Consumer and Community Engagement Model

An outcome of the WentWest — Health Consumers NSW Joint Consumer Engagement Project

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Consumer and Community Engagement Model:
An outcome of the WentWest– Health Consumers NSW Joint Consumer Engagement Project

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EXECUTIVE SUMMARY

In 2013 a partnership between WentWest and Health Consumers NSW was established to embark on a Joint Consumer Engagement project. The project aims included to embed consumer involvement across WentWest and to develop tools and resources for use across NSW.

Health consumers have been defined as people who use, have used, or are potential users, of health services including their family and carers. 'Engagement' encompasses activities that involve consumers or communities participating in health service decision-making, policy development, service design, delivery and evaluation.

Consumer and community engagement has been shown to have positive impacts within health services in Australia [6, 12, 31, 32, 33]. These positive impacts include: improved health outcomes for health consumers, improved collaboration with partners and stakeholders, as well as contributing to ethical practice and democratic engagement [1].

The model has been developed based on available evidence and recognised best practice – identifying six strategies that achieve best practice including:

- ensure consumer engagement is a priority
- address organisational facilitators
- actively include disadvantaged/marginalised groups
- build the capacity of consumers to engage
- build the capacity of staff to support engagement
- focus on outcomes and evaluation.

This available evidence is compelling but limited [1, 2, 10, 11]. The model has therefore been designed to contribute to and continually inform the evidence base for consumer and community engagement.

The aims of the Consumer and Community Engagement Model are:

- to improve consumer-centred care
- to work collaboratively with community to identify the unmet health needs of Australian communities
- to build the capacity and capability of health consumers to participate in the design, delivery and evaluation of their health care.

The model is focused in two areas:

- a 'process model' of the interaction between Consumer-Centred Care and the Top Down-Ground Up Engagement Processes
- an overarching view of the model and its five main elements: Guiding Principles, Consumers Involved in Governance, Critical Inputs, Processes and Key Outcomes.

Consumer-centred care is at the heart of the model – recognising that improving the experience and health outcomes of consumers is one of the primary objectives of consumer and community engagement. While the processes can be complex, the model demonstrates how engagement interacts with consumer-centred care and identifies inputs and outputs that can be monitored and evaluated.

The Top Down-Ground Up engagement processes define more than one type of engagement process that occurs in health services – primary care in particular:

A 'Top Down' approach: much engagement will be initiated by the organisation and will be focused on services already planned or being delivered (e.g. engaging with service users and carers to improve a particular service). Top Down engagement deals with known health needs and existing services. (Note that consumers can still play leadership or partnership roles in this type of engagement.)

A 'Ground Up' approach: a broader style of engagement takes place with communities to explore, to understand and to determine with communities how to better meet their diverse health care needs (and importantly this can be initiated by the service or the community). Ground-Up engagement identifies gaps in services, access issues and other unmet needs.

Guiding Principles provide a frame of reference for the way in which consumers and health services (and their staff and management) engage with each other.

Consumers Involved in Governance in clearly defined roles and structures ensures that the consumer perspective is always considered in decision making and that engagement is a priority.

Critical Inputs relate to many internal and external elements that are necessary in order for engagement to be effective. These have been identified within the model as Internal Capacity, Partnerships and Integration and Consumer and Community Capacity.

The Key Outcomes of engagement have been identified clearly within the model and are summarised as Evaluation and Evidence (with a focus on impact), Improved Health Outcomes (for consumer care and communities) and Capacity and Capability Building (of organisations, consumer representatives and communities).

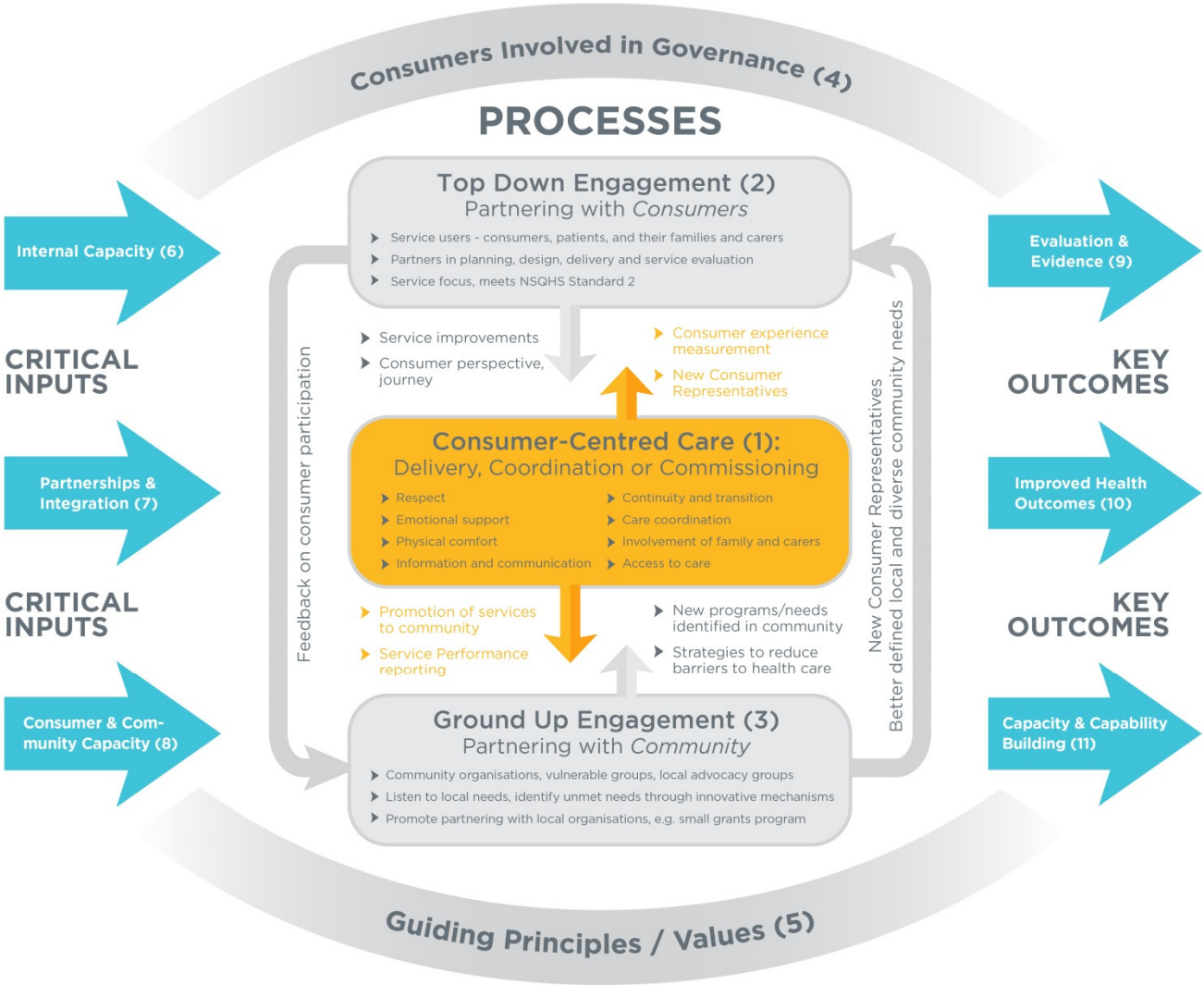

Figure 1: The Health Consumers NSW/Wentwest Consumer and Community Engagement Model

The Consumer and Community Engagement Model is an outcome of the WentWest-Health Consumers NSW Joint Consumer Engagement Project. The model has been developed with the general transition to Primary Health Networks in mind

and with WentWest and the communities of Western Sydney as a particular focus. In speaking with others in different health settings and in different locations we soon came to realise that the model is also relevant to health services and communities across Australia.

Health Consumers NSW and WentWest hope that this model provides consumers, communities and health services with clarity and guidance around consumer and community engagement. We see this model, as it is now, as a starting point and we expect that over the coming months and years it will be refined and adapted in response to the unknown challenges and innovations that the future will bring. In order to do this, and as part of our own commitment to quality and continuous improvement, we welcome and encourage consumers, communities and health services to contact us with any comments, feedback and criticisms of the model and its implementation.

CONTENT

ACKNOWLEDGEMENTS 2

EXECUTIVE SUMMARY 3

INTRODUCTION 8

BACKGROUND 8

- Definitions of consumer and community engagement 8
- Spectrums of engagement 10
- Rationale for CCE 12
- Impact and evidence of CCE 13
- Barriers to CCE 14
- Evidence-based strategies 16

LOCAL CONTEXT 28

- Project Background 28
- Partnerships 30

NATIONAL CONTEXT 31

- Primary Health Networks and the Community Advisory Committee 31
- National Safety and Quality Health Service Standards - Standard 2: Partnering with Consumers 31
- Consumer participation in other sectors 32

THE CONSUMER AND COMMUNITY ENGAGEMENT MODEL 33

- Model rationale 33
- The Top Down – Ground Up Engagement Model 34
- The overarching model and its elements 39

CONCLUSION 48

REFERENCES 49

INTRODUCTION

In 2013 a partnership between WentWest and Health Consumers NSW was established to embark on a Joint Consumer Engagement Project in Western Sydney. The project aims included embedding consumer involvement across WentWest and developing tools and resources for use across NSW.

The Consumer and Community Engagement Model is an outcome of the WentWest-Health Consumers NSW Joint Consumer Engagement Project. The model was first developed with WentWest and primary health care in mind, but it soon became apparent that it was applicable to consumer and community engagement across the NSW / Australian health care environment.

The model has been developed based on:

- the needs of health consumers and the communities in the Western Sydney region
- WentWest's experience and strengths
- evidence and best practice – outlining strategies to achieve best practice
- the national context, in particular the transition from Medicare Locals to Primary Health Networks and the National Safety and Quality Health Service Standards (NSQHS)

This document outlines the evidence underpinning the model, the context for WentWest and the model itself – particularly focusing on the Top Down-Ground Up Engagement Process.

BACKGROUND

Definitions of consumer and community engagement

The field of consumer and community engagement (CCE or just 'engagement') spans many definitions and has been called many things [1, 2]. The following definitions are used by a majority of health services and health consumer organisations in Australia.

Consumers are people who use, have used, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities [3, 4].

The term 'consumer' is preferred as it implies a person making rational decisions based on available information, whereas the

term 'patient' "tends to reinforce a hierarchical relationship where participation is neither valued nor encouraged" [1]. Also the term 'consumers' includes carers who often have an important role in health care decision making and care giving. Finally many health programs and services don't use the term 'patient' anyway and refer to 'clients' or even 'residents' (in the case of live-in facilities).

Community refers to groups of people or organisations with a common local or regional interest in health. Communities may connect through a community of place such as a neighbourhood, region, suburb; a community of interest such as patients, industry sector, profession or environment group; or a community that forms around a specific issue such as improvements to public healthcare or through groups sharing cultural backgrounds, religions or languages. [4]

Engagement has been used in this document to encompass activities that involve consumers or communities participating in (even initiating) health service decision-making, policy development, service design, delivery and evaluation.

Defining 'consumer representative'

A health consumer representative is a health consumer who has taken up a specific role to provide advice on behalf of consumers, with the ultimate aim of improving health care. A consumer representative is often a consumer member of a committee, project or event who voices consumer perspectives and takes part in decision making on behalf of consumers.

A health consumer representative may be nominated by and accountable to, a consumer organisation. Usually the role is working with a health service (or consumer organisation) and is often in a volunteer capacity. Sometimes the role comes with a small payment to cover the consumer's costs.

Confusion over who or what a consumer represents has been identified through research as impacting on the effectiveness of engagement [5, 6]. It is valuable for health services, staff and consumers to be aware of the different types of "representative" and what role they are recruiting for or fulfilling (although roles can shift over time). Consumers involved in CCE activities can fall into several categories [7]:

- Formal representation e.g. a consumer is part of a consumer organisation and has been formally appointed to represent the views of the

organisation's members.

- Descriptive representation e.g. a consumer is involved because they are recognised as 'typical' of the population they represent (perhaps a past or present service user).
- Symbolic representation where the consumer "may be seen, and may view themselves as symbolising representation, but in fact have no formal constituency to call upon or be accountable to" [5].

Representativeness can be problematic when the health service and the consumer are not clear on which category they fall into. Formal and descriptive representation are useful to health services and readily understood by staff and consumers, therefore it is ideal to identify upfront what type of consumer role is being recruited (e.g. a *'consumer representative'* vs a *representative consumer*). In relation to this, Australian evidence shows that recruiting consumers who are members of existing groups and networks (with or without formal roles) improves the effectiveness of CCE [6]. This has implications for best practice in relation to planning and recruiting for consumer roles.

Spectrums of engagement

In the field of community engagement there is a long history of defining spectrums (or ranges) of engagement. These spectrums define varying levels of, or approaches to, engagement, usually flowing from a lower degree of engagement to a higher (and sometimes ideal) degree of engagement. At each engagement level various techniques are possible and these should be selected based on the suitability to the respective consumers or community and health service goals.

The original spectrum is Arnstein's Ladder of Participation [27] – very much a hierarchy of engagement approaches which places significant value in citizen power:

- Citizen Power: Citizen Control, Delegated Power, Partnership.
- Tokenism: Placation, Consultation, Informing.
- Non-participation: Therapy, Manipulation

Acknowledging that a variety of engagement mechanisms are appropriate, there are several spectrums of participation that are more applicable to health CCE. Four of these have been

summarised in Table 1.

The Public Participation Spectrum [28] developed by The International Association of Public Participation (IPA2) is frequently referenced as a starting point for most spectrums, ranging from inform to empower. The Consumers Health Forum of Australia (CHF) supports a slightly different spectrum [5] that recognises nuances between listening and consulting and also the particular role of consumers in governance. CHF focuses on the increasing role for consumers in decision-making.

The National Safety and Quality Health Service (NSQHS) Standard 2: Partnering with Consumers Standard cites a similar spectrum [9] that shows increasing control of consumers in decision making, but also notes that regardless of which model is used the standard "aims to improve" CCE within health services.

One further spectrum of engagement highly relevant to regions with marginalised or hard-to-reach populations is from the Centre for Disease Control (CDC) [6]. This spectrum focuses on increasing community involvement, impact, trust, and communication flow. In particular *inform* is replaced with *outreach and empower* becomes *shared leadership*.

Table 1: Spectrums of engagement/participation

SPECTRUM SOURCE	Lower ← DEGREE OF ENGAGEMENT → Higher				
IPA2 [28]	Inform	Consult	Involve	Collaborate	Empower
CHF [29]	Inform	Listen	Consult	Partner	Govern
NSQHS Std 2 [9]	Inform	Consult	Partner	Delegate	Control (by consumer/ community)
CDC [30]	Outreach	Consult	Involve	Collaborate	Shared Leadership

Selecting a spectrum is ideally done in collaboration with key consumers and community stakeholders. It plays a strategic role in that it sets boundaries and expectations for an organisation's engagement program.

Rationale for CCE

The rationale behind why organisations participate in CCE varies across services, states and countries [2]. These arguments generally come down to the following sets of reasoning [1]:

1. **Ethics and democracy** – CCE is often viewed as an ethical and democratic right. The World Health Organisation's 1978 Declaration of Alma-Ata [8] is often cited in support of this position ("The people have the right and duty to participate individually and collectively in the planning and implementation of their health care"). CCE adds legitimacy to democratic decision-making and also is a strong argument for health services to recognise and plan for inequalities and diversity.
2. **Improved outcomes** – engagement has been shown to improve both policy outcomes (CCE provides policy makers with a users' perspective) and health outcomes (partly by ensuring that services are delivered effectively, closely targeted to people's needs).
3. **Improved relationships** – developing partnerships with consumers through engagement can make the health service more responsive to consumers' needs, investing in relationships that can then take a collaborative approach to solutions.
4. **Serves strategic/political purposes** – CCE can serve a range of strategic purposes: increase the legitimacy and credibility of decisions; increase public confidence in the policy process; and reduce political risk.

In the National Safety and Quality Health Service Standards, the Australian Commission on Safety and Quality in Health Care (ACSQHC) identifies rationales 1-3 above and goes on to argue that:

"An organisation cannot deliver care that is based on partnerships and addresses the needs and preferences of consumers and carers without seeking out, listening to, understanding and responding to consumers and carer experiences and expectations about health care.

It is critical that consumers and carers are involved throughout the continuum of health care safety and quality improvement, as [they] provide a 'reality check' that can help healthcare organisations understand how to make changes … that are meaningful to consumers and carers." (National Safety and Quality Health Service Standards, Standard 2: Partnering with Consumers, p6) [9]

Impact and evidence of CCE

Multiple authors have noted that despite the large body of published material related to CCE, reporting on the impact or evidence of engagement has been weak [1, 2].The participation of consumers in individual health care has been shown to improve health outcomes [9, 10] however there is limited evidence around the effectiveness of CCE in relation to its impact to health service outcomes or even that CCE "influences health agencies decisions in directions deemed desirable by the consumer or community group concerned" [10].

In a systematic review of literature carried out in 2002 reporting on the involvement of patients in the planning and development of health care, no comparative studies were identified, and while CCE had contributed to changes to health services, the impact or effects have not been reported [11]. The authors note in their conclusion "this absence of evidence should not be mistaken for an absence of effect" [11, p4].

The limited amount of evaluation and evidence around CCE has been partly attributed to the complexity of the area and that funding for research and evaluation is limited [10]. In fact there is little evidence that CCE activities within Australia are evaluated [1] although the introduction of the National Safety and Quality Health Service Standards [9] will hopefully lead to more extensive evaluation of CCE.

In spite of that limitation, there is evidence that CCE can result in improved health outcomes in primary care [6, 12, 31, 32]. A diverse range of models have been shown to be used across primary care settings [33]. For example in community health the idea of community control was common while in general practice the provision of information and consultation was more prevalent.

In recent Australian research [6] over 80% of staff and consumer representatives surveyed (of a large urban health service) agreed or strongly agreed that consumer representatives provided a link to the community. When asked for examples of the impact of consumer representatives, over 60% of staff and community responded with specific examples such as:

- Has made the Carer's Action Plan more responsive and raised important issues.
- Provided community perspective for development of discharge risk assessment tool.
- Provided impetus to establish a program to support families with a child in hospital.
- Insight into factors associated with discharge planning and management of patients in the community following discharge.
- Cut 'jargon' of meeting making it more people friendly.
- Committees seem to stay more on track when community representative is present and the work of committee is more transparent.
- Keep meeting focused on the 'patient' not the institution which is great.

Barriers to CCE

It has often been acknowledged that meaningful engagement is difficult and many authors have written about the barriers to CCE [1, 10, 12-15]. These can be grouped into three key areas: resources, consumer issues and organisational issues [1].

Resources

Insufficient resources are one of the most frequently named barriers with time and cost foremost - "consumer engagement is often expected to be completed within limited and unrealistic timeframes that restrict its effectiveness" [1]. Some engagement activities require more time (and funds) than others, particularly engaging consumers to participate in decision making. Adequate time to promote engagement and allow consumers to engage is essential to meaningful CCE – the alternative is rushed and tokenistic engagement (which damages future attempts to engage).

Consumer issues

Many issues impact on the ability of consumers to participate in CCE and these have been widely reported [1, 10, 13, 15]. These barriers range across a number of areas [1]:

- Lack of (and an imbalance of) resources and knowledge. Compared with health services staff or other stakeholders, consumers experience unequal access to resources, information, knowledge and influence.
- The valuing of expert and scientific knowledge above the lay knowledge of consumers [16] – even consumers themselves can fall into this way of thinking.
- Understanding the health system and the ability to discuss and critique it. Unfamiliar language, processes and norms all contribute to this barrier.
- Consumers own expectations can inhibit full engagement. Either poor expectations due to previous negative experiences can inhibit full participation by consumers, or high expectations can result in frustration and disappointment.
- Personal circumstances – health, carer responsibilities, or limited financial and time resources all restrict engagement by consumers.

Organisational issues

The barriers within health services to effective engagement have been detailed in the literature [1, 2, 12, 14, 17, 18]. There is strong agreement that these issues include [1, 18]:

- an unfamiliarity with working with consumers and negative attitudes towards CCE – "many managers lack the will to engage with consumers because they feel it imposes enormous burdens without any benefit" [1, p42]
- lack of knowledge, skills and experience in CCE – including how to talk to and work with consumers
- internal support for engagement, particularly from senior management
- organisational structures and staff movements frustrating engagement (the disconnect between different services or service boundaries is a an example of this)

- power relationships. These are a significant barrier – one that organisations and consumers need to be aware of in order to address. Several of the barriers listed as consumer issues are caused by, or contribute to the difference in power between services (and staff) and consumers.

Evidence-based strategies

While the evidence base for CCE has been patchy, there are best practices and recommendations provided in the research and industry literature. Much has been written about the facilitators of engagement, with many of these factors directly addressing the barriers to engagement [1, p44].

In a recent review of the implementation of The National Safety and Quality Health Service Standard 2: Partnering with Consumers, the Australian Commission on Safety and Quality in Health Care (ACSQHC) identified eight strategies employed by Australian and international health services who have successfully partnered with consumers [14]. These have been presented in Table 2 alongside facilitators identified in the literature [1]. The facilitators have been grouped into six key areas:

- **Leadership**
- **Valuing & responding to consumers input**
- **Good communication**
- **Accountability**
- **Capacity and resources**
- **Culture**

Table 2: Facilitators of successful consumer and community engagement

FACILITATORS OF SUCCESSFUL ENGAGEMENT	AUSTRALIAN COMMISSION OF SAFETY AND QUALITY ON HEALTH CARE (2014) [14]	LITERATURE REVIEW (GREGORY, 2007) [1]
Leadership	• Having strong committed leadership, with leaders communicating a strategic vision of partnerships throughout the organisation	• An organisational champion who works at a high level and can influence others [19]
Valuing and responding to consumers input	• Engaging consumers as partners throughout the organisation • Routinely collecting data about the experience of consumers, and feeding these data back to the governing body, managers and healthcare providers • Being responsive to changes proposed by consumers and supporting the improvement of care delivery and the environment	• A clear articulation of how consumers' views will be used, good feedback about what consumers have said, and details about how final decisions will be made
Good communication	• Sharing information about board activities and health service performance with consumers and the general community	• Good communication practice (appropriate language, well-prepared information, investment in developing good working relationships, and clear processes for engagement practice and meeting structures)
Accountability	• Having clear lines of accountability for partnerships with consumers at all levels within the organisation	• Accountability and trust
Capacity and resources	• Building the capacity of healthcare providers, managers, executives and board members and having a supportive work environment	• Good training and support for both consumers and staff [18] • An appropriate infrastructure to support people through

		engagement (e.g. a facilitator, funding, a plan, event or history) • Adequate time and resources [18] • Community workers to support the engagement program who are independent of planners and policy makers [13].
Culture	• Having an organisational culture that strongly supports learning and improvement.	• Previous successes (engagement is self-perpetuating – successes strengthen partnerships and increase confidence)

Building on these facilitators and others in the literature, a set of recommended practices have been identified. These include several practices that are particularly relevant to establishing a Primary Health Network.

These best practices have been organised into ***six strategies***, as shown below and discussed in detail over the page.

1. **Ensure consumer engagement is a priority**
   - Involving consumers from the start
   - Support for engagement from senior management
   - Consumers involved in governance

2. **Address organisational facilitators**
   - Internal governance for engagement
   - Built-in opportunities for consumers and community to initiate engagement

3. **Actively include disadvantaged/marginalised groups**
   - Recognition of the systemic nature and impact of health inequalities
   - Employing specific strategies to engage with disadvantaged/marginalised groups

4. **Build the capacity of consumers to engage**
   - Provide training to consumers
   - Support consumers who engage
   - Develop the capacity of consumers and community members to engage

5. **Build the capacity of staff to support engagement**
   - Provide staff with training
   - Support staff to effectively engage with consumers

6. **Focus on outcomes and evaluation**
   - Consumer experience data
   - Evaluate engagement
   - Focus on the outcomes of engagement

1. Ensure consumer engagement is a priority

For engagement to be effective, it is essential that organisations not only make consumer engagement a priority, but also appear to make it a priority. Two best practices associated with this are involving consumers in engagement right from the start, and support from senior management.

INVOLVING CONSUMERS FROM THE START

We have discussed the barriers to CCE and in particular the power imbalance between health services and consumers. Without an explicit understanding of this imbalance and determination to address it, services will find it difficult to design engagement to suit consumers (not just the health service). This imbalance can be significantly moderated if all CCE "starts from a consumers perspective" [1].

Best practice engagement involves consumers or community members right at the beginning to assist in designing the engagement. With their inherent understanding of the barriers and needs of the groups concerned, a handful of consumer representatives can contribute to planning engagement in a way that genuinely supports an equal partnership between services and consumers. This is recognised as particularly important when engagement is initiated by services (rather than consumers) [13, 17].

SUPPORT FOR ENGAGEMENT FROM SENIOR MANAGEMENT

Organisational support for CCE is critical to its success [1] and a number of key facilitators to engagement are identified in the next section, however one crucial factor is support from senior management. Supporting engagement 'from the top' is identified as a key principle for consumer participation [17, p6] and in a review of the literature, Gregory notes "if senior managers do not support and value consumer engagement, its practice will be undermined" [1, p42].

Support for engagement needs to be practical (resources are allocated) and cultural (talking about the value of engagement, leading by example). The leadership of an organisation is also responsible for fostering a culture of learning that recognises the importance of learning from both successes and failures [20] and places value on the personal experiences of consumers [5].

CONSUMERS INVOLVED IN GOVERNANCE

Meaningful involvement of consumers in the governance of an organisation is a best practice strategy to ensure that consumer engagement is a priority within an organisation. Depending on the approach taken, involving consumers in clearly defined governance roles and structures will ensure that the consumer perspective is included as early as possible, that opportunities to involve consumers are identified often and that the consumer and community engagement program is steered and monitored by consumers.

Involving consumers in governance is recognised within the National Safety and Quality Health Care Standards as an essential aspect of partnering with consumers [9]. With appropriate linkages to the Board and Clinical Council, the Primary Health Network's Community Advisory Committee provides one type of governance structure to achieve these objectives.

The **Australian Commission on Safety and Quality in Health Care defines governance** as:

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, and human resources) of the organisation are set, and the means by which the objectives are to be achieved. [9]

2. Address organisational facilitators

There are many organisational factors that are vital to successful CCE, a number of which have already been mentioned. Particularly important for establishing a Primary Health Network will be:

- establishing strong internal governance that embeds CCE at all levels of the organisation
- providing opportunities for consumers and community to initiate engagement with a large organisation that has the potential to be too large to be locally responsive.

INTERNAL GOVERNANCE FOR ENGAGEMENT

Using the definition of governance given above, internal governance is an essential framework to build an effective engagement program and needs to integrate with corporate and clinical governance systems. Organisations need to establish and resource governance frameworks that embody the principles and facilitators of successful engagement. This includes (but is not limited to):

- how consumers will be meaningfully involved in governance [9, 20]
- clear lines of reporting and accountability for engagement [10, 14, 20]
- key staff roles:

    - the organisational champion for engagement "who works at a high level and can influence others" [1, 19]
    - the dedicated engagement facilitator/coordinator [1, 12, 13] who can "support, engage, navigate and advocate for community representatives' participation and influence in health service policy and practice" [1]
- corporate policies supporting the recruitment, support of and engagement with consumers and community members [12, 19]
- integrate organisational systems to respond to consumer input – e.g. ensure the quality system is responsive to patient experience data and consumer views [20].

BUILT-IN OPPORTUNITIES FOR CONSUMERS AND COMMUNITY TO INITIATE ENGAGEMENT

It is well recognised that engagement initiated by a health service will tend to address an issue defined by the service, may use the language of the service and often suit the service in terms of the nature, timeframe and location of the engagement [1]. While consumers can still play leadership or partnership roles in these engagements, processes that allow consumers and communities to initiate engagement with health services are recommended, as this approach "can ensure that the breadth of consumers' concerns are addressed" [1]. For these approached to be effective they must be embedded in practice across the organisation, as one-off attempts to 'tick the box' of CCE will fail in the long run. Meeting the needs of consumers and communities requires services to implement multiple mechanisms that support a diverse range of consumer/community initiated engagement across the organisation.

3. Actively include disadvantaged/marginalised groups

One of the most challenging barriers to effective CCE is that disadvantaged groups have little opportunity for input [18]. In spite of efforts to recognise health inequality and to increase access to health care for disadvantaged or marginalised groups, many groups continue to have poor or limited access to appropriate services [21]. At the same time (and perhaps for the same reasons [10]) these groups are often not represented

in CCE. These groups include but are not limited to [21]:

- Aboriginal and Torres Strait Islander communities
- people living with a chronic illness, including mental illness
- people from culturally diverse backgrounds who may also have language and literacy problems
- socially or geographically isolated communities
- people with lower levels of literacy.

Health services must address the challenge of how to appropriately and effectively engage with disadvantaged groups and those "that continue to be systematically excluded" [15].

Those who are greatest in need to improve their situation are often the least able to do so.

Klein's Inverse Law of Participation [22]

RECOGNITION OF THE SYSTEMIC NATURE AND IMPACT OF HEALTH INEQUALITIES

It is important that health services know the communities that they serve and are aware of where inequality and disadvantage impacts on them. In order to not continue to perpetuate that inequality it is vital that the boards, management and staff recognise that those who are greatest in need to improve their situation are often the least able to do so (Klein's "inverse law of participation" [22, p413]).

The multiplying effects of disadvantage lead to a vicious circle of certain groups being less able to participate in decision making processes, leading to further disadvantage [23]. Some groups will need special focused attention and multiple targeted strategies. Planning for CCE *must* take these challenges into account, to do otherwise risks the health service perpetuating the very disadvantages it is working to eliminate.

EMPLOYING SPECIFIC STRATEGIES TO ENGAGE WITH DISADVANTAGED/MARGINALISED GROUPS

The barriers that prevent marginalised groups receiving appropriate care are the same as those that work against the engagement of these communities in CCE. Several strategies have been identified to address this entrenched disadvantage, these include [10]:

- building the capacity of consumers and the community to influence health services (see below)
- building the capacity of the health system to accept and value their views – with implications to staff training,

organisational governance and values (see below)

- **providing opportunities for the most marginalised in society to be heard.** This begins with recognition that engagement activities need to be appropriate for hard-to-reach groups (and may not be the typical committee roles or forums), and consumer representatives may need to be proactively identified, developed and catered for (for example giving young mothers some skills in meeting participation and offering free child care during activities).

4. Build the capacity of consumers to engage

As mentioned above, the importance of building the capacity of consumers and community to participate in engagement activities is well recognised [1, 9, 10, 12]. Consumers' ability to engage is limited by resources gaps in the form of time, finances, knowledge and skills. Health services must identify the factors that restrict people's ability to engage and provide resources to consumer and community groups in order to build capacity at the local level [10]. The ACSQHC recommends that organisations "provide support for patients, families and carers involved in governance (decision-making) to develop the necessary skills and capacity required for effective partnerships with their healthcare organisation" [20, p3].

PROVIDE TRAINING TO CONSUMERS

Training consumers to build their capacity to engage is considered best practice in CCE [1, 5, 9, 10, 12, 18, 20]. Training needs to address sufficient knowledge of the health service to be able to engage, skills around advocacy and effective communication, roles for consumers including the value of sharing personal experience and how to reflect the views of a network or constituency [5, 10]. Consumer representatives will require different levels of training as their levels of experience and skills grow.

SUPPORT CONSUMERS WHO ENGAGE

Providing support to consumers who are engaged with a health service (particularly those who hold representative roles) significantly contributes to their effectiveness and satisfaction [5, 12]. Support can range from:

- having a coordinator to debrief with or follow up problems [12]
- having access to data about services, consumer experiences and local consumer and community views [10]
- supporting a network of consumers across the organisation and providing a means for them to connect with and communicate with each other [5]
- having access to internet, workstations and printers
- receiving meeting papers in a suitable format and in a timeframe that suits the consumer (e.g. one week prior to the meeting)
- receiving reimbursement for costs or payment for meeting attendance.

A key tool in providing support and developing consumers is a register of consumer representatives and engaged community members. A professional method of contacts management is recommended to effectively manage a register with appropriate regard to privacy obligations.

DEVELOP THE CAPACITY OF CONSUMERS AND COMMUNITY MEMBERS TO ENGAGE

Most health services begin CEE activities needing to identify and recruit a number of suitable consumer representatives. These often need to be recruited from past or present service users, or from the community. Health services can increase the number of consumers able to become involved in CCE through supporting existing community and consumer groups such as resourcing peer support groups [10] or even sponsoring the establishment of new groups.

Another approach is to directly fund local community organisations to engage with their own members to identify health needs and barriers to service. Working with the leadership of established community groups and networks[1] is another way to engage with communities and develop representatives from diverse groups. Any activity that increases the community knowledge of what services are available and how to access them offers the chance to promote the CEE

[1] Such as local inter-agencies and forums (e.g. youth inter-agency coordinated by community officers in local councils)

activities and the CCE program (this is where invitations to join a consumer register are particularly useful).

5. Build the capacity of staff to support engagement

We have identified above the need to build the capacity of the health system to accept and value the views of consumers [10]. Many sources raise the importance of providing staff and management with the necessary skills and knowledge to support them to engage (or partner) effectively with consumers [1, 9, 17, 20]. Both training and support are essential to achieve this.

PROVIDE STAFF WITH TRAINING

Research shows that there can be confusion among staff about the role of a consumer representative, particularly around just who the consumer represents and about how to work with consumer representatives on committees. Staff have also questioned the value of consumers adding their personal experiences in committee discussions [5, 6].

Staff with active roles in engagement needs training in key skills including communication, group facilitation and meeting skills, however all staff who work in some way with consumers for CCE require a basic level of competency that addresses:

- understanding CCE – its purpose and the role of consumers
- appropriate language when working with consumers and cultural competency (when working with Aboriginal and Torres Strait Islander communities and other diverse groups)
- valuing the views of consumers and understanding how to apply learnings from the personal experiences of consumers.

SUPPORT STAFF TO EFFECTIVELY ENGAGE WITH CONSUMERS

Engaging with consumers and community is a complex undertaking and staff need to access support from management and colleagues in order to be effective. Effective support for staff can include:

- connecting staff across an organisation who are involved in CCE
- supporting a community of practice, which provides support, shares resources, collaborates on corporate policy and promotes an organisation culture that is positive towards engagement
- establishing a dedicated engagement coordinator as a key asset in the support and development of staff.

6. Focus on outcomes and evaluation

It is clear that there is a need for better evaluation of CCE and more evidence of the impact and effectiveness of CCE [1, 2, 9, 20]. Organisations benefit from becoming more rigorous in their collection and reporting of consumer experience data and evaluation of engagement, in addition to directly contributing to their already established accreditation programs and quality improvement systems.

CONSUMER EXPERIENCE DATA

The ACSQHC recommends that health services have systems in place to regularly collect and report on consumer care experience data (also referred to as patient experience data) "through quantitative patient surveys and qualitative narrative-based sources" [20, p3]. Consumer experience data is essential to health services understanding and improving the consumer experience. In addition consumers can be far more effectively engaged with improving services when they have access to the views and experience of service users [10].

(This is a large and evolving field – see the NSW Agency for Clinical Innovation and the Australian Commission on Safety and Quality in Health Care for information and resources.)

EVALUATE ENGAGEMENT

As identified earlier there is wide-spread consensus that the quantity and quality of evidence around CCE needs to improve [1, 2, 9, 10, 20]. Among the recommendations to do this is to ensure evaluation of the engagement activities and outcomes is planned early and reported. The ACSQHC recommends that services "contribute to the evidence base for patient-centred care by recording and publishing key organisational and patient outcome metrics over time" [20, p3].

FOCUS ON THE OUTCOMES OF ENGAGEMENT

While evaluation of the processes of engagement is recognised as valuable (particularly to improving those processes), focusing on the evaluation of the outcomes of CCE has been noted as particularly important in the context of measuring and communicating the impact of CCE [6]. This can range from impact to consumer outcomes or experience, to increasing effectiveness of meetings or improving access to a service for part of the community [5].

LOCAL CONTEXT

This model developed out of a partnership between Health Consumers NSW and WentWest (the then medicare local in western Sydney and now the Primary Health Network for the region).

Project Background

In 2013 a partnership between WentWest and Health Consumers NSW was established to embark on a Joint Consumer Engagement project. In late 2013 a HCNSW Project Manager was recruited to work with a Joint Project Advisory Committee (the JPAC) to deliver the following project goals:

Project goals:

1. Conduct a gap analysis of consumer and community engagement at WentWest, and develop and support new initiatives to embed consumer involvement at all levels of WentWest.
2. Develop a NSW Toolkit for Consumer Engagement which is built on identified good practice tools and resources for health services.

3. Engage health services across NSW in the development, evaluation, implementation and promotion of the Consumer Engagement Toolkit.
4. Engage with consumer representatives and engagement staff working with health services on the development of the toolkit.

The Gap Analysis conducted in early 2014 found that across WentWest:

- Some programs PARTNER very well with consumers.
- Some areas PARTNER and CONSULT well with community.
- Some programs CONSULT well with consumers.
- A small number of programs LISTEN to patients well.
- Most areas need to ENGAGE with consumers more, and PARTNER if not already doing so.
- Consideration should be given to involving consumers in GOVERNANCE.
- All areas working with clients/patients need to enhance patient experience measurement.

The work and model outlined in this document represents a significant outcome of the joint project, and it points to several further outcomes under development in 2015.

2014	Gap Analysis and recommendations
2014	Implementation assistance (e.g. Establishment of WentWest Consumer Engagement Staff Network)
2014	Consumer and Community Engagement Model, Top Down – Ground Up Engagement Processes
2015	Toolkit supporting consumers and community to engage
2015	Specification of online training modules for Competency in Consumer Engagement - For consumers, - For staff

Partnerships

WentWest recognises partnerships as a fundamental building block of what the organisation does. Major partnerships operate with the Western Sydney Local Health District (WSLHD), the Sydney Children's Hospital Network and the Aboriginal Medical Service Western Sydney (AMSWS). These partnerships have continued to strengthen over the past year, building on the key service integration initiatives of Personally Controlled Electronic Health Record (PCEHR), HealthOne, and Chronic Disease Management Program – Connecting Care in the community. The partnerships are collaborative and governed at the highest level. For example the WentWest-WSLHD Partnership Advisory Council, co-chaired by the CEOs of each organisation, provides oversight for all joint initiatives and supports their implementation with agreed resources.

In mid-2014 the WSLHD launched its Community and Consumer Engagement Framework. This framework promotes engagement across the LHD, supports the organisation to meet its obligations under the NSQHS Standards and acknowledges that when appropriate engagement will occur in partnership with key stakeholders.

It is important to acknowledge that each partner will have engagement activities that are specific to their own organisation and services, but that there are areas (particularly on integration projects) where a shared approach to engagement will result in better outcomes – for services and for consumers. Each partner will continue to identify opportunities to collaborate and not duplicate efforts in consumer and community engagement. Similar concerns would face every Primary Health Network and health district/hospital network.

Primary Health Networks and the Community Advisory Committee

The Horvath Review into Medicare Locals recommended Primary Health Networks establish Community Advisory Committees to advise the Primary Health Network Boards (alongside Clinical Councils) [34].

In mid-2014 the Department of Health had made the following statements about the Primary Health Network Community Advisory Committee:

- will report to the Primary Health Network Board and collaborate with Clinical Councils
- ensure local accountability and relevance of Primary Health Network activities
- promote patient centred decision making and needs identification
- representation reflects the diversity and needs of the local population
- alignment with Clinical Councils to be determined by Primary Health Networks, based on regional needs.

It is encouraging that community representation and accountability is being built into Primary Health Networks. However a high level advisory committee will not on its own ensure the consumers are involved in health service at all levels. Large health services face many barriers to engagement (see page 15) including having insufficient structures in place to ensure engagement throughout the organisation with clear accountability [1]. Defining a clear terms of reference for the Committee, which is linked with accountability for CCE across the organisation, will contribute to effective engagement for a Primary Health Network.

National Safety and Quality Health Service Standards - Standard 2: Partnering with Consumers

The National Standards (and therefore Standard 2: Partnering with Consumers) did not apply to Medicare Locals. The Standards are undergoing review and could eventually cover every health service administered or coordinated by a Primary Health Network.

The criteria to achieve the Partnering with Consumers Standard are:

- Consumer partnership in service planning: Governance structures are in place to form partnerships 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 in service measurement and evaluation: Consumers and/or carers receive information on the health service organisation's performance and contribute to the ongoing monitoring, measurement and evaluation of performance for continuous quality improvement.

It remains to be seen whether these standards apply to Primary Health Networks, or what will apply in their place.

Consumer participation in other sectors

Regardless of the future scope of the National Standards, CCE is being increasingly recognised and promoted by both Commonwealth and state governments. National initiatives such as the National Disabilities Insurance Scheme (NDIS) and reform of community aged care services (such as the Home and Community Care or HACC scheme) are placing increased focus on the needs of consumers and are introducing person-centred and consumer-directed approaches to service delivery.

Health services that have incorporated CCE into their practices and culture will be best placed to partner with such services from outside the health sector. Inter-sectorial collaboration and partnerships are being increasingly encouraged as part of integrated care. Potential partner organisations will be looking for health services that can meet the needs of the consumers they serve and who share a consumer-centred approach.

THE CONSUMER AND COMMUNITY ENGAGEMENT MODEL

Model rationale

The Consumer and Community Engagement Model is an outcome of the WentWest-Health Consumers NSW Joint Consumer Engagement Project. The model has been developed with the general transition to Primary Health Networks in mind, with WentWest a particular focus. We anticipate that the model will also have relevance for the overall Australian health care environment.

The model has been developed based on:

- evidence and best practice – incorporating the strategies discussed earlier
- WentWest's experience and strengths
- the national context – the transition from Medicare Locals to Primary Health Networks, and the National Safety and Quality Health Service Standards (NSQHS)
- the needs of WentWest and the Western Sydney region
- the consumer context – in addition to one partner being the peak state body for health consumers, two consumer representatives sit on the project advisory body (Allison Kokany, Consumer Consultant, WentWest and Dr John Leyden, Treasurer, Health Consumers NSW).

The aims of the model are as follows:

1. to have a positive impact on consumer-centred care, consumer experience and health outcomes: make an impact, measure it, communicate it
2. to work collaboratively with community and stakeholders to identify and communicate the unmet health needs (including the social determinants of health) of Australian communities
3. to build the capacity and capability of health consumers to participate in the design, delivery and evaluation of their health care.

The model is presented in two parts:

- a detailed view of the interaction between consumer-centred care and the 'Top Down-Ground Up engagement processes'
- an overarching view of the model and its elements, showing critical inputs, processes and key outcomes.

The Top Down – Ground Up Engagement Model

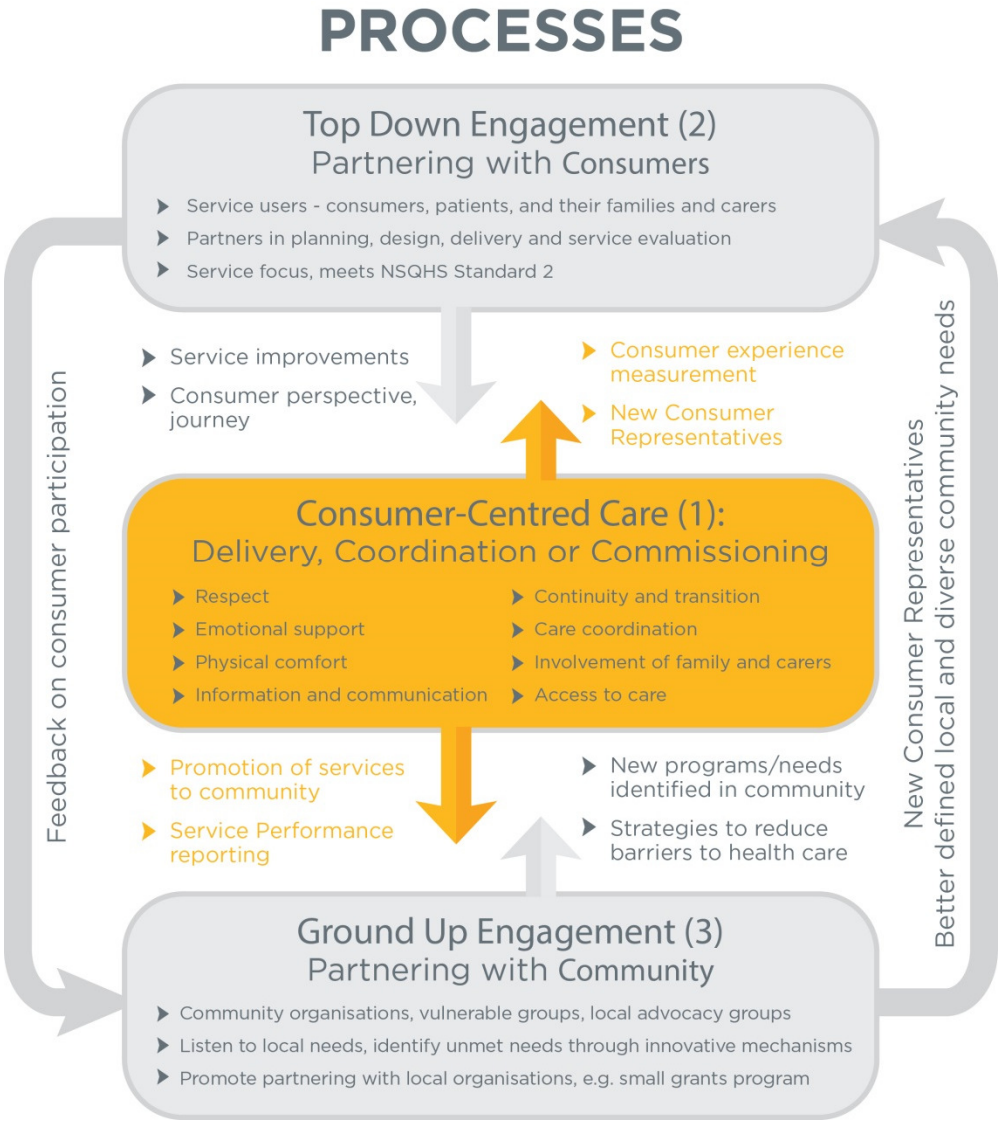

Figure 1: The Top Down-Ground Up Engagement Processes

Consumer-centred care - at the heart of consumer and community engagement

Consumer-centred care is at the heart of the model – recognising that improving the experience and health outcomes of consumers is one of the primary objectives of consumer and community engagement. The ACSQHC identifies that having "active and informed consumers as equal partners in decision-making processes at all levels of the healthcare system is … the central concept for both consumer engagement and patient-centred care" [20, p17].

In this model, CCE is recognised as a key organisational strategy to improve the quality of services (particularly around consumer experience, health outcomes and safety) and quantity of service (in terms of access to health care for diverse communities). This approach adopts the *improved outcomes* rationale for CCE mention above, although it is also consistent with the *ethical* and *improved relationships* rationale for engagement [1].

Consumer-centred care is health care that is respectful of, and responsive to the preferences, needs and values of patients and consumers [20]. The dimensions of consumer-centred care identified by the ACSQHC include [20]:

- respect
- emotional support
- physical comfort
- information and communication
- continuity and transition
- care coordination
- involvement of family and carers
- access to care.

Consumer-centred care remains paramount regardless of whether services are provided directly or if the organisation is responsible for service commissioning or coordination.

INPUTS TO CONSUMER-CENTRED CARE FROM THE ENGAGEMENT PROCESS INCLUDE:

Engagement with consumers offers a variety of benefits but at its most fundamental CCE must be focused on providing the following inputs to consumer-centred care:

- service improvements identified through the involvement of consumers and service users

- the consumer perspective and an understanding of the consumer journey
- new programs and needs identified within the community
- strategies to reducing the barriers to accessing health care.

OUTPUTS OF CONSUMER-CENTRED CARE THAT FEED INTO THE ENGAGEMENT PROCESS INCLUDE:

- consumer experience measurement (informs the top down process)
- new consumer representatives (feeds into the top down process)
- promotion of services to the community (feeds into ground up process)
- service performance reporting (feeds into ground up process).

The Top Down – Ground Up Engagement Process

There are many drivers for engagement, and clarity around what these are is critical for success [1, 2, 17]. In order to effectively engage with consumers and community over their health care, it is helpful for services to recognise that more than one type of engagement process occurs:

- A *Top Down* approach: much engagement will be initiated by the organisation and will be focused on services already planned or being delivered (e.g. engaging with service users and carers to improve a particular service). *Top Down* engagement deals with known health needs and existing services. (Note the consumers can still play leadership or partnership roles in these service oriented engagement processes.)
- A *Ground Up* approach: a broader style of engagement takes place with communities to explore, to understand and to determine with communities how to better meet their diverse health care needs (and importantly this can be initiated by the service *or the community*). *Ground-Up* engagement identifies gaps in services, access issues and other unmet needs.

The Top Down process deals with known health needs and existing services, while the Ground Up process identifies gaps in services, access issues and other unmet needs. Both of these types of engagement processes may apply any of the approaches to engagement identified earlier in the section on Engagement Spectrums.

Differentiating between these distinct engagement processes is useful to understanding and planning CCE within a health service, but it also allows a Primary Health Network to safeguard against the risk of becoming too large to be locally engaged and responsive [25]. If it is implemented with multiple mechanisms for communities and consumer groups to be able to initiate engagement with the health service, the *ground up engagement process* is a powerful tool for partnering with communities to improve health outcomes.

In addition, for services that are required to meet the NSQHS Standard 2 (and Primary Health Networks may be required to do so in the future), the *top down engagement process* is primarily where this standard will be achieved.

OVERSIGHT BY COMMUNITY ADVISORY COMMITTEE

In the case of a Primary Health Network, it is particularly important that the Community Advisory Committee is involved in the oversight of these processes. By being engaged with the Top Down-Ground Up processes, this body of community representatives will be both better connected to local consumer and community perspectives and also ensure that these perspectives are central to decision making and service design, commissioning and delivery across the region.

TOP DOWN ENGAGEMENT – PARTNERING WITH CONSUMERS

In summary, Top Down Engagement is the planned engagement with consumers that supports the design, delivery and evaluation of health services provided or coordinated by the organisation. It incorporates:

- partnering with consumers, patients, families and carers to improve the services already delivered
- consumer participation in the planning, delivery and service evaluation (e.g. through advisory groups, forums, focus groups)
- taking a service focus, and meeting NSQHS Standard 2.

The key outcomes of the Top Down Engagement Process are:

- service improvements, with the aim of seeing improved consumer outcomes and experience
- the consumer perspective and the consumer journey
- consumers as partners and advocates
- evaluation and feedback on consumer engagement.

GROUND UP ENGAGEMENT – PARTNERING WITH COMMUNITY

In summary, Ground Up Engagement is a dedicated process to seek out and to listen to the views, needs and priorities of consumers and diverse communities served by the organisation. It also provides a mechanism to report back to communities from time to time on organisational performance. It includes:

- a focus on community organisations, disadvantaged groups, and local advocacy groups
- listening to local needs, identifying unmet needs and barriers to access
- applying multiple mechanisms to listen to the community:
    - e.g. The Community Advisory Committee holds regular external meetings across the region – submissions can be made or invited from consumer organisations and community groups. These forums could also be used to report back to community what is being achieved however the balance should be on listening.
    - partner with and support community organisations to survey and report on their members health needs e.g. through small grants program
    - allow online submissions through a web interface. encourage creative use of technology to reflect the views and needs of communities.
    - support consumers and community to engage with health services through dedicated resources (page 44).

The key outcomes of the Ground Up Engagement Process

- better defined and understood local and diverse community needs

- evidence and community support for funding new or expanded programs
- new consumer representatives recruited to the Top Down Engagement Process
- increased community awareness of what services are available.

The overarching model and its elements

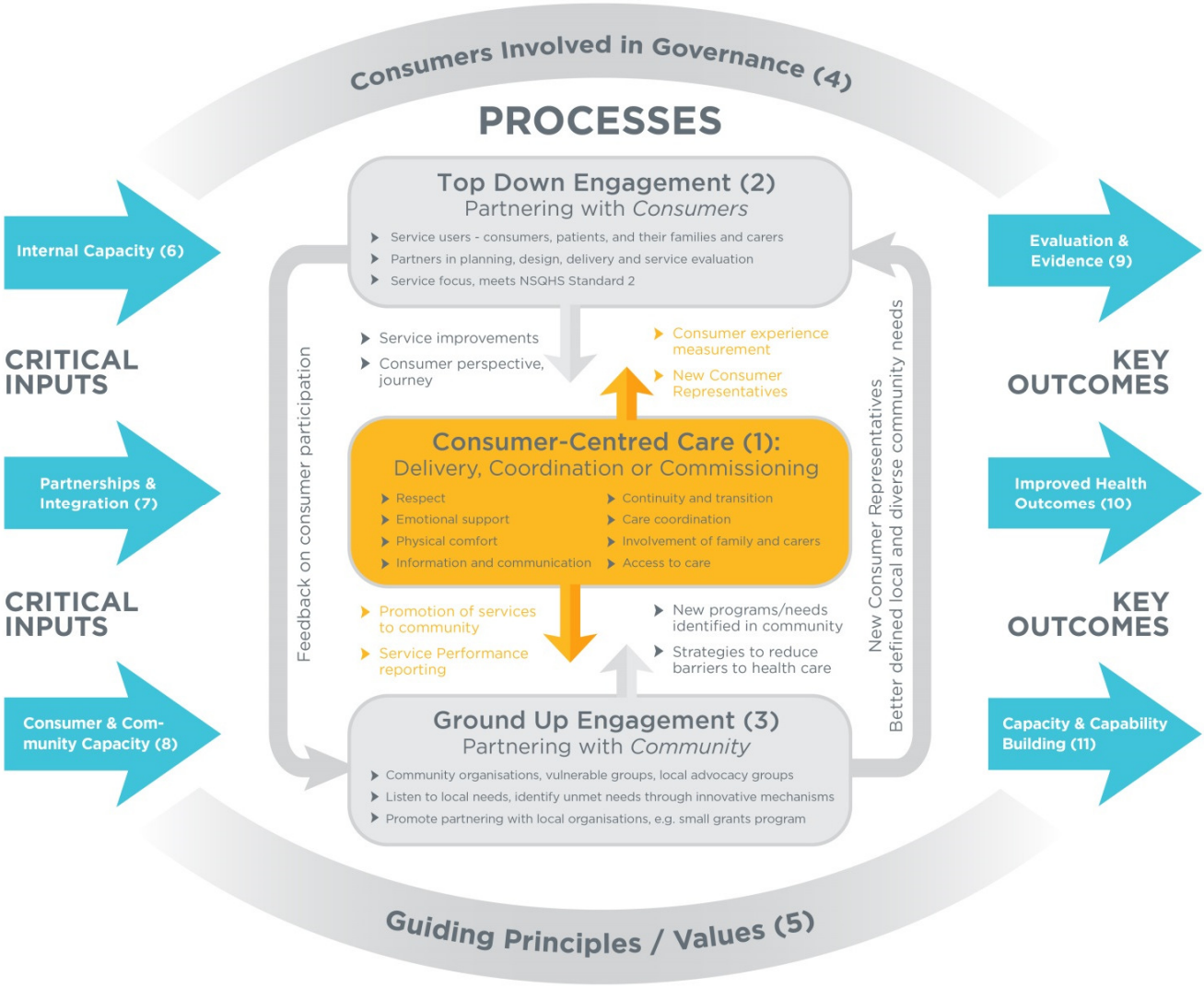

Figure 2: The overarching model for Consumer and Community Engagement

Consumers Involved in Governance

As discussed above (page 20), involving consumers in clearly defined governance roles ensures that the consumer perspective is considered in decision making and engagement is a priority. Depending on the approach taken, consumers in governance roles can also provide oversight of the engagement program including:

- identifying opportunities to involve consumers.
- providing links into communities and consumer groups.
- consumers acting as advocates for funding programs that improve care or increase services.
- monitoring and contributing to the evaluation of the engagement program.

With appropriate linkages to the Board and Clinical Council, the Primary Health Network's Community Advisory Committee provides one type of governance structure to achieve these objectives.

Guiding Principles / Values

It is highly recommended that consumer and community engagement is underpinned by defined values or a dedicated set of principles [26]. These provide a frame of reference for the way in which consumers and health services (and their staff and management) and will engage with each other. Principles guide the way in which all engagement processes are designed and implemented. The leadership of the organisation shows commitment to engagement by demonstrating these principles/values by example.

Guiding principles are often contained in an organisational consumer and carer engagement policy. In addition organisations are encouraged to reflect on whether their corporate values or principles reflect *consumer engagement as a priority* (see page 19).

Critical Inputs

As detailed in the sections above, there are many internal and external elements and facilitators that are necessary in order for engagement to be effective. These have been identified within the model as *Critical Inputs*, and grouped into *Internal Capacity*, *Partnerships and Integration* and *Consumer and Community*

Capacity. While it is possible to begin engagement without all of these in place, services should have assessed the status of these inputs and have plans in place for how to develop or enhance them.

INTERNAL CAPACITY

The internal capacity of an organisation to engage with consumers is a major factor in whether CCE is successful. In a complex undertaking like CCE, internal capacity is one area that organisations have most control over.

Internal Capacity includes:

Internal Governance

Internal governance has been outlined above (see page 21) and is defined as "the set of relationships and responsibilities established by a health service organisation between its executive, workforce, and stakeholders (including consumers)" [9, p5]. This includes:

- internal linkages with and supports for consumers involved in governance (e.g. secretariat for the Community Advisory Committee, protocols for engaging consumer committees)
- program, management and staff accountabilities for engagement (e.g. accountabilities built into position descriptions, competencies and performance management system)
- supporting policies and processes (e.g. that set out how to recruit, engage, induct, reimburse and support consumer representatives)
- links to clinical governance, quality improvement and accreditation systems and processes.

Internal resources

Lack of time and resources is one of the most frequently cited barriers to engagement (page 18). Internal resources are fundamental to engagement. These include:

- funding to support the organisation's engagement program
- a senior manager 'champion' for engagement with the ability to influence others
- a dedicated engagement facilitator to support engagement programs, consumer representatives and staff

- opt-in register of consumers, consumer representatives and community members for ongoing and future engagement activities.

Support staff to effectively engage

Engagement requires specific knowledge and skills sets that aren't necessarily present in an organisation (for more on supporting staff see page 26). All staff who engage at some level with consumers and community benefit from some training in basic competence in CCE. Supporting staff to engage effectively includes providing as a minimum:

- basic competency training is recommended for staff and this could be delivered in a supported online format. Competency training would cover understanding CCE and the role of consumers, appropriate language when working with consumers and valuing the views of consumers. Such a program has the potential to be rolled out widely across the organisation and potentially with other partners
- access to more advanced training for staff whose role involves significant responsibility for CCE
- support for staff involved in CCE, e.g. through a community of practice network.

PARTNERSHIPS AND INTEGRATION

Improving the experience and outcomes for consumers requires working across service and boundaries and integrating care with partners. Many health priorities involve multiple partners, providers and stakeholders, and therefore demand a shared approach to CCE. This critical input recognises partnerships are an integral part of improving integration (and with it consumer experience and outcomes) and this must be recognised in the planning and implementation of engagement activities. These partnerships include:

- key strategic partnerships including:
  - joint engagement activities
  - integration projects
- service providers – supporting and promoting appropriate engagement and consumer-centred care with partners
- community partnerships – leveraging and building partnerships with key stakeholders and community organisations.

Services are strongly encouraged to collaborate (if possible) with other services in the same region that are engaging with the same consumers and communities. There is a risk that multiple services can mirror poor service integration in their engagement activities – a confusing experience for consumers and ultimately less effective in improving care.

CONSUMER AND COMMUNITY CAPACITY

Building the capacity of consumers has been discussed above as evidence based best strategy (see page 24). In addition many regions may find it initially difficult to recruit enough experienced consumer representatives and will need to build the capacity of past or current patients or community members to move into the role of consumer representative. Particular skills and capabilities are needed for consumers to participate in Top Down and Ground Up engagement processes. Capacity can be developed through:

Provide training for consumers

Training includes:

- induction to the health service and if appropriate, to a particular committee
- face-to-face training courses already exist for appointed consumer representatives (e.g. training delivered by Health Consumers NSW and Health Issues Centre Victoria).
- basic competency training is recommended for new consumer representatives to address knowledge, rights and responsibilities and this could be delivered in a supported online format. Such a program has the potential to be rolled out widely. (Note that Basic competency training delivered online would not replace one or two days of face-to-face training that provides consumer representatives with skills in communication, analysis and advocacy skills.).

Toolkit Supporting Consumers and Community to engage

The Joint Consumer Engagement Project identified a key opportunity to build the capacity of consumers and community to engage with health services, particularly with the Top Down-Ground Up Engagement Processes. In particular there is a gap in the knowledge, information and resources available to support consumers and community organisations to engage with health services. This is especially true for smaller and marginalised groups often left out of the engagement process.

As part of the joint project, a toolkit targeted at consumers and community is under development with an expected launch date in mid-2015. The goals of the toolkit initially are to:

- increase the capacity of consumer representatives from diverse groups to apply for and participate in engagement activities with health services (e.g. the Top Down process)
- provide knowledge, information and tools that support consumers, community groups and marginalised communities to engage with health services (e.g. the Ground Up process).

As this resource grows it is intended that it will also:

- contribute to capacity building within the community for developing new and existing consumer representatives
- provide innovative and low cost methods of community needs identification and representation.

Build the capacity of local health and community groups to engage

As discussed above in Evidence based strategies (page 25), providing resources to consumer and community groups has been recognised as integral to building capacity at the local level. Some of the approaches to building local capacity include:

- seeding or supporting local health support groups (e.g. through resources or such as funding, providing a venue, printing materials or newsletter distribution)
- funding local community organisations to engage with their own members to identify health needs and barriers to service (e.g. through small grants)
- investing in the health literacy of communities while also

promoting opportunities to engage with the service (as a group or as individuals).

Key Outcomes

The model sets out to clarify the inputs and outputs of engagement when improving consumer-centred care is the primary objective. We have mentioned how essential it is to identify and measure outcomes of CCE. The key outcomes of engagement have been identified clearly within the model and are shown on page 39, and outlined below:

- Evaluation and Evidence
- Improved Health Outcomes
- Capacity and Capability Building.

EVALUATION AND EVIDENCE

Focusing on evaluation and evidence from the outset has been shown to be an important strategy in promoting and measuring effective engagement. This key outcome should include:

- outcome measures of the:
    - impact to services (how has consumer-centred care been affected?)
    - impact of engagement as perceived by consumer representatives and staff (what is the full range of impacts as defined by consumers and staff?)
- process evaluation of engagement activities (how can engagement be improved?)
- the collection and reporting of evidence around consumer and community engagement (contributing to corporate knowledge, industry knowledge and national/international evidence bases).

Note that the evaluation strategy for CCE should be conducted in consultation with consumers. Consumers will hold valid views on what should be measured and what constitutes a good or poor outcome.

IMPROVED HEALTH OUTCOMES

As a direct aim of engagement, improved health outcomes is naturally a key outcome of the process. These outcomes can cover a range of areas including:

- improved consumer outcomes, including consumer experience (measured through service evaluation, consumer stories and clinical outcomes)
- community outcomes through increased or enhanced provision of service (e.g. meeting a previously unmet need either through a new service, better access to a service or better tailoring of a service to community needs, reducing barriers to care)
- increased health literacy of consumers and community.

CAPACITY AND CAPABILITY BUILDING

While internal (organisational) capacity and the capacity of consumers and community has been identified as a critical input, the impact of effective engagement includes building on this capacity – and creating capability. In a virtuous circle, building capacity increases the likelihood of successful engagement, which develops greater capability among individuals to engage and increases the capacity of the organisation and communities to engage.

Capacity and capability building includes:

- increased internal capability (e.g. staff skills, infrastructure, and know-how (processes, checklists, guidelines)
- increased consumer representative capability (e.g. skills, confidence, knowledge and support networks)
- increasing the capacity of the organisation to engage (e.g. developing systems and building trust between staff and consumers)
- increasing the capacity of consumer and community organisations to engage with the organisation.

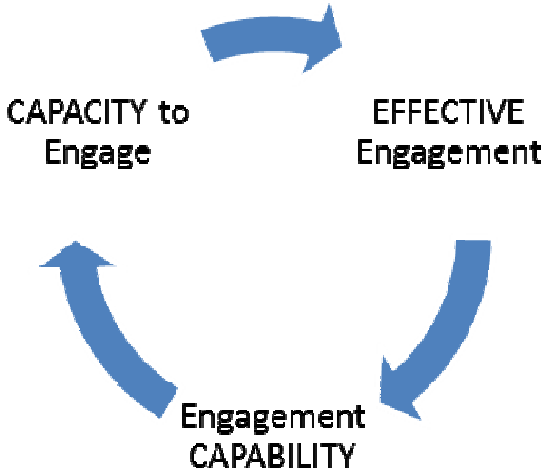

Figure 3: Virtuous circle - Building capacity -> Enhances engagement -> Develops Capability

CONCLUSION

The Health Consumers NSW – WentWest Consumer and Community Engagement Model is based on evidence and best practice and has been developed with a focus on how engagement improves consumer-centred care. There are many reasons for health services to embark on engagement programs, but the primary objective should remain to improve the experience and health outcomes for consumers and community.

The model is an outcome of the WentWest-Health Consumers NSW Joint Consumer Engagement Project. It has been developed with the general transition to Primary Health Networks in mind and with WentWest and the communities of Western Sydney as a particular focus. In speaking with others in different health settings and in different locations we soon came to realise that the model is also relevant to health services and communities across Australia.

Health Consumers NSW and WentWest hope this that model provides consumers, communities and health services with clarity and guidance around consumer and community engagement. We see this model, as it is now, as a starting point and we expect that over the coming months and years it will be refined and adapted in response to the unknown challenges and innovations that the future will bring. In order to do this, and as part of our own commitment to quality and continuous improvement, we welcome and encourage consumers, communities and health services to contact us with any comments, feedback and criticisms of the model and its implementation.

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