

# **Consumer engagement in Central Victoria**

**A literature review for health and  
community services**



**CENTRAL VICTORIAN**  
Primary Care Partnership

Suggested citation

Consumer engagement in Central Victoria. A literature review for health and community Services. (2015) Lavery S. Central Victorian Primary Care Partnership. Castlemaine <http://centralvicpcp.com.au/wp-content/uploads/2015/02/Consumer-Engagement-Literature-Review-2015.pdf>

## Contents

1	Executive Summary .....	4
2	Introduction .....	5
3	Method.....	5
4	Community and Consumer engagement.....	6
4.1	Person Centred Care .....	8
4.2	Shared Decision Making .....	9
4.3	Consumer engagement in health services .....	10
4.4	Consumer engagement in health policy .....	11
4.5	Community engagement.....	12
5	Models of consumer and community engagement .....	14
6	Why we need consumer engagement.....	15
7	Australian Context.....	18
8	Barriers .....	19
8.1	Consumer and service provider skills and attitudes.....	19
8.2	Population and Condition specific limitations.....	21
8.3	Organisational infrastructure support .....	22
8.4	Organisational and clinical culture.....	23
8.5	Diversity.....	23
8.6	Rural factors .....	24
9	Factors facilitating community engagement .....	25
9.1	Capacity Building: Consumers .....	25
9.2	Build capacity: Organisation.....	26
9.3	Diversity.....	27
9.4	Monitoring consumer experiences .....	28
9.5	Consumer and community engagement processes and tools .....	29
9.6	Evaluation .....	31
10	Research gaps .....	31
11	Conclusion .....	32
12	References.....	33

## 1 Executive Summary

Improved consumer engagement by organisations is critical to improve service planning, design, monitoring, evaluation and a fundamental part of quality control and improvement. However, health and social organisations are struggling to translate the concepts of consumer engagement into practice that is sustainable and meaningful. A rapid literature review was undertaken Central Victorian Primary Care Partnership by to assist health and social services in rural Victoria to analyse methods and models of engagement and develop strategies to engage consumers in the planning and implementation of local service systems.

A body of literature is slowly accumulating which suggests there is growing recognition by governments and health and community leaders of the need for a more active role for consumers in their own health and wellbeing and the development of local services. Consumer engagement is known to improve both the quality and safety of health services as well as individual health outcomes, whilst also making health services more responsive to the needs of consumers. However, there is limited 'hard' evidence in the literature that consumer engagement actually improves consumer outcomes. The convincing evidence for consumer participation has been related to participation at an individual level, where the consumer is engaged in making decisions about his or her own care and treatment options.

Although the principle of consumer engagement is widely supported, there are significant challenges in transforming the concepts into practice. The most frequently discussed barriers to effective consumer engagement are time and cost. However, involving consumers in decision making, particularly in the acute sector, can reduce costs as many consumers will choose less invasive surgical options and more conservative treatment. Other barriers for community and consumer engagement include lack of organisational infrastructure and resources, lack of skills and attitude of service providers and consumers, insufficient input by marginalised populations and disseminating information that does not meet the literacy level of the consumer. Studies have shown that information is more likely to be useful and clearer to improve consumers' knowledge, if consumers are involved in its development.

There is limited literature that demonstrates evidence of what is required for successful community and consumer engagement. Consumer groups have recommended that community engagement should be facilitated via enhancing health literacy, encouraging community participation and empowering consumers. In order to make consumer engagement normal practice within organisations requires appropriate policy, regulation and standards; availability of tools and information; training; clinical and patient champions; monitoring processes; evidence of effectiveness; incentives; and implementation plans. In addition, a commitment to organisational cultural change is needed to ensure consumer perspectives are respected, valued and integrated into planning, monitoring and evaluation of local services. There are many frameworks, guides, assessment and evaluation tools to support organisations to implement community and consumer engagement into organisational core business.

The absence of 'hard' evidence of the impact of consumer engagement should not be mistaken for an absence of effect. It is argued that there is sufficient evidence, albeit imperfect, on which to build strategies to strengthen consumer engagement.

## 2 Introduction

Improved consumers engagement by organisations is critical to improve service planning, design, monitoring, evaluation and a fundamental part of quality control and improvement. Much is known about consumer engagement in general, but less is understood about the issues for consumers and agencies in rural central Victoria. Consumer engagement is becoming a standard reporting item for health and social services across Australia. However, there is the risk that this can become formulaic and somewhat superficial, involving only the already engaged and enthusiastic core of community participants. Organisations are interested going beyond this, by looking at evidence based, effective and tailored models of engagement that are based on participatory processes and responses.

The aim of this literature review is to inform system improvement, support advocacy and consumer empowerment, through the engagement of consumers. This review will define consumer engagement and find examples and supporting evidence of successful consumer engagement in determining care pathways and in developing, designing and revising services and service systems.

## 3 Method

The literature review was undertaken Central Victorian Primary Care Partnership to assist health and social services in rural Victoria to analyse methods and models of participation and develop strategies to engage consumers in the planning and implementation of local service systems.

It is not an exhaustive literature review, but a rapid review to synthesize evidence in a timely manner to inform decision makers in health and social care settings. Community and consumer engagement is an emerging area of research which tends to utilise qualitative research methodologies rather than empirical methodologies (e.g. randomised trials).

The types of literature included were publically available peer reviewed and grey written documents, with the aim of restricting the search within the last 15 year period, where possible. The review only included written material that was published in English. The following forms of literature were included in the search:

- Systematic reviews on defining consumer engagement and implementing strategies to progress effective consumer engagement within health and social services.
- Non-systematic reviews in the form of reports, guidelines, evaluations, editorials, conference papers and commentaries were also included due to the nature of the project and focus on service system development.
- Primary research studies evaluating effectiveness of implementation processes and strategies (interventions or methodologies) that addressed community and consumer engagement. This included both quantitative and qualitative studies.

## 4 Community and Consumer engagement

There is a growing recognition of the need for a more active role for consumers in health care, with the aim of improving service delivery, consumer experiences and outcomes (Crawford et al., 2002). It is argued that consumer participation is not a privilege but a human right (Cohen & Ezer, 2013). The Declaration of Alma-Ata in 1978 states that people have the right and duty to participate individually and collectively in the planning and implementation of their health care (World Health Organisation, 1978).

There are a number of factors that have contributed to the growing impetus behind consumer involvement in health care. In the 1960s and 1970s saw the emergence of the patient rights' movement which has evolved in response to widespread human rights violation in the health setting. The patient rights' movement questions professional power and the traditional medical beneficence and paternalistic models (Will, 2011). This was fuelled by health professionals withholding information from patients 'to protect them', patients involved in medical research without their knowledge, media focus on major patient safety inquiries due to medical errors and the growing interest in complementary and alternative methods of healthcare (Edwin, 2008; Will, 2011).

Consumer and community engagement is one of the most complex areas of health care practice and research, and it is challenging to define accurately. A scoping meta-review revealed that consumer and community engagement in health is not defined uniformly and it does not incorporate a single concept and type of activity (Sarrami-Foroushani, Travaglia, Debono & Braithwaite, 2014). No similar meta-review was found for community services. Although the identified concepts vary considerably in their aims (e.g. improve one's own health, improve public health, monitoring service delivery), participants (e.g. service providers, researchers, policy-makers) and locations (e.g. governments, universities, health organisations), the majority of these concepts are directed at expanding the role of consumers and community members in determining health care (Attree et al, 2011; Sarrami-Foroushani et al, 2014). The process can involve different aspects or elements, such as consumer involvement, participation, collaboration, shared decision making, person centred care, partnership, empowerment (Ahmad, 2014; Coulter & Ellins, 2006). Attree et al (2011) have suggested that 'community engagement' is an umbrella term that could refer to various approaches, with different aims. However, it is the lack of precise definitions and multiple aims that make it challenging to measure and provide 'hard' evidence (Fudge, Wolfe & McKeivitt, 2011).

The Victorian State Government uses Fritze, Williamson & Wiseman (2009) definition of consumer engagement as a two-way process, in which:

'..... the aspirations, concerns, needs and values of citizens and communities are incorporated at all levels and in all sectors in policy development, planning, decision making, service delivery and assessment ... and governments and other businesses and civil society organisations involve citizens, clients, communities and other stakeholders in these processes.'

## Consumer Engagement in Central Victoria: A literature review

The terms 'engagement' and 'participation' are often used interchangeably. Aslin and Brown (2002) distinguish the difference in the terms by defining participation as the act of participating, in whatever form. This can include writing letters, attending events, or using other forms of communication. Engagement goes further than participation. It involves capturing people's attention with a subject that means something personally and is sufficiently important to demand their attention. It conveys the idea that someone is occupied, focused, and committed to an issue. So it is possible that people may be consulted, participate and even be involved, but not be engaged (Aslin & Brown, 2002).

Consumers acting as representatives of communities have fallen into three broad categories: those who represent themselves; those who represent specific communities or groups; and those who are asked to represent consumers or patients in general (Sarrami-Foroushani, 2012). Just how representative consumers are, or are meant to be, is a complex and much debated question within this field (Crawford et al., 2003). Recent research reiterates the need to examine whether the involvement of some, but not other, consumers, can lead to an increased marginalisation of some minority groups (Fudge et al., 2011).

Consumers can be engaged also in activities such as peer support, quality improvement, health related research, prioritising health services, developing or reviewing guidelines or consumer information and training of healthcare professionals (Fudge et al., 2011; Kitzhaber, 1993). Consumer and community engagement happens at a number of levels. These include:

- Individual: involvement in individual treatment and care (e.g. person and family centred care, self-management; shared decision making) (Health Issues Centre, n.d.)
- Program: involvement in co-design, implementation and evaluation of programs (e.g. consumers, carers or community members in working groups or committees) (Health Issues Centre, n.d.)
- Organisation: involvement in higher level decision making and governance (e.g. consumer advisory groups; consumer, carer and community members representatives at executive levels) (Health Issues Centre, n.d.)
- Government: involvement in development of government public policy (e.g. public consultation, focus groups, advocacy representation) (Caddy, 2001)

While the arguments for consumer and community engagement based on principles and consumer rights are strong, the evidence for this actually improving consumer outcomes is relatively weak compared to 'gold standard' measures of outcomes (Crawford et al., 2002, Simpson et al., 2009, Nilsen, Myrhaug, Johansen, Oliver & Oxman, 2006). The evidence is based on a limited number of randomised control trials and qualitative and descriptive statistical analyses. Most of the convincing evidence for consumer participation has been related to participation at an individual level, where the patient is engaged in making decisions about his or her own care and treatment options (Health Issues Centre, 2008).

## 4.1 Person Centred Care

Person centred care is 'healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers' (Australia Commission on Safety and Quality in Health Care [ACSQHC], 2010, p.7). In many cases, the alignment between what consumers want and what is provided is poor (KPMG International, 2014). The goals of patients are not given enough recognition in treatment choices, and the benefits of shared decision making and patient and carer involvement are not being realised. As a result, over diagnosis and over treatment are now a frequent hazard and a serious cost in many parts of the world (KPMG International, 2014).

Person centred care has been defined as 'Health care that meets and responds to patients' wants, needs and preferences and where patients are autonomous and able to decide for themselves.' (Coulter, 2002 cited in Pelzang, 2010, p.912). Berwick (2009) takes it a step further and defines person centred care as 'the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care'. Person centred care is the foundation principle for the Victorian State Government's service coordination and integration initiative, in that service delivery is driven by the needs of the consumers and the community rather than the needs of the system, or those who practice in it (Primary Care Partnerships, 2012).

Berwick (2009) a former USA Administrator of the Centers for Medicare and Medicaid Services, presented an 'extremist' view of person centred care:

'For better or worse, I have come to believe that we—patients, families, clinicians, and the health care system as a whole—would all be far better off if we professionals recalibrated our work such that we behaved with patients and families not as hosts in the care system, but as guests in their lives.....Three useful maxims [for person centred care] that I have encountered are these: (1) The needs of the patient come first. (2) Nothing about me without me. (3) Every patient is the only patient.'

The International Association for Public Participation (2004) and the National Safety and Quality Health Service (NSQHS) Standards (ACSQHC, 2012) have identified the core concepts for consumer and family centred care. These include:

- **Dignity and respect.** Consumers, families and/ carers' knowledge, values, beliefs, and cultural backgrounds are integrated into the planning and delivery of care.
- **Communicating and sharing information.** Communicating and sharing information between consumers and/or carers and service providers is timely, complete, and accurate in order for consumers to effectively participate in care and decision-making.
- **Participation.** Consumers, families and/carers are encouraged and supported in participating in care and decision-making at the level they choose.

## Consumer Engagement in Central Victoria: A literature review

- **Collaboration.** Consumers, families, carers, service providers, and health care leaders collaborate in policy, professional education and program planning, design, delivery and evaluation.

The limited evidence presented in the literature is mostly supportive of person-centred approaches to care (Dow, Haralambous, Bremner & Fearn 2006). The ACSQC (2011) cites a body of evidence illustrating an association between patient centred care and decreased readmission rates and healthcare acquired infections; improved delivery of preventive care services; reduced hospital stays and enhanced compliance with treatment regimens.

A review of the literature showed that communication between doctor and consumer, specifically asking questions about the patient's understanding, expectations and feelings and showing support and empathy can make a positive difference to consumer health outcomes (Stewart, 1995). There is also evidence that person centred care results in improved service provider, consumer and carer satisfaction and improved compliance to intervention recommendations (O'Donnell et al., 1999 cited in Dow et al, 2006).

Person centred approach promotes and facilitates: greater consumer responsibility, engagement in treatment decisions, feeling supported to make behavioural changes and feeling empowered to self-manage (Coulter, Parsons & Askham, 2008; Dow et al., 2006). Some self-management techniques with people with chronic illness have been found to result in improved health outcomes. A randomised trial demonstrated that a self-management approach reduced the use of hospital services and provided greater confidence to manage their gastrointestinal condition (Kennedy et al, 2004). In a meta-review, self-management and self-monitoring was found to enhance the effective use of medicine (Ryan et al., 2014).

The person who spends the most time and effort caring for a person with chronic conditions is themselves, a family member(s) or carer. People with chronic conditions are managing their condition for about 5,800 waking hours per year, yet will spend less than 10 hours with a healthcare professional (KPGM International, 2014). Often the considerable resource contained in that time and effort does not provide as much return as it could because service providers have not recognized how they can contribute to improving the consumer's capacity. Even when some recognition is given to how much 'work' consumers carry out in their own self-care, few healthcare organisations invest in any real training resource on consumers when compared to their paid staff (KPGM International, 2014).

Active participation in care and self-management, education and written action plans can lead to reduced hospital admissions and fewer visits to emergency departments, unscheduled visits to the doctor, and days off work/school and improved health status (Lahdensuo et al, 1999 Lorig et al., 1999).

### 4.2 Shared Decision Making

A literature review to explore the degree of match between consumers' preferred role during health decision making and actual participation roles concluded that consumers demand

more participation than is currently being offered. (Belanger, Rodriguez & Groleau, 2011; Tariman, Berry, Cochrane, Doorenbo, Schepp, 2010).

As an underlying principle of consumer engagement, shared decision making (SDM) requires the redistribution and recalibration of power between service providers and consumers (Sarrami et al, 2012). SDM refers to a style of communication that considers consumers' preferences and values as well as available clinical information (Curtis et al., 2010). Promoting consumer involvement in health related decisions makes communication between service provider and consumer more satisfying and assists in the selection of better treatment options for the consumer (Curtis et al., 2010).

Several systematic reviews examined communication factors that could affect the relationship between health care professionals and consumers. Fine et al (2010) reviewed the literature to study the clinician-consumer relationship and the distribution of power within such relationships. They reported that clinicians focus on medical or technical matters and avoid emotional encounters and dominate sessions, while consumers are more satisfied with supportive clinician behaviours (Fine et al., 2010). This demonstrates the importance of SDM in increasing consumers' satisfaction and implies that clinicians' communication styles can be a potential barrier for consumer engagement.

A review by Simmons et al (2012) of SDM in adults with mental health issues found that SDM interventions for depression, schizophrenia, substance use and other serious mental disorders appear to improve consumer involvement, satisfaction, and in one study, mental health outcomes. The review also found evidence that adults diagnosed with depressive disorders, that have higher involvement in care results in higher consumer satisfaction and lower depression scores (Simmons et al, 2012).

Effectively partnering with consumers requires acknowledgement of the skills, experiences and knowledge of the consumer and mechanisms to utilise consumer views systematically (ACSQC, 2010). Studies have concluded that quality written and verbal information that is personalised improves patients' knowledge, and that information is more likely to be useful and clearer if consumers are involved in its development (Coulter & Ellins, 2006; Nilsen et al, 2006). Bunge, Muhlhauser & Steckelberg (2010) examined the quality of information provided to consumers. They reported that although the information provided was in general based on good evidence and ethical guidelines, there was still a lack of evidence on the quality of the information provided, including important elements such as the pictures used, narratives employed, language levels and cultural aspects of the information.

### **4.3 Consumer engagement in health services**

The National Health Reform Commission has identified that one of the key levers for achieving system change and better health care for all Australians is a strengthened consumer engagement and voice (Keam, 2012). The move towards increased consumer engagement in health may reflect the recognition that many of the health problems faced by the community are complex, and go beyond the capacity or jurisdiction of any single organisation to change or control (Lasker & Weiss, 2003).

## Consumer Engagement in Central Victoria: A literature review

Effective engagement needs to be embedded in an organisation's culture and practice. It informs health service organisations about the needs of the people who use their services and people who may be potential users of services but are experiencing barriers to access. Consumer engagement is a mechanism that can enable health service organisations to better plan, design and deliver services that meet the needs of the people who use them, to identifying gaps in the service, and where there are opportunities to make improvements (Health Consumers Queensland, 2012; Keam, 2012).

The community can be powerful allies and advocates for driving change. Engagement is a key mechanism to build partnerships that leverage resources and enable services, consumers and communities to work collaboratively to achieve desired health outcomes. It can also be used to empower consumers to work actively as partners in their healthcare, unlocking the potential available for consumer behaviour to contribute to more efficient and effective healthcare delivery (Health Consumers Queensland, 2012; Keam, 2012).

The NSQHS Standards include a range of suggestions for health services related to partnering with consumers in governance, including (ACSQHC, 2012):

- involving consumers as representatives on the board or on existing committees
- creating a new, or using an existing, consumer advisory group to gain advice from consumers about specific issues or project
- creating a new, or using an existing, 'service user' group. This involves identifying and approaching a small group of consumers and/or carers that use the service to help identify and consider quality improvement strategies together
- systematically seeking feedback and information from consumers on governance issues.

The methods of consumer, carer and representative participation, the benefits of each of the methods, the drawbacks and difficulties experienced and recommendations to improve the process are summarised in a table in the appendix (National Resource Centre for Consumer Participation in Health [NRCCPH], 2002a).

### **4.4 Consumer engagement in health policy**

Consumer engagement in determining public policy gives greater substance to the idea of a democratic government where the power is vested with the people. Consumer engagement adds legitimacy to democratic decision making by encouraging participative democracy, public accountability, transparency, and creating a more informed and engaged public (Bowling, 1996; Nilsen et al, 2004). Engaging consumers in policy making is a sound investment and a core element of good governance (Caddy, 2001).

Consumer participation allows government to access wider sources of information, perspectives and potential solutions, resulting in more relevant, informed, relevant and targeted policies (Caddy, 2001; Gregory, 2008). Through consumer engagement, consumers become actively involved in making decisions about issues that will affect them (Gregory, 2008).

In a report describing consumer engagement, Caddy (2001) describes three levels of consumer involvement in policy making:

- **Information** – a one-way relationship where policy makers make information available to citizens; a basic precondition for engagement.
- **Consultation** – a two-way relationship in which citizens provide feedback to policy makers. This is based on prior definition of the issue by government and citizens are invited to contribute their views and opinions.
- **Participation** – citizens actively engage in defining the process and content of policy making. This acknowledges equal standing for citizens in setting the agenda, proposing policy options, and shaping the policy dialogue.

An argument for greater citizen participation in policymaking arises from the emergence of what have been called 'wicked problems'. These are problems that have many interdependencies, multi-causal and are highly resistant to resolution. They are emerging in the environmental, health and social domains, for example climate change, obesity and the Aboriginal and Torres Strait Islander disadvantage (Australian Commonwealth Government, 2007). Tackling wicked problems has been described as 'an evolving art' and highlights the need to effectively engaging stakeholders and citizens in understanding the relevant issues and in involving them in identifying possible solutions (Australian Commonwealth Government, 2007). The literature dealing with wicked problems stresses collaborative strategies and adequate time frames, which may incur significant costs and skills of collaboration that may be in limited supply (Holmes, 2011).

Genuine engagement in the 'co-production' of policy and services requires major shifts in the culture and operations of government agencies. It requires public servants to become enablers, negotiators and collaborators and citizens need to be willing to actively engage, and have the capabilities to meaningfully participate. This is especially challenging if citizens are disengaged and certain groups within the population are marginalised (Holmes, 2011).

#### 4.5 Community engagement

The word 'community' is a broad term used to define groups of people; whether they are stakeholders, interest groups, consumer groups, etc. (Queensland Department of Emergency Services, 2001). A community is defined as "*a group of people sharing a common interest (e.g. cultural, social, political, health, economic interest) but not necessarily a particular geographic association*" (Consumers' Health Forum of Australia, 2004, p.9). The linking of the term 'community' to 'engagement' serves to broaden the scope, shifting the focus from the individual to the collective, suggesting a more inclusive approach to ensure consideration is made of the diversity that exists within any community (Department of Environmental and Primary Industries, 2013).

"Community engagement is about involving the community in decision making processes, which is critical in the successful development of acceptable policies and decisions in government, the private sector and the community" (Chappell, 2008).

## Consumer Engagement in Central Victoria: A literature review

Community engagement is a planned process with the specific purpose of working with identified groups of people, whether they are connected by geographic location, special interest, or affiliation or identity, to address issues affecting their well-being (Queensland Department of Emergency Services, 2001).

Community engagement can take many forms; occur in different fields, in different ways and for various purposes (Fudge et al., 2011; Kitzhaber, 1993). There are also different levels of participation that define the public's role in any community engagement initiative. The International Association for Public Participation (IAP2) community engagement model, often replicated in the literature, provides some clarity of the levels of engagement (Figure 1 at p13).

There are examples in Australia where community engagement has impacted on health and social outcomes. Community participation effectively contributed to HIV/AIDS policy and national strategy development, and education and prevention initiatives (Commonwealth of Australia, 2005). Between 1994 and 1999 there was an 80 per cent decrease in new AIDS cases diagnosed in Australia and over 30 per cent in new HIV diagnoses (Commonwealth of Australia, 2005). Consumers with disability and community organisations had a strong role in informing the development of the National Disability Insurance Scheme, and contributed to the Scheme's focus on individualised funding and consumer choice (Pask, 2011). A joint campaign of the Consumers Health Forum and 60 national health organisations against changes to the Australian Pharmaceutical Benefits Scheme (PBS) resulted in a Senate Inquiry and the decision by the Australian government to defer medications to become listed on the PBS was reversed (Consumers' Health Forum of Australia, 2011). The papers do not explicitly state what factors contributed to the success of these approaches, beyond community engagement.

Swainston & Summerbell's (2008) rapid review looked at the effectiveness of community engagement approaches and methods for health promotion interventions. They identified that community coalitions<sup>1</sup> used in the planning and design of an intervention contribute to changes in behaviour. These included:

- reducing the number of alcohol related crashes
- improving a number of alcohol related behaviours
- improving the prevention of injuries to children
- promoting a healthy diet in children
- better effective use of bicycle helmet by children
- effective promotion of physical activity through walking.

---

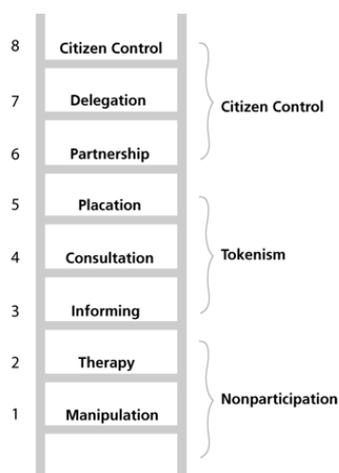
<sup>1</sup> Community coalitions are defined as 'formal arrangements set up to support collaboration between groups or sectors of a community. Each group retains its identity but they work together to build a safe and healthy community' (NHS National Institute for Health and Clinical Excellence, 2008).

## 5 Models of consumer and community engagement

Consumer engagement is poorly defined, with debate about whether an activity offers ‘true’ engagement or mere tokenism (Holmes, 2011). Consumer engagement is often represented as a ladder or hierarchy, ranging from low levels of engagement that offer little opportunity for consumer input, through to high levels that offer elements of consumer control or partnership (Gregory, 2008). For many authors, these ladder representations allow for a distinction between true consumer engagement and lesser activities. Baker and Collier (2003) argue that true engagement only occurs when consumers are actively and effectively involved in making decisions about issues that will affect their lives.

One of the best known models of consumer and community engagement is the Arnstein’s ladder of citizen participation (Arnstein, 1969). The Arnstein’s ladder (Figure 1) describes a hierarchy of engagement from non-participation to co-operation and delegation of full power and control to the citizens. This enables the public to influence decision making and be in control of the systems they are seeking to influence (Attree et al., 2011). The middle levels of the ladder (informing, consulting and placating) can be legitimate steps towards full participation, but are not techniques for full participation in their own right (Gregory, 2008). Arnstein’s concern with the middle levels of the ladder is that they offer methods of inviting consumers’ opinions with no assurance that those expressed opinions will be taken into account, resulting in a token or window-dressing ritual (Arnstein, 1969; Bishop & Davis, 2002).

Figure 1. Ladder of citizen participation

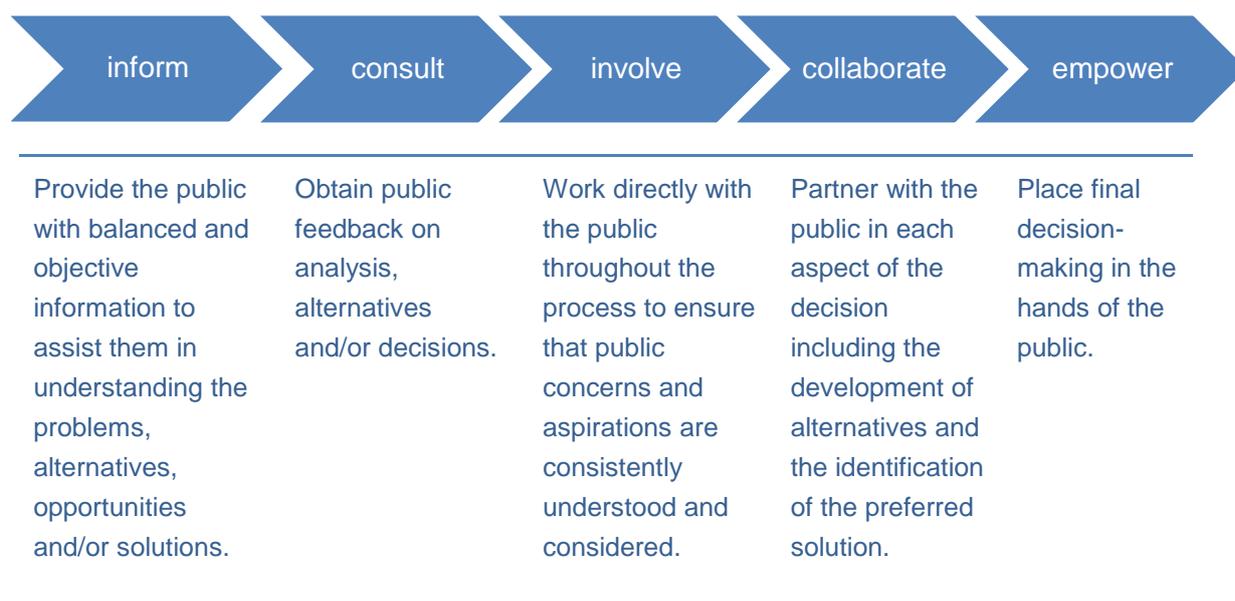


*Source Arnstein, 1969* It is argued that the ladder models are an imperfect way of describing engagement, particularly because they suggest an aspirational level of joint decision making and seem to make value judgements about lower levels of engagement (Anderson, Shepherd, & Salisbury, 2006). Bishop and Davis (2002) note that many forms of consumer engagement would fail to meet such a stringent test, and they question whether it is appropriate to judge all consumer engagement from this perspective

## Consumer Engagement in Central Victoria: A literature review

Recent models move away from ladders, to describe consumer engagement as a continuum of management techniques (Bishop & Davis, 2002). Like Arnstein's ladder, these models offer a spectrum from minimal engagement through to community control. But these models offer a set of choices for policy makers, rather than presenting a ladder as steps towards an ideal goal of full engagement. For example, the five-level continuum developed by the International Association of Public Participation (2004), show a spectrum of differing levels of participation that are legitimate depending on the goals, time frames, resources and levels of concern in the decision to be made (Figure 2).

Figure 2. Increasing level of public impact



Source: IAP2: <https://www.iap2.org.au/sitebuilder/resources/knowledge/asset/files/36/iap2spectrum.pdf>

## 6 Why we need consumer engagement

Consumer engagement is known to improve both the quality and safety of health services as well as individual and population health outcomes, whilst also making health services more responsive to the needs of consumers (Flinders University, 2000; Nilsen et al, 2004; Sarrami-Foroushani, 2014). Consumer perspectives to complement the health professional view can assist in making health information and services more balanced and relevant to consumers, and increase the chance of meeting the needs of consumers (NHMRC, 2006).

Politicians and health care leaders are increasingly recognising the importance of the perspective of consumers and families and experience of care as a key factor in health care quality and safety. Studies increasingly show that when health care administrators, providers, and consumers and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase (Institute for Patient and Family Centered Care, n.d.).

Among the most frequently reported effects of involving consumers was the production of new or improved sources of information for consumers (Crawford, 2002). There is strong evidence of the positive impact of consumer involvement in the development of patient

information; consumer input was found to result in information which was more relevant, 'readable' and understandable than that produced by clinicians alone (Nilsen et al., 2006).

A literature review which examined 42 studies detailing the effects of patient involvement in the planning and development of healthcare found that engaging patients improved information for patients and resulted in more accessible services (simplified appointment procedures; extended opening times, improved transport to the services and better access for people with a disability); the commissioning of new services (including crisis services, complementary medicine and fertility treatments) and the abandoning and modification of proposals for hospital closures (Crawford et al, 2002).

Consumer involvement in a mental health housing and support organisation resulted in improvements to service delivery including more flexible and responsive services, greater individualised support, enhanced feelings of connectedness among stakeholders and more equal partnerships (Lord, Ochocka, Czarny & Macllivery, 1998). Consumer and community engagement in user centred design and redesign has also been found to improve health service environments to better meet consumer needs (ACSQHC, 2011). An example of the how user-design process can improve consumer experience comes from Kaiser Permanente's work in the US. This work improved interaction and information sharing between staff and patients; improved staff efficiency; examination rooms that accommodate carers and families; increased attention to privacy and comfort in patient rooms; more comfortable waiting areas and easier check-in procedures and improved signage to help patients orientate themselves more intuitively (Altringer, 2010, cited in (ACSQHC, 2011) .

Engaging consumers as partners in healthcare has also been shown to improve the quality and safety of health services. Studies show that consumer engagement may result in better identification of adverse hospital incidents and events (ACSQHC, 2011a; Weingart et al., 2005). Similarly, a study involving acute care hospitals found consumer participation was associated strongly with favourable judgments about hospital quality and reduced the risk of suffering an adverse event (Weingart et al, 2011).

There was a reduction of medical errors when consumers provide practitioners with current information about their medications, medical histories and allergies and where consumers are actively involved in patient safety programs (Longtin et al, 2010). A hand hygiene promotion study in a clinical setting, examined the effect of patient education to increase practitioner hand-washing, and found hand soap consumption increased by 34% when patients were taught to ask staff to wash their hands (Coulter & Ellis, 2006; Longtin et al, 2010).

Improvements to rural primary health have also resulted from consumer engagement. A research synthesis of 689 empirical studies (national and international) linking health outcomes and rural community participation found evidence of benefits to health outcomes, including better access to and increased uptake of services, and more culturally appropriate and relevant services (Preston, Waugh, Larkins & Taylor, 2010).

## Consumer Engagement in Central Victoria: A literature review

A review by Crawford et al (2002) found that consumer engagement initiatives had an effect on organisational attitudes and culture to involving consumers. These included comments that staff attitudes to involving consumers became more favourable and that the culture of organisations changed in a way that made them more open to involving consumers. Some projects resulted in further initiatives aimed at strengthening the involvement of consumers.

Studies suggest that involving consumers in decision making can reduce costs (Fowler, 2012; Oshima, Lee & Emanuel, 2013). In a large study involving more than 3,000 consumers, researchers found that doctors tend to drive decisions and in most instances they did not inquire about the patient's preference or opinion. The vast majority of doctors favour interventions and recommended that the patients take the medication, have the screening test or proceed with the surgery (Zikmund-Fisher et al., 2010 cited in Fowler, 2012). However, a Cochrane Review demonstrated that informing consumers of the benefits and harms of treatment options, and using decision aids, reduced the number of people of choosing major elective invasive surgery in favour of more conservative options (Stacey et al, 2011).

Consumers involved in engagement activities welcomed the opportunity to be involved and has been associated with positive outcomes. As a result of their contribution, consumers have reported improved self esteem and confidence, as well as therapeutic benefits resulting from increased social interaction (Attree et al., 2011; Crawford et al, 2002; Omeni, Barnes, MacDonald, Crawford & Rose, 2014). Consumers felt they were being listened to by professionals, that their ideas were being acted upon and that their individual experiences were being used to help others (Crawford et al 2002, Fudge et al, 2011).

Consumers with acute and chronic health problems benefit when they are involved in their own care, both at home and in clinical settings, and evidence suggests that this can lead to better use of resources (Coulter & Ellins, 2007). One major review found that the majority of engaged individuals perceived benefits for their physical and psychological health (Attree et al., 2011).

The business theory underlying modern quality strategies is that organisations that meet consumers' needs, as judged by consumers, will thrive, and those that do not will wither (Berwick, 2009). The argument for consumer involvement in their own healthcare has been mainly based on moral grounds rather than an economic consideration. Organisations are increasingly realising the opportunities of harnessing consumer knowledge and power to put pressure on costs, to improve lifestyles and drive quality (KPMG International, 2014).

KPMG International (2014) states that a further change in the value proposition for healthcare will occur when their focus shifts from healthcare to a social model of health. To encourage more consumers to be more active in their health it is necessary to not only work with medical issues but to include functional, social and psychological issues (KPGM International, 2014). Disease-specific outcomes may not adequately reflect treatment effects in consumers with multiple coexisting conditions, severe disability, or short life expectancy. Consumers are more motivated to achieve something that they want and can recognize, For

example, a person with Parkinson's disease may establish goals of getting to the bathroom without assistance, using the Internet to communicate with a grandson at university or go to church rather than the biomedical manifestations of the disease (Rueben and Tinetti, 2012).

## 7 Australian Context

Consumer engagement is an established practice in the Australian policy making environment. Within the health sector, engagement is a fundamental part of government policy development and a statutory obligation for organisations such as the National Health and Medical Research Council (NHMRC) and the Australian Health Ethics Committee. (Horey & Hill, 2005 cited in Gregory, 2008). The funding organisation, the National Health and Research Medical Council (NHMRC), requires grant applicants to detail the process of consumer engagement planned for funded programs, and expects project reports to include a discussion of how consumer engagement was achieved (NHMRC, 2004). The Commonwealth funded Primary Health Networks, to be established across Australia in July 2015, are required to have a Community Advisory Committee to advocate to the board on behalf of the community, consumers' and carers' participation in health and social services (Health Issues Centre, 2014).

There is growing consensus within the Australian health care system to support partnerships between consumers and health professionals and organisations (ACSQHC, 2012). The Australian Charter of Healthcare Rights, developed by the ACSQHC, specifies the key rights of consumers when seeking or receiving healthcare services and was endorsed by the Australian Health Ministers for use across the country. Included in this charter is the right for consumers to participate in decisions and choices in individual care and health service planning (ACSQH, 2008).

The importance of the consumer voice is reflected in the NSQHS Standards (ACSQHC, 2011b). The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health service provision. Health services in Australia are required to meet the NSQHS Standards as they provide a governance structure for quality assurance and quality improvement. The standard 'partnering with consumers' aims to *"create a health service that is responsive to patient, carer and consumer input and needs"* through partnerships with consumers (ACSQHC, 2012 p.6).

Australian state governments have policies and processes in place to give a voice within government to consumers. In alignment with the Disability Discrimination Act 1992 the Victorian Disability Action Plan 2013-2016 prioritises participation of people with disability in everyday life and supporting their role in self-advocacy and promoting leadership opportunities. Consumer engagement is a required element of health policy development and health service planning, with some state governments including consumer engagement in the performance agreements of Departmental CEOs (Gregory, 2008). In Victoria, a participation policy for the health system, *Doing It With Us Not For Us*, was released in 2006 (DHS, 2006). Participation indicators have been added to the *Doing it with us not for us: Strategic direction 2010-13* (State Government of Victoria, 2011). The Victorian Health

## Consumer Engagement in Central Victoria: A literature review

Department funds the Health Issues Centre and the Centre for Health Communication and Participation to progress research, health professional education, evaluation, and training in consumer participation (The Victorian Auditor-General, 2012).

The Victorian Auditor-General's report (2012) found that the Victorian Health Department has set strong policy direction for consumer participation in health and supports research in this area. However, it has not comprehensively addressed all of its own obligations under the policy. Despite setting consumer participation expectations for health services, the department does not provide them with meaningful feedback to drive improvement.

### **8 Barriers**

A range of barriers to active consumer and community engagement are recognised in the literature. Although the ideal of consumer engagement is widely supported, there are significant challenges in transforming the concepts into practice (Abelson et al, 2003).

In a policy context, a review of consumer engagement practices in Western Australia concluded that the quality of much consumer engagement is dubious, with problems relating to the capacity of departments to undertake engagement, the stage in the policy-development process at which engagement is initiated, and the consistency of consumer engagement activities (Gillgren, 2005). In addition, there are concerns that a mandated requirement for consumer engagement may result in tokenistic processes that increase health inequities (Nathan, 2004).

The literature has identified several themes in relation to barriers to meaningfully engaging consumers. These include, skills and attitudes of consumer and service providers, insufficient input from vulnerable and marginalised population groups, lack of organisational infrastructure support, organisational culture and geographical factors (Markovic and Haby, 2011; MHMRC, 2006; Sarrami Foroushani et al, 2012

#### **8.1 Consumer and service provider skills and attitudes**

Consumer reports identify a range of barriers and issues for them in participating. Many of these issues are not well documented as consumer groups tend not to have access to the resources or infrastructure to either research and/or publish their experiences (NRCCPH, 2000).

The traditional consumer role, in a clinical setting is to be compliant, passive, and trusting. Consumer engagement requires new perspectives and approaches both on the part of the consumer and the service providers. Advocating community engagement may require consumers to adopt new roles and behaviours (Hibbard et al, 2009). Consumer and community engagement in health care will require specific skills and abilities of the individuals involved. For example, expecting consumers to use an electronic personal health record will require them to have a level of computer literacy, adequate cognitive ability, and access to computers and the internet (Ennis, Rose, Callard, Denise & Wykes, 2011).

Although consumer and community representatives have their own unique expertise, including a depth of understanding of how a health issue or problem impacts on consumers and the community, they can have a poor understanding of the system within which they are trying to achieve influence. They may also lack skills in advocacy and the strategies that may assist them to be heard and to achieve change (Nathan, 2004).

Users of health and social services have been reported to frequently complain that they are unreasonably expected to present their views in managerial or bureaucratic language (formal language or jargon) and failing to do so may mean that those views are not considered (Crawford et al, 2003). Health and general literacy are also issues in consumer and community engagement. Similar to other developed countries, almost 60% of adult Australians have low individual health literacy (Australian Bureau of Statistics, 2009). The design of health care facilities may make it more difficult for people with lower individual health literacy to access information and services that they need (ACSQHC, 2013; Coulter & Ellins, 2006). As a result they are poorly represented in consumer consultation and governance processes (National Health and Hospitals Reform Commission (NHHRC, 2009).

Consumer surveys have consistently shown that consumers want better communication with their doctors; even when many doctors considered the communication adequate or even excellent (Duffy et al, 2004; Stewart, 1995). Consumers need information that is often very different from the information that doctors think they need. KPGM (2014) research showed that, what patients felt was crucial information was ignored by clinicians. If consumers don't receive what they need to know, they will not be able to be as active in their own care. Information for consumers that they can use improves clinical effectiveness, safety and patient experience (KPGM International, 2014).

Relationships between the organisation and the consumers and within community groups may impact on the effectiveness of consumer consultations. There may be uneven power distribution among partners or lack of trust by the community in local organisations (Merzel & D'Afflitti, 2003; Swainston & Summerbell, 2008). As a consequence of unequal power relationships between consumers and providers, consumers may experience, or fear, discrimination as a consequence of providing negative feedback (NRCCPH, 2000).

Some consumers found the engagement processes physically, emotionally and financially demanding and exhausting. The physical demands of engagement were reported as particularly onerous by individuals with disabilities. Consultation fatigue and disappointment were negative consequences for some participants who had experienced successive waves of engagement initiatives. (Attree et al., 2011; NHS National Institute for Health and Clinical Excellence, 2008).

Studies have highlighted staff and organisational resistance, as significant barriers to effective consumer engagement (Omeni et al, 2014). Crawford et al (2003) found that in the social and community services that meaningfully engaging consumers they may require a fundamental shift in ideology and culture rather than the simple introduction of mechanisms of participation. Longtin et al. (2009) identified that for service providers, the desire to

maintain control, time limitations and personal beliefs factors could affect the involvement of consumers in the health care process. There is also reported widespread failure by service providers to properly understand the preferences of their service users and how the proposed interventions will affect their lives (Mulley, Trimble & Elwyn, 2012). Concerning is that service improvement initiatives designed to increase awareness of user involvement and enhance participation are not always effective in influencing professional knowledge, practice or attitudes towards user involvement (Rise, Grimstad, Solbjør & Steinsbekk, 2001).

Consumer and community engagement equally requires additional skills from service providers. Legare et al (2011a) have reported that in order to encourage health care professionals to help patients involved in the process of SDM both training and education and the provision of learning materials is required.

### 8.2 Population and Condition specific limitations

People's preference for involvement in decision may be dependent on characteristics such as age, educational level, disabilities and ethnic and cultural backgrounds (Curtis et al., 2010). In particular, children and adolescents participating in research come with many challenges. These challenges include managing the information exchange between all those involved, negotiating ethics approval, managing consent, redressing power imbalances, and managing how and when children become engaged in the research process (Australian Research Alliance for Children and Youth, 2009; Diclemente et al., 2010).

There are particular consumer group who are marginalised from participating in, or giving feedback to health services. The groups identified by participants in the NRCCP (2002) Health's Needs Assessment as being the most excluded from mainstream participation mechanisms were consumers who are:

- from a cultural and linguistic diverse backgrounds
- of Aboriginal and Torres Strait Islander descent
- living with chronic conditions, including mental illness
- living with a disability
- living in rural and remote areas
- living in poverty
- of low literacy
- socially isolated
- young
- older.

Some argue that consumer involvement in the mental health field is more complicated than in general medicine (Curtis et al., 2010). Participation can carry risks. One review found that for some psychiatric patients, access to their own health care information may increase their distress or may contribute to the deterioration of their condition (e.g. re-enforcing a paranoid delusion) (Ennis et al., 2011). The same reviewer found that although this was a real risk, it did not justify depriving those consumers from receiving their health-related information. It

would, however, necessitate the development of appropriate communication methods that could efficiently impart the information without causing the consumers any distress (Ennis et al., 2011). The stigma that is attached to some conditions may equally be a barrier to participation in healthcare, such as HIV or mental health related engagement (Diclemente, Ruiz & Sales, 2010).

### **8.3 Organisational infrastructure support**

The most frequently discussed barriers to effective consumer engagement are time and cost (Bullock, Mountford & Stanley, 2001; Oliver et al, 2004, Sarrami-Foroushani et al, 2014, Victorian Auditor General, 2012). Due to short term funding of programs and projects consumer engagement is often expected to be completed within limited and unrealistic timeframes that restrict the effectiveness of consumer engagement (Gregory, 2008; Swainston & Summerbell, 2008; Wiseman & Williamson, 2012). It takes time to plan engagement strategies, identify and meet with stakeholders and build trust with people to successfully engage with the community (Victorian Government Department of Sustainability and Environment, 2005).

When the timeframe for engagement is driven by the pressures of politics or a pre-determined organisational planning cycle, it can be difficult to fully engage consumers, particularly if the program aims to involve consumers in developing and implementing policy decisions (Bullock et al, 2001). The risk of not being able to secure further funding to guarantee the sustainability of the initiative, was also perceived to be a major barrier to the use of community engagement methods (Swainston & Summerbell, 2008; Wiseman & Williamson, 2012).

There are also the added operational costs of engagement including sitting fees or similar payments where engagement means foregoing income elsewhere, training for consumers and service providers, developing of resources (toolkits, guides, templates, visual aids) to support consumer engagement, development of information resources and the cost of running forums to facilitate sharing of experiences/ideas on consumer engagement (Owen & Ristovski, 2011). In particular, the financial cost of participation has been raised as a specific barrier (along with physical demands) for people with disabilities (Attree et al., 2011). The indirect costs to for example, volunteers, to participate is not well recognised at any policy and funding level.

On an individual level, time constraints are among the most frequently reported barriers to clinical change, including SDM (Cabana et al, 1999, KPGM, 2014). However, there is very little evidence to support this claim. A Cochrane systematic review analysed studies that used decision aids, which were embedded in interventions that measured consultation lengths. Two studies found that shared decision making interventions took longer than usual care; one found that it took less time than a traditional consultation, and six found no statistically significant difference in consultation lengths (Stacey et al, 2011).

## 8.4 Organisational and clinical culture

Organisations struggle to involve consumers in strategic planning, staff training and health service performance monitoring, and there is little evidence of consumer participation in evaluation activities (Victorian Auditor-General, 2012). Many organisations have a limited capacity to acknowledge and consult with a range of people within different groups which can result in excluding the more vulnerable populations (NRCCPH, 2000). Some models of care utilised by services often do not support participation; disempowering consumers through treating them as dependant, focusing on their disabilities rather than their abilities, failing to respect their rights, and failing to communicate (NRCCPH, 2000).

Organisational and professional culture, as well as the approach taken to involve consumers may also determine the extent to which various groups of consumers can become involved in decision making (Omeni et al., 2014). Modification of initiatives to ensure a better fit with the consumers and setting, the use of existing networks and social relations and identifying other relevant stakeholders are required in the implementation of new initiatives (Ennis et al., 2011).

At an individual level, some of aspects of current clinical culture could impose limitations in doctor-consumer communication. Implementing shared decision making by changing long-established communication styles has proven a challenge even for well educated and motivated professionals (Curtis et al., 2010). Fine et al (2010) reviewed studies on doctor-consumer relationships and observed that there was a mismatch of what the consumer needed and what the doctor was communicating. Changing current communications styles between doctors and consumers and enhancing consumers' participation requires significant cultural change (Fine et al., 2010).

## 8.5 Diversity

Although a great deal of innovative work is being done to increase consumer participation; policy makers, service providers often find it difficult to ensure the diversity of consumers and community members is reflected in participation initiatives (NRCCP, 2002). Health services report challenges in recruiting and retaining committee members who reflect the diversity in the local community, and/or building the capacity of members to operate at a strategic level (Victorian Auditor-General, 2012). There is little resourcing provided to consumers, especially marginalised consumer groups, to develop their capacity to participate (NRCCPH, 1999)

In a needs assessment undertaken by the NRCCPH (1999), found that where mainstream organisations had developed mechanisms for involving consumers, these structures and processes were often not appropriate to involving consumers from diverse backgrounds. In general, many groups of consumers were only involved when they were the focus of a specific, once-off project or strategy. This is often done outside any integrated approach to the development of appropriate services, which means this work is ad hoc and seen as something to be added on when funding is available, rather than being part of the core business of mainstream services (NRCCPH, 1999).

## 8.6 Rural factors

At a government policy level, in order for rural communities to play an active role in the policy-making process, it is necessary for their members to have access to resources. These resources include adequate funding, government training programs, education, leaders, and volunteers to support rural causes and initiatives. Many rural communities tend to lack one or more of these resources, a situation which interferes with their ability to effectively impact the policy-making process (Dukeshire & Thurlow, 2002)

In rural communities, the smaller populations mean that there are fewer people to inform decision-making or initiate action. This may prompt greater interactions between rural members in order to sustain the community, but may exclude the participation of the less vocal or less affluent sectors of the community. It is argued that access to community influence and benefits is dependent on becoming a privileged or elite community member through family tenure or wealth and status (Alexander, 2005). Evidence suggests that upon securing an elite status, community members are able to use their status to maintain their standing and influence in community decisions. This results in the privileged community influencing decisions on the entitlement to, allocation and timing of community resources, leading to greater exclusion for those without power or influence (Onyx, Edwards & Bullen, 2007; Ostrom, 2000; Wilson, 2005).

Rural and remote communities have also suffered over recent times from the reduction and loss of local services, including aged and community services, and community infrastructure as a result of local and global economic forces (Aged and Community Services Australia and the National Rural Health Alliance, 2005). This can lead to feelings of disconnectedness and anger, which may cultivate feelings of resentment and an unwillingness to participate in organisational engagement processes (Tasmanian Government, n.d.).

Accessing organisations may be more challenging in the rural context. It may be a long distance away and may not easily accessible or affordable by public transport. There may be a perceived stigma associated with a service and people do not want to be seen entering the premises, especially in relation to social services and mental health services (Flanagan & Hancock, 2010). This is amplified in small communities where people are more connected to, or at least know of, each other, resulting in a loss of anonymity. Therefore, if the purpose or topic of engagement is sensitive, some individuals may be reluctant to participate (Tasmanian Government, n.d.).

Consumers from culturally and linguistically diverse backgrounds (CALD) reported that poor English language skills prevented them from participating in activities (Queensland Government, 2011). Although there is government support to use interpreters, health services report a range of challenges in implementing their interpreter policies (Victorian Auditor-General, 2012). They report that funding for interpreter services has not kept pace with consumer needs; demand has increased and there is a shortage of interpreters in some languages. Health services in rural and regional areas face additional barriers, such as a

smaller local pool of accredited interpreters and increased travel time and costs (Victorian Auditor-General, 2012).

### 9 Factors facilitating community engagement

There is a range of literature discussing the importance of consumer engagement, but little literature actually demonstrating it successfully happening (Abelson et al, 2003). In Australia, there are many frameworks and guides to support organisations to implement community and consumer engagement into organisational core business, reflecting the commitment and intent of the government (Health Consumers NSW, n.d.; Health Consumers Queensland, 2012; Government of South Australia, 2012; Owen & Ristovski, 2011).

#### 9.1 Capacity Building: Consumers

Resourcing consumer and community groups is a vital step in building capacity to participate effectively as are programs at the local community level that bring people together to share concerns and take action (Nathan, 2004). Building on strengths and resources within the community (e.g. individuals' skills, networks of relationships) and supporting co-learning and empowerment will facilitate consumer engagement (Israel, Schulz, Parker & Becker, 1998).

To encourage active consumers, healthcare organisations need to understand the assets that the consumers, their family and carer possess that can be mobilized to better manage their healthcare. At an individual level, the investment of services to develop skills and capabilities of consumers, their carers and communities to support participation in their care may involve:

- new skills and job roles such as coaching and motivational interviewing
  - new ways of engaging to identify consumers' assets and develop the different options available to them
  - integrating a social model of health into practice
  - Incentives and new interventions to change behaviours
  - remote monitoring using technology backed up with case managers
  - intensive intervention to support the vulnerable or chaotic patients
  - building and supporting peer networks so patients can provide mutual support.
- (KPGM International, 2014)

Consumer groups in the health area have also recommended that community engagement should be facilitated via enhancing health literacy, encouraging community participation and empowering consumers; and in particular 'consumer representation' is advocated (NHHRC, 2009).

Consumer engagement requires a greater degree of consumer health literacy. Consumer information needs to adhere to quality standards, be user-tested, and to be useful it needs to be co-designed and co-produced. Information must also be designed to meet different levels of health literacy (KPGM International, 2014). In family support services, visual promotion and techniques were seen as the most effective strategy for engaging vulnerable families,

many of whom have difficulties with literacy (Cortis et al. 2009). In regards to shared decision making and self-management, goal orientated healthcare provides the healthcare organisation with the capacity to work with patients to achieve their own life goals. Consumers will have greater motivation to achieve something that they want and can recognise (KPGM International, 2014, Victorian Primary Care Partnerships, 2012).

## 9.2 Build capacity: Organisation

Effective consumer and community engagement requires building the capacity of the health system to accept and value the views of consumer and community representatives (Nathan, 2004). Changing service systems requires a commitment to sharing information, changing power relationships, fostering mutual trust and respect and to developing feedback and participation methods that create the kinds of information and activities that make organisational change imperative (NHS National Institute for Health and Clinical Excellence, 2008; NRCCPH, 2000).

Coulter, Edwards, Elwyn and Thomson (2011) have suggested a list of prerequisites that need to be in place in order to integrate consumer engagement, at an individual level, into clinical practice. These include:

- a) appropriate policy, regulation and standards;
- b) availability of tools and information; training;
- c) clinical and patient champions; monitoring processes;
- d) evidence of effectiveness; incentives; and
- e) implementation plans (Coulter et al., 2011).

Organisational commitment, local decision-making, and positive attitudes to community participation among staff are important aspects of health bureaucracies that enable effective consultation with the community (Putland, Baum & Macdougall, 1997). This includes a commitment to long-term investment, being open to organisational and cultural change, understanding how consumers want to work with services and applying consumer information to improve services (NHS National Institute for Health and Clinical Excellence, 2008; NRCCPH, 2000). Strategies to engage consumers need to include accountability to consumers and to demonstrate how consumer input has been utilised to improve services (NRCCPH, 2000).

An example of a health system that has re-orientated their services to the needs of the consumer with positive outcomes is the Nuka System of Care. The Southcentral Foundation's Nuka System of Care, based in Alaska, is a result of a customer driven overhaul from a centrally controlled bureaucratic system to a health care system where the Alaska Native people are in control (Gottlieb, 2012). It recognizes that disease and its treatment has social, psychological and cultural components as well as the traditional bio-medical issues. The consumer is treated as a customer and as an owner of their healthcare and their healthcare system. The governing board, which is composed entirely of customer-owners, sets the direction and the CEO creates an environment that ensures the organisation is working towards its vision and measure progress along the way. The

## Consumer Engagement in Central Victoria: A literature review

relationship-based, customer-owned Nuka System of Care has demonstrated measurable improvements in health care. These include:

- 52% increase in consumers enrolled to an integrated primary care team,
- Decrease in the average delay to schedule a routine appointment from 4 weeks to same-day access,
- Reduction in the number of individuals on the behavioural health waiting list from about 1,300 to nearly zero in a year.
- Reduction in Phone waiting times from 2 minutes to less than 30 seconds.
- 36% reduction in hospital days,
- 42% reduction in emergency care and urgent care usage, and 58% reduction in specialty clinic visits have been sustained for 10 and above years.
- Reduction in staff turnover to a quarter of the level it was 5 years earlier.
- 25% increase in childhood immunizations (Gottlieb, 2012).

Increasingly organisations are using volunteers and peer support to bridge the gap between the service provider and consumer. Repper and Carter (2010) describe models of peer support that have been developed and evaluated as having merit. These include informal and ad hoc support among consumers (often naturally occurring); organised but unpaid peer support generally undertaken by volunteers who take on roles as 'mentors' or 'peer buddies'; and paid peer support, where participants will generally be part of a team contracted to provide services to consumers. Using patients to educate clinical professionals has potential to change the culture of the organization and decisions about treatment (KPGM International, 2014).

A qualitative study of the community sectors demonstrated that using consumers as part of the team encourages other consumers to participate and feel more settled. They can share with each other and use that as a bridging gap and a way of opening doors (Flanagan & Hancock, 2010). Recruiting consumers as workers has also been identified as a way to both engage consumers and improve the status, self-confidence and skills of consumers who were initially difficult to reach (Barrett, 2008).

For some rural and isolated communities the timing of engagement processes will need to be planned around local and seasonal activities, for example, during harvest or shearing. Scheduled community events and opportunities such as festivals, agricultural shows or Rural Health Week are opportunities to learn more about local issues and experiences, or as a platform for engagement (Tasmanian Government, n.d.).

### 9.3 Diversity

Consumer participation must provide opportunities for the most marginalised in our society to assert influence on the care they receive. Changes to organisational cultures and structures, using participation processes that are appropriate for hard to reach groups as well as attention to building the capacities of marginalised consumer and community representatives are critical (Nathan, 2004).

According to the NSQHS Standards, '*Governance partnerships should be reflective of the diverse range of backgrounds in the population served by the health service organisation, including those people that do not usually provide feedback*' (ACSQHC, 2012, p12). It is important to include representation from a diverse range of backgrounds including CALD communities, Aboriginal and asylum-seeking and migrant populations. Organisations need to identify the types of consumers who access their services by undertaking a community profile, administering a survey, using demographic data and/or networking with other organisations or individuals in the community (ACSQHC, 2012).

To be inclusive of the diverse communities, services and educational resources should be culturally relevant and lay facilitators, researchers and health educators from the same cultural background as community members are recruited (NHS National Institute for Health and Clinical Excellence, 2008; Satterfield et al, 2003; Thomas, Fitzpatrick-Lewis, Rideout & Muresan, 2008).

The use of Aboriginal Liaison Officer (ALO), health worker or outreach worker supports Aboriginal consumers to access culturally appropriate services, information and facilitates communication (Elkin, 2011). The ALO has an advocacy role in identifying and alerting the organisation to issues or barriers to participation that the Aboriginal consumers are experiencing. These are strong steps in providing a providing a culturally safe health service, as is learning from and linking with Aboriginal Community Controlled Health Services (ACCHS) (Elkin, 2011). ACCHS are primary health care services that are initiated and operated by local Aboriginal communities. They deliver holistic, comprehensive and culturally appropriate healthcare to the community that controls it, through the locally elected boards of management (National Aboriginal Community Controlled Health Organisation, 2012).

#### **9.4 Monitoring consumer experiences**

Organisation practices need to be underpinned by the measurement and monitoring of patient experience. Satisfaction alone is now seen as an inadequate way of capturing information and prone to a number of biases, the patient's actual experience provides richer and more actionable information (KPGM International, 2014). A range of qualitative and quantitative methods are required ranging from individual patient stories and interviews through to real-time data capture through electronic devices. Organisations are increasingly realising that what has been focused on may not be important to consumers, what has been measured may not be what really matters, and rich data about how consumers actually experience care is essential (KPGM International, 2014).

The Southern Grampians & Glenelg Primary Care Partnership undertook a study to determine rural consumers' experiences of chronic conditions (Heenan, 2009). These findings emphasise the need to address interagency and cross agency assessment and care planning, consumer recall and consumer feedback systems. It is also found that enhancing consumer self-efficacy through individual and group education including what is expected as

part of their 'cycle of care' for their particular condition(s) and from their self-management support service, requires further focus (Heenan, 2009).

### **9.5 Consumer and community engagement processes and tools**

There are many assessment implementation toolkits to support organisations to integrate consumer engagement into the core practices and processes of an organisation (Banyule Nillumbik Primary Care Alliance, 2003; NRCCPH, 2002b). The Health Issues Centre conducted a review into the community participation tools currently being used by health systems, that have been evaluated and effective in engaging consumers in health decision-making (Bruce, Cordwell & McBride, 2008). The findings of this review demonstrate that the tools at individual level have been well evaluated and are valuable but further evaluation of tools is required at organisation and government (Table 1).

Table 1. Evaluation of community participation tools (Bruce et al., 2008).

Level of engagement	Focus of common tools	Tools identified	Evaluation
Individual	decision making processes	question prompt list, information packages, chronic disease self-management groups, shared decision-making tools	most evaluated, when implemented appropriately they are able to engage consumers in decision-making processes.
Program	seek feedback from consumers on possible improvements or on involving consumers in planning processes.	involvement of consumers on committees and reference groups	consumers are able to have input into the design of patient information and resources and in some cases have successfully contributed to committees and working groups
Organisational	seek the input of consumers and community members for planning or reforms	community advisory committees and community councils	minimal evaluations, but when conducted they generally reveal that the tools produce more benefits for health services than individual consumers.
Government	consult and engage with consumers and communities	legislation, policy and resources are being created to guide the implementation of consumer and community participation	minimal evaluations and ad-hoc.
Community	engage consumers and community to input into future health planning	citizen juries, interviews, surveys, focus groups public forums and advocacy	all methods seemingly identifying useful data to inform future health planning

### 9.6 Evaluation

Evaluation is an ongoing process which should be an integral part of the planning process. Consumers and carers should be actively involved in the planning of the evaluation design, implementation and dissemination of results (Health Issues Centre, 2008). Formal evaluation allows services to reflect upon the strengths and weaknesses of their consumer participation model, which will influence future participation and providing evidence to support the consumer participation model (Paediatric Integrated Cancer Service, 2013).

There are tools and processes that may be implemented to evaluate the effectiveness of consumer participation activities, with new evaluation tools still being developed (Scholl et al., 2011, Goss et al., 2011). The type of tool used will depend on what the health service aims to evaluate. These may include:

- the Partnership Self-Assessment Tool (USA) (National Collaborating Centre for Methods and Tools, 2008)
- Patient Based Care Challenge (Aus), (Clinical Excellence Commission, n.d.)
- Well Connected (UK) (Green & South, 2006 )
- Community Participation Evaluation Tool (South Australian Community Health Research Unit, n.d.)

Equally there are multiple evaluation methods to measure successful consumer engagement. These may include, but are not limited to: review of documents e.g. minutes of meetings, annual reports, newspaper reports; story telling e.g. sharing the narratives of the impact of the initiative; Focus group interviews and discussions; Informal feedback e.g. comments about how consumers experienced a meeting, ideas about what works or does not work; Observation e.g. whether people are satisfied, frustrated, whether they attend, speak when they come to an advisory meeting, appear more confident, cultural groups involved and not involved; face-to-face and telephone interviews, self-completed questionnaires; photos; statistic (Paediatric Integrated Cancer Service , 2013).

## 10 Research gaps

Although a body of literature is accumulating which suggests that consumer, carer and community participation in health is beneficial; there still remain significant gaps in the literature (Consumer Focus Collaboration, 2000). Several areas of conceptual confusion, discrepancies and imprecision of definitions and lack of clarity in relation to community participation that exist in the literature in relation to consumer engagement, can result in ambiguous results (Ennis et al., 2011; Preston et al., 2010).

Authors have observed, although there is a significant body of consumer engagement related literature, there remains a lack of evidence in relation to the effectiveness of strategies in specific topics or settings (Evans, Pilkington & McEachran, 2010). A number of reviewers reported a lack of adequate evidence on the participation of different groups of consumers, including children, mental health patients, palliative care patients and minority groups (Belanger et al, 2011; Duncan, Best & Hagen, 2010; Moore & Kirk, 2010).

Reviews identified that there were limited studies and where they did exist, many of the studies were not of good quality or had methodological limitations (Baker, Francis, Soares, Weightman & Foster, 2011; Duncan et al., 2010; Farrelly et al., 2013; Legare et al., 2011a; Preston et al., 2010; Ryan et al., 2010; Yancey et al., 2014). This makes it challenging to determine if current approaches are effective in increasing community and consumer participation.

There is also a lack of studies or evidence to suggest that consumer engagement models or processes, in the (Victorian) rural area, require a different approach to those developed in other settings.

## **11 Conclusion**

This review was undertaken to assist health and social services in rural Victoria to analyse methods and models of participation and develop strategies to engage consumers in the planning and implementation of local service. It is evident from the literature that the governments and health and social leaders recognise that consumer participation is critical for delivering services that meet the needs of consumers and people want to be more involved in their care. However, governments and organisations are struggling to translate the ideals of consumer engagement into practice in a sustainable, meaningful way. The lack of rigorous evaluation compounds the challenge for those that are seeking evidence based practice to inform future strategies to effectively engage the community and consumers.

While the evidence suggests that there are identifiable benefits of community engagement for the health system, the community and the individuals, the methods and approaches used varies and are not consistently replicated across all settings to allow the evidence to demonstrate which is the most successful. It is difficult, therefore, to attribute specific benefits to any one approach or method. Nevertheless, this absence of 'hard' evidence should not be mistaken for an absence of effect. There is sufficient evidence, albeit imperfect, on which to build strategies to strengthen consumer engagement. No evidence was found to suggest that rural or regional areas require a different (or similar) approach to metropolitan populations. There are government policies, frameworks, guides and assessment and evaluation tools to support services to integrate consumer engagement into practice at all levels of the organisation.

## 12 References

- Abelson, J., Forest, P., Eyles, J., Smith, P., Martin, E. & Gauvin, F. (2003). Deliberations about deliberative methods: Issues in the design and evaluation of public participation processes. *Social Science & Medicine*, 57, 239-251.
- Aged and Community Services Australia and the National Rural Health Alliance. (2005). *Older People and Aged Care in Rural, Regional and Remote Australia National Policy Position*, National Rural Health Alliance.
- Alexander, M. L. (2005). *Social inclusion, social exclusion and social closure: what can we learn from studying the social capital of social elites?* Paper presented at the International Conference on Engaging Communities, Brisbane, Australia
- Arnstein, S. (1969). A ladder of citizen participation. *AIP Journal*, p 216-224. Retrieved from <https://www.planning.org/pas/memo/2007/mar/pdf/JAPA35No4.pdf>
- Australian Bureau of Statistics. (2009). Australian social trends, June 2009: 4102.0. Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features20June+2009>
- Aslin, H. J. & Brown, V. A. (2002). *Terms of engagement: A toolkit for community engagement for the Murray-Darling Basin*. Canberra: Bureau of Rural Sciences.
- Attree, P., French, B., Milton, B., Povall, S., Whitehead, M. & Popay, J. (2011). The experience of community engagement for individuals: a rapid review of evidence. *Health & Social Care in the Community*, 19: 250–260. <http://dx.doi.org/10.1111/j.1365-2524.2010.00976.x>
- Australian Commission on Safety and Quality in Health Care (ACSQHC). (2010). Patient-centred care: Improving quality and safety by focusing on patients and consumers discussion. Sydney: ACSQHC. Retrieved from <http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/PCCC-DiscussPaper.pdf>
- ACSQHC. (2008). Australian Charter of Healthcare Rights. Retrieved from <http://www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/>
- ACSQHC. (2011). *Patient-centred care: improving quality and safety by focusing care on patients and consumers*. Sydney:ACSQHC. Retrieved from <http://www.healthissuescentre.org.au/documents/items/2010/10/353730-upload-00001.pdf>
- ACSQHC. (2012). *Standard 2: Partnering with Consumers Safety and Quality Improvement Guide*. Sydney: ACSQHC. Retrieved from [http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2\\_Oct\\_2012\\_WEB.pdf](http://www.safetyandquality.gov.au/wp-content/uploads/2012/10/Standard2_Oct_2012_WEB.pdf)
- ACSQC. (2013). *Consumers, the health system and health literacy: Taking action to improve safety and quality. Consultation Paper*. Sydney: ACSQHC.
- Altringer B. (2010) The emotional experience of patient care: a case for innovation in health care design. *Journal of Health Services Research and Policy*,15(3):174–177.
- Australian Research Alliance for Children and Youth. (2009). *Involving children and young people in research [electronic resource]: a compendium of papers and reflections from a think tank co-hosted by the Australian Research Alliance for Children and Youth and the NSW Commission for Children and Young People on 11 November 2008*. Sydney: ARACY and the NSW Commission for Children and Young People.
- Baker, Q. E. & Collier, A. (2003). Commentary: Inclusive community engagement: A grounding principle for collaborative problem solving. *Journal of Urban Health*, 80(1),

48-49. Retrieved from

[http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3456116/pdf/11524\\_2006\\_Article\\_BF02417841.pdf](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3456116/pdf/11524_2006_Article_BF02417841.pdf)

- Baker, P.R.A., Francis, D.P., Soares, J., Weightman, A.L. & Foster, C. (2011). Community wide interventions for increasing physical activity. *Cochrane Database of Systematic Reviews*, Issue 4. Art. No.: CD008366. DOI: 10.1002/14651858.CD008366.pub2.
- Banyule Nillumbik Primary Care Alliance, (2003). Consumer/carer participation project: The BNPCA consumer participation resource and training kit for service providers. Victoria: Banyule Nillumbik Primary Care Alliance
- Barrett, H. (2008). *Hard-to-reach families: engagement in the voluntary and community sector*, London: Family and Parenting Institute.
- Belanger, E., Rodriguez, C. & Groleau, D. (2011). Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliative Medicine*, 25, 242-61.
- Berwick, D.M., (2009). What 'patient-centered' should mean: confessions of an extremist. *Health Affairs*, doi 10.1377/hlthaff.28.4.w555
- Bishop, P. & Davis, G. (2002). Mapping public participation in policy choices. *Australian Journal of Public Administration*, 61: 14–29. <http://dx.doi.org/10.1111/1467-8500.00255>
- Bruce, N., Cordwell, L. & McBride, T. (2008). Models for engaging consumers and clinicians in policy: Evidence Check rapid reviews brokered by the Sax Institute for the Primary Health and Community Partnerships Unit, NSW: Department of Health.
- Bullock, H., Mountford, J. & Stanley, R. (2001). *Better policy-making*. London: Centre for Management and Policy Studies, Cabinet Office.
- Bunge, M., Muhlhauser, I. & Steckelberg, A. (2010). What constitutes evidence-based patient information? Overview of discussed criteria. *Patient Education & Counseling*, 78, 316-28.
- Cabana, M.D., Rand, C.S., Powe, N.R., Wu, A.W., Modena H. Wilson, M.H., Abboud, P.C. & Rubin, H.R. (1999). Why Don't Physicians Follow Clinical Practice Guidelines? *JAMA*. 282(15):1458-1465. <http://dx.doi.org/10.1001/jama.282.15.1458>.
- Caddy, J. (2001). *Citizens as partners: Information, consultation and public participation in policy making*. Paris: Organisation for Economic Cooperation and Development.
- Cancer Australia (2013). *Ways to involve consumers*. Cancer Australia. Retrieved from <http://consumerinvolvement.canceraustralia.gov.au/service-managers/ways-to-involve>
- Chappell, B. (2008). *Community engagement handbook: a model framework for leading practice in local government in South Australia*. South Australia: Government of South Australia and Local Government Association of South Australia.
- Clinical Excellence Commission.(2014) The Patient Based Care Challenge. NSW Health. Retrieved from <http://www.cec.health.nsw.gov.au/programs/partnering-with-patients/patient-based-care-challenge>
- Cohen, J. & Ezer, T. (2013). Human rights in patient care: A theoretical and practical framework. *Health and Human Rights Journal*, 15(2). Retrieved from <http://www.hhrjournal.org/2013/12/10/human-rights-in-patient-care-a-theoretical-and-practical-framework/>
- Commonwealth of Australia, (2005). National HIV/AIDS strategy: revitalising Australia's response 2005-2008. Canberra: Commonwealth of Australia

## Consumer Engagement in Central Victoria: A literature review

- Commonwealth of Australia. (2007). *Tackling wicked problems: a public policy perspective*. Canberra: Commonwealth of Australia
- Consumers' Health Forum of Australia. (2004). *A Model Framework for Consumer and Community Participation in Health and Medical Research*. Consumers' Health Forum of Australia. Retrieved from [http://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/r33.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/r33.pdf)
- Consumers' Health Forum of Australia. (2011). Media Release: Government decision on listing of medicines welcomed by health consumers. Consumers Health Forum of Australia. Retrieved from <https://www.chf.org.au/pdfs/med/med-PBS-deferrred-1.pdf>
- Cortis, N., Katz, I. & Patulny, R. (2009). *Engaging hard-to-reach families and children Stronger Families and Communities Strategy 2004–2009*, Occasional Paper No. 26 , Canberra: Commonwealth of Australia.
- Coulter, A. (2002). *The autonomous patient: ending paternalism in medical care*. London: Stationery Office (for the Nuffield Trust).
- Coulter, A., Edwards, A., Elwyn, G. & Thomson, R. (2011). Implementing shared decision making in the UK. *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, 105 (4), 300-304.
- Coulter, A. & Ellins, J. (2006). *Patient-Focused Interventions: A Review of the Evidence*. London: The Health Foundation.
- Coulter, A. & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *Br Med J*, 335: 24-27.
- Coulter, A., Parsons, S. & Askham, J.(2008). *Where are the patients in decision-making about their own care?*, Denmark: World Health Organization, on behalf of the European Observatory on Health Systems and Policies.
- Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, 325(7372):1263. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC136920/>
- Crawford, M., Rutter, D., Thelwall, S. (2003). *User involvement in change management: A review of the literature*. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). Retrieved from [http://www.nets.nihr.ac.uk/\\_\\_data/assets/pdf\\_file/0007/64339/FR-08-1201-018.pdf](http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0007/64339/FR-08-1201-018.pdf)
- Curtis, L. C., Wells, S. M., Penny, D. J., Ghose, S. S., Mistlerl, L. A., Mahone, I. H., Delphin-Rittmon, M., Del Vecchio, P. & Lesko, S. (2010). Pushing the envelope: shared decision making in mental health. *Psychiatric rehabilitation journal*, 34, 14-22. Retrieved from [http://planetreegrove.com/wp-content/uploads/2013/05/Pushing-the-Envelope\\_-SDM-in-Mental-Health.pdf](http://planetreegrove.com/wp-content/uploads/2013/05/Pushing-the-Envelope_-SDM-in-Mental-Health.pdf)
- Department of Environmental and Primary Industries. (2013). *Effective engagement*. State Government of Victoria. Retrieved from <http://www.dse.vic.gov.au/effective-engagement/introduction-to-engagement/what-is-community-engagement>
- Department of Human Services (2005). *Doing it with us not for us. Participation in your health service system 2006-09: Victorian consumers, carers, and the community working together with their health services and the Department of Health*. Melbourne: Victorian Government Department of Human Services. Retrieved from [http://health.vic.gov.au/consumer/downloads/do\\_it\\_with\\_us.pdf](http://health.vic.gov.au/consumer/downloads/do_it_with_us.pdf)
- Diclemente, R. J., Ruiz, M. S. & Sales, J. M. (2010). Barriers to adolescents' participation in HIV biomedical prevention research. *Journal of Acquired Immune Deficiency Syndromes*, 54, S12-S17.

- Dow, B., Haralambous, B., Bremner, F. & Fearn, M. (2006). *What is person-centred health care? A literature review: A report for the Department of Human Services as part of the Best Practice in Person-Centred Health Care for Older Victorians Project*. Melbourne: Victorian Government, Department of Human Services.
- Duffy, F.D., Gordon, G.H., Whelan, G., Cole-Kelly, K., Richard Frankel, R. et al. (2004). Assessing competence in communication and interpersonal skills: the Kalamazoo II report. *Acad Med*, 79(6), 495–507.
- Dukeshire, S & Thurlow, J. (2002). *Challenges and Barriers to Community Participation in Policy Development*. Nova Scotia: Rural Communities Impacting Policy
- Duncan, E., Best, C. & Hagen, S. (2010). Shared decision making interventions for people with mental health conditions. *Cochrane Database of Systematic Reviews*, Issue 1. Art. No.: CD007297. <http://dx.doi.org/10.1002/14651858.CD007297.pub2>
- Edwin, A. K., (2008). Don't lie but don't tell the whole truth: the therapeutic privilege – is it ever justified? *Ghana Medical Journal*, 42(4), 156-161
- Elkin, L. (2011). Breaking down barriers: the importance of Aboriginal consumer engagement. *Journal of Consumer Health Forum of Australia*, Issue 8. Retrieved from [https://www.chf.org.au/pdfs/chf/HV-JUNE2011\\_Elkin.pdf](https://www.chf.org.au/pdfs/chf/HV-JUNE2011_Elkin.pdf).
- Ennis, L., Rose, D., Callard, F., Denise, M. & Wykes, T. (2011). Rapid progress or lengthy process? electronic personal health records in mental health. *BMC Psychiatry*, 11:117. Retrieved from <http://www.biomedcentral.com/1471-244X/11/117>.
- Evans, D., Pilkington, P. & McEachran, M. (2010). Rhetoric or reality? A systematic review of the impact of participatory approaches by UK public health units on health and social outcomes. *Journal of Public Health*, 32(3), 418-426.
- Farrelly, S., Brown, G.E., Flach, C., Barley, E., Laugharne, R., Henderson, C. (2013). User-held personalised information for routine care of people with severe mental illness. *Cochrane Database of Systematic Reviews* 2013, Issue 10. Art. No.: CD001711. DOI: 10.1002/14651858.CD001711.pub2
- Fowler, F.J. (2012). *Shared Decision Making & Medical Costs*. Foundation Perspectives, Informed Medical Decisions Foundation. Retrieved from [http://informedmedicaldecisions.org/wp-content/uploads/2010/10/Perspectives\\_SDM-Cost\\_v2.pdf](http://informedmedicaldecisions.org/wp-content/uploads/2010/10/Perspectives_SDM-Cost_v2.pdf)
- Flanagan, S. & Hancock, B. (2010). Reaching the hard to reach, lessons learned from the VCS (voluntary and community sector). A qualitative study. *BMC Health Services Research*, p. 10:92.
- Flinders University. (2000). *Improving health services through consumer participation: A resource guide for organisations*. Department of Public Health, Flinders University and the South Australian Community Health Research Unit. Retrieved from <http://www.healthissuescentre.org.au/documents/items/2008/08/226533-upload-00001.pdf>
- Fudge, N., Wolfe, C. D. A. & McKeivitt, C. (2011). Assessing the promise of user involvement in health service development: ethnographic study. *BMJ*, Online first, <http://dx.doi.org/10.1136/bmj.39456.552257.BE>.
- Fritze, J., Williamson, L. & Wiseman, J. (2009). *Community Engagement and Climate Change: Benefits, Challenges and Strategies*. Melbourne: McCaughey Centre, VicHealth Centre for the Promotion of Mental Health and Community Wellbeing Melbourne School of Population Health, University of Melbourne In collaboration with the Victorian Council of Social Service and Council on the Ageing.

## Consumer Engagement in Central Victoria: A literature review

- Gillgren, C. (2005). *Embedding community participation in public sector culture and practice*. Western Australia: Citizens and Civics Unit, Department of Premier and Cabinet.
- Gottlieb, K.(2012). The Nuka System of Care: improving health through ownership and Relationships. *Int J Circumpolar Health* 2013, 72: 21118  
<http://dx.doi.org/10.3402/ijch.v72i0.21118>
- Government of South Australia. (2012). *Framework for Active Partnership with Consumers and the Community Policy Directive*. Adelaide: Government of South Australia.
- Green, J. & South, J. ( 2006 ) Key concepts for public health practice: evaluation. England: Open University Press.
- Gregory, J. (2008) *Engaging consumers in discussion about Australian health policy: Key themes emerging from the Australian Institute of Health Policy study - Discussion paper for the AIHPS National Citizen Engagement Forum*. Melbourne: Australian Institute of Health
- Health Issues Centre, (n.d.) Improving Consumer Participation. Retrieved from <http://healthissuescentre.org.au/health-services/consumer-engagement-guide/improving-participation/>
- Health Issues Centre. (2008). *A guide to enhancing consumer and carer participation in Victoria's Integrated Cancer Services*. Melbourne: Metropolitan Health and Aged Care Services Division, Victorian Government Department of Human Services.
- Health Issues Centre. (2014). Primary Health Network consumer engagement framework. Retrieved at <http://healthissuescentre.org.au/government-policy/projects/current-projects/primary-health-network-consumer-engagement-framework/>
- Health Consumers NSW (n.d.). Consumer representatives program. Sydney: NSW Ministry for Health.
- Health Consumers Queensland. (2012). *Consumer and community engagement framework*. Brisbane: Queensland Government.
- Heenan, F.(2009). Chronic conditions consumer journeys project: rural consumers' experiences of chronic conditions living in Portland & District. Victoria: Southern Grampians and Glenelg Primary Care Partnership.
- Hibbard, J. H. (2009). Using systematic measurement to target consumer activation strategies. *Medical Care Research and Review*, 66, 9S-27S. <http://dx.doi.org/10.1177/1077558708326969>
- Holmes, B. (2011). Citizens' engagement in policymaking and the design of public services, research paper no. 1, 2011–12. Canberra: Department of Parliamentary Services, Parliament of Australia.
- Institute for Patient and Family Centered Care (IPFCC). (n.d.) Advancing the practice of patient and family-centered care in primary care and other ambulatory settings. How to Get Started. Bethesda, USA: IPFCC.
- International Association for Public Participation. (2004). IAP2 Public participation spectrum. Australia: IAP2
- Israel, B.A., Schulz, A.J., Parker, E. A. & Becker, A. B. (1998) Review of community-based research: assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19:173-202.
- Keam, S. (2012), Consumer Engagement Part 1. *The Quarterly. Royal Australian College of Medical Administrators*. Retrieved from [http://racma.edu.au/index.php?option=com\\_content&view=article&id=530&Itemid=277](http://racma.edu.au/index.php?option=com_content&view=article&id=530&Itemid=277)

- Kennedy, A.P., Nelson, E., Reeves, D., Richardson, G., Roberts, C., Robinson, A., Rogers, A.E., Sculpher, M. & Thompson, D.G. (2004). A randomised controlled trial to assess the effectiveness and cost of a patient orientated self management approach to chronic inflammatory bowel disease', *Gut*, 53 (11), 1639-45.
- Kitzhaber, J. A. (1993). Prioritising health services in an era of limits: the Oregon experience. *British medical journal*, 307, 373-377.
- KPMG International. (2014). Creating new value with patients, carers and communities. Publication number:13122. KPMG International
- Lahdensuo, A. (1999). Guided self management of asthma - how to do it, *British Medical Journal*, 319, 759-760.
- Lasker, R. D., & Weiss, E. S. (2003). Broadening participation in community problem solving: A multidisciplinary model to support collaborative practice and research. *Journal of Urban Health*, 80(1), 14-47.
- Légaré, F., Stacey, D., Turcotte, S., Cossi, M., Kryworuchko, J., Graham, I.D., Lyddiatt, A., Politi, M.C., Thomson, R., Elwyn, G. & Donner-Banzhoff, N. (2014). Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database of Systematic Reviews*, Issue 9. Art. No.: CD006732. <http://dx.doi.org/10.1002/14651858.CD006732.pub3>
- Longtin, Y., Sax, H., Leape, L.L., Sheridan, S.E., Donaldson, L. & Pittet, D. (2010). Patient Participation: Current Knowledge and Applicability to Patient Safety. *Mayo Clinic*, 85(1), 53–62. <http://dx.doi.org/10.4065/mcp.2009.0248>
- Lord, J., Ochocka, J., Czarny, W. & Macliverty, H., (1998). Analysis of change within a mental health organisation: A participatory process. *Psychiatric Rehabilitation Journal*, 21(4), 1–33.
- Lorig, K., Sobel, D., Stewart, A., Brown, B., Bandura, A., Ritter, P., Gonzalez, V., Laurent, D. & Holman, H. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization – A randomised trial, *Medical Care*, 37(1), 5-14.
- Merzel, C. & D'Afflitti, J. (2003). Reconsidering community-based health promotion: promise, performance, and potential. *American Journal of Public Health*, 93(4):557-74.
- Nathan, S. (2004). Consumer participation: The challenges to achieving influence and equity. *Australian Journal of Primary Health*, 10(3), 15-20.
- National Aboriginal Community Controlled Health Organisation (NACCHO). (2012). Annual report 2011-2012. NACCHO.
- Moore, L. & Kirk, S.(2010). A literature review of children's and young people's participation in decisions relating to health care. *J Clin Nurs*, 19(15–16):2215–2225. Retrieved from <https://www.escholar.manchester.ac.uk/api/datastream?publicationPid=uk-ac-man-scw:83083&datastreamId=POST-PEER-REVIEW-PUBLISHERS.PDF>
- Mulley, A., Trimble, C. & Elwyn, G. (2012). Patients' Preferences Matter: stop the silent misdiagnosis. UK: King's Fund. . Retrieved from [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/patients-preferences-matter-may-2012.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/patients-preferences-matter-may-2012.pdf)
- National Collaborating Centre for Methods and Tools (2008). *Partnership Self-Assessment Tool*. Hamilton, ON: McMaster University. (Updated 27 April, 2010). Retrieved from <http://www.nccmt.ca/registry/view/eng/10.html>.
- National Resource Centre for Consumer Participation in Health (NRPPPH). (2002a). Methods of consumer participation: fact sheet no. 2. Canberra:NRCCPH

## Consumer Engagement in Central Victoria: A literature review

- NRCCPH. (2000). Feedback, participation and consumer diversity, a literature review. Canberra, Australia: Commonwealth of Australia
- NRCCPH. (2002b). Primary care self assessment tool for community and consumer participation. Canberra: NRCCPH
- National Health and Hospitals Reform Commission (NHHRC). (2009). *A Healthier Future for all Australians: Final report of the National Health and Hospitals Reform Commission*. Canberra: NHHRC.
- NHMRC. (2006). *Guide to effective participation of consumers and communities in developing and disseminating health information*, Canberra: Australian Government.
- National Health and Medical Research Council. (2006). *Guide to effective participation of consumers and communities in developing and disseminating health information*. Canberra: Australian Government. Retrieved from [http://www.nhmrc.gov.au/\\_files\\_nhmrc/media\\_releases/20110205/givepub.pdf](http://www.nhmrc.gov.au/_files_nhmrc/media_releases/20110205/givepub.pdf)
- NHS National Institute for Health and Clinical Excellence. (2008). *Quick reference guide: Community engagement*. London: NHS National Institute for Health and Clinical Excellence. Retrieved from [www.nice.org.uk/nicemedia/live/11929/39565/39565.pdf](http://www.nice.org.uk/nicemedia/live/11929/39565/39565.pdf).
- Nilsen, E.S., Myrhaug, H.T., Johansen, M., Oliver, S. & Oxman, A.D. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews*, Issue 3. Art. No.: CD004563. <http://dx.doi.org/10.1002/14651858.CD004563.pub2>
- O'Donnell, M., Parker, G., Proberts, M., Matthews, R., Fisher, D., Johnson, B., & Hadzi-Pavlovic, D. (1999). A study of client-focused case management and consumer advocacy: the Community and Consumer Service Project', *The Australian and New Zealand Journal of Psychiatry*, 33 (5), 684-93.
- Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., Gyte, G., A Oakley, A., & Stein, K. (2004). Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. *Health Technology Assessment*, 8(15): p. 1-148, III-IV.
- Omeni, E., Barnes, M., MacDonald, D., Crawford, M. & Rose, D. (2014). Service user involvement: impact and participation: a survey of service user and staff perspectives. *BMC Health Services Research*, 14:491. <http://dx.doi.org/10.1186/s12913-014-0491-7>
- Oshima Lee, E. & Emanuel, E.J. (2013) Shared Decision Making to Improve Care and Reduce Costs. *N Engl J Med*; 368, 6-8. <http://dx.doi.org/10.1056/NEJMp1209500>
- Onyx, J., Edwards, M. & Bullen, P. (2007). The intersection of social capital and power: An application to rural communities. *Rural Society*, 17(3), 215-230.
- Ostrom, E. (2000). Collective action and the evolution of social norms. *The Journal of Economic Perspectives*, 14(3), 137-158.
- Owen, D. & Ristovski, A. (2011). *The Guide to Consumer Engagement*. Tasmania: Advocacy Tasmania.
- Paediatric Integrated Cancer Service (2013). A toolkit for consumer participation and engagement. New Zealand: Paediatric Integrated Cancer Service and Australian and New Zealand Children's Haematology Oncology Group
- Pask, R. (2011). Getting the whole picture – consumer participation in health policy. *Health Voices, Journal of the Consumer Health Forum of Australia*, 9.
- Health Voices*.

- Pelzang, R. (2010). Time to learn: understanding patient-centred care. *British Journal of Nursing*, 19 (14), 912-917
- Preston, R., Waugh, H., Larkins, S. & Taylor, J. (2010). Community participation in rural primary health care: intervention or approach?, *Australian Journal of Primary Health*, 16(1) 4–16. <http://dx.doi.org/10.1071/PY09053>.
- Putland, C., Baum, F. & Macdougall, C., (1997). How can health bureaucracies consult effectively about their policies and practices?: some lessons from an Australian study. *Health promotion International*, 12 (4), 299-309.
- Queensland Department of Emergency Services. (2001). *Charter for community engagement*. Brisbane: Community Engagement Unit, Strategic and Executive Services, Queensland Department of Emergency Services.
- Queensland Government. (2011). Barriers to engagement with culturally and linguistically diverse communities. Queensland Government. Retrieved from <http://www.qld.gov.au/web/community-engagement/guides-factsheets/cald-communities/introduction/barriers.html>
- Repper, J. & Carter, T. (2010). *Using Personal Experience to Support Others With Similar Difficulties: A Review Of the Literature on Peer Support in Mental Health Services*. London: University of Nottingham. Retrieved from <http://www.togetheruk.org/wpcontent/uploads/downloads/2011/11/usingpersexperience.pdf>.
- Rise, M.B., Grimstad, H., Solbjør, M. & Steinsbekk, A. (2011). Effect of an institutional development plan for user participation on professionals' knowledge, practice, and attitudes. A controlled study. *BMC Health Serv Res*, 11(1):296.
- Rueben, D.B & Tinetti, M.E. (2012) Goal-oriented patient care — an alternative health outcomes paradigm. *N Engl J Med* ; 366, 777-779, DOI: 10.1056/NEJMp1113631
- Ryan, R., Santesso, N., Lowe, D., Hill, S., Grimshaw, J., Pictor, M., Kaufman, C., Cowie, G., Taylor, M. (2014). Interventions to improve safe and effective medicines use by consumers: an overview of systematic reviews. *Cochrane Database of Systematic Reviews* 2014, Issue 4. Art. No.: CD007768. <http://dx.doi.org/10.1002/14651858.CD007768.pub3>
- Sarrami-Foroushani, P., Travaglia, J., Debono' D.& Braithwaite' J. (2014). Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review\_ *BMC Health Services Research*, 14, 402 Retrieved from <http://www.biomedcentral.com/1472-6963/14/402>
- Sarrami Foroushani, P., Travaglia, J., Eikli, M., Braithwaite, J. (2012). Consumer and community engagement: *A review of the literature*. Centre for Clinical Governance Research, Australian Institute of Health Innovation, Faculty of Medicine, University of New South Wales, Sydney, NSW 2052 and the Agency for Clinical Innovation, New South Wales.
- Satterfield, D.W., Volansky, M., Caspersen, C.J., Engelgau, M.M., Bowman, B.A., Gregg, E.W., Geiss, L.S., Hosey, G.M., May, J., & Vinicor, F. (2003). Community-based lifestyle interventions to prevent type 2 diabetes. *Diabetes Care*, 26(9):2643-52.
- Scholl, I., Koelewijn-van Loon, M., Sepucha, K., Elwyn, G., France Légaré, F., Härter, M. & Dirmaier, J. (2011). Measurement of shared decision making - a review of instruments. *Zeitschrift fur Evidenz Fortbildung und Qualitat im Gesundheitswesen*, 105(4), 313-24.
- Schwappach, D.L.B. (2010). Engaging patients as vigilant partners in safety: A systematic review. *Med Care Res Rev*, 67(2):119-148.

## Consumer Engagement in Central Victoria: A literature review

- Simmons, M., Rice, S., Hetrick, S., Bailey, A. & Parker, A. (2012). Evidence Summary: Shared decision making for mental health – what is the evidence? Orygen Youth Health Research Centre
- South Australian Community Health Research Unit. (n.d.) Community participation evaluation tool. Retrieved from <http://som.flinders.edu.au/FUSA/SACHRU/Toolkit/PDF/1.pdf>
- Stacey, D., Légaré, F., Col, N.F., Bennett, C.L., Barry, M.J., Eden, K.B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Thomson, R., Trevena, L. & Wu, J.H.C. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, Issue 1. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub4
- State Government of Victoria. (2011). *Doing it with us not for us: Strategic direction 2010–13*. Melbourne: Department of Health, State Government of Victoria.
- Stewart, M.A. (1995). Effective physician-patient communication and health outcomes: a review. *Can Med Assoc J*, 152 (9): 1423-1433
- Swainston, K. & Summerbell, C. (2008). The effectiveness of community engagement approaches and methods for health promotion interventions. Rapid review phase 3, NICE National Collaborating Centre University of Teesside. Retrieved at [www.nice.org.uk/nicemedia/live/11929/44493/44493.pdf](http://www.nice.org.uk/nicemedia/live/11929/44493/44493.pdf).
- Tariman, J. D., Berry, D. L., Cochrane, B., Doorenbos, A. & Schepp, K. (2010). Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review. *Annals of Oncology*, 21, 1145-51.
- Tasmanian Government (n.d.) Rural and isolated communities: a guide to engagement. Tasmania: Department of Premier and Cabinet Tasmanian Government.
- Thomas, B.H., Fitzpatrick-Lewis, D., Rideout, L. & Muresan, J.W. (2008). What is the effectiveness of community-based/primary care interventions in reducing obesity among adults in the general population? Hamilton, Ontario: Effective Public Health Practice Project, McMaster University. Retrieved from [www.ephpp.ca/PDF/2008\\_PHAC%20ORR.pdf](http://www.ephpp.ca/PDF/2008_PHAC%20ORR.pdf).
- Victorian Auditor-General. (2012). Consumer Participation in the health system. Melbourne: Victorian State Government.
- Victorian Government Department of Sustainability and Environment. (2005). Effective Engagement: building relationships with community and other stakeholders: Book 1 an introduction to engagement. Melbourne: The Community Engagement Network
- Victorian Primary Care Partnership. (2012) Victorian service coordination practice manual 2012. Melbourne: Victorian State Government
- Will, J. F. (2011). A brief historical and theoretical perspective on patient autonomy and medical decision making: Part II: The autonomy model. *Chest*, 139, 1491-1497. Retrieved from <http://journal.publications.chestnet.org/article.aspx?articleid=1087975>
- Wilson, L. (2005). *Social exclusion and social capital in Northern Adelaide: The role of social networks in reproducing social inequity*. Paper presented at the Social Change in the 21st Century Conference, Carseldine, Australia.
- Wiseman, J. & Williamson, L. (2010) Community engagement and climate change: learning from recent Australian experience *International Journal of Climate Change Strategies and Management*, 2(2), 134-147

- World Health Organisation. (1978). Primary Health Care: report of the International Conference on Primary Health Care, Alma-Ata, U.S.S.R., 6-12 September, 1978. Geneva: W.H.O.
- Weingart, S., Pagovish, O., Sands, D., Li, J., Aronson, M., Davis, R., Bates, D. & Phillips, R. (2005). What can hospitalised patients tell us about adverse events? Learning from Patient Reported Incidents. *Journal of General Internal Medicine*, 20, 830 – 836. DOI: 10.1111/j.1525-1497.2005.0180.x.
- Weingart S, Zhu J, Chiappetta L, Stuver S, Schneider E, Epstein A, David-Kasdan J, Annas C, Fowler Jnr L & Weissman J. (2011). 'Hospitalised patients' participation and its impact on quality of care and patient safety' *International Journal for Quality in Health Care*, 23(3), 269 – 277.
- Yancey AK, Kumanyika SK, Ponce NA, McCarthy WJ, Fielding JE, Leslie JP, Akbar J. (2004). Population-based interventions engaging communities of color in healthy eating and active living: a review. *Preventing Chronic Disease*, 1(1), A09.

Appendix

<b>Method for consumer participation</b>	<b>Benefits of using the method</b>	<b>Drawbacks/difficulties experienced</b>	<b>Recommendations to improve the process</b>
Consumer satisfaction surveys	<ul style="list-style-type: none"> <li>•direct feedback</li> <li>•if worded correctly, outcomes can be measured</li> <li>•highlights problem areas</li> </ul>	<ul style="list-style-type: none"> <li>•responses only from those strongly positive or negative</li> <li>•random response</li> <li>•may not cover full scope of consumer concerns, gaps</li> <li>•survey hard to design well</li> <li>•literacy difficulties</li> <li>•people may not say what they really think in case they offend</li> <li>•limited to agenda set by organisation</li> </ul>	<ul style="list-style-type: none"> <li>•surveys should be done at the time of service delivery</li> <li>•good survey design is essential</li> <li>•survey needs to be in various languages</li> </ul>
Complaints mechanisms	<ul style="list-style-type: none"> <li>•essential</li> <li>•special incidents and can be easily identified and addressed</li> <li>•formal procedure</li> <li>•available to all</li> <li>•ensures organisation accountability</li> </ul>	<ul style="list-style-type: none"> <li>•people reluctant to give negative feedback in case it makes the situation worse or results in a reduction of services</li> <li>•people may be put off by the formality</li> <li>•difficult for consumers to find out how to complain through the system</li> <li>•minor complaints may go unnoticed</li> <li>•Requires staff understanding the value of complaints</li> </ul>	<ul style="list-style-type: none"> <li>•thank people for complaining and follow up promptly and effectively to the person's satisfaction</li> <li>•institute formal Quality Assurance mechanisms</li> </ul>
Public meetings	<ul style="list-style-type: none"> <li>•opportunity for anyone to attend and have their say</li> <li>•good media coverage for the issue/organisation</li> <li>•benefits for major issues</li> </ul>	<ul style="list-style-type: none"> <li>•poor attendance</li> <li>•issues re confidentiality in rural areas</li> <li>•risk of dominant individuals bias</li> <li>•difficult to obtain a cross section of people on specific issues</li> </ul>	<ul style="list-style-type: none"> <li>•Provide free food/creche/transport</li> <li>•consider venue and time of meeting</li> </ul>
Focus groups	<p>direct feedback results in rich information on people's ideas and feelings - difficult to get any other way</p>	<ul style="list-style-type: none"> <li>•poor attendance</li> <li>•issues re confidentiality in rural areas</li> <li>•lots of data to sort through</li> <li>•may not be representative of all consumers, carers or the community.</li> </ul>	<p>use independent facilitator</p>
Community representatives	<ul style="list-style-type: none"> <li>•there can be good cross section of views leading to</li> </ul>	<ul style="list-style-type: none"> <li>•time factor</li> <li>•a person may want to be involved for the 'wrong' reasons</li> </ul>	<ul style="list-style-type: none"> <li>•structured, regular training and orientation for representatives</li> </ul>

## Central Victorian Primary Care Partnership

on boards, management committees etc	<ul style="list-style-type: none"> <li>• healthy debate</li> <li>• gives an outside perspective</li> <li>• reality check for organisations</li> <li>• encourages accountability</li> <li>• keeps the community in touch</li> </ul>	<ul style="list-style-type: none"> <li>• difficult to keep representatives informed on complex issues</li> <li>• representatives have a long learning curve</li> <li>• drop off rate high, most too busy to attend</li> </ul>	<ul style="list-style-type: none"> <li>• the service must have realistic expectations of the representatives and their abilities</li> </ul>
Phone-in	<ul style="list-style-type: none"> <li>• anonymous</li> <li>• accessible</li> </ul>	very limited response for time and effort put in	only worth doing for 'hot' issues
Toll free information and referral	<ul style="list-style-type: none"> <li>• provides service to isolated communities</li> <li>• free</li> <li>• anonymous</li> </ul>	costly to advertise	
Direct consumer feedback at time of service	can act immediately	consumers may not be honest with concerns if they relate to the worker they speak to	follow up immediately or pass on to the manager if appropriate
Approach community groups	<ul style="list-style-type: none"> <li>• wide cross section reached, staff are personally involved</li> <li>• captures richer verbal feedback</li> </ul>	<ul style="list-style-type: none"> <li>• time intensive</li> <li>• not representative</li> <li>• difficult to give feedback to groups</li> </ul>	Local councils/community centres could assist with identifying relevant groups and targeting feedback

*Source: Table reproduced (with slight modification) from NRCCP in Health, 2002a [Originally adapted from: A guide to community participation, One Community - One purpose project, Riverland, 1997].*

The principle of consumer participation in the planning and implementation of health care is increasingly being recognised as critical to the development of health and social systems which promote the health and wellbeing of communities (NRCCPH, 2000). On an individual level, consumer participation allows individuals and their families to play an active role in their treatment and care planning, supporting shared decision making and self-management where appropriate. At a systemic level, engaging with consumers allows service improvements, through partnerships to enhance systems, processes, policies and models of care (Department of Human Services, 2005).