



Models for engaging consumers and clinicians in policy: rapid reviews

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An **Evidence Check** Review
brokered by the Sax Institute for the
NSW Department of Health

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Suggested Citation:

Bruce, N., Cordwell, L., McBride, T. Models for engaging consumers and clinicians in policy: *Evidence Check* rapid reviews brokered by the Sax Institute (<http://www.saxinstitute.org.au>) for the Primary Health and Community Partnerships Unit, NSW Department of Health; (2008).

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1

Community participation tools: engaging consumers in health decision-making effectively

Review Question 1:

What community participation tools are currently being used by health systems in other states and countries? Have these been evaluated? If so, have these tools been shown to be effective in engaging consumers in health decision-making?

EXECUTIVE SUMMARY

This literature review was conducted by Health Issues Centre for the Sax Institute. It aimed to answer three questions:

1. What community participation tools are currently being used by health systems in other states and countries?
2. Have these been evaluated?
3. If so, have these tools been shown to be effective in engaging consumers in health decision-making?

This review identified a moderate level of documented studies and projects that had used community participation tools to engage communities and consumers. The review found that community participation tools being used by health systems at five key levels: individual care and treatment; ward/program; organisation; government; and community.

Individual level

At the level of individual care and treatment, common tools focused on enabling consumers to be involved in decision-making processes. Tools identified included a question prompt list, information packages, chronic disease self-management groups, and shared decision-making tools. The majority of these tools have been evaluated and findings suggest that when they are implemented appropriately they are able to engage consumers in decision-making processes.

Ward and program level

Community participation tools used by health services at the ward and program level focused on seeking feedback from consumers on possible improvements or on involving consumers in planning processes. This type of involvement usually occurred through the involvement of consumers on committees and reference groups. Several tools that are used at a ward and program level have been evaluated by internal evaluators. The evaluations revealed that 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. The review identified one project that had documented the health and wellbeing benefits to consumers from their participation.

Organisational level

The review identified an increasing number of community participation tools that are being applied by health services to engage consumers at an organisational level. Common tools focused on consulting with consumers and communities and seeking the input of consumers and community members for planning or reforms. Community advisory committees and community councils were common tools for engaging consumers at an organisational level. Evaluations of these tools are minimal, but when

conducted they generally reveal that the tools produce more benefits for health services than individual consumers.

Department of Health level

At the government, and particularly health department level, participation tools are being applied to consult and engage with consumers and communities. Legislation, policy and resources are also being created to guide the implementation of consumer and community participation. Evaluations of consumer and community participation tools at the government level are minimal and ad-hoc.

Community level

At a community level, common tools used to engage consumers and communities include citizen juries, interviews, surveys and focus groups, with all methods seemingly identifying useful data to inform future health planning. Also at the community level, public forums and advocacy initiatives are being implemented to enable communities and consumers to contribute towards improving the health and wellbeing of their community.

Key findings

In summary, the key findings of this review were that:

- There is a need for more rigorous and independent evaluations of community participation tools to improve knowledge of what tools are effective in engaging consumers in health decision-making.
- Documented examples of consumer and community participation in health are patchy and ad hoc with most projects and studies using descriptive methods to report finding rather than using impact and outcome evaluations.
- There is strong evidence on the effectiveness of interventions at the individual level of care, which enable individual consumers and their carers to be involved in decision-making processes. However, the evidence on the effectiveness of consumer involvement at the ward/program, organisation and government level is less convincing.
- There are a small number of examples where consultations have been conducted with communities and consumers on the key priorities of health care. These have generally produced useful data and conclude that consumers want to have a say in decision-making with regard to priority setting, medical treatments and resource allocation.
- Community advisory committees (CACs) and reference committees are common tools used by health services to engage with its community. These examples suggest that consumers involved in CACs are able to have input into the programs and services and are valued by services. However, the

impact of the consumer contribution has not been systematically evaluated and is at risk of being tokenistic.

- State health departments are involved in developing legislation, policy and guidelines to support consumer and community engagement. This work is driving the consumer and community participation reforms in the health services.

SEARCH STRATEGY

Key questions explored

This review seeks to answer the following three questions:

- What community participation tools are currently being used by health systems in other states and countries?
- Have these been evaluated? If so, have these tools been shown to be effective in engaging consumers in health decision-making?

Search strategy

This review was conducted between January and February 2008. It examined relevant Australian and international studies that relate to consumer and community participation in health that were published following 2000. This review was not intended to be systematic but instead aimed to provide an account of the state of the evidence related to the question.

The search strategy had several stages:

1. Stage one focused on reviewing *Health Issues* Journal and the Cochrane Collaboration, including Health Knowledge Network Reviews.
2. Stage two focused on reviewing studies and materials available on Department of Health sites for each Australian state, well-known research centres and peak health bodies in Australia.
3. Stage three focused on the formal search of journals and databases. Academic databases were searched using the following key terms: 'consumer participation', 'community participation', 'community engagement', 'evaluation and community participation', 'evaluation and consumer participation', 'patient participation', 'patient involvement and health', 'community advisory committees and health', 'patient information, community consultation and health', 'participation strategies', 'participation tools'. Databases searched included Medline, Pub Med, Ovid. Journals searched included the Australian and New Zealand Journal of Public Health and *Health Issues* Journal.
4. The final stage involved a search of relevant international organisations including Picker Foundation, WHO and INVOLVE.

Literature review limitations

A number of limitations to the literature review exist:

1. The extensive literature on consumer participation—much of which does not appear on indexed databases—is dispersed across a wide range of publication types.

2. There are few evaluations of community participation tools. Evaluations that do exist are mainly process evaluations.
3. The review predominately focuses on engagement in service planning, policy development and organisational issues. However, a brief review of the literature on community participation at the individual care level was conducted.
4. The review predominately includes Australian studies; however, relevant international studies have been included.
5. Time constraints and the restrictions on the scope of the review.

Definitions

When searching, this review used the following definitions developed by the Victorian Department of Human Services:

- **Consumers** are people who are current or in some contexts potential users of health services.
- **Carers** are family and friends providing unpaid care to consumers.
- **Communities** are groups of citizens who have interests in the development of an accessible, effective and efficient health and aged care service that best meets their needs.
- **Representatives** are consumer, carer or community members who are nominated by and accountable to an organisation of consumers, carers or community members.
- **Nominee** is the term used to describe somebody who is not an exclusive representative or has special links with a particular group or groups (Department of Human Services, 2006b).

LITERATURE REVIEW

Consumer and community participation

This review uses the definition of participation developed by the Victorian Department of Human Services:

Participation occurs when consumers, carers and community members are meaningfully involved in decision-making about health policy and planning, care and treatment, the wellbeing of themselves and the community. (Department of Human Services, 2006b)

Community participation is not a new concept and its origins can be traced to the social movements of the 1960s, when feminism and environmental movements advocated the involvement of citizens in decision-making processes (Carter & O'Connor, 2003). With respect to consumer involvement in health, the World Health Organization's Declaration of Alma Ata identified the active involvement of communities in health care as a key tenet in achieving health for all (World Health Organization, 1978).

Rationales for community participation in health are broad, with participation identified as an essential principle of:

- health development
- community capacity building
- development of social capital (DHS, 2006, p.5).

Participation is also seen as 'an aid to improving health outcomes and the quality of health care; as an important democratic right; and as a mechanism to ensure accountability' (DHS, 2006, p.5).

Within health systems, community participation occurs at a range of levels: individual, ward/program, health service, department of health (Department of Human Services, 2006b) and for a range of purposes: information, consultation, partnership, decision-making and control (Arnstein, 1969).

The findings of the literature review are presented according to the level of the health system in which they are implemented. The main levels at which community participation tools were being used included:

- Individual care level
- Ward/program level
- Organisation level
- Government, predominately the health department level
- Community level

The community participation tools identified by this review are listed in Table 1. The tools that were identified through this review as being evaluated are highlighted.

Table 1: Community participation tools

LEVELS	EVALUATION
Individual	
Question prompt list	<input checked="" type="checkbox"/>
Information package	-
Shared decision-making	<input checked="" type="checkbox"/>
Chronic Disease Self-Management	<input checked="" type="checkbox"/>
Ward/program	
Development of patient information	<input checked="" type="checkbox"/>
Consumers and carers as partners with providers for program planning and evaluation	<input checked="" type="checkbox"/>
Consumers on committees	<input checked="" type="checkbox"/>
Consumer Reference Group	<input checked="" type="checkbox"/>
Organisation	
Consumers participate in providing feedback and complaints management	<input checked="" type="checkbox"/>
Consumers and carers as partners with providers for service planning and delivery	-
Community Advisory Committees	<input checked="" type="checkbox"/>
Health Community Councils	-
Staff training on consumer participation	-
Consumers involved in staff selection	<input checked="" type="checkbox"/>
Health Promotion Planning	-
Government	
Consultations on policy and practice	-
Legislation	-
Quality of Care Reports	-
Consumer Participation Policy	-
Consumer participation training	-
Community	
Citizen juries	<input checked="" type="checkbox"/>
Focus groups	<input checked="" type="checkbox"/>
Questionnaire	<input checked="" type="checkbox"/>
Telephone survey	-
Interviews	-
Advocacy	-
Patient and public forums	<input checked="" type="checkbox"/>
Consumer training	-
Consumer Representation Programs	-

Evaluation

Evaluations are generally conducted to review the process of implementing an initiative, its impacts and any outcomes it may have had (Hawe, 1991). This review identified that evaluations of consumer and community participation initiatives are generally ad hoc and internal. This finding is supported by Gregory, who undertook a review of consumer participation for the Australian Institute of Health Policy Studies (Gregory, 2007).

In her review, Gregory claimed that when evaluations of community engagement are conducted they are often descriptive, with very few evaluations exploring impact and outcome measures. Le Gates and Stout also discussed the barriers to such evaluations, claiming that current descriptive evaluation processes are flawed as they provide no indication as to whether consumers or community members have been able to contribute to decision-making (LeGates & Stout, 2003).

This review has aimed to include community participation tools and strategies that have been evaluated and to examine their impacts on consumers, communities and health services.

Participation at the Individual level

This section of the review includes studies and projects that have implemented community and consumer participation at the individual level.

Participation at the level of individual care aims to enable consumers and their families or carers to participate in decisions about their own care and treatment. Approaches to consumer participation generally involve information provision and support, to enable consumers to make informed decisions. Participation tools are often available to consumers through a health provider; however, in some cases—as with cancer—tools can be obtained through peak bodies and consumer organisations.

This review identified a moderate number of tools that have been used to engage consumers at the individual level of care.

Information – Question prompt lists

The Cochrane Collaboration has undertaken a number of reviews examining the effectiveness of consumer participation tools at the level of care and treatment (Lewin SA., Skea ZC., Entwistle V., Zwarenstein M., & Dick J., 2001; O'Connor AM. et al., 2001).

One Cochrane systematic review undertaken by Kinnersley et al. (2007) assessed the effects of interventions delivered to patients prior to consultations. Interventions included in the review were written materials, coaching, audiotaping of consultation, coaching plus written materials, coaching plus computer program and coaching plus

written materials plus video. The review found that interventions which assist people to address their information needs in consultations increased the number of questions asked during the consultation, and may increase patient participation in the consultation and improve patient satisfaction (Kinnersley et al., 2007).

One researcher, Phyliss Buttow, has undertaken several studies to examine the impact of consumer involvement in the use of question prompt lists and shared decision-making. For example, an evaluation of a cancer consultation preparation package was undertaken in New South Wales with 164 cancer patients (Buttow et al., 2004). Patients were randomly assigned to receive a cancer consultation preparation package (CCPP) or to a control group 48 hours before their first oncology appointment. The package contained a questions prompt sheet, booklets on clinical decision-making and patient rights, and an introduction to the clinic (Buttow et al., 2004). The evaluation concluded that patients who received the CCPP asked significantly more questions, tended to interrupt the physician more, and challenged the information more often.

Similar results were also found in a study involving 65 female cancer patients who were randomised to receive either a package (booklet and 15-minute video) designed to facilitate shared decision-making, or a booklet on living with cancer. The study found that patients receiving the package were more likely to declare to their oncologist, their preferences for information and treatment and their perspectives on the costs, side-effects and benefits of treatment. The study found that doctors introduced considerably more new themes in the consultation with the intervention subjects than they did with the controls (Brown et al., 2004).

Shared decision-making

Another study conducted in Australia by similar authors examined the effect of shared decision-making for consumers and their carers. The study by (Gattellari, Butow, & Tattersall, 2001), evaluated the impact of shared decision-making and the achievement of preferred role on patient anxiety, recall of information, and satisfaction. Their findings were that patients who reported a role in shared decision-making were most satisfied with the consultation and with the information about treatment and emotional support received (Gattellari et al., 2001).

Advanced care planning

Creating mechanisms to promote consumer involvement in decision-making for end-of-life care has led to health services offering advanced care planning. Advanced care planning is a process whereby individuals are able to make decisions about their end-of-life care including the types of treatment, levels of intervention and individuals responsible for making decisions. An impact evaluation of the program concluded that advanced care planning has made a significant impact on the amount of involvement consumers are having in regard to their future care (Austin Health, 2006). There is evidence that as a result of advanced care planning individuals are receiving health care in their place of choice and are avoiding receiving unwanted and often burdensome treatments (Austin Health, 2006).

Chronic disease self-management programs

Within the past 10 years, chronic disease self-management programs have emerged as an intervention to enable patients to receive information about their condition and develop appropriate skills to manage their condition. A recent Cochrane review found that lay-level self-management interventions, compared with usual care, for people with chronic conditions may, in the short term, improve participants' self-efficacy, self-rated health and use of cognitive symptom management techniques, leading to a reduction in health stress (Foster G., Taylor SJC., Eldridge SE., Ramsay J., & Griffiths CJ., 2007).

One such chronic disease self-management program is the Expert Patients Programme, an initiative of the United Kingdom Department of Health. It is a lay-led self-management program that aims to support people to increase their confidence, improve their quality of life and better manage their chronic condition. Training and information is a key component of the program.

http://www.dh.gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/DH_4102757

The findings of an internal evaluation of the Expert Patient Programme are included on the Department of Health's website. The findings suggest that, of the individuals that had completed the program:

- 45% felt more confident that they would not let common symptoms interfere with their lives
- 38% felt symptoms were less severe for four to six months after completing the course
- 33% felt better prepared for consultations with health professionals.

An independent evaluation of this program is currently being conducted and the findings will be significant as Effing et al., 2003, suggested there is still insufficient evidence to formulate clear recommendations regarding the form and contents of self-management education programs for chronic obstructive pulmonary disease.

Participation at Ward/Program level

Community participation at the ward or program level has emerged in the past 10 years as a common approach for quality improvement as well as a mechanism for ensuring programs and services are meeting the needs of consumers and carers.

In this section, community participation tools that have been implemented at the ward and program level are presented. The review found that the main rationale for involving consumers and community members at this level was for the development of patient information and to have input into program planning and evaluation. The examples presented have all been evaluated.

Development of patient information

Involving consumers in the development of written patient information has been identified by a Cochrane review as leading to more effective information (Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006). The review found that involving consumers in the development of patient information material led to products that were more relevant, easier to read and more understandable to patients, without any corresponding increase in anxiety. A small study to examine consumer involvement in the development of patient information conducted by Health Issues Centre (Health Issues Centre, 2006a) supported this finding. The study suggested that consumer involvement in the development of material was an important factor in the overall quality of material.

The Royal Women's Hospital in Victoria has enhanced its information provision to women through the involvement of consumers at all levels of information development. Consumers sit on information advisory committees, write information with staff and provide advice to staff on how information can be made more meaningful, useful and accessible (Johnson, 2007). In one case, women worked with clinicians to design a booklet for use in pregnancy clinics (Johnson, 2007).

An internal evaluation of the process to develop patient information at the Royal Women's Hospital found that women reported the booklet produced with women's involvement was an improvement on previous information provision. They also suggested the booklet increased their confidence in the information presented. There were mixed results from midwives and doctors on their use of the booklet.

Consumers and carers as partners with providers for program planning and evaluation

There are currently a range of approaches being undertaken by health services to involve consumers and carers in program planning and evaluation. Common approaches include inviting consumers to be members of reference and advisory committees and conducting qualitative research to ensure consumers' views inform the development of programs. Comprehensive approaches to community participation are often multifaceted and include a range of mechanisms for consumers to have input.

One such example was an initiative of the Austin Bowel Cancer Consortium where consumers had active input into the development of a Clinical Support Systems Program model. The project enabled consumers to share their experiences of care through semi-structured qualitative interviews, to participate on a Consumer Reference Group and to have input into the report on the interview findings (Naksook, Romios, & Spink, 2003).

An evaluation of consumer involvement in this project was conducted by Health Issues Centre. Data for the evaluation was collected through semi-structured interviews with 18 consumers who had been involved in the process. Consumers indicated that being involved in the project had increased their understanding about colorectal cancer and

treatment options, the situation of other consumers and how they cope. They felt optimistic about the impact of their involvement and were pleased about resources they had developed through the project (Naksook et al., 2003).

Similarly, as part of the Commonwealth Department of Health and Ageing Enhanced Primary Care Packages of 1999–2000, consumers contributed to several projects. Consumers participated on project committees, provided input into an expressions of interest process and contributed to the development of marketing and recruitment material (Allwell, Spink, & Robinson, 2004).

The National Resource Centre for Consumer Participation in Health undertook an evaluation of the consumer participation component of the Sharing Health Care Initiative Demonstration Projects. For the evaluation, a case study methodology was applied to two projects, one in Queensland and one in the ACT. The findings reported that 'consumers had greatly enhanced the quality of the project materials and had helped to tailor that material to specific people in the community' (Allwell, Spink et al., 2004, p.4). The project had attempted to involve consumers in the analysis and interpretation of data but it was found that 'the task was not a good match with the consumers skills and interests' (p.5). Involving consumers in the national program evaluation was identified as equally problematic due to the nature of the projects and consumers wanting to have input at a local level (Allwell et al., 2004).

A comprehensive approach to consumer participation was a feature of *Take the Pressure Down*, a three-year pilot project to improve health outcomes and quality of life for consumers with, or at risk of hypertension in two shires in Victoria.

A consumer reference group was established to guide the project. All members either lived in the catchment area or were using services in the catchment and had either been diagnosed with high blood pressure for were caring for someone with the condition. The role of the consumer reference group was to provide input into the design, implementation and evaluation of the project, particularly as it related to consumer involvement in the high blood pressure program (Hider, Hurworth, Gill, & Wilcox, 2003).

A process and impact evaluation process was conducted for the *Take the Pressure Down* project. This evaluation identified that consumers had made an enormous contribution to the overall hypertension project through:

- the provision of consumer perspectives
- involvement in needs analysis
- engagement of general practitioners
- development of resources and information material
- influencing the steering committee
- instigating a hand-held record
- promoting the program at local and state conferences (Hider et al., 2003).

Through their involvement in the project, consumers had shared the knowledge they gained through their involvement with their local community, support groups and doctors.

All consumers expressed positive outcomes from their participation in the consumer reference committee explaining they now had:

- a better knowledge about high blood pressure
- the ability to self-manage their high blood pressure
- an improvement in their hypertension
- an improvement in their overall health and wellbeing.

With regard to decision-making, consumers explained they were 'more confident in talking to doctors' and 'more confident in expressing their thoughts'. As some of the consumers participated in the projects' six-week Better Health Self- management Program, the evaluators suggest that not all the stated outcomes can be attributed to the consumer reference committee (Hider et al., 2003).

Only a small number of projects have been described in this section; however, the evaluations reveal that consumers are able to have input into the design of both patient information and are able to contribute to committees and working groups. One study suggested possible health and well being benefits for consumers from participating however more evaluations are needed to support this finding.

Participation at Organisational level

Health services provide various rationales for involving consumers at an organisational level. These include:

- funding requirements
- to improve health outcomes
- to enhance quality of care
- to ensure accountability,
- to enable services and programs to meet community needs.

This review found a diverse range of approaches for involving consumers at an organisational level. Approaches included involving consumers in complaints management, service planning and delivery initiatives, staff selection and health promotion planning. Common tools included community advisory committees, health councils and consultations. Legislation, policies and staff training on consumer participation for managers and staff also emerged as useful enablers for implementing approaches.

Consumers participating in providing feedback and complaints management

An interesting approach for involving consumers in complaints management was implemented by BreastScreen Victoria (Varney, Connely, & Phillips, 2005). The project involved a local consumer group in viewing the consumer complaints reports from the service; and a state-wide consumer group viewing reports from services before they went to the state-wide quality group. Reports on complaints were then tabled at a board meeting and implementation and recommendations adopted. Consumers were regularly updated about the process.

An internal evaluation of BreastScreen Victoria's approach revealed that collaboration between service managers and consumers was a viable method of complaints review for BreastScreen Victoria. The evaluators concluded that consumers displayed a willingness to offer their views and to engage in debate (Varney et al., 2005).

In Alice Springs, new methods for seeking feedback from Aboriginal consumers at the Alice Springs Hospital was the aim of the *Implementing Consumer Feedback into Continuous Quality Improvement Framework at Alice Springs Hospital*. The project was a joint initiative of the Alice Springs Hospital and two local Aboriginal organisations (National Resource Centre for Consumer Participation in Health, 2001). The project aimed to identify and develop culturally appropriate avenues for Aboriginal consumer participation and feedback regarding the services at Alice Springs Hospital and to ensure methods developed were in line with the quality improvement framework at the hospital. Methods used to engage Aboriginal consumers and consumer groups included:

- face-to-face meetings
- written correspondence
- outreach
- project advisory group

An internal evaluation of the project was conducted. This revealed that the project had contributed to consultation, communication and partnership development between Aboriginal consumers, consumer groups and health providers. However, the evaluation concluded that consumers and community groups were tired of continually being asked to offer suggestions and not seeing recommendations acted upon.

Consumers and carers as partners with providers for service planning and delivery

A variety of approaches for involving consumers as partners with providers for service planning and delivery were identified. Approaches were generally led by the health service and involved consumers and community members having input at various stages of the initiative.

At the South West Primary Care Partnership, consumers were involved in the design of service information hubs. To guide the project a consumer reference group was

established with 15 service users. This group conducted a consultation and outreach strategy and members took on roles as educators, researchers, facilitators, representatives, collaborators and volunteers (Ermacore, 2004).

There was no informal evaluation of the South West Primary Care Partnership initiative; however, the project coordinator noted the following key elements as crucial to the process:

- Clarifying values and developing policy as an important underpinning to a strong consumer strategy
- Consumer capacity building to enhance the quality of the consumer input
- Using an eclectic range of methods to match the purpose effectively
- Seeing consumer participation as an element of community development
- Seeing the struggle between bureaucracy and community as the locale for consumer-driven service improvements
- Strengthening the powerbase at the consumer/community level to enhance the outcomes for health consumers within the struggle between competing interests

(Ermacore, 2004).

Similarly, to inform the re-development of the Royal Dental Hospital Melbourne, dental health service users were invited to participate in eight focus groups, during the course of which dental health service users were given the opportunity to have input into the design of the new hospital, to offer suggestions and to share their experiences (Holm, Oliver-Weymouth, & Wright, 2001).

The process at the Royal Dental Hospital Melbourne was also not formally evaluated. However, the project team concluded that the focus group format had created a safe place for consumers to speak about their experiences and had provided a lead into the ongoing development of the community advisory committee. The experiences of consumers also provided useful material to guide the future re-development of the dental service (Holm et al., 2001).

Health promotion planning

Health promotion planning usually involves bringing together key stakeholders to identify priority health and wellbeing issues to be implemented in a community of interest. In order to develop its health promotion plan, Caulfield Community Health Service conducted a series of workshops and surveys with community members to identify and prioritise local health and wellbeing needs and develop a wide range of health promotion strategies aiming to address these needs (Caulfield Community Health Service, 2006). No evaluation of the approach was conducted.

Consultations

Barwon Health implemented an extensive community consultation involving both qualitative and quantitative methods to inform its future service planning (Capp, 2005).

Stage 1 involved eight focus groups with 64 participants (men, women, low and high SES, below 40 years, above 40 years, Italian men and Italian women); stage 2 involved a telephone survey of 400 members of the Geelong community (men, women, low and high SES, below 40 years and above 40 years). No formal evaluation of the approach was conducted; however, key findings suggest the community was able to make a useful contribution to future planning as recommendations included:

- Priorities and expectations were for timely access to public hospital, emergency care and aged care
- For many, cost was less relevant than a quality service
- Shortened waiting times and increased staffing levels were strongly supported
- Increased taxes were the best means of financing the health system they sought
- Community-based services were less relevant than hospital services
- Health education was supported
- An egalitarian approach to resource distribution was favoured
- Strong support for the community to be involved in decision-making in public health care
- Little support for priorities being determined by politicians, administrators, and, to a lesser extent, medical professionals

Community advisory committees and health councils

Increasingly, community advisory committees have become a common tool for engaging consumers and community members at the organisational level of a health service. Within Victoria, community advisory committees are a legislative requirement for metropolitan and regional health services. Similarly, in Queensland, health community councils are included in the Health Act as an approach for communicating with the community. The experiences of implementing community advisory committees have been documented by various resource officers (Daye J. et al., 2003; Moss, 2003; O'Neill & Mullins, 2002; Slater, 2002).

In Victoria, The Peter MacCallum Cancer Centre established its community advisory committee (CAC) with eight members—all lay people—and had either experienced cancer or had a family member receive cancer services. The CAC acts as an advisory group to the board, management team and staff by providing comment on strategy and planning initiatives. CAC members also sit on committees and working groups throughout the health service and members have contributed to the development of the consumer participation plan, resources and the development of a resource centre (Moss, 2003).

In Queensland, health community councils have been established at Bundaberg Health and North Burnett Health. These advisory bodies aim to give communities a more direct say in the performance and quality of local health services (www.health.qld.gov.au/bundaberg/council.asp).

The establishment of community advisory committees occurred in acute facilities as well as in primary health services. In Victoria, community advisory committees were developed by several Victorian Primary Care Partnerships, with some utilising their community advisory committees to develop a consumer charter of rights and responsibilities (Dawson, 2003) .

Divisions of General Practice have also established community advisory or Reference groups. At the Central Australian Division of General Practice, the consumer reference group was established to develop an arena where consumers were able to have input into the division's activities both internally and externally (Central Australian Division of Primary Health Care Consumer Reference Group, Central Australian Division of Primary Health Care, & Waltja Tjutangu Palyapayi Resource Centre, 2001). Members of the reference group have had a role in:

- reviewing a resource guide on consumer participation
- development of an implementation plan for training rural and remote Aboriginal consumers
- Undertaking a workshop.

Similarly, the Mallee Division of General Practice established a community reference group to make strategic recommendations to the division's board of management. This reference group supported the establishment of community focus groups throughout the Mallee region to address relevant community health issues. Many of the focus groups developed into local community groups, which continued to meet to address local health issues.

Evaluations of community advisory committees

While community advisory committees and reference groups continue to be used as an approach for community participation, formal evaluations of the effectiveness and impact are limited. Findings of the available evaluations of such committees are presented here.

One inquiry undertaken by the Victorian Government's Family and Community Development Committee concluded that community advisory committees:

...had progressed through an initial development stage and are now operating as a valued link between communities, consumers and Metropolitan Health Services.

(Parliament of Victoria, 2004)

Additional findings of this inquiry were that community advisory committees make a valuable contribution to the furtherance of community and consumer participation and representation in metropolitan health services. The authors of the inquiry recommended that resourcing for community advisory committees needs to be

maintained by each metropolitan health service at a responsible level, adequate to maintaining the functional ability of the committee (Parliament of Victoria, 2004).

Reflections from resource officers involved in coordinating community advisory committees provide useful insights into the benefits and challenges of coordinating community advisory committees. One resource officer suggested that community advisory committees can bring community issues to the table, which enables health services to understand community concerns and to take action (Daye J. et al., 2003). In addition, the provision of support and information to committee members has led to them becoming knowledgeable about health issues and able to inform the community of changes and developments at the health service (Daye J. et al., 2003). However, another resource officer concluded that recruiting a diversity of perspectives, particularly from certain cultural groups, has been a challenge for committees (Moss, 2003).

To examine the views of consumers participating on advisory committees within Primary Care Partnerships, a small study was conducted by Health Issues Centre. The study revealed that within Primary Care Partnerships consumers have been involved in:

- contributing to interviews for new staff
- informing PCP policy
- participating in planning days
- providing advice and comments on specific issues
- commenting on service directories and Internet sites for PCPs.

Consumer members of these committees generally gave a positive assessment of their involvement but recommended that additional support be provided to them to enable them to participate fully (i.e. administrative support, transport (Dawson, 2003).

Challenges for managing community advisory committees in rural Australia were documented in an internal evaluation of the Central Australian Division of General Practice Consumer Reference Group. The evaluation revealed that community members did not feel they were representatives of the community and also felt that they lacked the skills and knowledge to participate effectively. In addition, travel was identified as a key barrier impacting upon participation, with some consumers driving 500 kilometres to attend meetings (Central Australian Division of Primary Health Care Consumer Reference Group et al., 2001).

Supporting consumers in an appropriate way was seen as a key enabler to the process at the Mallee Division of General Practice. 'It is our view that an unsupported community representative on a board of directors is "tokenism" and will achieve very little in terms of genuine community participation in the organisation' (Mutton B., 2004, p.20).

Consumers involved in staff selection

A very direct way of engaging consumers at an organisational level occurred at the Northern Area Mental Health Services where consumers were involved in staff selection. The process involved appointing consumers to staff selection panels. Consumers were provided with appropriate training and information to enable them to participate (Grimshaw, 2003). A formal evaluation of the initiative found that the process influenced the culture of the service, including factors like the quality of staff appointments, staff attitudes and practices (Grimshaw, 2003). The initiative was found to have increased mutual respect and enhanced relationships between consumers and staff.

Consumers involved in undertaking a community health needs assessment

Identifying community needs in a systematic way was an approach taken by the community reference committee at the Monash Division of General Practice. It employed one member of the committee to coordinate a community health needs assessment. No evaluation of the process was conducted; however, all committee members were able to provide input into the methodology of the project, the analysis of key findings and the overall recommendations (Zauder, 2006).

Staff training

Training for managers and health professionals is increasingly being identified as a key enabler for effective community and consumer participation. Health services are often engaging their community development and engagement staff to facilitate training sessions. However, Southern Health—a large metropolitan health service in Melbourne www.southernhealth.org.au—funded Health Issues Centre to deliver 10 workshops to middle managers on consumer and community participation. Workshops involved presentations on theory and practice, interviews with consumers and health professionals involved in consumer participation, and planning exercises to enhance the skills and awareness of managers. An evaluation of this training has yet to be conducted.

This review found a small number of evaluations of community participation tools being applied at the organisational level. The focus of the evaluations are generally on the process of involving consumers and community members with very limited analysis of the impacts on health services or consumers from participation initiatives.

Participation at Health Department level

State health departments are increasingly designing and implementing policies and processes to involve consumers and communities in consultation and decision-making processes. Key tools used at a health department level include:

- legislation
- training

- consultations
- committees.

Quality and safety is seen as a key driver for community participation at a health department level. Very little evaluation of community participation at a government level has been undertaken.

Legislation

Within Victoria and Queensland, legislation has been created to advise on the functioning of a district health council and community advisory committees.

The Health Services Act 1991 (Qld) contains a statutory provision enabling district health councils to engage their community (Queensland Parliamentary Counsel, 2007):

Section 8(1)(a) provides for the functions of district health councils to ‘identify and assess the health needs of people living in the council’s districts or who may use public health services delivered in the district.’

Section 23(1) gives district health councils authority to ‘establish consultative committees to provide a way for members of the public to express their views about the planning and delivery of public health services in the district.’

Section 8(1)(g) allows the district health council to ‘advise and make recommendations to the manager for the district about the matters mentioned in paragraphs (a)....’

The Health Services Act 1988 (Vic) outlines the membership of a community advisory committee:

Section 65ZB(2) the board of a public health service must ensure that the persons appointed to a community advisory committee are persons who are able to represent the views of the communities services by the public health service.

Guidelines were developed by the Victorian Department of Human services to assist public health services to ‘develop effective community advisory committees that can advise on consumer, carer and community participation at all levels of the public health service (Department of Human Services, 2006a). This review found no evaluations of the impact of the legislation in Victoria or Queensland.

Consultations on policy and practice

Cancer service reform

Cancer service reform is a key priority for the Victorian Department of Human Services given the increasing prevalence of cancer. As part of the service reform, Health Issues

Centre undertook a study on consumer participation in Victorian cancer services and developed a guide to enhance the involvement of consumers and carers in the work of integrated cancer services (Department of Human Services, 2007). To develop the resource, 10 focus groups for consumers and carers and seven telephone interviews with cancer support group facilitators were conducted. Consumers also participated as members of the project reference group (Cordwell, Dawson, & McBride, 2006). No evaluation of the implementation of the resource has been conducted; however, anecdotal evidence suggests the resource has assisted integrated cancer services to plan for consumer participation.

A similar project related to cancer service reform was undertaken in Scotland at the University of Stirling. Researchers visited nine different locations across Scotland, and, using open meetings and small discussion groups, listened to people's views of cancer and cancer care.

http://www.cancercare.stir.ac.uk/projects/pig_summary.htm

Health service reform

Health Consumers' Council of Western Australia undertook a series of consultations with consumers for the Western Australia Health Reform Committee. The methodology involved 11 community consultations, a series of consultation meetings with Indigenous communities, a state-wide survey, web-based electronic response and submissions from community-based organisation. A total of 231 community members participated in the community consultation process (Health Consumers' Council, 2004).

Three common expectations identified through the consultations included:

- Health professionals and the health system as a whole should be more compassionate
- The health system should be more flexible to accommodate the circumstances of individuals
- Health services should be located and managed in the community so that health services truly reflect the needs of community members.

No formal evaluation of the project was conducted but the authors of the report noted several barriers to implementation. Barriers included insufficient time and funding to conduct the consultation. They strongly recommended sufficient funding and time be allocated if similar consultations are conducted in the future (Health Consumers' Council, 2004).

Quality of care reports

Since 2004, all Victorian Public Health Services have been required to produce quality of care reports. These reports are a key strategy to ensure accountability of health services, to promote changes in systems and professional practices, to provide consumers with information, and to establish a process that reports on and promotes continuous improvement (Department of Human Services, 2006c). Involving

consumers in the development of quality of care reporting is a requirement of acute health services' funding in Victoria.

Training

State health departments are funding training for consumers and community members as well as hosting training and briefings for department staff. For example, Health Issues Centre receives funding from the Victorian Department of Human Services to conduct training for consumers and community members. It is also funded to provide briefings and training on consumer participation to the Department of Human Services.

In addition, to enhance the skills and capacities of consumers, the Victorian Quality Council is presently implementing a *Consumer Leadership Project*, which involves extensive training, support, information and networking for 20 consumer leaders www.health.vic.gov.au/qualitycouncil

Health promotion reform

The Victorian Health Promotion Foundation commissioned a study to identify the Victorian communities' knowledge of, attitudes towards and support for, health promotion and disease prevention (Pennay & Bateman, 2007 p.iii). The methodology for the study involved a literature review, 14 key opinion leader interviews, eight group discussions with participants from metropolitan and rural areas and a survey questionnaire to 1000 Victorians. The survey questionnaire was conducted with 1000 Victorians—600 from metropolitan areas and 400 from rural and regional areas.

Patient and public forums

Throughout England, patient and public forums have been operating since 2003 to bring the views and concerns of patients and communities to their local Primary Care Trust or National Health Service Trust. Since inception, 572 forums have been working with almost 5000 volunteer members. Key issues addressed through the forums have included infection control, health service and facilities, GP services, transport and parking, mental health, community involvement, out-of-hours services, health information, older people's services and disability services (Commission for Patient and Public Involvement in Health, 2006).

Involving consumers on committees

It is common practice—and in some cases a legislative requirement—that health departments involve consumers or lay people on advisory committees and policy committees. A study undertaken by Health Issues Centre for the Victorian Department of Human Services concluded that half the committees of the department involve consumers, and that the process of involving consumers, carers and community members is viewed as positive by those engaged (Health Issues Centre, 2006b). In addition, the study revealed there was a lack of a consistent approach for recruiting and supporting consumer involvement.

Participation at the community level

A range of approaches where consumers and community members had been consulted on and involved in decisions at a community or population level were identified through this review. Tools identified for consultation and engagement included citizen juries, surveys, focus groups and community representative programs.

This review found only a limited number of internal evaluations of community participation methods at the community and population level. These findings are consistent with a Cochrane systematic review of consumer engagement undertaken by Nilsen, Myrhaug et al. (2006), which found that little research has been done to determine the most appropriate strategies for involving consumers in health care decisions at the population level (Nilsen et al., 2006).

Citizen juries/nominal group technique

Citizen juries are one approach for involving communities in the decision-making process. Their use in Australia with regard to health systems has been limited, although two examples were found in the review.

The first example included two citizen juries which were undertaken in Western Australia under the auspices of the Medical Council of Western Australia (Mooney, 2004). The first jury was convened in March 2000. Its recommendations were:

- Greater priority setting in health
- Equity, based on equal access for equal need
- Positive discrimination for disadvantaged people
- More spending on prevention and public health ahead of treatment and disease
- More spending for rural and remote health ahead of urban health (p.76).

The second jury, convened in February 2001, focused on equity in health services. Equity was defined as 'equal access for equal need'. The jury applied the equity principle to three areas of inequity in WA health services and participants were given money to allocate across the three areas:

- Aboriginal versus non-Aboriginal health care
- Rural and remote healthcare versus urban health care
- Aged versus other health care.

The jury allocated money to all areas with greatest priority given to reducing inequalities in Aboriginal health (p.76).

The second recorded example of a citizen jury occurred during a two-day forum hosted by Southern Health. The forum aimed to elicit the opinions of community members and health industry representatives on relevant public health issues (Australian Institute for Primary Care, 2004). Community members were recruited through a variety of

community networks and health services. A total of 89 participants participated in the forum; of these, 68 per cent were female.

The authors provided the following evaluation reflections on citizen juries in the final report. Citizen juries provided an opportunity for a very well informed, in-depth analysis of specific issues. The jury process meant that participants had high quality information, an opportunity to ask questions of experts and to discuss the issues among themselves (Australian Institute for Primary Care, 2004).

Focus groups

The Centre for Health Economics at Monash University commissioned a focus group study of health care priority setting at the individual patient, program and health service level (Shrimpton, 2007). This study aimed to identify whose values should inform decision-making in the health area and whether the influence of different groups should vary with the level of decision-making. The methodology involved eight focus groups with 54 members of the public, and health professionals. Four focus groups were held for the general public and four focus groups held for health professionals and state government health bureaucrats.

No evaluation of the approach was undertaken but the authors were impressed by the sophistication of views expressed by members of the public (Shrimpton, 2007). The authors concluded that allowing open-ended discussion of ethical issues in a supportive environment allows participants to explore alternatives they may not have thought about, to think about their values more deeply, and to engage in public reasoning in justification of their views (Shrimpton, 2007 p.13).

Interviews

A study aiming to determine whether the general public had a central role to play in informing priority setting in health care was conducted in central Sydney (Wiseman, 2003). It involved interviewing a convenience sample of 373 citizens attending two medical clinics.

Respondents in the study were presented with three difference levels of priority setting: across health care programs; across medical; and at a global/population level. To assist citizens in making informed decisions, they were provided with information about current levels of funding and cost-effectiveness of alternatives.

Interviews focused on three key components:

- Do you feel the preferences of the general public should be used to inform priority setting at each level?
- Does your willingness to use public preferences depend upon the level of priority setting?
- Who else's preferences should be used to inform priority setting at each level?

Results suggest the public want to have a say in priority setting across health programs, across medical procedures and across population groups. The authors suggested that an interviewer-assisted questionnaire can provide useful information about public preferences to inform resource allocation (Wiseman, 2003), p.1009).

Advocacy

Women's Health In the North ran a community education program that has focused on 'Working Well With Your GP'. Through the program, women have been supported to develop recommendations to inform the work of general practitioners in their area. The recommendations were provided in a report to the local Division of General Practice (Tascone, 2005).

Cancer Voices Australia is a network of people concerned about the issues impacting on people with cancer. It works with partners to achieve change and where possible reduce the impact of cancer by promoting a better quality of life for those affected. State Cancer Voices have been set up in New South Wales, Victoria, South Australia, Queensland, Australian Capital Territory and Western Australia, <http://www.cancervoicesaustralia.org.au/index.htm>

Community representative and nominee programs

Community representation and nominee programs are a feature of the work of state-based peak health consumer organisations including:

- Consumers' Health Forum of Australia
- Health Issues Centre
- Health Consumers' Council (WA)
- Health Consumers Alliance South Australia
- Health Care Consumers Association of ACT.

Such programs nominate consumers and community members for government, research and health policy committees and consultations. No evaluations of the programs were identified in this review.

Learning and development opportunities for consumers and communities

The provision of learning and development for consumers and communities is provided by several consumer health organisations in Australia including:

- Breast Cancer Network Australia
- Consumers' Health Forum
- Health Issues Centre (Vic)
- Health Consumers' Council (WA)
- Health Consumers Alliance South Australia
- Health Care Consumers Association of ACT.

SUMMARY OF KEY FINDINGS

In summary, the key findings of this review were that:

- There is a need for more rigorous and independent evaluations of community participation tools to improve knowledge of what tools are effective in engaging consumers in health decision-making.
- Documented examples of consumer and community participation in health are patchy and ad hoc with most projects and studies using descriptive methods to report finding rather than using impact and outcome evaluations.
- There is strong evidence on the effectiveness of interventions at the individual level of care, which enable individual consumers and their carers to be involved in decision-making processes. However, the evidence on the effectiveness of consumer involvement at the ward/program, organisation and government level is less convincing.
- There are a small number of examples where consultations have been conducted with communities and consumers on the key priorities of health care. These have generally produced useful data and conclude that consumers want to have a say in decision-making with regard to priority setting, medical treatments and resource allocation.
- Community advisory committees (CACs) and reference committees are common tools used by health services to engage with its community. These examples suggest that consumers involved in CACs are able to have input into the programs and services and are valued by services. However, the impact of the consumer contribution has not been systematically evaluated and is at risk of being tokenistic.
- State health departments are involved in developing legislation, policy and guidelines to support consumer and community engagement. This work is driving the consumer and community participation reforms in the health services.

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2

Community participation tools: engaging selected special interest groups in health decision-making effectively

Review Question 2:

For older people residing in the community who are at risk of hospitalisation and may become long stay patients:

- a. What are the best ways to identify/best access points for people at risk of hospitalisation due to physical or mental problems?
- b. What models to prevent inappropriate admission have been evaluated?
- c. What is the evidence that the models are effective in preventing admissions?

EXECUTIVE SUMMARY

This literature review was conducted by Health Issues Centre for the Sax Institute. It aimed to answer:

What evidence is there about the most appropriate and effective approaches and tools for engaging the following special interest groups in health decision-making?

- a. Aboriginal and Torres Strait Islander people
- b. People from culturally and linguistically diverse (CALD) groups
- c. People with disabilities
- d. Youth and families with young people
- e. People with a mental health condition.

This review found that there is a need for more rigorous and independent review of appropriate and effective approaches and tools for engaging special interest groups. In Australia it seems there is a considerable body of grey literature on engaging communities. However, many of the approaches and tools identified have been in the general area of special interest group engagement rather than the specific area of health. Queensland Health, however, is singled out for the breadth of work available, together with a Queensland state government department dedicated to community engagement.

It appears there is not much dedicated work to be found in the formal literature. It was not possible in this brief literature review to include a comprehensive presentation addressing this topic. Therefore, where possible, other literature reviews were considered and their approaches included here. Some links to a variety of key sources are also presented and listed at the end of this section without direct reference within the body of work.

The evidence around approaches and tools for engaging special interest groups in health decision-making appears to follow a set of core principles. These key standards cover approaches and tools by which engagement is reported to be effective. The term 'approach' in this instance is deemed to be a way of undertaking that deals with an issue in a particular way, and from a fresh angle, in order to get closer to achieving change. The key standards identified to attain effective approaches include the need to follow effective communication strategies, and the delivery of non-tokenistic, collaborative ways that include respect for the group.

Effective tools for engaging groups in health decision-making also present common characteristics. The term 'tools', for the benefit of this review, refers to the ways by which engagement takes effect. Tools that fitted this criterion were seen to be those that were planned and used by those being engaged. Furthermore, any decision-

making by those within the groups are made within a social and cultural framework that incorporates their values and background. Effective tools include the ongoing support and facilitation of such decisions.

Importantly, a divide between government policy and engagement at the local level presents the possibility of barriers to the effective delivery of engagement tools. The projects reported on in this review are divided between the ideal—as presented with policy—and the practical—concerned with the implementation of the policy at the ground level.

REVIEW STRATEGY

This review was conducted between January and February 2008. It examined relevant Australian and international studies that relate to consumer and community participation in health. It was not intended as a systematic review but instead aimed to provide an account of the state of the evidence related to the questions. The process to conduct the review is detailed below.

Familiarisation with the different fields for each review

- Health Issues Centre previous reviews and Endnote libraries
- Health Issues Centre library
- Cochrane Collaboration
- Internet databases (e.g. Google academic, Dogpile)
- Other local reviews (e.g. Health Knowledge Network).

Systematic review of each state in Australia

- Government bodies
- Research centres
- Peak bodies
- Local government
- Community health services.

Formal search

- La Trobe on-line library – journals, databases including:
 - Australian Public Affairs
 - Humanities and Social Sciences Collection
 - Aboriginal and Torres Strait Islander Subset
 - Indigenous Studies Bibliography
 - ATSI health.
- Other databases, including Medline, Medscape, CHAIN.

A range of search terms were used including the following:

Search terms – general	Terms used in combination
Engage/communities Engage and communities Engage/communities and health Engagement and health Engagement tools Engagement approaches Engagement tools and health Engage disabilities	Engage ATSI and community health Families with young people and engagement Mental health and engagement People with a disability and engagement Access and services and health Ethnic/CALD/communities and engagement

Further search

- Systematic search of other countries previously identified
- Systematic search of journals of interest to the review (e.g. Australia and New Zealand Journal of Public Health)
- International organisations including the Picker Foundation, WHO, and INVOLVE UK.

Literature review limitations

Some literature review limitations have been discussed previously, such as the overlap of findings between the special interest groups. Of further note are the following limitations:

- Disparity in the amount of literature between groups. For instance, there was considerable literature available on ATSI groups yet much less for the young.
- There was an absence of critical reviews concerning engagement approaches and tools for special interest groups. Therefore, instances of difficulty or concern could not be identified.

LITERATURE REVIEW

Introduction

Special interest groups have been termed by some as 'hard to reach' (Brackertz & Meredyth, 2007). The Brisbane Declaration made at the International Conference on Engaging Communities (World Health Organization, 2005) attempted to address issues presented as barriers to engagement by finding ways to circumvent them, in ways that advantage not only the special interest groups but also the whole community. This conference proposed that all engagement must have integrity, be inclusive, allow sufficient dialogue for those being engaged to influence the direction of the dialogue, and, importantly, to have the capacity to carry out any decisions in a way that is sustainable. The influence of this statement echoes throughout the review.

It must be noted that several of the special interest groups overlap, so papers found that address both youth and mental health, or CALD peoples and mental health or CALD people and disability, have been found. Whenever possible, this review has selected literature that represents approaches taken in respect of the group under review.

This review was aimed primarily at literature from around Australia as well as some from overseas. However, of note is how the relevant literature from overseas—beyond general principles of engagement—lacked the immediacy of Australian literature.

This review considered the evidence for effective approaches and tools in engaging special interest groups of: Aboriginal and Torres Strait Islander people; people from culturally and linguistically diverse (CALD) groups; people with disabilities; youth and families with young people; and people with a mental health condition.

Overview of consumer/community engagement

In Brisbane, the World Health Organization held an *International Conference on Engaging Communities* (2005). From this conference came the Brisbane Declaration for Community Engagement. The twelfth point for this declaration states that the conference representatives:

Further recognise that inclusive engagement requires that Indigenous peoples and the poor and marginalised, are adequately resourced to participate meaningfully in the broader community and that they have a stake in the outcome and benefit equitably as a result of being involved. (World Health Organization, 2005)

Numerous papers presented at this conference are cited in this review as they are a source of considerable input towards the debate on engaging special interest groups. Following the Brisbane Declaration, a small group of interested participants set up a working group to put together an evaluation framework for community engagement (Hendricks, 2007). The framework remains in draft form but has taken the core principles of integrity, inclusion, deliberation, influence, capacity and sustainable decisions to form a set of indicators, rating scale and questions by which to assess the value of community engagement.

In Europe the World Health Organization Regional Office for Europe's Health Evidence Network's reported further on the effectiveness of empowerment to improve health. Wallerstein (2006) described a number of strategies that effectively engaged different and marginalised populations in health decision-making. Key messages from this review links community empowerment, autonomy of decision-making, building on proven strategies, strengthening community connections, building trust and the facilitation of participation as ways to include communities in discussions on making decisions about their health.

Consumer engagement for the purposes of this literature review is the process of involving consumers in health decision-making that can affect special interest groups or individual consumers within the group. The tools and approaches to be discussed here provide a broad overview of the ways engagement with special interest groups can occur. It is seen how:

Consumer engagement is the process of involving consumers in the planning and development of policies and services. In the health policy context ... consumer engagement is about involving consumers in developing and implementing the policies that will affect them as health consumers.

(Gregory, 2007a p.7)

The Queensland Government has a *Charter for Community Engagement* (Queensland Government, 2001). This document describes community engagement as being:

... the process of working collaboratively with groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting their wellbeing.

(Queensland Government, 2001 p.6)

In *Conceptualising consumer engagement: A review of the literature* (2007) Gregory proposed that there is little literature on consumer engagement in the health field, particularly in Australia, except for health service delivery areas such as hospitals and some specific health programs. It is also proposed, however, that the ideals of

consumer engagement are not readily translated into practice. Indeed, Aslin and Brown (2004) suggested that:

Engagement implies commitment to a process which has decisions and resulting actions. So, it is possible that people may be consulted, participate and even be involved, but not engaged.
(Aslin & Brown, 2004 p.5)

Indeed, Ife (2002 p.101-118) wrote of his concern of so-called 'experts', who assume they have specialist knowledge and it is this knowledge they need to use with which to 'help' the community. Instead he proposes there is a local knowledge with local 'experts' to be listened to, valued and respected. Therefore this review emphasises an approach that is collaborative in nature and utilising principles of outreach.

In response to various projects conducted by the Health Issues Centre concerning the engagement of some special interest groups such as Aboriginal and Torres Strait Islander (ATSI) people as well as people from culturally and linguistically diverse (CALD) backgrounds, an internal document has been produced setting down engagement principles for setting up ATSI and CALD support groups (Health Issues Centre, 2008). This document collated these principles under key headings as follows:

- **Communication**
 - Dialogue with key stakeholders and community members within their community
 - Identify key community members
 - Anticipate use of interpreters
 - Establish culturally appropriate strategies identified during with the group
- **Partnership and collaboration**
 - Establish common purpose
 - Be guided by the key stakeholders and community members
- **Respectful and inclusive**
 - Planning, putting into practice, valuing community decisions
- **Culturally safe and comfortable**
 - Community consultation results in culturally appropriate action in culturally appropriate places
- **Directed, organised and structured collaboratively**
 - Community decisions respected, valued, supported and integrated into ongoing development

- **Collaborative leadership**
 - Support actions following supported community decision-making
 - Building on community leadership capacities
 - Reflective practice
 - Set in place ongoing reflection and ability to make process improvements.

These principles of engagement are reflected throughout this document. The review noted how current literature concurs with these principles; it is hoped to build on and further expand on developing assumptions about engagement.

For an overview of a consumer engagement framework for Australian health policy, an article in the Health Issues Journal (Gregory, 2007b) described how 'eight interacting issues influence the practice of consumer engagement: purpose, type, initiator, who is engaged, timing, techniques, practical issues, and contextual issues' (Gregory, 2007b p.22). She further proposed a range of tools by which to conduct the engagement, from one-on-one suggestions such as surveys to group strategies such as citizens' juries. With such general approaches in mind this review now looks at the engagement of specific special interest groups in turn.

Engaging Aboriginal and Torres Strait Islander people

In 1997, the Commonwealth of Australia published *Bringing Them Home: Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from their Families* (Commonwealth of Australia, 1997). Recommendation 52 in that report suggested that funding should be made available (among many other recommendations) for:

- Provision of training and work placements for Indigenous researchers, archivists, genealogists and counsellors
 - Involvement in the design and delivery of training for the above
 - Outreach and publicity relating to their services
 - Outreach and Indigenous community education
- (Commonwealth of Australia, 1997 p.315-316).

Among the recommendations on these pages key words used were: 'networking', 'involvement', 'outreach', 'community education', 'support', 'advocacy', 'assistance', 'training' and 'consultation'. These words point to the tools of choice identified within the literature in this review.

Relevant work

De Weaver and Lloyd (2005) in their paper at the Brisbane Conference on Engaging Communities emphasised the importance of collaboration between bureaucracy and Indigenous communities to achieve true engagement. Using two case studies De

Weaver and Lloyd described how poorly some agencies have engaged with Indigenous groups and provide recommendations on how to do it better. One case described how the traditional knowledge and cultural beliefs of one Aboriginal group were not considered by an agency intent on developing an education program. At evaluation, one key informant said:

Aboriginal people are not in control. They don't manage their culture. They're not managers, controllers or owners – only clients or recipients ... we are fighting a system from the outside. (p.8)

The implication being that without control and collaboration it is not possible to engage effectively with Aboriginal populations. Instead the authors proposed that engagement practices which facilitate capacity building rather than being of a directive nature be adopted.

Building Better Partnerships (Victorian Government Department of Human Services, 2006) is a Victorian Government initiative that set a groundwork for the engagement of Aboriginal populations proposing the acknowledgement of Aboriginal history, language and culture in order to build on the future. This document presents the engagement of Aboriginal community as underlined by effective communication, which is underpinned by seven guiding principles of demonstrating respect: choosing the right words; non-Aboriginal people taking responsibility for learning about Aboriginal people; non-Aboriginal people being self-aware about their own cultural assumptions and prejudices; demonstration of honesty and integrity in communication; provision of adequate information that is relevant to Aboriginal communities and which minimises bureaucratic language; follow-up after community involvement and provide feedback on outcomes and next steps to take. Beyond these principles it is proposed that community ownership should be valued along with the use of Aboriginal role models and an insistence that any engagement occur according to Aboriginal need.

Case studies are presented to demonstrate engagement. One study described the development of an Aboriginal-specific health service site in the eastern metropolitan region of Melbourne that was established with, and according to, the Aboriginal health needs identified by Eastern Aboriginal Health as a model of shared responsibility. In another study, Aboriginal Health Promotion and Chronic Care (AHPACC) identified a need for chronic disease prevention among Aboriginal communities where a Victorian Aboriginal community controlled health organisation and the Office for Aboriginal and Torres Strait Islander Health established links between Aboriginal community and mainstream health services (Victorian Government Department of Human Services, 2006).

In central Australia there are diverse groups of Aboriginal communities. Alice Springs is a place where a number of such groups with complex health issues come into contact with the health system. Local health services decided to include the local Aboriginal populations in health service improvement. The aim of *Implementing Consumer*

Feedback into a Continuous Quality Improvement Framework at Alice Springs Hospital was to:

... identify the most culturally appropriate methods of receiving Aboriginal consumer feedback about services at Alice Springs Hospital to improve Aboriginal health outcomes and health services.

(National Resource Centre for Consumer Participation in Health, 2001)

The original aim of this project was to receive 'Aboriginal consumer feedback'. However, first it was seen as essential to engage the local Aboriginal populations in order to achieve this aim successfully. This was accomplished by working with the local Aboriginal Councils and communities in order to build trust and partnerships so that health services and Aboriginal communities could work together. This was attained through the development of engagement tools such as partnerships, using local community languages in developing questionnaires, face-to-face interviews and the design of posters and pamphlets with the local populations.

A key recommendation from this project was the planned formation of an Aboriginal consumer advisory group with the development of an independent consumer participation team. A cursory check via the internet has found references to Aboriginal advisory groups in and around Alice Springs as well as staff training about engaging Aboriginal populations for hospital staff.

Engagement of Aboriginal populations was of particular concern for Consumer and Provider Partnerships (CAPPS) in Health for the Alice Springs Hospital (2006). A partnership was formed between the hospital and two Aboriginal organisations—the Tangentere and Arrernte Councils. Of concern were ways to develop culturally appropriate avenues for consumer participation. An advisory group was developed to represent Aboriginal perspectives. Two studies considered how Aboriginal men and women approach their health differently and proposed that engagement should occur differently.

McCoy (2006), in his ethnographic study, described the engagement of Aboriginal men as requiring the respect of men's Aboriginal health beliefs and a greater understanding of, and working with, local Aboriginal healers. He proposed that in order to engage with Aboriginal men their sense of healing space that exists outside the hospital walls needs to be respected. It was seen how they considered the space within hospitals and clinics as belonging to women that was not a comfortable space for Aboriginal men to discuss their health issues.

BreastScreen Victoria (2007) conducted research into barriers in breast cancer screening for Aboriginal and Torres Strait Islanders. Their examples of barriers to engagement included:

- Cultural beliefs about health and disease causation
- Geographic isolation
- Embarrassment/concept of shame and the privacy of women's business;
- Distrust and fear of government agencies.

Strategies developed from these findings recommended:

- Use of culturally appropriate language and communication
- Act in partnership with community
- Exercise of patience, understanding and respect when interacting with Aboriginal women.

The Victorian Government (2006) website <http://www.health.vic.gov.au/koori/> outlines strategies for engaging Kooris. Included are strategies for building partnerships as well as various documents about respecting culture, and Koori-initiated documents, with a Koori news journal and health information. Such sites providing Koori-specific information could prove useful in accessing strategies to engage hard-to-reach communities.

The New South Wales Department of Planning presented a report on engaging communities (Elton Consulting, 2003a). This report recommended that Aboriginal people should be contacted and asked if they wish to be involved in any planning issue or process that may be of interest to them. Although this report did not refer specifically to health it provided clues on ways to make an initial approach to ATSI communities about their health issues. In order for engagement to be successful it was suggested that:

- Contact is made with traditional owners and other Indigenous people with rights and interests in the area. Discuss with them the most appropriate means of consulting with Aboriginal people and agree with them on a process for engagement.
- Seek advice from the local Aboriginal Land Council or ATSIC Regional Office on how to identify relevant traditional owners or authorised community representatives with an interest in the area.
- Ensure both men and women are included as they may be responsible for different places and spheres of interest.
- Identify and adhere to any process or protocols that Indigenous people have established for community engagement. Allow time for leaders to consult with their communities.

- Consider whether people might feel more comfortable being consulted by others of the same gender.
- Respect Indigenous people's rights to choose the time, location and format of the consultation.
- Recognise that some communities may have different approaches to authority and the appropriateness of sharing personal information or opinion. It may take some time to build up trust.

Resource guides for engaging communities

To support effective and meaningful consumer and community participation, government departments are developing resource guides to enable health services and government departments to better engage with consumers and communities. One guide for consulting with Aboriginal and Torres Strait Islanders was developed by representatives of Aboriginal and Torres Strait Islander Commission (ATSIC) and the Aboriginal and Torres Strait Islander Service (ATSIS). The guide aims to provide Western Australian's Indigenous people with a greater opportunity to set agendas in partnership with government (Department of Indigenous Affairs, 2005).

A guide to community engagement methods and techniques was developed by the Queensland Government to assist public officials and other practitioners to engage with citizens and stakeholders. The guide provides a suite of engagement techniques and principles to guide the selection of techniques (Elton Consulting, 2003b).

A handbook to guide the design and implementation of community engagement strategies for Queensland Health District has been developed (Queensland Health, 2002).

A resource to support Victorian Community Advisory Committees to develop Community Participation Plans has been developed by the Victorian Department of Human Services (<http://www.health.vic.gov.au/consumer/pubs/cacg.htm>).

Results of database search

Two key publications identified Aboriginal and Torres Strait Islander views on engagement of their populations. The first was written by ATSIC (2003) following the Australian Government's summit on alcohol in Parliament House. ATSIC wrote in their Journal (Aboriginal and Islander Health Worker Journal) an article entitled *Talking about grog: Engaging and informing communities* how government needs to recognise the underlying causes of alcohol misuse and to engage Aboriginal communities under their terms if there is to be any success in tackling the problem. They argued that any way forward must work in collaboration with Aboriginal leaders rather against them.

The next paper, written by (Mawson, Madgwick, Judd, & Fergie, 2007), considered how a community health service incorporated Indigenous health into their governance. A case study presented how a newly constituted Aboriginal controlled health service was instituted. They followed the key principles of maintaining respect for elders, the obligation for Aboriginals to look after one's family and friends, to share food and money, management roles for women and the recognition of past injustices for Aboriginal peoples. This resulted in a phased-back control of health services to the Aboriginal community with the input of key members of the community together with a community-wide approach in the implementation of health programs.

Cameo case

Northern Territory, Australia

Indigenous communities in Australia face many challenges, and a range of methods have been used to address community issues. Recent models have relied solely on community development approaches, but this project—which focuses on remote communities—is piloting a different model.

Many communities are torn by conflict between and within families. This can make it difficult to succeed with a traditional community development model. The Strong Family model focuses instead on harnessing the strength of the Aboriginal family, which, even under enormous pressure, has remained the core of Aboriginal life. The program develops community capacity by concentrating first on building the capacity of family members to identify and tackle the issues that face them. The families then form a core that can build community strength from the bottom-up. The approach requires a different way of working with families, communities and services from traditional approaches.

(Cummings & Dean, 2005)

Engaging people from culturally and linguistically diverse (CALD) groups

Ip, Johnson and Everingham (2005) argued with their 'Brisbane' paper that CALD groups as with other groups that are harder to reach 'are too often not involved in the decisions that directly affect their lives' (p.1). Khakbaz (2005) further argued that the engagement of culturally diverse communities require two conditions—that of building the capacity of communities to participate and to be able to do so within a system that is sufficiently flexible to accomplish such capacity building.

Griffiths (2005) proposed moving multicultural mental health into the mainstream with strategies that include a national approach which focuses on specific needs of those with a CALD background. She suggested that a framework which provides for a

structural re-development of approach is required to bring about permanent change in attitudes and participation.

Strategies exist to engage groups that are hard to reach such as CALD groups. There are ways by which it may be possible to encourage diversity of voice for participants in cancer support and training. Research from Scotland (Brittain, 2001) recognised a need to identify and 'engage' hard-to-reach groups as an initial step. To achieve these aims they conducted extensive fieldwork, going out to the communities rather than expecting members of the community to go to them.

Previous work identified

In Australia, a key project, *Consumer and Provider Partnerships in Health Project* aimed to strengthen, enhance and sustain Community Advisory Councils in Western Australia so that effective consumer participation in the planning, delivery, monitoring and evaluation of local health care services occurred with ongoing training of members of the Community Advisory Councils. This report conveyed how consumers' needs and expertise were included, successfully, in participation and training planning through the inclusion of local community advisory councils (2007). Described was a purposive attempt to engage culturally and linguistically diverse groups (CALD), disability and Aboriginal groups. Views from these groups were sought with the intention of establishing strategies for inclusion into the planning, delivery and evaluation of their health. Suggestions such as: developing a critical mass of representation; a consideration of distinctive cultural and health needs; accessibility of participation; and development of trust with respect for difference were all proposed as ways to engage these groups. Similarly, in Melbourne, Brackertz and Meredith (2007) asked why some groups are hard to reach and proposed that strategies to engage these communities need to be geared to the target population.

The NSW Government Department of Planning (Elton Consulting, 2003a) proposed ways of engaging people from culturally and linguistically diverse backgrounds. These comprehensive strategies provide a guide on how CALD communities can be engaged in discussions on health decision-making. They suggested:

- Identifying representative bodies to contact for advice, depending on the ethnic composition of your area. (If in doubt, contact the NSW Community Relations Commission, Ethnic Communities Council or nearest Migrant Resource Centre.)
- Using appropriate methods to publicise community engagement events
 - Ethnic media
 - Existing community networks
 - Multicultural organisations.

- Community engagement needs to be conducted in a language that people can understand. This includes written and spoken language
 - Translations of publicity
 - Written information
 - Surveys and reporting in languages other than English
 - Interpreters for presentations and input from participants.
- Allowing resources and time for the translation and interpretation of publicity, background and presentation material and reporting of outcomes.
- When translating material into different languages, making sure the style and content are culturally appropriate.
- Using accredited interpreters and avoiding reliance on family members and friends.
- Being familiar with established protocols when working with an interpreter.
- Considering whether people might feel more comfortable being consulted by others of the same gender, or from the same community.
- Recognising that some people may be illiterate in their own language as well as English—they will require verbal communication strategies, not formats that rely on literacy such as surveys.
- Avoiding venues that could cause offence to certain groups; for example, licensed clubs with alcohol or gaming machines, church halls.
- Making allowances for cultural practices or events that may reduce attendance. Avoid conflicts with festivals and holy days.
- Considering culturally appropriate dietary requirements for refreshments. If possible use caterers from the ethnic community.
- Wearing appropriate clothing that does not offend any group.
- Being aware that some cultures have different commitments to time and do not consider it important to arrive at the time specified.
- Being sensitive to rifts and rivalries within and between cultural groups. In these cases consider the need for separate processes.

- Considering any specific cultural patterns of relating. It may not be culturally appropriate for women to speak out in front of men. Consider the need for seating and speaking protocols and for separate consultations.
- Being sensitive when asking for some types of information. The concept of community engagement may be unfamiliar to some people who may not trust the process. They may be cautious in providing information or expressing a personal viewpoint. Seek collective, rather than individual views; for instance, through focus groups rather than individual survey, to help allay these fears.
- Being sensitive to the particular needs of new migrants, refugees and humanitarian entrants, who may have additional fear of authority, concerns about confidentiality, an eagerness to please, and a poor understanding of what is expected of them in the community.

Results of database search

Papers found during the database search seemed to agree that the facilitation of community discussion in the form of focus groups enabled engagement of CALD communities. Smith (2007) described the approach used by a community health centre to create information for their CALD community that both informed and engaged that group. She described ten steps taken in the development of their approach to the project. These were: defining their purpose; with whom do they need to consult? What is the capacity of the organisation to take on the project? and the levels of participation they need from the organisation; What resources are needed? What tools and methods do they need to select? How to evaluate the project; how to implement the project; what did they achieve? How to make changes sustainable? Smith described how they used focus groups and working with individual community members as their main tools of engagement to prepare DVDs with health information developed to address the needs specific to the local communities. These strategies concurred with those described by Rayal (2002) who compiled similar strategies of engaging CALD communities in the UK.

One project described how CALD communities were included and listened to. Named 'Listening to ethnic communities about diabetes' was promoted as delivering best practice in CALD community engagement (Karantzas & Kirwan, 2004). Though the health professionals in this project had expertise in diabetes control, they worked through their different CALD communities to develop culturally-specific programs as an engagement strategy. These communities were of Chinese origin, Mediterranean and Pacific Islander and the strategies included the identification of key people within each of the identified communities, and, with their guidance, ran focus groups with the intention of finding ways to support the different CALD groups to access culturally-specific diabetes information. Resulting from this project was the development of a culturally-specific resource directory. It was launched through community radio with the input of key group members.

Chan and Quine (1997) also described the use of focus groups to identify the health needs of migrants from China. With the help of interpreters, Chinese health workers participated in a series of focus groups. In following up on suggestions from the focus groups it was planned for specially trained health care workers who were proficient in Cantonese and Mandarin to take a key role in communicating health information to these communities. Such strategies encouraged decision-making to be taken by the Chinese community.

Cameo case

The Chinese Cancer Society of Victoria Inc. (CCSV), established in 1996, is a registered charity that supports people from a Chinese background whose lives are affected by cancer—from diagnosis through to recovery or bereavement. The Society provides services that are run by members of the Chinese community; among them health professionals, cancer survivors and carers.

In one project the Society put together a DVD 'Life a long journey forward' for the use of consumers, their families and friends. The DVD explores the experiences of people affected in some way by cancer as a way to support those from a Chinese cultural background through cancer treatment in Australia. It is produced in English, Mandarin and Cantonese. 'We all experience the world through our own language and culture and this is particularly the case in times of distress' the DVD explains. It also aims to provide health professionals with insight into cancer for someone from a Chinese background.

(Chinese Cancer Society of Victoria, 2003)

Engaging people with disabilities

Disability, under the *Disability Discrimination Act 1992*, means that people who have a disability could have:

- Total or partial loss of the person's bodily or mental functions; or
- The presence in the body of organisms causing disease or illness; or
- The malfunction, malformation or disfigurement of a part of the person's body; or
- Disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- A disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour.

The NSW Government Planning Department (Elton Consulting, 2003a) has set out strategies on engaging people with disabilities. These same strategies can also be used as ways to approach and tools to engage people with a disability:

- Ensure the venue and its associated facilities are accessible for people with a disability.
- Consider not only people in wheelchairs or with mobility problems but also people with hearing aids who may need a hearing loop installed, appropriate facilities for people with vision impairment, choosing a venue that enhances ability to listen and concentrate and is free of features that might trigger particular conditions.
- Allocate resources and allow sufficient time to meet any specific needs, such as providing information in alternative formats (Braille, Plain English, audio), signing or interpreting services and support workers.
- Hold small gatherings rather than large meetings to enable greater participation by people with communication or cognitive difficulties.
- Be sensitive to language when referring to people with disabilities and avoid words and phrases that stereotype, stigmatise or demean individuals with a disability.
- Allow enough time for people with communication or cognitive difficulties to express their views.
- Community engagement events need to be short for those who need care and for carers who usually have only limited time away from their responsibilities.
- Consider the need for help with transport or other support and allow extra time.

Results of database search

The Centre for Developmental Disability Studies carried out a literature review for the NSW Department of Ageing, Disability and Home Care (Centre for Developmental Disability Studies, 2004). It concerned appropriate and effective models of client participation in their own care planning. Reported was how people with a disability and their carers had formed their own support networks and ways of being involved in the planning of care. They considered that it was important to link in with these established ways in order to expand horizons and consequently take control of and be participants in their own care. This review considered involving individuals within the broader scheme of their community and within service provision. Highlighted was the importance of ensuring that staff are trained in a way to support such a model of care.

The Brotherhood of St Laurence (Hillier, 2007) described a project where they put such strategies into action, identified in the previous literature review. It was proposed that people living with a disability become isolated and their activities of daily life, social participation and actions are restricted due to lack of financial ability, limited access to transport as well practical difficulties associated with disability. Hillier reported how the Brotherhood included people with a disability in health promotion activities to increase their physical activity and improve nutrition and mental health. Such tools of engagement facilitated feelings of self-worth and built on past employment, hobbies and interests. The use of volunteer peer mentors also encouraged an expansion of leisure and recreational activities appropriate to the needs of the individual and carers of people with a disability.

This approach was proposed to improve the quality of life and sense of belonging as well as motivating participants to become involved in their community and improving their social networks. Respite was also given to carers, but rather than staying at home, they were reported to enjoy meeting other carers during an organised leisure activity. It seemed that the interaction between the people with a disability, their carers and the volunteers provided an environment for dynamic social exchanges.

Quibell (2005) described her involvement in a *Living history project* that explored the experiences of living with a disability. As tools of engagement, this project used the telling of stories, the sharing of experiences and the discovery of ways of being heard. Participants in this project considered that this project promoted a greater understanding by others of the difficulties faced by those living with disability. It also provided the opportunity for the 22 participants with a disability and 17 carers to speak for themselves. Importantly, it was felt that it led to social, systems, personal and lifestyle changes for those involved. One participant who used a wheel-chair stated:

My pet thing is kerbs, cobblestones, footpaths, and I know they are being changed but around [this area] cobblestones are a problem. Literally a pain in the neck because I drive a chair with chin control ... it took about 30 years to get this street's footpath done with many letters from me ... it was done in 1998.

(Quibell, 2005 p.8)

Cameo case

A project, Oak Enterprises, described how people with a disability are employed with funding from the federal government and presented as a case study in the Department's e-news (Department of Families, Housing, & Community Services and Indigenous Affairs, 2008). Funded by Supported Employment Services, Oak Enterprises provides vocational activities through a variety of occupations, which are integrated with support services. Their vision named 'Bridging the Gap to

Independence' reflects their stated approach to flexible, specialised support for people with disabilities, in the workplace, day centres and accommodation. The intention is to foster independence and community integration, as well as increased self-esteem and enhanced quality of life.

Youth and families with young people

The website of the Australian Institute for Family Studies (2008) contains little concerning the engagement of youth and families with young people. It is concerned with engaging other organisations in the development of funding and research. Some of these organisations were studied to identify tools of engaging this group.

The website of the Brotherhood of St Laurence did provide several concrete examples of ways to engage youth and families with young people. An example of such a project is provided in the report *Changing Faces in Craigieburn and Roxburgh Park*, which describes engagement of the Craigieburn and Roxburgh Park community and programs for local families (Kelly, Levi, & Denney, 2002). Although the target of this report was not specifically young people, young people were identified as important within the community context. The strategies used were designed as all-encompassing for engaging communities in general but in ways that no one group was excluded. These were: a comprehensive review of the community to develop a profile of the demographics, strengths, gaps, existing organisations and services and the state of future planning and development of the areas; identification and consultation with key community members; community consultations and strategic planning with the communities. The intention to 'directly engage the community in shaping services that meet their needs most effectively' (Kelly et al., 2002 p.4).

This approach was supported by a Victorian Government publication (Office for Children, 2007). The strategic framework states that there is:

A focus on ... family-focused practice, which recognises that a range of means exist to engage children and young people, and that services need to identify and consider their wishes and needs within the context of family circumstances and through interventions that focus on the family as a whole.

(Office for Children, 2007 p.4)

The government of Western Australia sought direct input from young people via a feedback mechanism The Youth Register is a list of young people who have expressed an interest in becoming a member of a government board or committee. The register matches young people with government agencies, boards and committees so that they

can play an important role in government decision-making. Some young people are supported to provide policy advice on particular issues; others are consulted about the best approach to an issue and some oversee government enterprises (Government of Western Australia, 2008).

A Northern Territory government publication (Millonig, 2006 p.3) emphasises that to be effective in reducing smoking by young people: 'Any new efforts need to engage youth in their own campaigns that recognise and oppose the forces that attract them to smoke'. In NSW, a program entitled 'Play now, act now' <http://www.playnowactnow.net.au/07/> is a competition that engages young people in the development of resources around health, political, ethical issues of drug and alcohol use.

Indeed, Queensland Health (2002) proposed a range of methods for working with particular populations to identify their issues. Questionnaires, focus groups, interviews and community consultation can identify both the issues and the way to approach them. In this way the NSW Government commissioned a series of focus groups to provide creative feedback as well as proposing that action research is a method of effective engagement with young people (Department of Communities, 2002). Action research has been described as an ideal way to engage people, not only in the identification of their own concerns but also in discovering ways to improve their situation (Dick, 2003; Wadsworth, 1998).

Results of database search

Many of the findings from the database search equated youth health engagement with employment or as members of a family. Health engagement was seen in holistic terms as 'being employed' or as 'being a member of a family'. Youth engagement was seen as a part of training and education or by capturing their role within the family. For instance, the Dusseldorp Skills Forum (2007) placed finding out about youth health in the context of their social health.

Long (2006), in his discussion about youth engagement, 'The Flipside of Gen Y' explained that account must be taken of their social context as well as training and education, and the socio-economic impact of their household. Long reported that good health was important to youth identity but that health information must engage them at work, study or at leisure.

One project described the engagement of university students at leisure (Platt, Fairnie. I., & Douglas, 2005). New students were presented with the opportunity to develop social networks based on volunteering at the university. In this way they were included in assisting with health promotion programs as well as health and fitness programs inside and outside the university. Their engagement was facilitated with ongoing support and training.

Another paper explored the importance of family connections in the health of young people (Robinson, 2006). Strong, caring family relationships were seen to promote a range of healthy behaviours, and health practitioners were encouraged to facilitate and support the development of such environments. Here it is argued that health practitioners be fully trained in supporting families with whom they are in contact, and to engage young people and their development into adults within the context of family as a whole. In this way young people are understood, supported, and encouraged in their health decisions.

Approaching young people within their locality is also proposed by Nabben (2007). He suggested that youth participation must take a whole-community approach and that engagement practices need to be designed in the contexts of their lives. Nabben proposes that such engagement is complex and could require an advocate to ensure their needs are promoted. He also warned against tokenism when considering the needs of youth and the ultimate risk of their alienation.

Cameo case

The City of Swan, Perth, Western Australia, Australia (Local Government)

“Youth Development” is widely used to describe types of activities that engage young people in order to assist in their positive development. The City of Swan instead applied the term more as community development with young people. The City has developed a model that focused on creating and supporting opportunities for communities to develop their own youth activities, rather than local governments themselves running them.

The City of Swan youth development model—by coming back to core community development principles—is creating active, committed communities working to enhance the opportunities for their local young people. This is most visually evident by the fact that within the City there are four independent community-based youth services/centres, and other significant community-based youth initiatives.
(Strelein, 2005)

People with a mental health condition

The WHO describes mental health as:

... a state of complete physical, mental and social wellbeing in which the individual realises his or her own abilities, can cope with the normal

stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.

(World Health Organization, 1986)

Organisers of the upcoming International Conference on the Promotion of Mental Health and the Prevention of Mental and Behavioural Disorders consider that the creation of opportunities for social engagement, inclusion and connectedness are important to mental health and social participation. For details see:

http://www.margins2mainstream.com/call_for_papers.php#determinants

In April 1992, the Australian Health Ministers endorsed the National Mental Health Strategy as a framework to guide mental health reform over the period 1993 to 1998 (Australian Health Ministers & Commonwealth of Australia, 2003). The Strategy provided a framework for national mental health reform to move from an institutionally-based mental health system to one that is consumer focused, with an emphasis on supporting the individual in their community. The Strategy was re-affirmed in 1998 with the *Second National Mental Health Plan* and again in 2003 with the endorsement by all health ministers of the *National Mental Health Plan 2003–2008*.

In terms of engagement the latest National Mental Health Strategy explains that:

Ultimately, the strategy seeks to engage all members of the community in a partnership to improve the mental health of the Australian community. The 2003–2008 Plan will see partnerships with other sectors such as housing, education, welfare, justice and employment, to assist with the recovery of those experiencing mental health problems and mental illness. (Australian Health Ministers & Commonwealth of Australia, 2003 p.3)

The National Mental Health Plan Steering Committee (2003) published a consultation paper on the National Mental Health Plan that incorporated the notion of engagement for long-term support and mental health care. The need for an overall inclusive approach to the development of a national mental health strategy was found throughout the document: 'That mental health care should be responsive to the diverse needs of the Australian population ...' (p.8).

A report entitled *Weaving the Net: Promoting Mental Health and Wellness Through Resilient Communities* (Mental Health Council of Australia, 2006) proposed that engagement for mental health needs to take a whole-community approach. This report proposed nurturing and building trust to 'catalyse engagement' (p.9), and also the engagement of community members to facilitate civic engagement. Such engagement that included local health services and education facilities was seen to build and activate social networks that led to a community approach to improving mental health. Case studies from around Australia were cited that described how different communities were engaged, with feedback from those who participated. Here common

themes were found to be woven throughout, such as the value of service coordination, networking, the tyranny of distance and participation in outcomes.

Results of database search

Stacey and Herron (2002) referred to the National Mental Health Strategy and a need to include consumer participation in its implementation. They argued that this cannot be achieved without a process of engagement, dialogue and partnership with consumers. They also proposed that barriers are structural in nature and result in insufficient training and support for mental health workers to put policy into practice, and clarity about who their consumers are and ultimately how to engage them. Research from New Zealand (Nairn, Coverdale, & Claasen, 2006) suggests that there needs to be greater understanding of the portrayal of mental illness by media outlets to prevent the development of engagement barriers between community and those with a mental illness. The authors were concerned that an overly dramatic portrayal of mental illness promotes a sense of isolation, which encourages people to attempt to hide any illness.

An example of a different approach is where a dental program set about identifying consumers with mental illness and complex dental health problems (Burchill, Fernbacher, Lewis, & Neil, 2006). They argued that poor dental health and hygiene can lead to long-term issues of poor diet and infections. It was noted that health workers within the program needed a high level of training and understanding to cope with the range of behaviours they faced. They identified as effective the combined engagement strategies of:

- Assertive outreach
- Health promotion
- Collaboration with other mental health teams for cross-promotion
- Efficient, flexible and sensitive clinical care
- A funding model which guarantees free care
- Peer modelling.

For successful local uptake of national and state policy, complex structural and organisational change is considered necessary (Tobin, Matters, Luxin, & Smith, 2001). This paper argues for models of mental health care that actively engage the larger policy picture with services and consumers at the local level.

Descriptions of such processes are achieved by Lammers (2002), who presented case studies of consumers engaged at the local level. He described how mental health consumers were active within hospitals and communities, contributing towards improvements in mental health care that take into account the needs of those receiving that care. He suggested that it is only possible to achieve such engagement with successful role models and a process of mentoring others within the consumer community of mental health. Such mentors, who have experienced mental illness, act as dialogue facilitators for people with mental health conditions.

Cameo case

Illawarra Institute for Mental Health

In this case focus group discussions were used to explore the opinions of young people with mental health illness to reduce help-seeking barriers and increase appropriate help-source engagement. Most of those who attended agreed that getting some kind of help was good. Consistent with previous research, participants suggested that strong positive relationships with potential help-givers were very important for their current help-seeking. A context of trust and confidentiality was also very important. Participants explained they were more likely to seek help if they trusted a potential help-source to understand their problem and to offer useful help. The young people described approaches that were consistent with assertive outreach, follow-up and therapeutic alliance. They articulated the importance of strong relationships with help-givers for maintaining engagement. Participants thought that help is efficacious when they are free to make choices and is important to continued engagement. In the view of the researchers, all strategies that promote appropriate help-seeking must be implemented within a context of relationship and trust. Furthermore, all strategies must be implemented in such a way that young people are empowered.

(Wilson & Deane, 2000)

SUMMARY OF KEY FINDINGS

In summary, the key findings of this review were that:

- There is a need for more rigorous and independent evaluations of community participation tools to improve knowledge of what tools are effective in engaging consumers in health decision-making.
- There are common effective approaches and tools between the special interest groups.
- There is a lack of formal literature that documented and critiqued effective approaches and tools.
- It was possible to identify literature that described approaches and tools for the engagement of special interest groups in areas other than health.
- Despite the lack of literature in some areas, some good accounts of approaches and tools to engage special interest groups in health decision-making, especially at the ground level, are available.
- Community health services are seen to have important roles in the coordination of engagement projects.
- Strong policy at federal and state level, which supports and is coordinated with action at the local level, provides the impetus and confidence to implement special interest group engagement.

GUIDES AND PUBLICATIONS

There follows a collation of some practical ideas and information on community engagement that includes the engagement of diverse groups and which can be applied to health.

Australian Government

Australian Government publications on community participation:

<http://www.aifs.gov.au/sf/participationonline.html>

Queensland

A Queensland government website entitled 'Get Involved' provides guides to getting involved in Queensland Government decision-making. A series of publications provide practical ideas and information on community engagement:

http://www.getinvolved.qld.gov.au/share_your_knowledge/resources/guides_publications.html

Link to the Brisbane Conference on Engaging Communities:

<http://www.engagingcommunities2005.org/ab-theme-4.html>

Victoria

The Department of Sustainability and Environment produced a document on 'Effective Engagement'. The following site outlines the principles of community engagement, the benefits, a toolkit for developing engagement plans and case studies. While targeting the environment, the resources have relevance in many other contexts:

<http://www.dse.vic.gov.au/DSE/wcmn203.nsf/childdocs/-0B996EB412EAB883CA2570360014F01A?open>

Western Australia

'Public Participation' links to other sites and resources, including how to get funding, how to facilitate a consultation and where to get recognition through awards. The links take you to other innovative community engagement sites around Australia and the rest of the world:

<http://www.citizenscape.wa.gov.au/index.cfm?event=publicParticipation>

Aboriginal and Torres Strait Islander Partnerships

'Communicating Across Cultures' is a resource designed to assist people wishing to consult with Aboriginal communities. This site provides a series of protocols for use when dealing with individuals and communities to assist communication across cultures:

<http://www.atsip.qld.gov.au/resources/cultures.cfm>

International sites

Asset Based Community Development Institute, Northwest University, USA, presents an approach to engagement with a series of documents considering the strengths in the community rather than just focusing on the deficits or needs:

<http://www.northwestern.edu/ipr/abcd/kelloggabcd.pdf>

Centers for Disease Control and Prevention presents a comprehensive analysis of community engagement as it relates to health. It includes some literature for review:

<http://www.cdc.gov/phppo/pce/index.htm>

Healthy Cities, Healthy Communities presents information about building healthy communities with tools, tips, theory and stories. Their definition of engagement includes:

“What builds health, it turns out, also builds community, public safety, wealth, and families. These are systemic tasks that require all the energy and creative thought a community can muster, from everyone who can make a difference, from business, the media and government to the poor and unrepresented.”

http://www.well.com/user/bbear/hc_articles.html

International Association for Public Participation

International Association for Public Participation’s ‘Public Participation Toolbox’ presents techniques to share information with ways to inform, contact, connect and involve the community. It details various techniques of engagement with advantages and disadvantages of each tool:

http://iap2.org/associations/4748/files/06Dec_Toolbox.pdf

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3

Internet-based consultation as an approach for engaging consumers, in health and non-health sectors

Review Question 3:

For older people residing in the community who are at risk of hospitalisation and may become long stay patients:

- a. What are the best ways to identify/best access points for people at risk of hospitalisation due to physical or mental problems?
- b. What models to prevent inappropriate admission have been evaluated?
- c. What is the evidence that the models are effective in preventing admissions?

EXECUTIVE SUMMARY

***In the new 'networked society' communities are no longer 'local, all encompassing and stable' but instead communities are being created of shared interests and ideologies.
(Wellman et al., 2003 p.20)***

This focussed literature review was conducted by Health Issues Centre for the Sax Institute. It aimed to review what evidence exists from the health and non-health sectors about internet-based consultation as an approach for engaging consumers, including:

- a. The effectiveness of internet-based consultation for engaging consumers
- b. Methods for increasing access to electronic consultation
- c. Advantages and disadvantages
- d. Any existing guidelines.

This review found that the development of internet-based consultation is gaining momentum. However, it seems that the development of tools and processes for conducting internet-based consultations are occurring in an ad hoc way and lack systematic evaluation. The review identified that there is considerable opportunity to consult and engage consumers and communities using internet-based technologies, and there are examples of it throughout Australia and internationally.

Internet-based consultation provides an avenue for enhancing the dialogue in a whole-community approach that includes all stakeholders. Rather than replacing effective consultation methods with internet-based consultation, organisations would be advised to implement internet-based consultations as a strategy for extending their reach to include groups that would otherwise be excluded.

This literature review also reveals a need for a 'whole-community' policy. Such a policy would value collaboration between state and federal governments, between health and community services, business groups and individuals, in order to implement effective and sustainable internet-based community initiatives.

Further to the development of internet-based consultations must be a recognition of the need to apply the core principles of engagement such as listening to community needs, respect for cultural characteristics, working 'with' rather than 'for' community, and ensuring sustainable action.

This review concluded there was a real need to conduct systematic process and impact evaluations of internet-based consultation initiatives. Evaluation approaches should

use qualitative and quantitative methods and involve communities from the beginning in the design and implementation of the evaluation.

The effectiveness of internet-based consultation for engaging consumers

This review examined the effectiveness of internet-based consultation for engaging consumers and communities. It found that internet-based consultations allow consumers and communities to participate at their convenience and are an avenue for fostering information exchange, support, and the development of ideas. Internet-based cancer support groups for breast cancer patients were found to provide a range of health and wellbeing benefits for women who used them.

Methods for increasing access to electronic consultation

Government agencies within Australia are increasingly exploring the feasibility of implementing internet-based consultations, including the use of blogs and on-line polling. Internet-based consultations are being developed in the context of eDemocracy and common tools being considered include on-line surveys, polling, email lists and discussion groups. Access and equity are two key principles that need to be considered when implementing internet-based consultation approaches.

Advantages and disadvantages

This literature review considered the advantages and disadvantages of electronic consultation. It proposes that such modes of communication present considerable advantages. These involve:

- Connecting communities and individuals within community
- Connecting communities with health and social services thereby encouraging two way flows of information and knowledge
- Connecting services across time and space
- Extending notions of connectedness rather than diminishing them
- Providing modes of communication between members of a social group such as young people or people with a particular health or social concern.

However, progress has brought about its own challenges. These involve:

- Divisions between those who have and those who do not have access to electronic communication.
- Those who cannot afford such access or who do not have the knowledge to use electronic technologies.
- Those who, through their use of these modes of consultation, become prey to lack of controls.

Existing guidelines

This review notes that there exists a considerable number of guidelines which are informal and devised by and for specific on-line groups. It is apparent that guidelines for electronic use are guidelines only in the sense that they cannot necessarily

translate into controls. Therefore, those who use such forms of engagement need to appreciate the possibility of inappropriate uses of electronic consultation or engagement. Judicious use of such forms of engagement is advised, and careful consideration should be given to the various guidelines for successful and sustainable engagement.

REVIEW STRATEGY

This review was conducted between February and March 2008. It examined relevant Australian and international studies that relate to internet-based consultation as an approach for engaging consumers that were published following 2000. It was not intended as a systematic review but instead aimed to provide an account of the state of the evidence related to the questions. The process to conduct the review is detailed below.

Familiarisation with the different fields for each review

- Cochrane Collaboration
- Internet databases (e.g. Google academic, Dogpile).

Systematic review of each state in Australia

- Government bodies
- Research centres
- Peak bodies
- Local government
- Community health services.

Formal search

- La Trobe on-line library – journals, databases including:
 - Informit, Ovid, CINAHL, PubMed, BMJ
 - Humanities and Social Sciences Collection
 - On-line Journals: Australian Journals On-line, ISI Web of Knowledge
 - Sage Journals
 - Oxford Journals
 - Health Promotion International.
- Other databases, including Medline, Medscape, CHAIN.

A range of search terms were used including the following:

Search terms – general	Terms used in combination
Ehealth	Evaluation and consultation
e-health	Impact evaluation and internet based consultation
Public opinion	Rural and remote and consultation
Community consultation	Engaging consumers and communities
Internet based consultation	Internet based consultation and communication
On-line based consultation	
Edemocracy	
Evaluation	
Blogs	
Internet based cancer support groups	
On-line forums	

Further search

- Systematic search of other countries previously identified
- Websites associated with eDemocracy.

Literature review limitations

The following limitations were associated with this review:

- Time constraints.
- The absence of systematic evaluations concerning internet-based consultations; therefore, critical instances could not be identified.
- Restrictions on the scope of the review.

LITERATURE REVIEW

Introduction

To conduct this literature review it was necessary to define the term 'internet-based'. Consequently, for this question we took as the definition of 'internet-based' information to be information exchanged via:

... a network that links computer networks all over the world by satellite and telephone, connecting users with service networks such as e-mail and the World Wide Web.

(Encarta Dictionary UK English)

Therefore, this review question considered a range of ways that the internet could be used for communication and consultation. These included internet-based information, email communications, on-line questionnaires, video streaming, forums, blogs, surveys, polling and e-bulletins. Of note is the frequent occurrence of combining telecommunication with electronic internet-based communication in ways that could be said to be interactive. This review also notes an overlap in findings for the effectiveness, the advantages and disadvantages of internet-based consultation.

The effectiveness of internet-based consultation for engaging consumers

Increasingly, within Australian and also around the world, studies and projects are being undertaken to involve citizens in internet-based consultations. These internet-based consultations are happening through a range of strategies and are being led by both public and private sectors. Findings on the effectiveness of these processes are slowly emerging.

Work conducted by access2democracy—a non-profit organisation based in Athens and New York—has suggested that two of the key drivers for internet-based engagement are a feeling among citizens that they are being 'left-out' of political processes, and the need by governments to find ways to engage their citizens (Korakas, 2004).

Quan-Haase and Wellman (2002b) claimed that communication and engagement via the internet has the capacity to support many information exchanges among geographically dispersed people. What has been found about the effectiveness of these internet-based exchanges is presented here.

Information provision

Increasingly the internet is being used to provide health information to consumers, and consumers are also becoming more comfortable with using the internet to access health information. To examine the effectiveness of a website that provides health information, researchers in the United States compared the use of a diabetes

information website between high school students ($n=51$) and clients of a Medicaid clinic ($n=50$) [(Whitten, Mackert, & Love, n.d). Through observations, the researchers found that:

- The interactive survey (Are you at risk?) which assessed users' risk level for diabetes was the most engaging aspect of the site for clients.
- The 'why should you care?' and 'how to keep your risk low?' sections were very popular with both students and clients.
- The interactive sections of the website were the most engaging and interesting for both clients and students.
- The clients welcomed the introduction section on how to use the site but the students found this boring.
- There is a possible relationship between an individual's health literacy and the amount of knowledge they are able to gain through a website.
- Health information provided on websites needs to be kept simple.

Within Queensland, videoconferencing has been used as a platform to deliver health information to rural communities (Faulkner & McClelland, 2005 p.91). Videoconferencing facilities are available in every community, and health information sessions have been conducted by Women's Health Queensland. The videoconferences usually last for 90 minutes and can often involve up to 12 sites. An evaluation of the process found that 89 communities participated in the videoconferencing, with the following impacts identified:

- Women tend to discuss the video-conference with family and friends
 - Increased collaboration between services within communities
 - Increased use in health services; follow-up events occurring as a result of the videoconference
 - Increased understanding of the role of local health services
- (Faulkner & McClelland, 2005).

Information and support

Internet cancer support groups are emerging around the world as an avenue to foster exchange between people who are experiencing cancer. These internet cancer support groups are generally used by women and particularly for women who have experienced breast cancer. Studies examining the effectiveness of these groups have found that internet cancer support groups produce numerous health and wellbeing benefits for women. Some of the benefits include:

- Reducing depression and cancer-related trauma, as well as perceived stress, among women with primary breast carcinoma (Winzelberg et al., 2003).
- Receiving/giving information; receiving/giving social support; optimism toward breast cancer, increased skill or ability to cope with the disease, improved mood, decreased psychological distress, and strategies to manage stress (Rodgers & Chen, 2005).

- Feeling empowered by the exchanges of knowledge and experience (Terp Høybye, Johansen, & Tjørnhøj-Thomsen, 2005).

Rodgers and Chen (2005) have also been interested in the use of on-line technology to engage women with breast cancer. They undertook a longitudinal content analysis of 33,200 postings from an on-line breast cancer bulletin board, and then collected "life stories" from 100 women randomly selected from the bulletin board. They observed that, over time, there was a positive shift shown in women's attitude towards the breast cancer and on-line community, and a positive correlation between the amount of participation by a woman and her psychosocial wellbeing.

Considerations

Eun-Ok et al. (2007) and Im and Chee (2008) suggested there are challenges to ethnic minorities and particularly ethnic minority women when it comes to their use of on-line cancer support groups. Eun-Ok et al. (2007) proposed that cancer patient groups tend to be middle-aged, well educated female and middle class. Im et al. (2007, p.335) concluded that "the selective characteristics of cancer patients attending internet patient support groups reflect their interactions with their environments, and that gender and ethnicity are crucial factors influencing interactions". Im and Chee (2008) were so concerned at why ethnic minority cancer patients—particularly women—do not participate in internet-based support groups that they undertook a literature review using a feminist perspective. They concluded that in order to understand the reasons ethnic minority women do not use internet -based cancer support groups it is important to recognise the following influences:

- Gender and ethnic differences in attitudes towards internet-based cancer support groups
- Gender and ethnic differences in approaches to seeking help
- Gender and ethnic-specific contexts.

Electronic democracy

Internet-based consultations are increasingly being developed as a platform to foster citizen participation in democratic processes. This work is happening in Australia as well as internationally under the banner of eDemocracy. Korakas (2004) claimed: 'it is possible that eDemocracy can enrich and reinvigorate democratic dialogue between policy makers and citizens, encouraging a greater sense of citizenship making citizens feel better represented and closer to politics and institutions' (Korakas, 2004).

For example, the Victorian Department of Sustainability and Environment (2007) sees that electronic democracy 'increases the number and variety of people who exercise their democratic rights through comments sent to decision-making bodies with regard to proposals and issues'. It claims that electronic democracy is effective in the following ways, in that it:

- Creates a virtual public space where people can interact, discuss issues and share ideas.
- Allows citizens to participate at their own convenience.
- Can reach a potentially large audience readily.
- Facilitates interactive communication.
- Costs little to set up.
- Disseminates large amounts of information effectively and without distortion.

Steps to implement eDemocracy have been occurring in Europe and there is potential for Australia to learn from recent examples. At an E-participation and Local Democracy Symposium in Budapest an example on the use of eDemocracy in Greece was presented (Korakas, 2006). In reflecting on the process of conducting on-line voting and surveys, Korakas warned that the 'adoption of ICTs to "enhance" democracy must be backed with increased accountability, transparency, security, privacy, and democratic control mechanisms otherwise it can pose a real threat' (Korakas, 2006, p.8).

Based on his work in Greece, Korakas shared the following reflections on the implementation of eDemocracy approaches:

- Badly implemented, eDemocracy, can be used as an excuse to 'justify' policies on the grounds as being in line with the 'eVoices' of the people.
- Citizens are eager to participate in the policy formation process, if it is for real.
- eDemocracy does not compete or substitute traditional institutions. It builds on them.
- eDemocracy processes and citizen involvement must be integrated in real policy-making processes to have real effect. The sole introduction of on-line questionnaires and forums does not automatically make things better.
- eDemocracy can become a tool for a more democratic global governance scheme, but only if existing or future global governance institutions adopt them and basic conditions are met (accessibility, capacity, knowledge, culture of participation).
- eDemocracy should not be exclusively bonded with the PC and the internet: necessary penetration of these to deliver real eDemocracy for all citizens might never come. We have to keep looking at highest penetration mediums and potential future convergence of technologies.
- Collaboration, exchange and pooling of information and resources is needed on a global scale, to deliver transferable good practice and learn from others' mistakes.
- eDemocracy is still in its infancy: real experiments are crucial for the development of good practice early on (Korakas, 2006).

Whyte and Macintosh (2002) suggested evaluations of eDemocracy initiatives have not developed as quickly as public debate about their potential impacts. They argued that evaluations of eDemocracy approaches need to be conducted using both qualitative

and quantitative methods in order to create an understanding of the contexts that underpin their successful implementation.

Methods for increasing access to electronic consultation

Increasing access to electronic and internet-based resources has been both a priority and a challenge facing local and international policy-makers. For example, in Australia, a key policy priority has been to increase access to electronic technologies for rural and remote communities; internationally, a common challenge has been to ensuring access to electronic technologies for socially vulnerable and impoverished communities.

As internet-based technology advances, access and equity issues will need to be addressed if the internet is to be used by public institutions for consultations. This review found examples of broad approaches being undertaken by large institutions to increase consumers' and communities' access to electronic consultation. The review also found descriptions of commonly used internet-based tools and this information has also been included.

Broad approaches

Many of the challenges facing actions to increase access to electronic consultations were covered at the 14th International Congress on Information Technology in 2004. At this conference the Secretary General of CIVICUS suggested that to move forward with electronic democracy, a comprehensive sustainable development approach was needed to ensure that people become 'part of the structure of political rights, democracy and participation' (Naidoo, 2004, p.3). To increase access to and use of electronic consultation he recommended:

1. Discussion and Engagement – strengthen, expand, and diversify citizen engagement through effective and meaningful on-line discussions.
2. Information and Civic Education – Increase the use and relevancy of democratic information that inform citizens about elections, governance, the media and public affairs to help us meet public challenges.
3. Capacity – Build the skills, experiences, and capacity of citizens, for example, to extend access to computer education.

To increase citizen access to technologies he recommended the following:

- a. Foster market conditions conducive to the provision of affordable communications services.

- b. Explore other complementary means, including access through publicly available facilities.
- c. Give priority to improving network access, especially in underserved urban, rural and remote areas.
- d. Pay particular attention to the needs and constraints of the socially underprivileged, people with disabilities and older people and actively pursue measures to facilitate their access and use.
- e. Encourage further development of "user-friendly", "barrier-free" technologies, including mobile access to the internet, as well as greater utilisation of free and publicly available contents in a way which respects intellectual property rights.
- f. Re-invent governments in ways that revitalise democracy, requiring new organisational forms, innovative technology application, intersecting public-private partnership.
- g. Create new responsibilities and roles for civil servants. They need to ensure high-quality information and analysis within properly organised novel forms of democratic involvement and in a new relationship to politicians.

Electronic democracy

The Australian Government Department of Finance and Deregulation is interested in the use of internet-based consultations, and particularly the use of blogs, to engage Australian citizens. In 2007 it sought public submissions to examine the potential use and effectiveness of an Australian Government Blog as a tool for public consultation (Australian Government Department of Finance and Deregulation, 2008).

The Australian Government defines a blog as:

a website which provides a list of text articles, videos or opinion pieces and allows people visiting the website to post their own comments on the articles.
(p.5)

The submission process revealed strong support for a nationwide consultation blog as it was seen as an effective way 'to encourage free and frank expression of opinion across social and economic divides' as well as to provide 'true collaboration where citizens have the opportunity to actively shape policy' (Australian Government Department of Finance and Deregulation, 2008, p.4). The Australian Government reported on the key findings of the submission process; these included the following:

- People would be keen to register to participate in government discussion and 'would tell their friends about it'.

- People would like to receive an acknowledgement or reply to encourage their ongoing participation.
- Discussion is likely to be thoughtful and include a range of perspectives.
- Issues of credibility and representation were raised.
- People expect the discussions and consultations to be moderated by government.
- People expect the site to be secure and offer privacy.
- The skills and expertise of people managing the site is critical to its success, including their ability to not stifle or steer the discussion.
- The consultation blog should be supplementary to existing processes.
- People like the concept of a one-stop-shop for consultations, claiming its potential to 'facilitate greater citizen engagement'

(Australian Government Department of Finance and Deregulation, 2008, p.4).

Within Queensland it seems that the Queensland Government is committed to using the internet, interactive digital television and mobile communication systems, to increase public participation in government decision-making (Queensland Government, 2004). Its commitment to eDemocracy is driven by a desire to provide avenues for individuals and communities in Queensland to engage with each other, become informed about issues, and consult and exchange views on matters of public concern.

To implement its policy platform, the Queensland Government is working towards achieving the following priorities:

- Continuing to build on-line consultation opportunities and further developing the government's community engagement website (www.getinvolved.qld.gov.au), including refining its functionality, usability, look and feel.
- Actively exploring national and international trends regarding the use of different ICTs for government and community democratic engagement.
- New initiatives including developing ways to use and promote on-line tools to augment existing community engagement activities such as Ministerial Regional Community Forums.
- Working with other government agencies and levels of government to increase their capability to undertake on-line engagement regarding policies and services.
- Building capacity of those involved in democratic engagement to make the best use of eDemocracy processes and tools

(Queensland Government, 2004)

One example of a project in Queensland has involved cultural institutions such as libraries and museums partnering with remote communities to create digital cultural content. In some cases remote communities have been trained in the use of digital technologies and supported to create their own digital postcards and storyboards which can be accessed on-line (Russo & Watkins, 2005).

Similarly, in Victoria, the Department of Sustainability and Environment is committed to implementing electronic democracy. They have developed guidelines for government agencies and key stakeholders to use for developing internet-based consultations and recommend that the public be able to participate in expressing their opinions through websites, via email and on-line voting.

Consumers' involvement in e-health

To enhance the interest and involvement by consumers in e-health, Consumers' Health Forum of Australia (CHF) has implemented several e-health projects to improve consumers' access to their own health information, and to access clinical knowledge and tools to optimise their personal health outcomes.

The Consumers' Health Forum is currently implementing a project 'to influence government investment in the e-health agenda by encouraging appropriate demand from consumers for various e-health initiatives' (www.chf.org.au). The key objectives of the project are to:

- Encourage consumer demand nationally for various e-health initiatives that enable them as active partners in their own health.
- Empower consumers to lobby health care providers, professional health service organisations and statutory bodies, to adopt e-health initiatives that improve consumer outcomes.
- Inform consumers about e-health opportunities for consumers through workshops, the CHF website, newsletters, publications and other media opportunities as they arise.
- Liaise with the Australian Government Department of Health and Ageing to inform consumers nationally of e-health initiatives in their state or region.
- Continue to support consumer representatives on national e-health committees, and provide informed consumer representation that is well linked to health consumer organisations and networks.
- Maintain CHF activities that provide consumers with an opportunity to give input on and be kept informed about e-health developments across Australia.

Methods to consult

The literature and available guidelines detail several common tools that are being used to engage consumers in internet-based consultations. Such tools include list serves, newsrooms, internet-based polling and internet surveys.

Anabel Quan-Haase and Barry Wellman (2002b), through their work on internet and social capital, suggested that internet users regularly participate in on-line communities through list serves and newsgroups (Quan-Haase & Wellman, 2002b). In one paper Quan-Haase and Wellman (2002b) cited a study by Horrigan (2002) that investigated the reasons people seek out mailing lists and news groups. The common reasons identified included:

- Seeking out individuals who share similar interests
- Being involved in related trade associations (50 % of respondents)
- Being a part of a shared interest groups (50 %)
- Participating in sports fan clubs (31 %)
- Participating in television fan clubs (29 % (Horrigan, 2002)).

Internet-based polling and surveys conducted via computer networks are being used by some institutions to obtain quick input from large numbers of people. The International Association for Public Participation (2006) claim they are appropriate for attitudinal research and can provide instant analyses of results. They can also be used in multiple areas and some are finding that the novelty of the technique is improving the response rate.

Internet or web-based response polls can provide input from individuals who may be unlikely to attend meetings or normally respond to a consultation. When setting them up, planners need to be careful that they don't create polls which generate more information than they can respond to. The results of such polls are often not statistically significant as it is difficult to control for reach or representation (International Association for Public Participation, 2006) .

Advantages and disadvantages of electronic consultation to engage consumers

Discussions are currently taking place within the Australian community about whether the increasing use of the internet and associated technologies leads to concomitant increased community advantage (ABC Radio, 2008). This review of the literature acknowledges that such topical discussions are incomplete but nevertheless has attempted to capture its essence.

Advantages in the use of electronic consultation will be considered first, addressing in turn different forms of electronic use together with their purposes. However, it must be noted that the presented reasons in favour of electronic engagement being an 'advantage' can also implicate disadvantages which will then be considered in the following section.

Advantages

This review regards the notion of creating advantage for those at a disadvantage as being core to the notion of advantage when considering the use of electronic consultation. The advantages will be considered according to those forms of consultation identified earlier in this review.

Surveys

It is noted that internet-based surveys, although still in their infancy, are becoming increasingly popular because they are believed to be faster, better, cheaper, and easier to conduct than surveys using more traditional telephone or mail methods (Schonlau, Fricker, & Elliott, 2002). Schonlau, Fricker and Elliot discussed advantages and disadvantages of using electronically based surveys. In brief, they proposed that:

- Internet surveys may be preferable to mail or telephone surveys when a list of e-mail addresses for the target population is available, thus eliminating the need for mail or phone invitations to potential respondents.
- Internet surveys are well-suited for larger survey efforts and for reaching some target populations that are difficult to reach by traditional survey methods.
- Web surveys are conducted more quickly than mail or phone surveys when respondents are contacted initially by e-mail, as is often the case when a representative panel of respondents has been assembled in advance.

The use of 'Survey Monkey'—one form of internet survey—is said to allow advantages for those surveyed as well as for those conducting the survey. Flicker, Savan, Kolenda, and Mildenerger (2008) described the use of web-based surveys for social research in Canada. They reported on how participation between service providers and community members via the internet facilitated communication on a range of Canadian health and social issues. It was proposed that such approaches using internet surveys as a communication tool could be an important way to address complex environmental and social issues.

Connecting with social networks

One of the key advantages identified from the advances of modern electronic communication is the ability to communicate with those who can respond to such electronic consultation. Boyd and Ellison (2007) proposed that since the introduction of social networking via the internet millions of users have integrated sites such as MySpace, Facebook, Cyworld and Bebo into their everyday lives. They argued that people connect with other people on these sites:

... based on shared interests, political views or activities. Some sites cater to diverse audiences, while others attract people based on common language or shared racial, sexual, religious identities. (p.2)

Baker (2008) proposed that his research showed how people, especially young people, become engaged in blogging to work through personal problems, with others who have

had similar experiences, which may then assist them in solving their difficulties. In this way people become engaged in an on-line community where they can share experiences, seek help yet remain largely anonymous if they wish. While reporting on the results of Baker's research on the ABC radio program *The World Today* (2008), the suggestion was made, 'that blogging can be good for your health'. Indeed, Baker proposed that 'people who actually started to blog, felt more socially integrated'. One of those interviewed for *The World Today* said:

I'm kinda a grumpy, short-fused person so it turned into sort of like occasionally venting about people or situations at work and I found that when I would reiterate like a frustrating situation, it kind of made it comical and I could see the funny side to it.
(ABC Radio, 2008)

The interview explained how she also shared her blogs with her mother and friends, confirming—as Baker explained—that through the use of these 'on-line diaries' people could become more connected to the real world through their social and on-line networks.

Hookway (2008) from the University of Tasmania has conducted extensive social research into the development of blogs since 1999. He suggested that blogs are a bottom-up way of finding out about what people in the community are thinking and:

A new way of constructing self and doing community in late modern times ... a new addition to the qualitative researcher's toolkit ...
(Hookway, 2008 p.91)

The notion that electronic communication extends contact with communities appears to be a strong advantage for internet-based forms of communication. A further way for people to 'meet' others with whom to share their experiences is through the use of on-line forums such as the one for advanced breast cancer named bcaus:

<http://www.advancedbreastcancergroup.org/>

Women from around Australia who have been diagnosed with advanced breast cancer (metastatic breast cancer) 'meet' at this forum. They can share experiences, information, knowledge, connections with each other in a way not available from other sources. Moderated by other women with advanced breast cancer, this site has proven to be popular as a way for breast health services to 'hear' about and engage with the concerns of these women that would otherwise not necessarily be available.

Knowledge transfer: Engaging social networks through the internet

Information, and health information in particular, is becoming increasingly sought-after through the internet. A concomitant rise in information sites on the internet has grown to fill such a need.

The Cochrane consumer library provides evidence-based information and seeks, in return, consumer reviewers and feedback as part of their collection of evidence:

<http://www.latrobe.edu.au/cochrane/HKN/HKNBulletins.html>

<http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/ForPatients.html>

This review has found other instances of engaging social networks via the internet and where exchange of knowledge occurs. These are now considered.

Quan-Haase, Wellman, Witte, and Hampton (2002) argued that when the internet is incorporated into the 'routine practices of everyday life' the level of community engagement and the amount of 'social capital' is augmented. They further proposed there is a community fear that electronic communication—including the television and the internet—could lead to a weakening of private relationships, a decline in community gatherings and a general disengagement from community life. Yet, recent evidence suggests that rather than leading to less community involvement, electronic communication has supplemented a sense of community. Indeed Quan-Haase et al. (2002) proposed that their research showed how those who interact on the internet increase their social interaction within the 'lived' community. These findings are supported by further work from this group (Wellman et al., 2003) who suggested that the sense of community needs to be reconsidered in the light of new modes of communication.

Hargittai (2007) differentiated between the users of such electronic communication. Her research showed how social network sites are more likely to be used by younger people; a phenomenon also remarked on by Baker (2008). Both authors, together with Wellman et al. (2003), acknowledged how, as these young people age, the use of electronic communication and social interaction will become embedded in community life.

Engaging rural communities

Jain and Jain (2008) wrote to the editor of the Rural and Remote Health on-line Journal stating how scientific publications have undergone considerable change with electronic technology. They commented on how: 'on-line discussion facilitates interaction, exchange of ideas and healthy debate and provides opportunity for readers to react'. It is this same technology that other literature proposes has led to increased engagement with rural communities.

Rural people and their communities can feel isolated by their experiences of disease, social circumstances, in their work and/or by distance. This is a common cause of disadvantage frequently discussed by the Rural and Remote Health Journal: <http://www.rrh.org.au/home/defaultnew.asp>

Russo and Watkins (2005) reported on how increasing use of technology strengthens local industry, thus presenting rural communities with an opportunity to engage in traditional forms of community with greater knowledge and know-how. Ways of

connecting such communities can be achieved through electronic consultation, through the dissemination of information, purposive seeking of feedback, connecting communities through forums, blogging, email trees, and with the broadcasting of e-news and on-line journals. One such e-news is put out by the Department of Human Services in Victoria:

http://www.dhs.vic.gov.au/rrhacs/ph_bulletin/bulletin140208.htm

Another is posted by the Rural Health Foundation, which advertises itself as a non-government, not-for-profit organisation that provides an education and information lifeline to rural and remote health professionals:

<http://www.rhef.com.au/>

E-news bulletins share information throughout Australia as a way of connecting disparate self-help groups:

<http://thewesterninstituteofselfhelpwishinc.createsend.com/viewEmail.aspx?cID=69488E0A337D9EEC&sID=DD1721BC1297F1B6540AA5A2134D6B3D&dID=5CB9CB5A1CE688CE>

Women's Health Queensland Wide has used such a technology platform to deliver health information to rural communities (Faulkner & McClelland, 2005). They reported on the success of their venture proposing that:

... the social capital provides benefits for communities under the principles of bonding, bridging and linking ...
(Faulkner & McClelland, 2005 p.1).

They concluded that this model works in health service provision and 'delivers benefits to health professionals and the community beyond content' in that the technology engages the community as a whole (p.1).

Martini (2005) also reported on a rural community engagement project using interactive multimedia. The intent was to engage a community in Western Australia with an action research study as a way of enabling a community to solve its problems collaboratively. Results showed how communications between health services and community improved considerably.

Filling the gap with technology?

There appears to be an increasing use of electronic technology to fill the gaps in medicine. These gaps have been identified as complex areas of communication across time and space so that doctors can link with patients in remote centres, but also assists in the collation of complex information that was originally collected manually. In current times experts share their findings and knowledge of these forms of communication at conferences where the possibility of presenting findings without attending is available. It is argued that by professionals developing their own consultation networks the

development of professional knowledge about improving community engagement is facilitated:

http://ec.europa.eu/information_society/newsroom/cf/itemdetail.cfm?item_id=3573

Indeed, some commentators propose that the internet is replacing formal medical opinion for consumers of health information, and access to on-line information removes the need to go to your local doctor.

http://www.emarketer.com/Articles/Print.aspx?id=1005835&src=print_article_graybar_article&xsrc=print1_article

Whether such information sources are beneficial for community engagement in their health outcomes is currently under debate and will be discussed later.

Interactive engagement with multiple technologies

The majority of the studies used for this review have indeed reported on the benefits of using multiple technologies that include electronic versions. It seems that the advantages become more obvious when single methods are used alongside and with other modes of communication. The Women's Health Queensland project, previously described, explained how video-conferencing alongside email support, video-streaming and an internet chat room have multiple uses for health and community services. These uses include:

- Enabling rural communities to participate in research via focus groups
- Peer support networks for isolated individuals
- Outreach in launching government policies or consumer activism
- Special events such as memorial service for families who have experienced a neonatal death or miscarriage
- Increasing rural representation on communities and boards in South East Queensland (Faulkner & McClelland, 2005).

Hookway (2008) argued that using blogs together with other tools offers an extension to social networks not previously available. He used the examples of off-line diaries, tape recorders and telecommunications to complement on-line writing as a way for to researchers to access and understand social processes across space and time.

Disadvantages

It seems that in the development of electronic consultation disadvantages occur. These are either enhanced by existing disadvantage or exist in the presence of the developing technology. Many of the studies already reviewed discuss the advantages but they also consider the disadvantages. For instance, Schonlau et al. (2002) recognised problems with on-line surveys in that participant selection can be difficult as addresses are not geographically identified. On-line identification also presents a form of selection bias towards people who are technologically proficient.

Hargittai (2007) identified how the internet amplified the social divide. Her study of university-age students documented how those with parents of low socio-economic status were less able to use the internet while those who came from a higher socio-economic grouping were seen to be the greatest users.

The Queensland Women's Health Project identified, among the many advantages, some key barriers (Faulkner & McClelland, 2005). Lack of access to the necessary facilities was one barrier. Another was the lack of finances to fund the programs so that all the communities would have equal access. Such barriers raise the risk of groups or communities who are not 'connected' missing out on accessing the benefits and knowledge from electronic consultation and communication. Martini (2005), from Western Australia, also considered that the lack of facilities precluded a number of local residents from taking part in her action research project.

Jain and Jain (2008) identified a lack of access to the internet as well as the non-ownership of computers as leading to a considerable 'shortcoming' in the development of electronic communication. Furthermore, they were concerned about how older people were more 'comfortable' with traditional letter writing and not willing to learn the new technologies.

Information on the internet in general and veracity of websites have been considerably critiqued by commentators. This includes the validation and authentication of information content. Commentators are concerned that people may consider on-line information to be more reliable than that available from more formal, traditional sources. Below is a series of sites where some of this commentary takes place:

http://www.ehealthurope.net/comment_and_analysis/296/finding_reliable_health_information_on-line

<http://www.cbc.ca/health/story/2008/02/11/breastcancer-on-line.html>

Is it possible for lay people to understand on-line health information?

<http://www.americanchronicle.com/articles/52593>

Warning about on-line information:

http://www.nzherald.co.nz/topic/story.cfm?c_id=137&objectid=10496221

Existing guidelines

Discussion presented here about the review of internet guidelines will be interspersed with website addresses for ease of access to the reader.

It could be argued that the majority of guidelines found in this literature review for use with electronic consultation and communication are informal, in that they have been developed by a group for the use of that group, without regard to a legally proscribed format. However, some formal guidelines were found that had been developed by an

organisation or government that could be termed authoritative. Interestingly, the US legislature appears to be moving towards legislative control of personal privacy with regard to electronic information. It must be noted that there may already be some form of legislative control with legally-based guidelines, which this review was unable to discover.

Internet law sites:

Australia

<http://www.apf.gov.au/library/intguide/SP/Australiainternet.htm>

USA

<http://www.internet-law-attorneys.com/internet-law.html?qclid=CLS34u-Zi5lCFQybPAodORvjDw>

UK

<http://www.snet.net/support/legal/interact.shtml>

Calls for legislation to secure people's privacy such as current legislation being considered by the American Congress:

<http://www.govhealthit.com/on-line/news/350219-1.html?type=pf>

Questionnaire guidelines

Lumsden, who works for the Institute for Information Technology, Canada, has authored many papers on guidelines for questionnaire design for on-line surveys:

http://iit-iti.nrc-cnrc.gc.ca/personnel/lumsden_jo_e.html

One particular paper of note is entitled *On-line – Questionnaire Design Guidelines* (Lumsden, 2006). She proposed that such survey guidelines should combine the principles from the fields of web design and traditional questionnaires. Lumsden set out easy-to-follow steps towards the development of a simple survey.

Developing guidelines for on-line groups

Some authors consider that it is essential to define on-line groups both in quantitative and social terms (Ridings, 2006; Xu, John, & Boucouvalas, 2006). Some websites, however, present practical guidelines to setting up chat room and on-line forums; these appear easy to use:

<http://www.dtcc.edu/cs/rfc1855.html>

<http://www.albion.com/netiquette/>

<http://www.caringon-line.com/chat.html>

Dealing with groups of people at a distance using electronic consultation presents its own challenges in terms of guideline development. Paulus (2007) discussed the development of such guidelines with distance learning within a theoretical framework that concentrates on peer interaction. She suggested that establishing common ground is essential and that the group needs to develop collaborative ways of working within a practical framework rather than with an imposed method.

Formal guidelines

In Australia the Federal Government and the ACT provide some formal guidelines to assist government agencies with their use of websites, particularly concerning personal information. These guidelines are clear and appear to be of practical assistance to agencies wishing to consult with its community via the internet:

http://www.privacy.gov.au/internet/web/index_print.html

The Australian Federal Government has recently developed a site with guidelines to facilitate the interaction between government and community via e-technology. They cite the key principles as being commitment, community focus, community capability, mutual respect and trust, flexible interactivity together with responsibility and accountability:

http://www.agimo.gov.au/services/consultation_blog

These guidelines have a reference to further guidelines from the OECD on community engagement:

<http://www.oecd.org/dataoecd/9/11/35176328.pdf>

The Queensland Government has also produced some guidelines for on-line community engagement:

http://www.getinvolved.qld.gov.au/share_your_knowledge/resources/ceconnect/index.html

The above site also has reference to guidelines for e-democracy and the use of emerging technologies:

http://www.getinvolved.qld.gov.au/share_your_knowledge/resources/documents/pdf/edemocracy_pf.pdf

This review noted considerable concern about the posting on the internet of accurate health information and the need for guidelines not only for internet sites but also in the management of health information as discussed in the following on-line paper:

http://www.mja.com.au/public/journal/34_1_2005/randall.html

Indeed, the Federation of State Medical Boards in the USA has seen fit to publish their own guidelines to ensure 'the delivery and accessibility of health care' (p.2):

http://www.fsmb.org/pdf/2002_grpol_Use_of_Internet.pdf

The intention of these guidelines was to support the interaction of physicians and patients.

For further resources a collation of websites of guidelines are presented below.

Internet links and guidelines

<http://www.library.ci.corpus-christi.tx.us/internetuseguide.htm>

<http://www.doe.virginia.gov/VDOE/Technology/OET/internet-safety-guidelines-resources.pdf>

http://www.fsmb.org/pdf/2002_grpol_Use_of_Internet.pdf

<http://www.isoc.org/HMP/PAPER/122/html/paper.html>

http://www.dhrm.state.va.us/hrpolicy/policy/pol1_75.pdf

<http://www.unc.edu/~twTaylor/teaching/300/archives/netiquette.html>

<http://blog.plaxoed.com/?p=41>

<http://www.surveymonkey.com/>

Chat room and forum guidelines

<http://www.caringon-line.com/chat.html#GUIDELINES>

<http://www.copd-international.com/Library/chat-guidelines.htm>

<http://www.supernanny.co.uk/Help/User-Guidelines.aspx>

<http://www.webhostingtalk.com/rules.php>

SUMMARY OF KEY FINDINGS

In summary, the key findings of this review were that:

- There is a need for more rigorous and independent evaluations of internet based consultation.
- Internet-based consultations allow consumers and communities to participate at their convenience and are an avenue for fostering information exchange, support and the development of ideas.
- Internet-based cancer support groups for breast cancer patients provide a range of health and wellbeing benefits for women who use them.
- Government agencies within Australia are increasingly exploring the feasibility of implementing internet-based consultations including the use of blogs and on-line polling.
- Internet-based consultations are being developed in the context of eDemocracy; common tools being considered include on-line surveys, polling, email lists and discussion groups.
- Access and equity are two key principles that need to be considered when implementing internet-based consultation approaches.

Advantages of internet-based consultations include:

- Connecting communities and individuals within community
- Connecting communities with health and social services thereby encouraging two-way flows of information and knowledge
- Connecting services across time and space
- Extending notions of connectedness rather than diminishing them
- The provision of modes of communication between members of a social group such as young people or people with a particular health or social concern.

Key challenges to the use of internet-based consultations include:

- Divisions between those who have and those who do not have access to electronic communication

- Those who cannot afford such access or who do not have the knowledge to use electronic technologies
- Those who, through their use of these modes of consultation, become prey to lack of controls.
- A considerable number of guidelines exist that are informal and devised by and for specific on-line groups.
- It is apparent that guidelines for electronic use are guidelines only in the sense that they cannot necessarily translate into controls.
- Judicious use of such forms of engagement is advised; as is careful consideration of the various guidelines for successful and sustainable engagement.
- Internet consultation is best used in combination with other modern technologies together with traditional forms of consultation to reduce the risk of bias and increase participation.

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