 Functional Organisational Chart for Domiciliary Care SA (120)
Formal Organisational Committee Structures

At organisational and network levels the most common ways for consumers to be involved in health services, is through formal committee structures, such as on boards (or sub-groups of boards), advisory groups, panels, and community councils. Several studies have identified the need for consumers or community members to be linked to consumer or community organisations and to possess higher level skills to be effective in these formal decision making structures within health services (52, 121). When evaluations were conducted, they generally revealed that the involvement of consumers or community members on committees and formal structures produced more benefits for health services than for individual consumers or community members (43). In a study by Health Issues Centre it was revealed that there was a lack of a consistent approach for recruiting and supporting consumer involvement in committees and formal structures in health services (43).

Molyneux et al. (2012) identified in their study that the key influences on the impact of consumer and community engagement in committees are:

- how committee and group members are selected and their motivation for involvement;
- the relationship between groups or committees, health workers and health managers; and
- provision of adequate resources and support (122).

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addition the health service needs to provide a structured and supported program, and improve staff understanding of the range of possible roles for community representatives (52).

Gibson et al. (2011) explores the concept of ‘weak’ and ‘strong’ public engagement (121) as it relates to governance, with a focus on neonatal networks, and the participation of parents on the network boards. The concept of ‘weak’ and ‘strong’ public engagement provides an understanding of equality and inequality of consumer and community engagement in network Board processes. A ‘strong’ public engagement process is one where consumers are not only involved in discussions but also in decision making. ‘Weak’ public engagement is where consumers are involved in discussions but have little chance of influencing decision making. Gibson et al. used this as a conceptual framework for a study of neonatal networks and parental involvement in these neonatal networks on Boards. Results showed that parents played different roles on network boards, depending on how the different networks conceived and organised parental involvement. They identified three types of roles, each with differing levels of participatory parity and ‘weak’ and ‘strong’ public engagement. These are as ‘sources of information’, ‘consultants’ or as ‘representatives’ of other parents (121). With parents as sources of information, parents are seen as a source of raw data collected in a number of ways e.g. via a survey or via the use of focus groups to be analysed and the results fed into the networks decision making. With parents as consultants, parents not only possess important information about the services but they make a contribution via being involved in decision-making during board meetings. Difficulties identified with this approach were the small numbers of parents who could participate, and that they were open to accusations of not being representative of the wider parent population that the network served. The final role of parents on the network board is to represent the views of other parents who have used neonatal services. This is where parents are linked to a wider group of parents who use neonatal services. The advantage of this is that it potentially increases the numbers and diversity of parents who can contribute to the decision making processes either directly or indirectly. There is greater opportunity for parents to place on the board agenda issues of importance to them as they emerge through their own group discussions. An example was provided of one network who adopted the parents as representative’s approach. There were parents groups based in neonatal units who sent representatives to a regional parents’ group, which in turn sent two representatives to the network board. A disadvantage of this process for parents involved, was the workload and time commitments to fulfil the role requirements (121).

Kendell et al (2014) in their evaluation of an advisory committee conclude that it was an effective method for involving consumers in the project. However, they stress that there is no one-size-fits all approach to involving consumers in projects, and when considering an opportunity for consumer and community engagement, health services need to consider

- the most appropriate model for engagement,
- the relevant consumer and community groups to be included,
- the recruitment strategy, and
- the availability of human and financial resources to support consumer and community engagement (123).

A study published by O’Toole et al provides a case study of how youth welfare services in Aberdeen, Scotland and Warrnambool, Victoria, Australia have developed new governance models to involve the young people, who have been recipients of the services, to now including the young people as community representatives in the governance of these services (124). They have developed a conceptual framework for distinguishing ‘passive charity’ from ‘community governance’ (124).

The Royal Manchester Children’s Hospital (RMCH) Youth Forum was established as part of the new Youth Engagement Structure. The Forum is run entirely by its youth members aged 11 – 25, with
staff attending for support. The members involved feel strongly about improving services for young people. The members represent themselves and provide a voice for young people’s thoughts on health issues and are, therefore, an important influence on Trust policy and procedure, and Trust design and delivery. The Youth Forum members have provided invaluable input to the development and delivery of hospital services for young people. Achievements include input into the design of the new Children’s Hospital, as well as being invited to represent the Trust in local, regional and national conferences and events (125).

There is the potential to establish Child Advisory Groups in health services as a way to engage children in health service decision making. Whereas specific examples within the health sector could not be found within the literature, the Western Australia Office of Children and Youth has developed guidelines for establishing child focused advisory groups, which also provides a facilitation guide, and suggestions for other participatory methods of effectively engaging children. Case studies are also provided of how these advisory groups have worked in other sectors (126). This guide is available via a hyperlink in the Western Australian Commissioner for Children and Young People Participation Guidelines (2013 p. 7) (127).

**Partnering for Hospital Design and Building Initiatives**

An example of how two Victorian health services involved consumers and the community in new hospital building development projects is referred to in the Victorian Auditor-General’s Report (6). The health services undertook a co-design process, which is about collaborating with, and understanding the experiences of consumers and staff to develop and build better health services. Consumer participation was embedded in the governance structure for these projects and includes consumer groups with roles to:

- represent the views of consumers in the planning processes for new hospital developments
- provide feedback, guidance and advice on the plans for new developments
- provide specific advice on facilities at the new development
- provide advice to the planning teams, planning groups and architects on making the new hospital development a welcoming environment for consumers.

The health services have also consulted the local ATSI community on making the new hospital culturally safe and welcoming. It is also using a wide variety of mechanisms to keep the community informed about the project, including community and web forums, newsletters, social media, and presentations to local community groups (6).

Thompson et al. (2011) conducted in-depth interviews with urban, rural and remote Aboriginal people affected by cancer to explore their beliefs about cancer and experiences of cancer care. Information relevant to hospital services, including building design was extracted from the interviews. Design considerations were identified. However, the critical issues were for Aboriginal people to be able to build trust in health services. Promotion of cultural safety, support for Aboriginal family structures and respecting the importance of place and community to Aboriginal patients were identified as crucial (128).

Derbyshire Children’s Hospital involved children in the design and planning of their new hospital in 1996 and have gone on to work with children in different ways and on different issues (129). Cooke (2004) states that the hospital staff asked themselves a fundamental question, which was ‘Whose hospital is it anyway?’ She states that this was the single most important principle to have adopted when they began as it shaped the way they went ahead with the design and planning of the hospital. They partnered with a group of community artists who had experience in working with young children. To get the children engaged in the process they used scenarios to engage the children through art, play, music, craft, and role-play. They conducted many play sessions in schools,
community venues, shopping centres, and play groups in different areas of Derbyshire to ensure they captured the views of children from different ages, backgrounds and experiences with the health services. Parents were involved in some sessions, but not all. Staff and planners, technical advisers and managers all participated in the process. From the analysis of the artwork and role-play they developed some basic principles which became their central guide for the detailed hospital planning to follow (129).

Deitz (2012) describes how he used art as a successful method of engaging with young children to design medical imaging equipment that reduced children’s anxieties and distress (33). He also went to where children are more confident and comfortable to participate, rather than bringing children into the hospital environment.

**Determining and Embedding Consumer Centred Values**

The Hillingdon Hospitals NHS Foundation Trust, UK, engaged staff and consumers to determine the health service’s values and to identify an acronym that would remind staff what these values are. They conducted focus groups with staff and at the ‘Patients in Partnership’ annual meeting. The acronym CARE received the highest votes to represent the values of Communication, Attitude, Responsibility and Equity. It was recognised that the word ‘Safety’ was a much needed addition to CARE, so it was added, making the acronym ‘CARES’. The Putting People First (PPF) steering group was set up, chaired by the Director of People to ensure that the Trust’s operational and corporate processes were underpinned by CARES (125).

**Experience-Based Co-Design Method**

Piper et al. (2012) report on an evaluation study of experience-based co-design to improve the experiences of patients accessing emergency departments in New South Wales public hospitals (130). Experience-based co-design (EBCD) is a specific methodology that seeks to capture and understand how people feel and experience a process or service when they come into contact with it. It includes staff and the lived-experience of the emergency department consumers in the quality improvements made within health services. All sites were able to demonstrate that a number of strategies were implemented to address the issues raised by consumers, family members and staff during the process. Piper et al. note in their conclusions the similarities the EBCD methodology has with other types of initiatives, such as the collection of patient and carer stories to understand the perspective of the end user of the service; the collection of practitioner stories as a means of clarifying, valuing and prioritising their stances and potential input; and the Studer Group program (see https://www.studergroup.com/). They state that what is common across these initiatives and programs is the emphasis on everyday experience, and the involvement of practitioners and consumers in thinking about how to improve services, not just experientially and aesthetically, but also functionally and organisationally (130).

**Open Access Board Meetings**

In Victoria, since March 2012, health services are required to hold at least one open access board meeting per year that the general public are able to attend. The aim is to foster interaction between boards and consumers, increase awareness and understanding of health services and provide a forum for information sharing. Through this initiative community members can have opportunities to gain an understanding of the rationale, context and environment for board plans and decisions and to participate in decision-making processes. The guidelines state that open access board meetings should focus on areas of community interest, such as plans for capital developments and service delivery changes (6). As it is a new innovation, no evaluation of this initiative has been conducted to date to determine whether it is effective or not.
**Community Collaborative – Implementing Policy-Relevant Programs**

A Community Collaborative is a consumer and community engagement method described by Potter (2010) where consumers and community members partner with health professionals to plan and implement policy-relevant programs (131). These are usually short term arrangements for the duration of the program. Potter evaluated three Community Collaboratives and identified organisational features associated with how the groups prioritised consumer and community engagement, among other competing goals which they legitimately could pursue. Results from the study are applicable to a wide range of consumer and community partnerships with health professionals. These include the need for consumers and community members involved in this type of policy initiative to possess additional ‘civic-based’ skills, beyond those needed in service delivery initiatives. In addition organisational and professional change may be required to address professional dominance (131).

**Community Level Methods**

Common methods used to engage communities in decision making include citizen juries, interviews, surveys, focus groups and public forums. However, Bruce et al. (2008) found that limited internal evaluations of community engagement methods at the community and population level (43).

Nilsen et al. (2013) in their Cochrane Systematic Review included one trial, comparing different methods for involving the community in determining health priorities (telephone discussion, face-to-face group meeting, and mail survey). The results showed that a face-to-face meeting is most likely to engage community members and may result in different community health priorities than by telephone (84). There was a lack of response to the mail survey so this was not able to be included in the study results. In addition they concluded that little research has been done to determine the most appropriate strategies for involving community in health care decisions at the population level (84).

Citizen juries are one approach to engage communities in the decision-making processes of health services which provide an opportunity for a well informed, in-depth analysis of specific issues. Citizens juries enable participants to receive high quality information, ask questions of experts, and discuss the issues among themselves before making recommendations. Bruce et al. discuss three Australian examples of where citizen juries have been used by health services. One health service used a citizen jury for a priority setting processes, another to explore ways to reduce inequalities in Aboriginal health, and the other to explore community views on the relevant public health issues within the region for the health service to address (43).

In the UK, Patient and Public Involvement (PPI) forums have been operating since 2003 to bring the views and concerns of consumers and communities to their local health services. Every NHS Trust and Primary Care Trust in England has a PPI Forum. PPI Forums have a number of primary roles, which include:

- Obtaining views from local communities about health services and make recommendations and reports
- Making reports and recommendations on the range and day to day delivery of health services
- Influence the design of and access to NHS services
- Providing advice and information to patients and their carers about services.

Since inception 572 forums have been working with almost 5000 volunteer members. Many key issues have been identified through the forums and addressed by health services. The Commission for Patient and Public Involvement in Health manages and coordinates the PPI Forums (132).
**Consumer Engagement Population-Level Interventions**

A paper by Australian authors Sanders and Kirby (2011) examines consumer engagement strategies that can be employed throughout the process of program development, evaluation, training, and disseminations, and in ‘scaling up’ a parenting intervention. They argue for a multilevel public health approach to parenting interventions which require strong consumer perspectives to enable the interventions to be more responsive to the preferences and needs of families, and to ensure greater population reach of interventions. They draw on large-scale dissemination trials to illustrate how consumer input can result in an increasingly differentiated suite of evidence-based parenting programs. Sanders and Kirby argue that this approach requires health services to build relationships with consumer groups and to work collaboratively with them (133).

**Safety and Quality Improvement**

A systematic review of evidence by Doyle et al (2013) found that patient experience is clinically important and clearly links the patient experience of health care with clinical safety and effectiveness. The conclusions of the systematic review support the case for the consumers having a role in identifying poor and unsafe practice and to help enhance effectiveness and safety. They also conclude that clinicians should ‘resist sidelining patient experience as too subjective or mood-oriented, divorced from the ‘real’ clinical work of measuring safety and effectiveness’ (p. 1). Consumers provide a unique perspective on safety and quality risks, prioritisation of issues and acceptability of proposed solutions.

There is a requirement now for health services to engage consumers in the analysis of organisational safety and quality performance, and enable consumers to participate in the planning and implementation of quality improvements. There is also a requirement to engage consumers in the evaluation of patient feedback data and the development of actions to address improvements that are required.

This section will focus on examples from the literature for how this may be achieved. As the WCHN is a state wide paediatric service and is keen to further engage children and young people in safety and quality improvements, the first component of this section will provide insights from the literature in how children and young people. This will be followed by the sub themes of:

- Consumer Feedback and Complaints Management
- Consumer Stories
- Real Time Feedback
- Quality of Care Reports to the Community
- Consumers Involved in Staff Selection.

**Methods for Engaging Children and Young People**

There are few examples in the literature of ways that health services have engaged children and young people to improve the safety and quality. There are several case studies of how children and young people have been engaged within schools and the broader community. These can be drawn upon to understand the types of methods and techniques to use, and the types of skills required to do this effectively. These examples are contained within a range of resources which guide services in ways to engage with children and young people. These resources can be utilised by health services to gain input into quality improvement. However, several of the papers referred to in earlier sections of this literature review have made mention of the fact that one of the barriers for health services is not having the skills to engage with children and young people. These are skills
which can be learnt, or the process can be outsourced to people with expertise. In the earlier example from Derbyshire Children’s Hospital in the UK about engaging with children and young people in the design and development of their new hospital, identified that where health professionals knew they didn’t have the skills, they collaborated with a community group who did have expertise to achieve their ambitious program of engagement. They learnt from the community group during the process and were more confident in their skill base for future engagement processes.

Aubery and Dahl (2005) conducted a systematic review to identify effective practices for engaging with vulnerable children. They identified that there very few studies, however, there was evidence to support the view that engaging children under twelve is enhanced by the use of activity-based techniques (134).

Derbyshire Children’s Hospital use different methods to gather information from children and families. A key learning has been that questionnaires provide superficial information, but focus groups with children have been much more enlightening. The focus groups have been conducted in schools. Their experience has shown that children are more confident in an environment where they feel comfortable and is ‘their own territory’. The two distinct age groups Derbyshire Children’s Hospital have engaged in focus groups have been the 10 and 11 year olds, and the 14-16 year olds (129). They also conduct focus groups with parents of children who have had the experience of being in hospital. Cooke (2004) states that working with children in focus groups require three distinct actions from the facilitator:

- Careful thought and clarity about what is wanted: What do you need from them to take your task forward?
- Careful design of the overall shape of the session and ‘exercises’ which allow children of different abilities or levels of confidence to join in and contribute.
- Make it fun. Keeping the attention of young people for a prolonged period of time is hard work and requires a sense of humour and an honest confidence in the task (129).

These recommendations by Cooke (129) are congruent with Australian guidelines developed to assist organisations to involve children and young people. These guidelines are useful for health services to use, to ensure age appropriate methods and ethical processes are used.

Examples of four Australian guidelines are:

- **The NSW Commission for Children and Young People** (2013). They have developed guidelines for organisations to meaningfully and effectively involve children and young people in decision making. The guide highlights the importance of seeing children and young people as partners with adults in the decision-making process. The guideline is titled ‘Citizen Me! Engaging Children and Young People in your Organisation’. There are also templates provided for information sheets and consent forms (135).

- **The Western Australian Commissioner for Children and Young People** (2009) has published participation guidelines for involving children and young people. Four steps provide the structure to the process. There is a need to review, reflect and respond during each step, and between each step for the whole process (127). There are many hyperlinks to other resources within this document, as well as engagement case studies with children and young people.

- **The Tasmanian Commissioner for Children** (2013) has published a practical guide for involving younger children in decision making (136). There are many practical activities included which assist organisations to engage effectively with children. There are also activities to assist children to express themselves, and an evaluation form to evaluate the engagement processes.
The Office for Youth, South Australian Government (2005) has published a Youth Consultation Toolkit. This tool kit assists organisations to learn how to effectively consult using various methods with young people between 12 and 25. The tool kit contains practical information sheets outlining different methods of consultation, as well as providing tips about which consultation method to use for the purpose of the consultation (137).

**Consumer Feedback and Complaints Management**

Consumers have a right to comment on their care, and to have any concerns addressed. Consumer feedback provides health services with important and meaningful information to drive quality and safety improvements. It is important that health services offer consumers multiple opportunities and ways to provide feedback (6).

There are various approaches to how consumer feedback and complaints are managed in health services, with most health services not including consumers or community members in the feedback and complaints reviewing processes. One method which is gaining momentum in health services, underpinned by the principle of a partnership approach, is to involve consumers in reviewing feedback and complaints. Conneely et al. (2005) evaluated a program where consumers and health service managers collaborated to review complaints as part of a health service’s Complaints Committee. They concluded that consumers displayed a willingness to offer their views and to engage in debate and that it was an effective strategy for their health service (138).

The Cleveland Clinic established Patient and Family Advisory Councils for each of its 26 institutes. The Patient and Family Advisory Councils comprise former patients and family members as well as health professionals and health service managers. They meet regularly to discuss issues relevant to patients and families, review patient feedback and complaints and provide input on areas for improvement and to monitor progress (139). It appears that they have approached this area of collaborative review of feedback and complaints by integrating consumers into the review of consumer feedback and complaints, and monitoring the recommendations for service improvement. However, no literature could be found to determine whether this strategy has been evaluated.

It must be stressed that the process of engaging consumers in reviewing consumer feedback and complaints through committee process has not replaced the immediate response and management of feedback and complaints within the health service. The committee process is a collaborative service improvement approach to reviewing and looking at system and practical issues to address issues. It is also an accountability strategy.

**Consumer Stories**

Manchester Mental Health and Social Care Trust (MMHSCT) created a collection of innovative digital patient experience stories. This was put in place to enable MMHSCT to build dignity and respect into its procedures. The MMHSCT wanted to bring their patients’ experiences to life, and to the attention of commissioners, in more innovative and emotive ways. The programme allows consumers to share their experiences of healthcare via short movies created in carefully facilitated workshops. These stories offer an opportunity to learn important lessons by walking in the storyteller’s shoes for a few minutes. The stories explore themes around compassionate personalised care, the importance of swift interventions and involvement in care planning processes. The stories are shown at the beginning of each Board meeting, they are used to support value-testing exercises during recruitment, to challenge mental health stigma, and to promote recovery. They also contribute to a much wider patient experience program to improve clinical outcomes and increase confidence in MMHSCT services. An outcome of the patient stories program has been in 2013, MMHSCT received the highest score in England in ten questions in the national patient survey.
Over the course of the year there has been a shift in complaints about care (reduced by 45%) and a reduction in management costs associated with investigations. There was a reduction in clinical negligence claims of 50%. In a recent survey, out of 2018 patients, 94% indicated that the staff that provided their care were helpful, and 95% of service users would recommend the Trust to friends and family. The program has facilitated improvements and efficiencies in patient communications as staff are spending less time investigating complaints, and more time providing patient care. Because of the innovative approach, the Trust anticipates a more efficient use of resources to promote learning and improve clinical outcomes. This program is already starting to impact in a positive way upon existing feedback systems, adding value by bringing to life what we already know. This in turn enhances the patient experience, increasing public confidence at a time of funding restraints and major service transformation (125).

**Real Time Feedback**

Health services are implementing innovative ways of gathering ‘real time’ consumer feedback, especially in acute care settings, rather than only relying on survey results from annual or biannual surveys. This is called ‘real time’ feedback (6, 139, 140). The methods include:

- senior management walk-rounds to talk with consumers about their experiences of the health service (also known as Leaders Rounding);
- hand-held devices or computers in the wards/departments for consumers to provide instant feedback (specific software can be used to assist in the ease of collating and analysing this feedback);
- utilising consumer and community members, who are members of health service committees, to interview inpatients using a structured format;
- utilising medical, nursing and/or allied health students on placement in the health service to interview patients using a structured format;
- providing patients with feedback cards at the commencement of the morning nursing shift and then having a ‘neutral person’ collect them during the day;
- patient liaison officers talking with patients; and
- post discharge phone calls.

Some commentators discussed the issue of the need to have a ‘neutral person’ involved in the feedback process as it was though that consumers would not provide honest feedback to health service staff. Nilsen et al. (2013) in their Cochrane Systematic Review included two trials, which compared using consumer interviewers with staff interviewers as data collectors for patient satisfaction surveys. They found small differences in satisfaction survey results, with less favourable results about the health service obtained when consumers were the interviewers (84).

**Quality of Care Reports to the Community**

Since 2004 all Victorian Public Health Services have been required to produce quality of care reports to the community and disseminate them widely within the health service and the broader community (141). Consumers are involved in the development of these reports in partnership with health services. It is a requirement of acute health services’ funding in Victoria. The Victorian Department of Health states that annual quality of care reports ensures:

- accountability of health services
- promotes changes in systems, professional practices and promotes continuous improvement
- provides consumers with information.

A quality of care report describes the systems and processes in place in health services to monitor and improve quality. It emphasises what these systems do, particularly the results and outcomes of the monitoring, and the action taken as a result of any identified quality issues.
Quality performance indicators on each of the minimum reporting requirements should also be included in annual quality of care reports. The mandatory quality and safety minimum reporting requirements are:

- infection control
- medication errors
- falls prevention and management
- pressure wound prevention and management
- continuity of care (141).

**Consumers Involvement in Staff Selection**

A very direct and effective way of engaging consumers and community members is in decision making processes about staff selection. Although this process appears to be widespread and implemented in many health service, formal evaluations are limited.

An evaluation of how mental health consumers were involved in staff selection at Northern Area Mental Health Services in Melbourne was discussed by Bruce et al. (43). The process involved appointing consumers to staff selection panels. The consumers received training and information to enable them to participate. The evaluation demonstrated that the process of involving consumers influenced the culture of the service, including factors like the quality of staff appointments, staff attitudes and practices. Mutual respect between consumers and staff was enhanced, along with relationships.

Sancehz-Bahillo et al. (2012) conducted a study to develop the ‘Service Users Informed Tool for Staff Selection’ as a systematised way of engaging consumers in the recruitment and selection of staff. The evaluation of the impact of consumers using the tool demonstrated that the engagement of consumers in the recruitment and selection of staff is significantly enhanced by the tool. They state that it can be adapted and refined for use in a range of services, with local input from consumers of those services (142).

**Review and Development of Information**

Consumers and community members have a role in supporting health services to ensure that information used by health services is clear, easy to understand, and relevant to the needs of the consumers or community members who are the target audience for that information (5, 84).

A Cochrane systematic review by Nilsen et al. (2013) identified there was moderate quality evidence that involving consumers in the development of patient information material resulted in material that was more relevant, readable and understandable to patients, without affecting their anxiety. Effectiveness was found to vary according to how the written information was used (84). The following areas will be discussed in more detail: the Need for Strategic and Coordinated Approach; Good Practice Guidelines; and Methods for Engaging Consumers.

**The Need for a Strategic and Coordinated Approach**

Most health services appear to approach involving consumers and community members in the development and review of health information in an ad hoc manner, and often rely on individual health professionals or departments to identify a need, and seek input from consumers as they see
the need. There is no accountability measure in the health services to ensure that resources are allocated, guidelines are followed and consumers or community members are effectively involved in the process.

Where health services have been more effective in raising the quality of consumer information they have had a strategic approach, and coordinated process for:

- identifying consumer information needs for the health services with input from consumers;
- implementing an equitable approach to prioritising the development of consumer information based on consumer and community need;
- identifying the necessary resources and managing those resources;
- ensuring writing and review guidelines based on health literacy principles are established, implemented and monitored within the health service;
- ensuring effective consumer and community engagement methods are used;
- ensuring document and quality control; and
- ensuring dissemination and utilisation strategies are in place.

The Victorian Auditor-General’s report (6) identified one health service with a Patient Information and Education Working Group to lead and advise on the production of consumer information. This health service had guidelines and an evaluation form to assist staff in developing appropriate patient information. It also trained consumers to review patient information, and had commenced reviewing all of its patient information.

The Royal Women’s Hospital in Victoria engages women at all levels of information development as a way to enhance its information provision. Consumers are members of the Information Advisory Committees, write information with staff, and provide advice to staff on how information can be made more meaningful, useful and accessible (143). Evaluation of the process to develop a patient information booklet found that women reported the booklet produced with women’s involvement was an improvement on the previous booklet. However, the evaluation showed that there were mixed results on how midwives and doctors used the booklet and the frequency with which they provided it to women in the clinical setting (143).

**Good Practice Guidelines**

There are many good practice guidelines and toolkits available to assist health services understand what is important to consider in writing health information for consumers and the community, especially taking into consideration health literacy principles, and ways to work with consumers and community members to develop and review health information. For example:

- SA Health (2012) in their Policy Guideline, Guide for Engaging with Consumers and the Community Policy Guideline (115), include two health literacy tools relevant to health information development. Tool 7 is Assessing Readability. Tool 8 is Writing Health Information.
- Coulter and Ellins (2006 p. 34) in their literature review, summarise the good practice guidelines for producing consumer health information, and recommend the key principles (20).
- The Health Literacy Universal Precautions Toolkit has a section on the process of writing health information and engaging consumers to review health information (118).
- The US Government has developed a comprehensive range of toolkits that are available on the CDC’s website (see [http://www.cdc.gov/healthliteracy/developmaterials/guidancestandards.html](http://www.cdc.gov/healthliteracy/developmaterials/guidancestandards.html)).
These include:

- A Tool for Developing and Assessing CDC Public Communication Products (144),
- A Plain English Thesaurus for Health Communications (145)
- A health literacy guide to writing and designing easy to read web sites (146).

Evidence shows that when consumers, who will be the ‘end users’ of that information, and health professionals work collaboratively to develop health information, it is more relevant to the needs of the consumers and more effective as a communication tool (20).

**Methods for Engaging Consumers**

There are many and varied approaches for health services to engage with consumers and/or community members to develop and/or review written health information. The methods used will often depend on the time and resources available, and the openness of health professionals to engage with consumers in a collaborative way.

Methods for engaging consumers or community members can include surveying consumers, one-on-one interviews, focus groups, partnering with consumers on project groups to develop information, collaborating with other interest groups to develop information, and extensive face-to-face consultations with consumers who will be end users of the information.

Nilsen et al. (2013) in their Cochrane Systematic Review included a study which tested an information leaflet about patient-controlled analgesia (PCA). The method of involving consumers in the development of the information was through a series of focus groups. Consumers informed the design of the leaflet as participants of focus groups (84). Nilsen et al. also included a study that tested information material about endoscopic procedures. Individual interviews with consumers were used to inform the development of the material (84). Both methods of engaging consumers (focus groups and individual interviews) produced information material that was more relevant to the needs of consumers, than information material produced by health professionals alone.

Some examples of how other health services have approached working with consumers and community members are:

- A rural health service formed a Critical Friend’s Group, which consists of eight community members from diverse backgrounds and ages within the community. The critical friend method has its origins within the Education Sector, where a critical friend is encouraging and supportive, but who also provides honest and often candid feedback that may be uncomfortable or difficult to hear. In summary, a critical friend is someone who agrees to speak truthfully, but constructively, about weaknesses, and problems. In this health service the Critical Friends Group’s role is to provide critical feedback on written information such as template letters to patients, signage, pamphlets, health information sheets, and posters. The Critical Friend’s Group met for an orientation to the role and agreed that their preferred method of working was via email, with the occasional face-to-face meeting as required. To date they have provided extensive feedback on a range of written information and have always ensured that the information is clearly written and understandable, and contains relevant information to consumers or community. One staff member coordinates the Critical Friends Group and is the main contact for disseminating the information and communicating with the group (147). The Group utilise SA Health’s guidelines as a basis to review health information, as well as their own interpretation of how clearly the information reads. The health service doesn’t have a strategic approach to developing or reviewing health information, the work with the Critical Friend’s Group is on an ‘as needed’ basis.
• Kidsafe SA has used a partnership model to develop information on child safety for Aboriginal people that is culturally appropriate, easy to read and visually appealing for people with lower levels of health literacy (148). These resources were developed through a collaborative partnership between Kidsafe SA, Aboriginal Resource and Management Support Unit (ARMSU), and Burns SA, and through extensive face-to-face engagement with Aboriginal families with young children. They have been highly commended for the cultural fit, and have been adopted Australia wide by a range of health services. The resources are also used as part of a workforce training program to train Aboriginal health workers in child safety.

Partnerships which Reflect the Community and Support People from Diverse Groups and Vulnerable Populations

It is imperative for health services to address the health needs of the whole population they serve, not just the people who willingly access their health services. To this end there is a need for health services to fully understand the demographics of the population that they serve and to monitor population changes over time. This is to ensure that health services continue to meet these population changes and diversity within the community, and that health services are engaging with people from these population groups to improve health services and health outcomes. There is growing research within Australia that clearly demonstrates the link between culture, language and patient safety outcomes. Providing an increased voice to vulnerable or disenfranchised populations is important to improving health equity (119).

Diversity is a key principle of SA Health Policy Framework for Active Partnerships with Consumers and Community (10). They state that health services need to develop:

Partnerships that are reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people who do not usually provide feedback. The health service engages with individuals and groups including Aboriginal and Torres Strait Islander people, people with a disability, older adults, young people, people with a mental illness and people from cultural and linguistically diverse backgrounds.

The main areas identified in the literature related to developing partnerships which reflect the community and support people from diverse groups and vulnerable populations include: Strategic Approach; Cultural Safety and Formalising Links with Community Groups and Organisations; and Community Development Approach.

Strategic Approach

One of the challenges for health services is to identify and understand the various population groups who experience disadvantage and are vulnerable to developing poor health outcomes as a result. In addition it is important to identify those population groups who do not access health services and the reasons why. To this end, a strategic approach is needed. It is crucial for health services to identify and understand the community groups/agencies/organisations that do have relationships with the population groups who are vulnerable and do experience disadvantage, and formalise these working relationships. These steps are supported by various research underpinning guidelines for working with Aboriginal and Torres Strait Islander peoples and communities, and Culturally and Linguistically Diverse peoples and communities (64, 65, 149).

At a strategic level some health services have developed a Framework/Plan for Engagement with Vulnerable Populations, which clearly identifies the vulnerable population groups that potentially
would need to access the health service and then the methods for effective engagement. Health Consumers Alliance SA have developed a Framework of Engagement Practice with Vulnerable South Australian Communities that WCHN can draw upon as an example (150).

**Cultural Safe Places and Formalising Links with Community Groups and Organisations**

For vulnerable Indigenous populations, the following were identified as contributing positively to the engagement process between the health services and the community. These were widespread community involvement; an explicit focus on Indigenous population as a whole and high risk individuals in particular; the use of Indigenous health workers; and regular contact with participants were identified (34).

The Victorian Auditor-General’s Report (2012) identified health services that had made sound efforts to improve participation by the Aboriginal and Torres Strait Islander (ATSI) community in accessing services and being recognised within the ATSI communities as being culturally safe places. As a first step, they have improved the identification of ATSI patients through improved policies and data systems, staff training, and awareness-raising in the ATSI community. Cultural symbols are important to create a welcoming and culturally safe environment for ATSI consumers. The most common examples seen at the audited health services were flying the ATSI flags, and displaying artwork and cultural artefacts, and a plaque recognising the traditional owners. Additional examples at some health services include celebrating major events such as National Aborigines and Islanders Day Observance Committee (NAIDOC) week, holding smoking and cleansing ceremonies, and allocating a space that meets the spiritual and cultural needs of ATSI patients, families, staff and community members. The health services also employ Aboriginal Health Liaison Officers to support patients and families throughout their care journey, and promote links between the health service and local ATSI community (6).

Riggs et al. (2012) conducted a study that aimed to explore ways to enhance the engagement of refugee families and service providers in maternal and child health services in Melbourne. They concluded that formalising links and notifications between settlement service providers and maternal and child health services would be an effect way to improve service access, along with a systems-oriented, culturally competent approach to service provision, and having continuity of nurse/midwife and interpreter would increase client-provider trust and ongoing engagement (151).

A US study compared five different approaches to recruiting consumers from minority populations who normally didn’t participate in health research. The approach that was most effective was developing relationships with a partner-led approach. The effectiveness of this approach supports the other research recommendations to develop strong formalised links with community based organisations who work most closely with vulnerable and hard to reach people (152).

The ACT Government have published a Community Engagement guide which supports this approach and states that formalising links with community groups and peak bodies is an important strategy to support engagement with community groups, especially those from vulnerable and hard to reach population groups (149). The publication provides guidelines for how to engage with people who are ‘hard to reach’; working with children and young people; working with people who are vulnerable and disadvantaged; and working with Aboriginal and Torres Strait peoples.

Watson’s (2005) paper identifies effective methods that promote engagement by families in community services and examines the strength of the evidence base underpinning these methods. There may be lessons within this paper which WCHN can apply. The paper is based upon a review of
literature from peer-reviewed journals. Watson concludes that it is important to make the service attractive to families. If they feel threatened, or if by attending they are labelled as failures, they will feel uncomfortable attending. Other agencies will also not refer to a health service or program unless they see merit in it, so relationships need to be developed within the service provider community and links formalised (153). Watson’s conclusions are congruent with Riggs et al. (151), the ACT Government (149) and Horowitz et al.(152).

Tomacos et al. (2009) conducted a literature review on health literacy and vulnerable groups and make recommendations for engaging with vulnerable groups through a health literacy lens (114).

**Community Development Approach**

Community development is identified as a means of engaging people who, for a variety of reasons, are reluctant to engage with a health service. Baum et al. (2012) describes a range of community development initiatives that have been effective engagement strategies with vulnerable and hard to reach people and communities in the Northern Territory and South Australia (154).

**Supporting and Informing Consumers who Partner with the Health Service**

There is a requirement that health services will provide training and support to consumers and community members who partner with the organisation and take on an active role in the health service, whether this is on committees, reference groups, working parties, councils or other types of formal forums. This can take the form of a consumer training program, which includes an orientation to the health service and to the role they take on. This is for purpose of enhancing their partnership role in the health service and the consumer or community member’s confidence to perform in the role, though there are some specific consumer tools and resources on various health consumer websites, such as Cancer Australia (155).

Health services need to effectively communicate expectations for consumer engagement to consumers and community members, and build their capacity to meet these expectations. Clear consumer engagement policies and training opportunities are essential to embedding consumer engagement within organisational culture (6). The three sub-themes to be discussed are: Consumer Training; Support and Capacity Building; and Communicating with Consumers.

**Consumer Training**

There were no literature found which could provide evidence to support the type of training programs most effective for consumers and community members to support their engagement with health services.

A study by Johnson et al. (2006) found that for consumer and community engagement to be effective within health services there is a need to create systems and structures to ensure consumers and community members are appropriately supported in their various roles. Training, ongoing support, and capacity building needs to be continually available. This was seen as the responsibility of both the health services and peak consumer organisation in the state, rather than just being seen as the responsibility of the individual consumer or community member to seek out their own training opportunities (156).

It is highly recommended that health services partner with the state based peak health consumer organisation to develop the most relevant orientation and training programs to suit the needs of the
consumers and community members who will be participating in that health service. This relationship will provide further opportunities for training programs to be developed for consumers and community members who are taking on leadership and advocacy roles within the health sector.

The needs of rural and remote consumers and community members need to be considered, along with consumers and community members who may not be able to attend training in a central metropolitan health service during office hours. Web based orientation and training programs may meet the needs of these people. No web based orientation and training programs for consumers could be located during the search.

There are many reports and toolkits available to advise health services on the types of orientation and training required for consumer to participate in health services. A range of resources available to inform health services consumer training programs include:

- Victorian Integrated Cancer Services, Consumer Participation Toolkit (157);
- Cancer Australia, Tools for Consumers (155);
- Cancer Australia, Consumer Training and Mentoring Guide (158);
- Consumers Health Forum, Consumer Representatives Training and Support Project, Final Report (159);
- Victoria’s Northern Central Metro PCP, Advocacy, Leadership, Community Participation. A training program for health consumers and carers (160);
- Neami National, Training to support Consumer Participation (Launching Pad) (161).

**Support and Capacity Building**

The main areas identified in the literature related to support and capacity building relates to the following areas: Strategic Leadership; Facilitator/Coordinator Support; Mentoring; and Reimbursement.

**Strategic Leadership**

Meyers (139) describes a strategic way to support consumers and build their capacity. It is the leadership position of the Chief Experience Officer within the Cleveland Clinic, which has been created and charged with raising the organisation’s commitment to ensuring a high quality patient and family experience, and humanising the delivery of health care. The Chief Experience Officer position not only focuses greater attention to the patient experience, but fulfils both a symbolic and strategic goal. The position reports directly to the Chief Executive Officer, who provides overall leadership and for the organisation, and coordinates patient experience goals with other aspects of clinical care (139). This level of leadership and organisational resource was identified as vital to support building the organisation’s capacity to support consumers and community engagement and for it to be integrated into the health service (139).

**Facilitator/Coordinator Support**

Nathan et al. (2013) examined the ways to maximise the input and impact of community representatives who are involved in formal organisational processes in health services such as committees/advisory groups/working parties and other similar forums (67). Their findings bring attention to the need for health services to employ a facilitator/coordinator that can:

- Support consumers by building confidence and skills
- Engage consumers in an agenda for action
- Assist consumers to understand and navigate the health service and system
- Advocate to staff for community representative’s engagement and influence in health service policy and practice
- Advocate externally to outside groups and build coalitions.
Nathan et al. conclude that their study offers a new model for synthesising the key roles of coordinating and facilitating community engagement in health services which may be transferable to other health service settings (67).

**Mentoring**

The Victorian Integrated Cancer Services state that mentoring of consumers is an invaluable and effective way to support and build the capacity of ‘new’ consumers to actively partner with health services to learn about their role and what may be expected of them. One approach is to introduce new consumers or community members to those who have already been involved in committees or other service improvement activities (157).

**Reimbursement**

Reimbursement for expenses and payment for time attending meetings is a SA Health policy, which is current being reviewed. Organisations who have strong consumer engagement practices, stated that there are basic principles which should underpin a health services’ approach to reimbursement and payment. These are:

- consumers not being out of pocket for attending agreed events such as meetings, functions or training
- reimbursement coming from an arrangement that is predetermined and preapproved
- consumers having the option of opting out of local reimbursement arrangements
- consumers not being impeded in receiving reimbursement by onerous administrative procedures (157).

**Communicating with Consumers**

The main areas identified in the literature related to communicating with consumers relates to the following areas: Develop a Database; and Develop a Communication Plan.

**Develop a Database**

Several health services maintain databases of consumers who have expressed an interest to participate in the health service. Victorian Integrated Cancer Services have outlined a template for developing a database in Appendix 5 of their Toolkit (157). Some health services have on-line registers for consumers and community members to register their interest. Two examples of this can be seen on the following websites for:


**Develop and Implement a Communication Plan**

It is recommended that health services develop and implement a communication plan to ensure information sharing with consumers and community members who participate in the health service and also who have put their names forward to be willing to participate for specific issues (157). The purpose of a communication plan is to ensure that all stakeholders are provided with appropriate, up-to-date information. This will vary with the level of involvement with the health service. There also needs to be a clear mechanism for how consumers and community members involved with the health service can provide feedback to the health service.
It is recommended that the communication plan:
- identifies consumer and community stakeholders
- defines what it is you want to communicate to your consumers, i.e. what’s on, participation opportunities
- defines how information can be fed back from consumers to your organisation
- determines a range of strategies for effectively communicating with them
- encourages engagement of stakeholders and foster commitment
- develops user-friendly information sharing through access to information about the aims and specific projects being undertaken by your organisation
- promotes the concept of service improvement (157).

Organisational requirements to support consumer and community engagement

Organisational, cultural and contextual factors affect the integration of consumer and community engagement in health services. There are a number of themes which the Australian Commission on Safety and Quality in Health Care have identified as foundational organisational requirements to support partnerships with consumers and the broader community (3).

- Leadership and strategic vision
- Governance framework
- Skilled and informed workforce
- Environment (physical and policy)
- Evaluation and monitoring
- Access to records.

It is beyond the scope to address each of these organisational requirements in this literature review. Skilled and informed workforce will be the focus of a separate scoping paper to be developed further into the WCHN project. This will inform the staff training program to be developed.

However, some relevant points will be raised to support the need for developing these organisational requirements to sustain and support consumer and community engagement. Many health services fail to adequately attend to these foundational issues and consumer and community engagement can result in a series of ad hoc, unauthentic, and disconnected activities.

Luxford et al. (2011) investigated organisational facilitators and barriers to patient-centred care in US health care institutions renowned for improving the patient care experience (16). A conclusion of that study was the organisations that have succeeded in fostering patient-centred care have gone beyond mainstream frameworks for quality improvement based on clinical measurement and audit. They have adopted a strategic organisational approach which is patient focused.

The organisational attributes and processes that are facilitators for making care more patient-centred are:
- Strong, committed senior leadership
- Clear communication of strategic vision
- Active engagement of patient and families throughout the institution
- Sustained focus on staff satisfaction
- Active measurement and feedback reporting of patient experiences
- Adequate resourcing of care delivery redesign
- Staff capacity building
- Accountability and incentives
- Culture strongly supportive of change and learning (16).

The principal barriers against transforming delivery of patient-centred care were:
- Changing the organisational culture from ‘provider-focus’ to a ‘patient-focus’.
- Length of time it takes to transition towards such a focus (16).

The Victorian Auditor-General’s Report (2012) stated that visible interest and support from the chief executive officer (CEO), management and the board are vital to the successful integration of consumer and community engagement into health services (6).

In addition:
- Leaders and managers at all levels need to create the conditions in which a high standard of patient-centred care is delivered consistently.
- Clinical teams perform best when their leader’s value and support staff and ensure their main focus is on patient care, and create time to care.
- Need to be clear about purpose – which is developing effective leadership and a culture that puts patients’ needs first.
- Can’t be left to chance (6).

As a result of the findings of the Francis Inquiry, the King’s Fund (2013) prepared a report, Patient-Centred Leadership: Rediscovering our purpose. It summarises the main findings of the Francis Inquiry in relation to leadership and culture, and sets out what needs to be done to avoid similar failures in future (7). Reports such as these are seminal publications which should closely inform all health services and health systems to ensure ‘the needs of the patient come first’. 
Conclusions

The literature on consumer and community engagement in health services is extensive. The literature search and review identified that were complex and inter-related concepts, approaches and methods. The challenge was to identify the best evidence to support the development of a Consumer and Community Engagement Strategy, which would meet NSQHS Standards and enable meaningful and authentic engagement of consumers and community in partnerships in direct care and partnerships in organisational design and governance.

Whereas the evidence to support consumer and community engagement in direct care and organisational design and governance is compelling, there were few comparative studies and evaluations of consumer and community engagement methods that would be transferable to all health service contexts. Whilst valuable and informative, much of the literature about methods of consumer and community engagement in health services did not provide the level of evidence required to conclusively and definitively provide a strong evidence base for the development of the WCHN Strategy. Instead there are a range of options for WCHN to consider, some of which have a strong evidence base, some are evaluated and may be transferable, and others are descriptions of what other health services have found useful and published an account of. A key finding is that consumer and community engagement methods are often context specific and there is no ‘one size fits all’ approach to consumer and community engagement.

An exciting opportunity exists for WCHN to utilise this literature review as a spring board for ideas as they move forward to strengthen consumer and community engagement. However, this is underpinned by another key finding, which is that effective, meaningful, and sustainable consumer and community engagement will only be achieved if the appropriate organisational attributes and processes are in place.
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