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***Consumer participation in health:  
Understanding consumers as social  
participants***

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**ISP Seminar Series**

**May 2011**

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## **Acknowledgements**

**This seminar is supported by the Institute for Social Participation at La Trobe University and Health Issues Centre.** For more information on this seminar contact Tenzin Bathgate [t.bathgate@latrobe.edu.au](mailto:t.bathgate@latrobe.edu.au)

**Institute for Social Participation: (ISP):** The Institute for Social Participation's primary role is to undertake research that provides new knowledge on social participation and influences policy and practice with the objective of facilitating 'inclusion'. [www.latrobe.edu.au/isp/](http://www.latrobe.edu.au/isp/)

**Health Issues Centre (HIC):** Health Issues Centre is an independent, not-for-profit organisation that promotes equity and consumer perspectives in the Australian health system; the mission of which is to improve health outcomes for Australians, especially those who are disadvantaged. [www.healthissuescentre.org.au/](http://www.healthissuescentre.org.au/)

Is it possible to define consumer participation in health as a type of social participation and a mechanism for social inclusion? This is one of a number of questions explored in this paper to identify the links between consumer participation in health and social participation.

The paper begins by exploring the definitions of the terms ‘consumer participation’ and ‘social participation’. It examines potential links between consumer participation in health and social participation and then proceeds to broader questions around consumer empowerment, social inclusion and the nature of the evidence-base for consumer participation in health. It concludes with a series of questions, which form a starting point for discussion.

This discussion paper is timely in the lead-up to the ‘Consumers Reforming Health’ conference being held in Melbourne in July 2011. Participation is one of the themes of the conference and conveners have invited discussion on ‘participation as a viable strategy to develop, maintain and better address consumer and community needs, allocate resources and develop health priorities, health services and programs, improve health outcomes and reduce costs’.

References that inform this discussion paper include:

- Brodie, E. et al. (2009). *Understanding participation: a literature review*. Institute for Volunteering Research, Involve, NCVO, United Kingdom.
- Hill, S. & Draper, M. (accepted 2011). Chapter 2: A new conceptual framework for advancing evidence-informed communication and participation in S. Hill (Ed.), *The Knowledgeable Patient: Communication and Participation in Health*. Wiley-Blackwell.
- Institute for Social Participation, La Trobe University (2009). *Social Participation: a contribution to understanding, research and policy*. Working Paper.
- Nilsen, E. et al. (2010) *Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. A Cochrane Review*. The Cochrane Collaboration 2010, Issue 1. John-Wiley and Sons.
- Victorian Department of Health (2009) ‘Doing it with us not for us’ policy (Victorian Government Department of Health 2009).<sup>1</sup>

## DEFINITIONS

**Defining consumer participation:** Consumer participation is a broad-ranging term that is defined in various health contexts. Horey and Hill (2005) describe the confusion in the meaning around consumer participation that “bedevils any attempts to think structurally and politically about improving the health system through participative and responsive means”.

<sup>1</sup> The ‘Doing it with us not for us’ policy defines participation as occurring: “when consumers, carers and community members are meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your views, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives”.

Hill and Draper (2011) point out that the common usage of the term consumer participation “to mean a lay member of a health service or policy committee has tended to dominate and obscure the other meanings of the term’ which describe consumer participation as ‘a social movement, or a strategy to re-orient the health system”.

In the United Kingdom, and increasingly in Europe, the term ‘patient and public involvement’ (PPI) has been preferred over ‘consumer participation’ in health. Tritter describes the term ‘consumer’ as particularly contested because of how individual consumerism is linked to patient choice using “the language of rights” (Tritter 2009).

Brodie et al. link the term participation to social and political context listing four dimensions of participation(2009): i) it involves individuals directly in decision making which is an important element of accountability in institutional democracy ii) it empowers communities and builds social cohesion iii) it aids reform in public services that can lead to both increased efficiency in service delivery and services better suited to people’s needs iv) it is associated with personal benefits for individual participants such as increased satisfaction and self-confidence that result from individuals being able to influence change.

Generally speaking consumer participation in health and social policy literature is discussed as part of:

- A human rights-based argument advocating consumer participation in health promoting the ‘primacy of the individual’(Tritter 2009). For instance the Australian Charter of Healthcare Rights states that consumers have the right to be included in decisions and choices about care (ACSQHC nd). Moreover, the World Health Organization (WHO) defines participation as a central element in its International Classification of Functioning, Disability and Health (ICF) (WHO 2010).
- Regulatory contexts for planning, evaluation and delivery of services. Tritter writes that in a regulatory context consumers “can be involved in the training and appointment of healthcare professionals and the generation of evidence (involvement in research)” (Tritter 2009).
- An implied patient-centred approach to healthcare. The Australian Commission on Safety and Quality in Healthcare states that a patient-centred approach is integral to quality improvement and safety standards and “is an innovative approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families” (Institute for Patient- and Family-Centred Care Website [www.ipfcc.org](http://www.ipfcc.org) cited in (ACSQHC 2010)).
- An emerging policy discussion in national and local governance that extends beyond healthcare and includes reference to allied concepts such as social participation, social inclusion/exclusion and social capital (Brodie, Cowling et al. 2009). In Australia this policy development has encompassed the establishment of the federal social inclusion policy agenda (Social Inclusion Board 2009).

Kirby et al. (Kirby, Lanyon et al. 2003) use the term ‘participation’ purposefully as an active verb. “We use the term participation not simply to mean ‘taking part’ or ‘being present’ but as having some influence over decisions and action. We also use the terms ‘involve’ (passive verb) and ‘participate’ (active verb) interchangeably” (Kirby et al. 2003). Moore writes that consumer participation “means any way in which consumers actively influence the healthcare system” (Moore 2006).

Hill and Draper (2011) offer a conceptual framework that allows flexibility in the definition of consumer participation that positions the overall aim of consumer participation under the umbrella of consumer empowerment. The authors identify communication and participation as essential to their overarching conceptual framework of consumer empowerment “that integrates the world of multi-directional communication, the world of social participation and knowledge drawn from evidence of experiences and evidence of effects”.

Hill and Draper describe four pillars of consumer empowerment and draw on two of these pillars (scientific method and democratic processes) for their proposed conceptual framework (see Table 1).

<b>Table 1: Four pillars of consumer empowerment</b>
<b>Conducting scientific/empirical research in order to improve quality of care and health outcomes</b>
<b>Supporting consumers through strengthening democratic processes in health systems including shared decision-making processes.</b>
<b>Contributing to informed consumer choice within health markets</b>
<b>Establishing and strengthening consumer health law and consumer rights mechanisms including informed consent and complaint mechanisms</b>

Other researchers have also proposed models that vary in their breadth, focus and theoretical underpinnings. For instance, Bruni et al. (2007) draw on a framework named ‘Accountability for reasonableness’ that provides an ethical framework for public involvement in health that “establishes a moral foundation for public involvement that enhances the legitimacy and fairness of priority setting” (Bruni, Laupacis et al. 2007). Tritter (2009) develops a conceptual model that proposes “a framework for differentiating the aim of involvement activities’ taking into account the degree of direct decision making that participants are delegated, the extent to which participants are acting as sole agents or as part of a group, community or population and the degree to which their participation is responding to a pre-existing agenda (reactive) or is helping to shape it (proactive)” (Tritter 2009).

**Defining social participation:** Hyppa et al. (2008) describes social participation as how an individual or group actively participates in societal activities within formal and informal groups. Social participation is defined by Brodie et al. (2009) as “collective activities that individuals may be involved in as part of their everyday lives”.

The term social participation is closely allied with social inclusion and social capital. A review of the refereed journals undertaken by the Institute for Social Participation for the preceding 10 years yielded articles primarily in the field of healthcare and disability in which the terms Social Participation, Social Inclusion, and Social Capital were often used interchangeably (Hooijdonk, Droomers et al. 2008; Hsieh 2008; Institute for Social Participation 2009a; Hernandez, Robson et al. 2010). For example, it is through social participation that individuals or groups achieve social inclusion. However the degree of social participation is impacted by the social capital of individuals. Social capital can be defined as the economic and social outcomes that individuals or groups contribute to and acquire through community involvement (Productivity Commission 2003) although it also more broadly refers to social links between individuals, communities, institutions, and government.

Drawing on a rights-based philosophy and a literature review (Institute for Social Participation 2009a) the recently formed Institute for Social Participation (ISP) at La Trobe University includes three components in its definition of social participation: “i) the individual’s human right to experience self-determined modes of engagement in all aspects of society, for instance work/health/education/relationships; ii) societal responsibility to provide conditions necessary for the above that enables people to experience self-determined modes of social engagement; iii) it includes reference to the concepts of Social Capital and Social Inclusion.”<sup>2</sup>

The Victorian Department of Health’s definition of participation in the ‘Doing it with us not for us’ policy links participation to consumer empowerment and specifically to consumer engagement in meaningful decision-making<sup>3</sup> which, like the ISP definition of social participation, has its origins in a rights based philosophy.

Peter Canavan (2004) also identifies these issues for Australian health consumers generally: “no matter what the specific focus in the health response, it is the passion of human rights and empowerment, and the fight for an equitable and supported place in the allocation of public services and resources which demands that all Australians be given that place”.

<sup>2</sup> ISP Minutes and Action Sheet, ISP Executive Meeting, 28 October 2009.

<sup>3</sup> In the ‘Doing it with us not for us’ policy ‘participation’ is defined in the following way: *Participation occurs when consumers, carers and community members are meaningfully involved in decision-making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your views, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives.*

## Linkage

The link between social participation and consumer participation is implicit and not always explicitly defined. For instance, participatory mechanisms for consumers in health services may be embedded in planning, monitoring and evaluation of services, promotion and support for self-determined healthcare decisions but not necessarily defined in terms such as 'social participation' and 'consumer engagement/consumer empowerment' (Hill & Draper 2011). There is both a lack of definition of individual terms, including the term 'participation' and interchangeable usage of terms allied to participation (Institute for Social Participation 2009a; Institute for Social Participation 2009b; Hernandez, Robson et al. 2010). The task of defining social participation is made more complicated because much of the literature concerning social participation is not necessarily framed as being about social participation (Brodie et al. 2009).<sup>4</sup>

Empowered consumers who engage directly with shaping health service provision, can be potentially categorised as social participants. Such consumers range from individuals advocating on their own behalf to more formalised entities of consumer participants operating under the umbrella of consumer advocacy groups. There are, however, significant groups of people who are not participants in their own health service delivery because they are not engaged in decision-making or are severely limited in decision-making.

The challenge for service providers is how to appropriately facilitate meaningful consumer participation in health, particularly for those groups that continue to be systematically 'excluded'. It is here that one finds the overlap between social exclusion and lack of social participation. A report by Vinson provided in the context of the Australian Government's social inclusion policy agenda, specified that the groups most likely to experience social exclusion are: Indigenous people, people with disabilities, single parents, youth and women in disadvantaged situations, older people, unpaid caregivers, gays, bisexuals, transgendered people, and culturally and linguistically diverse minorities who may be immigrants or refugees (Vinson 2009).

The capacity to participate also presupposes foundations of access, knowledge, information, understanding, confidence, agency, engagement and advocacy. Consumers, carers and community members from socially excluded backgrounds face a number of specific barriers in accessing healthcare and optimising health outcomes.

These include:

- a lack of understanding of consumer/patient rights and responsibilities
- a lack of familiarity with the health system; particularly relevant for recently arrived communities and refugees
- a lack of knowledge and confidence to engage in participation, planning, monitoring and decision-making activities,
- a lack of ability to challenge the quality of care received, participate in decision-making and or make complaints known to relevant health

<sup>4</sup> Brodie et al. (2009) contend that the literature on participation tends to provide an institutional/policy perspective.

authorities.

Brodie et al. (2009) have identified how “important questions regarding inclusion and inequality of resources arise when exploring those less likely to participate”. Social inclusion debates in Australia and overseas have specified that groups most likely to be socially excluded are those which have diminished access to civil, political and social rights and opportunities (Silver and Miller 2003; Vinson 2009). Research identifies that, at least in the UK, those most likely to publicly participate are affluent, older white, middle-class men (Brodie et al. 2009).

Much of the recent policy development around social inclusion in Australia and overseas is linked to discourse around citizenship and democracy. For instance, from a sociological point of view participation can be conceived as a hall mark of good democracy; contribute towards social cohesion; create more appropriate service delivery and produce more confident and engaged citizens (Brodie et al. 2009).

A focus on social exclusion is inherently linked to community cohesion and wellness. In this context health is not simply an absence of disease but a sense of wellbeing and social connectedness underpinned by infrastructure such as access to housing, education, transport and other necessities of social cohesion.

### **Issues of definition and coverage**

In the health domain Gregory (2007) uses the term ‘consumer engagement’ as opposed to ‘consumer participation’ and states that the terms ‘citizen engagement’ or ‘community engagement’ may better capture the intent of the work involved. Gregory also points out that the word ‘consumer’ “often encourages focus at the level of the individual health user” (2008) (see also Hill & Draper 2011).

Similarly, Brodie et al. (2009) points out that social participation literature has tended to focus on a single form of participatory activity without reference to the broader societal context in which it takes place, such as inequality in resource distribution. On the basis of available literature Brodie et al. ascertain that “broadly speaking, many participatory activities are to some extent dominated by the well-resourced and that to understand participation more fully it is therefore necessary to look at individuals and their participatory activities not in isolation but in the wider context of their lives and communities - or indeed explore why some choose not to engage or are prevented from participating” (Brodie et al. 2009, p.16).

The former National Resource Centre for Consumer Participation in Health (NCPH) advocated that “at a philosophical level, there is a need to balance the view of the consumer as an individualised economic actor with a social model of clients as social agents acting within a family and community context” (NRCCPH 2002). The NRCCPH points to the example of the Coordinated Care Trials where the clients (people with complex health needs who required service provision for a long period of time) were treated in the



research design as “atomised individuals, rather than as members of families and communities” (NRCCPH 2008).<sup>5</sup>

### EVIDENTIAL ISSUES

Horey and Hill (2005) make the point that more effective consumer participation also requires an evidence base for consumer participation, knowledge-building and iterative research. The NRCCPH (2008) identifies the importance of a number of evidence-based research frameworks and advocates:

- employing evidence-based models of consumer participation in research
- evaluation of consumer participation based on evidence

Scientific approaches (such as evidence-based healthcare and systematic reviews) are also central to the consumer empowerment conceptual framework proposed by Hill and Draper (2011). More broadly the NRCCPH advocate i) communication and dissemination of consumer participation research and practice and ii) using research methods and techniques that are participatory and that include researchers as part of the research team. Hill and Draper (2011) extend this platform by pointing out the need for institutional commitment to implementing the findings of evidence-based research. As a member of Cancer Voices Victoria has pointed out the “term ‘research participant’ is yet to reach its full participatory potential” (Roos 2007).

One of the barriers in evaluating the concept of patient-centred or consumer-centred healthcare is the lack of standardised indicators across service providers and jurisdictions, “making the necessary comparisons and benchmarking needed to improve service delivery difficult” (ACSQHC 2010). Margaret Wohlers advocates the need for outcome indicators which “encompass evidence of shared decision-making and collaboration” and the need for evaluation indicators “to reflect the individual nature of each activity or program” (2002). In contrast to ACSQHC’s assessment, mentioned earlier, she does not identify a standard set of indicators.

The development of robust indicators can address the broader issue of identifying social context but more refinement is necessary. In the area of social participation research Richard et al. write that while “there is a wealth of data on personal and interpersonal correlates of social participation, very few studies have investigated the possible role of resources available in the community environment” (Richards, Gosselin et al. 2008). A large-scale Swedish study which investigated social participation and coronary heart disease, reflects a move towards focusing on personal and interpersonal correlates of social participation (Sundquist, Lindstrom et al. 2004).

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<sup>5</sup> The Australian Institute for Patient-and Family-Centred care advocates that *family-centred care should become the norm across the health care system* Crock, C. (2008). Patient and family centred care in Australia. How to design a respectful, ethical healthcare system that is people and family centred, invites the public to have and equal voice and improves quality, safety and cost effectiveness. Submission to NHMRC.

In the domain of social exclusion significant work is underway in Europe and the UK to identify social inclusion indicators – and Australia is following suit. The levels and kinds of consumer participation in health is both a potential indicator of inclusion/exclusion. The development of robust social inclusion indicators are potentially of assistance in strengthening the evidence base for evaluating both consumer participation in health and social participation generally.

One of the most comprehensive projects in recent years for measuring social inclusion was undertaken by the National Coordinating Centre for Health Technology Assessment (NCCHTA) on behalf of the Department of Health (United Kingdom). The key aim of the NCCHTA review was to develop an instrument to measure social inclusion. The authors did not find any “single, tested and sound measure of social inclusion that is an accepted standard measure”. Moreover, rigorous measures of psychometric properties appear to be very limited (Huxley, Evans et al. 2006). An article by Dalemans et al. highlights the limitations of current instruments for measuring social participation for particular health groups (Dalesman, de Witte et al. 2008). Work is under way, however, in individual fields to develop measures (Secker, Hacking et al. 2009).

The European Union (EU) has adopted a set of commonly agreed and defined indicators to assist the monitoring of member states in promoting social inclusion (Vinson 2009). Under the Australian Government’s Social Inclusion policy agenda a compendium of social inclusion indicators has been drawn from these EU indicators, with additional supplementary indicators. These indicators fall under seven broad headings (Australian Government 2009).

- Poverty and low income
- Lack of access to the job market
- Limited social supports and networks
- Effects of the local neighbourhood
- Exclusion from services
- Health
- Contextual (health and social expenditure)

The road to a robust evidence base for evaluating participation has some way to go. Preston et al. point out that while community participation in health is popular in policy it is not matched by an “equivalent commitment to measuring the outcomes of community participation” (Preston, Waugh et al. 2010).

A recent Cochrane review (Nilsen, Myrhaug et al. 2010) found that there was little evidence from the highest ranking levels of evidence – randomised control trials (RCTs) – of the effects of consumer involvement in healthcare decisions at the population level. The authors identified that RCTs can potentially provide such evidence.

A study surveying 689 empirical studies conducted by Preston et al., which examined rural community participation and health outcomes, found evidence of beneficial health outcomes and increased uptake of services as a

consequence of community participation (Preston, Waugh et al. 2010). Given the lack of good quality higher level studies in this survey the authors concluded that “further attention to the analysis and reporting of the community participation aspect of primary healthcare and public health interventions is warranted, as absence of evidence of an effect is not the same as absence of an effect” (Preston et al. 2010).

Gregory has pointed to the surfeit of literature discussing the importance of consumer engagement in health policy, and, by contrast, the lack of evaluation of consumer engagement outcomes in health policy. She sums up that: “The field remains under-theorised, with a lack of case studies that demonstrate both successes and failures in engagement and outline the planning processes involved. Much of the current literature provides either broad theoretical discussions about the value of engagement, or ‘how to’ approaches that are designed to guide planning but offer little suggestion about how to make decisions about the trade-offs raised “ (Gregory 2007).

## **KEY QUESTIONS ARISING FROM DISCUSSION PAPER**

The following questions, drawn from this paper, concern the interface between consumer participation/social participation/social exclusion and clarifying the role of research in consumer participation in health. The underlying aim of these questions is to identify whether social participation is a useful concept in understanding consumer participation in health and how to define the consumers of most concern – those mostly likely to be excluded from participation in health. For instance, what are the consequences of not differentiating between consumers when examining consumer participation in health? Which consumers are invited to participate in health matters, what population groups are included and what population groups are absent, and for what purpose? What are the structures and processes that facilitate consumer participation and what is the evidence for evaluating consumer participation?

**1) Is social participation a useful concept for interrogating consumer participation in health? If so why? If not, why not?**

**2) Who participates? How can groups or individuals participate in health systems that have systematically excluded them?**

**3) Participation in what? What does participation mean in practice for excluded population groups? What spaces are different population groups invited to participate in?**

**4) How do we know if we are having the effects we seek? Given that the impact of participation is highly context specific how should the impact of consumer participation be evaluated?**

**5) What role can a university community play in advancing consumer participation in health?**

## REFERENCES

- ACSQHC (2010). Patient-centred care: improving quality and safety by focusing care on patients and consumers. Discussion paper. Draft for public consultation. ACSQHC. Sydney, ACSQHC: 1-81.
- ACSQHC (nd). Australian Charter of Healthcare Rights. ACSQHC: 1.
- Australian Government (2009). Social Inclusion. A compendium of social inclusion indicators. How's Australia fairing? Canberra.
- Brodie, E., E. Cowling, et al. (2009). Understanding participation: A literature review.
- Bruni, R. A., A. Laupacis, et al. (2007). "Public involvement in the priority setting activities of a wait time management initiative: a qualitative case study." BMC Health Services Branch 7(186).
- Canavan, P. (2004). "Because it's personal: What good advocacy can achieve and how." The Australian Health Consumer 1(2003-2004).
- Crock, C. (2008). Patient and family centred care in Australia. How to design a respectful, ethical healthcare system that is people and family centred, invites the public to have and equal voice and improves quality, safety and cost effectiveness. Submission to NHMRC.
- Dalesman, R., L. de Witte, et al. (2008). "Measures for rating social participation in people with aphasia: a systematic review." Clinical Rehabilitation 22: 542-555.
- Gregory, J. (2007). Conceptualising consumer engagement: a review of the literature. Consumer engagement in Australian health policy: Investigating current approaches and developing new models for more effective consumer participation. Melbourne, Australian Institute of Health Policy Studies: 1-63.
- Gregory, J. (2007). "A framework of consumer engagement in Australian health policy." HIC(91): 22-27.
- Gregory, J. (2008). Consumer engagement in Australian health policy: Final report of the AIHPS research project. Consumer engagement in Australian health policy: Investigating current approaches and developing new models for more effective consumer participation. A. I. o. H. P. Studies. Melbourne, Australian Insitute for Health Policy Studies.
- Hernandez, L., P. Robson, et al. (2010). "Towards Integrated Participation: Involving Seldom Heard Users of Social Care Services." British Journal of Social Work 40: 714-736.
- Hill, S. and M. Draper (2011). Chapter 2: A new conceptual framework for advancing evidence-informed communication and participation in Hill, S. (ed) The Knowledgeable Patient: Communication and Participation in Health. In press., Wiley Blackwell.
- Hooijdonk, C. V., M. Droomers, et al. (2008). "The diversity in associations between community social capital and health per health outcome, population group and location studied." Journal of Epidemiology 37: 1384-1392.

Horey, D. and S. Hill (2005). Engaging consumers in health policy. 3rd Health Policy Roundtable. Canberra: 10.

Hsieh, C.-H. (2008). "A Concept Analysis of Social Capital Within a Health Context." Nursing Forum 11(6): 699-707.

Huxley, P., S. Evans, et al. (2006). Development of a 'Social Inclusion Index' to capture subjective and objective domains (Phase 1). Final report to the NCCRM. United Kingdom. RM04/JH27.

Hyppa, M., J. Maki, et al. (2008). "Long-term stability of social participation." Social Indicator Research 88: 389-396.

Institute for Social Participation (2009a). Social Participation: a contribution to understanding, research and policy. Working Paper. Melbourne, La Trobe University: 35.

Institute for Social Participation (2009b). Minutes and Action Sheet. ISP Executive Meeting. Melbourne, La Trobe University: 1-2.

Kirby, P., C. Lanyon, et al. (2003). Building a culture of participation. Involving children and young people in policy, service planning, delivery and evaluation. N. C. Bureau and P. R. Consultancy. London, Department for Education and Skills: 1-68.

Moore, K. (2006). "Consumer participation: A personal reflections." Health Issues(89): 4.

Nilsen, E., H. Myrhaug, et al. (2010). "Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. ." Cochrane Database of Systematic Reviews.(1).

NRCCPH (2002). Consumer participation in Australian Primary Care: A literature review.

NRCCPH (2008). An introduction to participation in health. Information series H. I. Centre, The National Resource Centre for Consumer Participation in Health: 1-5.

NRCCPH (2008). Key resources in participation in health. Information Series H. I. Centre, The National Resource Centre for Consumer Participation in Health: 1-5.

Preston, R., H. Waugh, et al. (2010). "Community participation in rural primary health care." Australian Journal of Primary Health 16: 4-16.

Productivity Commission (2003). Social Capital: Reviewing the Concept and Its Policy Implications. P. Commission. Canberra.

Richards, L., C. Gosselin, et al. (2008). "Staying connected: neighbourhood correlates of social participation among older adults living in an urban environment in Monteval, Quebec." Health Promotion International 24(1): 46-57.

Roos, I. (2007). "One Swallow doth not a Summer Make: What Does it Mean to Consult Consumers? ." Health Issues(94): 9-11.

Secker, J., S. Hacking, et al. (2009). "Development of a measure of social inclusion for arts and mental health project participants." Journal of Mental Health 18(1): 65-72.

Silver, H. and S. M. Miller (2003). "Social Exclusion. The European Approach to Disadvantage." Indicators 2(2): pp. xx-xx.

Social Inclusion Board (2009). Australian Social Inclusion Board (2008), Outcomes of the meeting of the Board on 2 April, 2009

Sundquist, K., L. Lindstrom, et al. (2004). "Social participation and coronary heart disease: a follow-up study of 6900 women and men in Sweden." Social Science & Medicine 58: 615-622.

Tritter, J. Q. (2009). "Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world." Health Expectations 12: 275-287.

Victorian Government Department of Health (2009). Doing it with us not for us. Strategic direction 2010-13. Participation in your health service system: Victorian consumers, carers, and community working together with their health services and the Department of Health. R. a. R. H. a. A. C. S. Division. Melbourne.

Vinson, T. (2009). Social Inclusion. The origins, meaning, definition and economic implications of the concept of social inclusion/exclusion., Commonwealth of Australia.

WHO (2010). "International Classification of Functioning, Disability and Health (ICF)." Classifications. Retrieved 29 November, 2010, from <http://www.who.int/classifications/icf/en/>.

Wohlers, M. (2002). "Developing evaluation indicators for consumer and community participation." Health Issues(72): 24-29.