



THE UNIVERSITY OF  
NEW SOUTH WALES



CENTRE FOR CLINICAL GOVERNANCE RESEARCH

# PUBLIC INVOLVEMENT IN HEALTH SERVICES



LITERATURE REVIEW, CITATIONS AND  
ABSTRACTS

***The Centre for Clinical Governance Research in Health undertakes strategic research, evaluations and research-based projects of national and international standing with a core interest to investigate health sector issues of policy, culture, systems, governance and leadership***

## ***Public involvement in health services Literature review, selected citations and abstracts***

### **Duration of project**

June 2006

### **Search period**

1966 to June Week 3 2006

### **Key words searched**

Advisory councils or committees  
Citizens' councils  
Consumer organizations  
Consumer or patient advocacy  
Consumer or patient participation  
Patients or consumers or citizens  
Public involvement  
Health planning councils

### **Databases searched**

- Medline from 1966
- Embase: Excerpta Medica from 1988
- CINHALL from 1982

### **Criteria applied**

We searched the terms listed above. All articles that met the criteria were included in the review. An analysis of the results, plus a bibliography including citations and abstracts of these articles is presented on the next pages.

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## 1 INTRODUCTION

In this report we provide a review of the literature on public participation in health services. We identified the literature using the search strategies outlined in section 2, *Method*, of this report. The authors used a variety of search terms, relating to patient, consumer and public participation in health services, to interrogate three databases: Medline, searched from 1966, Embase, from 1988 and CINHALL, from 1982. Grey literature, including organisational reports, evaluations and handbooks on participation and materials was also identified. Relevant journals were hand searched for additional references, not identified through the previous methods. The bibliographies of relevant articles and reports were searched for any additional materials. The literature was reviewed by the first author, and then interrogated using Leximancer, concept analysis software. The results were reviewed for validity and updated and synthesised by the second author. This document provides a broad overview of the role of, and participatory mechanisms for, the public in health services.

## 2 METHOD

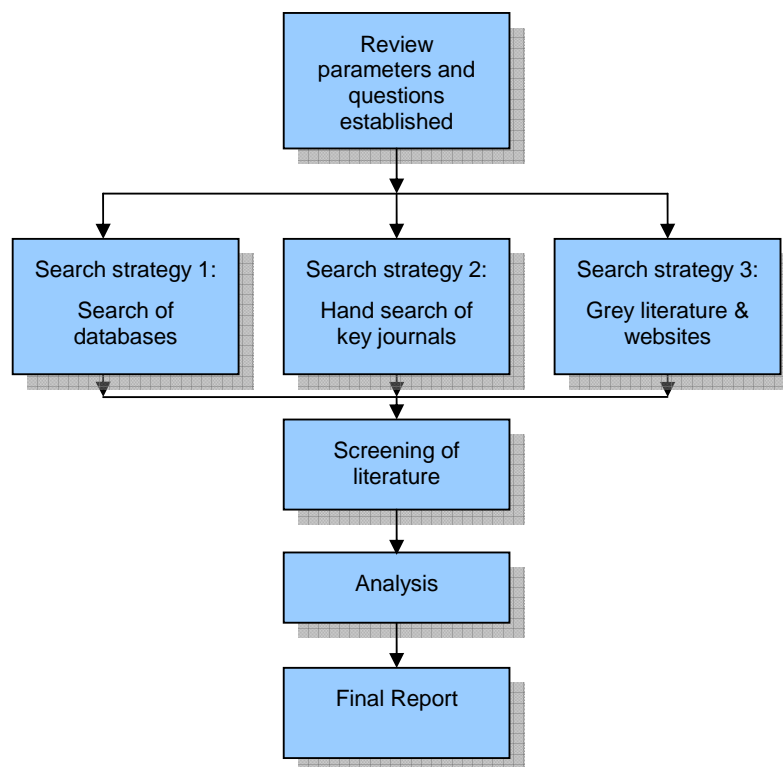
### 2.1 Overview

We conducted a bibliographic investigation using Medline, CIHNAL and Embase, interrogating the terms listed in Table 1 below. The search uncovered 722 articles. The articles were downloaded into Endnote version 9.0. These were supplemented with additional articles identified through searches of grey literature (n=16) and hand searching of journals (n=29). Having removed duplicates and incomplete or inappropriate references, we then created a Word file of all references, citations to the articles and abstracts where they were available. We then conducted an analysis of the citations and abstracts using Leximancer, a computerised concept analysis tool, and derived a conceptual map which summarises the key concepts in the literature. We then used this map and the ranked list of concepts to further analyse the literature.

### 2.2 The review process

Figure 1 provides a schematic diagram of the review process. It shows how five stages and three search methods were used to conduct the analysis of the literature.

**Figure 1: Schematic diagram of the research process**



## 2.3 Search strategies

### 2.3.1 Search strategy 1: search of databases

Databases were systematically scrutinised to find all relevant published literature. Endnote version 9.0, a software package for further processing and analysis.

With the systematic reviews, two authors independently reviewed the relevance of references, identified key articles, and qualitatively analysed them. The search terms were as follows (Table 1). “\$” is used for truncation in the databases searched. “Exp” refers to exploding the category, that is, searching as widely as possible.

**Table 1: Search terms**

1. exp Patients
2. consumer\$
3. citizen\$
4. exp Advisory Committees
5. Advisory Council\$
6. exp Health Planning Councils
7. Citizen\$ Council\$
8. exp Consumer Participation
9. exp Patient Participation
10. exp Consumer Organisations
11. exp Consumer Advocacy
12. Patient Advocacy
13. Public involvement

### 2.3.2 Search strategy 2: hand search of journals

Hand searches were conducted of key journals using the search terms in Table 1. The journals were selected mainly because of the frequency with which they deal with issues of public involvement in health care. A second factor was the availability of the journals to the researchers. These following journals were hand searched for 2004-2006:

- British Medical Journal
- Clinical Governance: An international journal
- Health Expectations
- Health Policy and Planning
- International Journal for Quality in Health Care
- Social Science and Medicine.

### 2.3.3 Search strategy 3: grey literature and websites

Grey literature includes materials such as unpublished reports and evaluations, policy documents, guidelines and handbooks relating to public involvement in health services. We used the search terms identified in Table 1 to conduct these searches. A total of 16 additional references were identified using this method. These references were included in the Endnote file and Leximancer analysis.

Websites of health services in Australia, the United Kingdom, the United States of America, Canada and New Zealand were searched for key organisational documents relating to public or consumer involvement. The selection of material was limited to English speaking documents.

Key websites searched included:

- Department of Health, United Kingdom
- Health Canada
- National Institute for Health and Clinical Excellence (UK)
- New Zealand Ministry of Health
- Organisation for the Economic Co-operation and Development
- State Departments of Health, across Australia
- World Health Organization.

All of these websites provided additional links to other relevant agencies and reports. Both published and unpublished articles and reports were downloaded.

## 2.4 Analysis of searches

### 2.4.1 Database search

A large body of literature on incident reporting was identified through the three databases selected. This literature covers incident monitoring and reporting processes and mechanisms, as well as the use of this approach in patient safety and quality improvement. Table 2 presents the results of this search. As previously, where “\$” is used for truncation in the databases searched, “exp” refers to a MESH term which has been “exploded” for the widest possible capture of the term.

**Table 2: Search results**

SEARCH TERMS	DATABASE RESULTS: NUMBERS OF ARTICLES		
	MEDLINE	CINHAL	EMBASE
1. exp patients/	35771	80708	1984747
2. exp consumers/	44920	835	6826

3. citizen\$. mp.	5803	1394	3756
4. 1 or 2 or 3	85322	82770	1992164
5. exp advisory committee/	3883	456	458
6. advisory council\$	286	114	113
7. health planning council\$	708	3	1
8. citizen\$ council\$	6	4	9
9. 5 or 6 or 7 or 8	4843	573	580
10. 4 and 9	389	41	164
11. exp consumer participation/	20289	3814	49
12. patient participation	10704	1770	782
13. public involvement	132	55	134
14. 11 or 12 or 13	20289	4182	830
15. 9 and 14	287	13	3
16. exp consumer organisations/	21188	4275	25
17. exp consumer advocacy/	2090	1060	56
18. exp patient advocacy/	18986	4295	171
19. 16 or 17 or 18	41012	9370	251
20. 9 and 19	404	15	6
21. 10 or 15 or 20	504	53	165

After screening for relevance, a total of 722 articles was identified. Once duplicates were removed, 687 articles remained. The abstracts of all these references were read and those references which were incomplete, not directly relevant to the topic (such as those relating to broad environmental health campaigns or those relating to patient's participation in their own health care), or contributed little additional information were removed. This left a final total of 312 articles. The authors used a grounded method<sup>1 2</sup> of analysis which included reviewing this literature to secure a clear categorisation of topics.

#### 2.4.2 Hand search of journals

Articles identified through the hand search of key journal had already been identified through the database search. A total of 29 additional in-press articles and editorials were identified in this manner.

#### 2.4.3 Grey literature and websites

The grey literature contributed additional useful references (16), particularly an evaluation of the Citizens' Council of the (UK) National Institute for Clinical Excellence (NICE),<sup>3</sup> and handbooks and evidence guides for consumer participation in health and other public services.<sup>4-7</sup> While user literature is rarely peer-reviewed, it does show current thinking in the field. The bibliographies of these publications provide additional references and links to other organisations, evaluations and reports.

#### **2.4.4 Content analysis**

We assessed 357 articles, papers and reports using Leximancer, concept analysis software. Leximancer facilitated the creation of a map and ranked list of the core concepts embedded in the public involvement literature.

### 3 FINDINGS AND DISCUSSION

#### 3.1 Leximancer analysis

The concept map of public involvement in health services is presented in Figure 1. From the map we can identify several broad clusters of concepts relating to: the role of the public and patients in health services: the level and focus of their involvement, i.e. health services, policy and care; and the processes and types of involvement they undertake, including through councils and consumer advisory boards. At the centre of the map is a large cluster of concepts which relate to the study of the methods and outcomes of participation.

The concept map provides a visual representation of the central issues surrounding the involvement of the public in health services. The literature is, in essence, answering four key questions: Which consumers are involved in health services? Why should consumers participate in health services? At what levels are consumers currently involved in health services? What are the mechanisms for the involvement of consumers in health services?

**Figure 1: Concept map of key concepts relating to public involvement in health services**

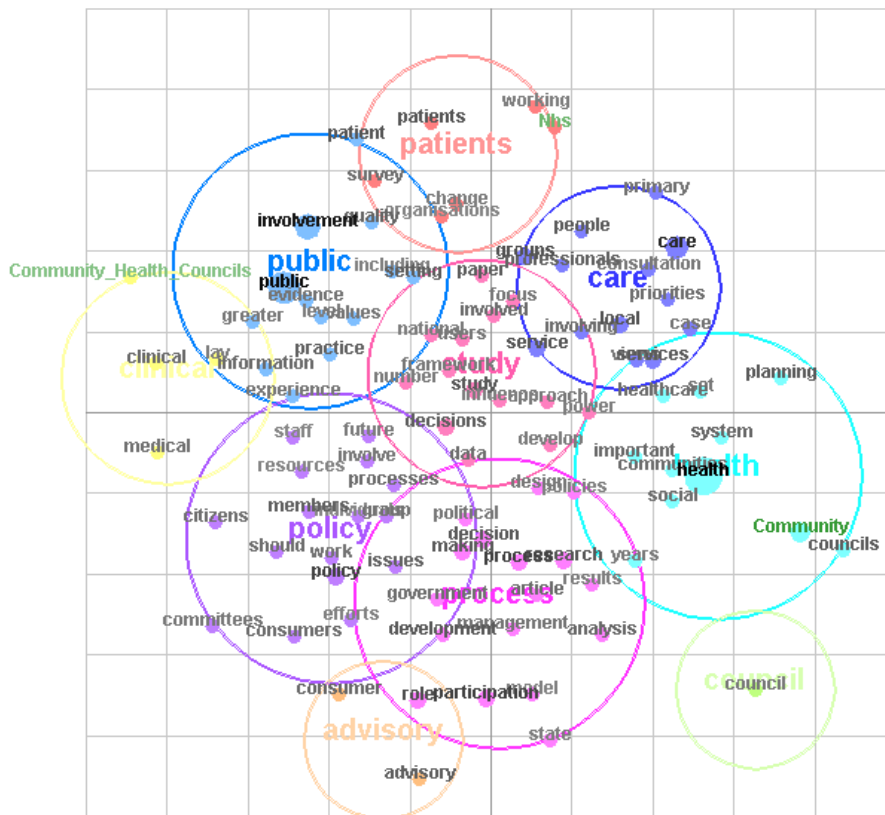


Table 3 provides a ranked list of the concepts contained in the map. The list provides insights into the relationships of concepts with each other, and the overall importance of concepts in the literature. Health is the number one concept, as would be expected, as this concept refers to the individual as well as organisational context for consumer involvement.

The list also provides further insights into the literature. Who is involved in health services? The list includes; public, community, patients, patient, people, consumers, groups, citizens, users, community and individuals. Workers include professionals and other staff. At what level are the public involved? Structurally they are involved at community, local, service or services, primary care, health system, state, national and political levels. What is the focus of their involvement? In policy, development, planning, decision making, quality, clinical practice, priority setting, management, and resource deliberations. What are the mechanisms for their involvement? Participation, councils, advisory group membership, surveys, committees, giving their views, focus groups, influencing, consultations and community health councils.

**Table 3: Ranked map of key concepts relating to public involvement in health services**

Concept	Absolute Count	Relative Count	Concept	Absolute Count	Relative Count
health	519	100%	NHS	30	5.7%
public	409	78.8%	survey	29	5.5%
involvement	293	56.4%	citizens	29	5.5%
care	183	35.2%	priorities	29	5.5%
Community	133	25.6%	medical	28	5.3%
process	99	19%	group	28	5.3%
participation	98	18.8%	primary	27	5.2%
policy	95	18.3%	work	27	5.2%
role	67	12.9%	management	26	5%
groups	62	11.9%	case	26	5%
local	61	11.7%	evidence	26	5%
patients	58	11.1%	values	25	4.8%
patient	57	10.9%	committees	24	4.6%
service	56	10.7%	users	24	4.6%
research	54	10.4%	council	24	4.6%
study	52	10%	experience	24	4.6%
development	52	10%	political	24	4.6%
planning	51	9.8%	views	24	4.6%
services	51	9.8%	set	24	4.6%
decision	50	9.6%	design	23	4.4%
making	49	9.4%	focus	23	4.4%
councils	48	9.2%	greater	23	4.4%
people	48	9.2%	involve	23	4.4%
paper	47	9%	framework	23	4.4%
setting	47	9%	approach	23	4.4%
decisions	45	8.6%	consultation	23	4.4%
advisory	44	8.4%	years	22	4.2%
members	43	8.2%	lay	21	4%
practice	42	8%	number	21	4%
professionals	40	7.7%	state	21	4%
issues	40	7.7%	develop	21	4%
quality	39	7.5%	national	21	4%
consumer	36	6.9%	change	21	4%
system	36	6.9%	future	21	4%
analysis	35	6.7%	level	21	4%
important	34	6.5%	results	20	3.8%

information	33	6.3%
clinical	33	6.3%
article	33	6.3%
processes	32	6.1%
communities	32	6.1%
involved	32	6.1%
healthcare	32	6.1%
social	31	5.9%
data	31	5.9%
consumers	31	5.9%
should	30	5.7%
involving	30	5.7%
government	30	5.7%

influence	20	3.8%
working	20	3.8%
efforts	19	3.6%
policies	19	3.6%
including	19	3.6%
model	19	3.6%
organisations	17	3.2%
Community Health Councils	17	3.2%
resources	17	3.2%
staff	16	3%
individuals	16	3%
results	20	3.8%
influence	20	3.8%

## 3.2 A brief assessment of the literature

In this section we further examine the four key questions about public involvement in health services as identified by the Leximancer analysis. This review is brief. It is intended to provide an overview of the key findings and highlight issues of concern, to the Clinical Excellence Commission (CEC), rather than an in-depth discussion of the topics.

### 3.2.1 Which consumers are involved in health services?

The movement to involve consumers and the community in health services has been around since the 1970s<sup>8</sup> and has been debated vigorously for as long.<sup>9-11</sup> The debate centres on whom is to be invited to participate. As one article puts it: “patients, consumers, clients or customers?”<sup>12</sup> More particularly, who are participants meant to represent?

Draper (1997) identified a list of the types of participants in health services:

- Individuals (members of the public or citizens)
- The individual who is receiving or has received health care services (a user, consumer or client of services)
- Carers or family members who support individuals who receive health care
- Potential consumers (with unmet needs)
- Groups of consumers (who may share a common condition or experience)
- Consumer organisations (including advocacy, self-help and consumer groups and networks)
- Population sub-groups or communities (such as people from Aboriginal and Torres Strait Islander Backgrounds, who may also have unmet needs).<sup>13</sup>

The question of representation centres on which groups or communities are asked to participate, and the ability of the individuals to represent adequately the needs and concerns of group (or community) from which they are said to come.<sup>9 14 15</sup> A individual may be a nominee of someone (accountable to the group they represent for their involvement), a representative (responsible to the group for ensuring its views and policies are advanced) or simply a member with no formal responsibility to feedback information to the group, or to verify their opinions against that group.<sup>16</sup>

Nominees or representatives generally come from three types of communities or groups (although multiple memberships by a single individual are common).<sup>17</sup> The first is as a member of a local or geographic community, for example, people who live within the catchment area of the service.<sup>18</sup> The second is as a member of social or relational community, or what has been termed a community of interest<sup>19</sup> (for example, gender specific groups, groups based on ethnicity, age or disability, political interest groups and so on). The third is as a representative of an organisational community or advocacy group (for example an informal support group for young women with breast cancer may become a formal organisation, with a president, members, and the ability to raise funds and commission research).<sup>20</sup>

### 3.2.2 Why should consumers participate in health services?

The organisational support for the involvement of patients or users is said to be based on a shift in perspective of health systems from being service delivery organisations to being patient centred and patient-led.<sup>21</sup> This is usually thought of as a way ensuring accountability<sup>22</sup> and transparency.<sup>23</sup> While these principles are often said to be promoted by health services, there remains confusion about what patient centeredness and patient leadership<sup>24</sup> might mean, and how effective consumer participation actually is, in ensuring transparency.<sup>25</sup>

Nonetheless, the benefits of public participation in health services are numerous.<sup>5 6</sup> Public participation in health services is said to: assist in the identification and representation of the needs and concerns of the community;<sup>26</sup> alleviate public concerns about potentially controversial issues (eg, genetic testing);<sup>27</sup> result in the creation of a joint vision for public health programs or interventions;<sup>28</sup> increase the ability of representatives to advocate for their communities;<sup>29</sup> improve accountability, change management and resources allocation processes;<sup>16</sup> generate better options;<sup>30</sup> provide a consumer perspective on organisational issues; and encourage greater understanding between managers, workers and consumers.<sup>31</sup>

Common barriers to public involvement include: power differentials between communities and the services seeking their input; inadequate time for consultation; inadequate community infrastructures and knowledge; lack of resources or managerial skills.<sup>32-34</sup> The risks of public participation include fears of power redistribution and the unpredictable, uncontrollable and time-consuming nature of the process, and concerns centred on of issues like paternalism and racism on the part of the participants.<sup>16 33 31 35</sup>

Consumers and communities will participate if they feel the issue or activity is important or if they feel that their action will make a difference. People will also participate if different forms of involvement are acknowledge and valued, they are enabled to participate, if supportive structures are in place and if the process for participation is not alienating.<sup>36 37 38</sup>

### 3.2.3 At what levels are consumers currently involved in health services?

The public is now involved at various levels of health services and systems. Both the Organisation for Economic Co-operation and Development<sup>4</sup> and the World Health Organisation<sup>8 39</sup> have encouraged and assisted in the participation of the public in health services. At a national and State level, Australia,<sup>34</sup> Canada,<sup>40</sup> the UK<sup>5</sup> and the US<sup>41</sup> have all encouraged and created (and disbanded) various forms of public participation, including Community Health Councils,<sup>42</sup> public partnerships,<sup>43 44</sup> advisory committees<sup>45</sup> citizens juries<sup>46 47</sup> and advisory councils.<sup>44 48</sup>

The UK's National Institute for Clinical Excellence's Citizens Council provides a pioneering model for citizen participation. Although not without critics,<sup>49 50</sup> the Council, comprising 30 members of the general public, was evaluated in 2005 and found to be an "undoubted success".<sup>51</sup> This achievement was attributed to "... an appropriately concrete question, facilitation which balances the requirements of inclusivity and deliberation, and a properly supported expertise space..." Those conditions were seen to result in "... ordinary members of the public ... contribut[ing] to a national level debate." <sup>3: p4</sup> NICE's Citizen's Council is unusual in the context of public participation, because its specific brief is to provide NICE with opinions about the key issues informing the development of NICE's guidance on treatments and care in the NHS. In other words, the Citizen's Council is not a forum for consultation with representatives of communities, it is instead a forum for the deliberation of social values which affect NICE's guidance to the NHS and clinicians.

### 3.2.4 What are the mechanisms for the involvement of consumers in health services?

A common debate on the literature on participation is the question of whether participation is "real" or a simply tokenism.<sup>52-54</sup> Arnstein's (1969) seminal paper argued that only community control, delegated power (for the community) and genuine partnership was not tokenism, which was said to include placation (where the community is asked to give their opinions on a problem, but they are not given a participatory role in solving those problems), consultation and information. Manipulation (where the community is left "in the dark" about issues) is considered non-participation.<sup>33</sup> More recent writings, however, have argued against Arnstein's position, in particular in the conceptualisation of consultation and information provision as sui generis tokenism.<sup>16 55</sup>

That said, there are various ways in which individuals are involved in health systems. These include:

- Representation on advisory boards and committees
- Membership of citizens juries, panels or councils
- Providing input and involvement in the planning process through focus groups, surveys and public hearings
- As partners in joint planning structures
- In providing active consultation, advice and comment
- As members of committees and task groups examining particular issues

- As part of evaluation teams for organisation and its services
- By collecting, receiving and feeding back information
- By participating in forums, workshops and conferences.<sup>16 31 38 46 47 56-61</sup>

Once engaged with a health system, the public can contribute in broad ways. Their involvement can include participation in: decision making, needs assessments, priority setting, planning, service and strategy development, service delivery, and evaluation of the service.<sup>31 16 62</sup>

#### 4 WHAT CAN CEC LEARN FROM THIS LITERATURE?

CEC is proposing to institute a citizens' engagement and advisory council comprising 6-10 skill-based members. Members will not be required to represent anyone else, or provide feedback to or be connected to any specific group.

The literature supports as a positive strategy steps made to engender consultation with the community and encourage the involvement of groups such as this. There are no applicable studies comparing the benefits of different types of models. Where research has been conducted it is generally social science or policy assessments of single exemplars of consumer involvement.

The literature does almost universally support engagement with the community in this way, and it is in line with governments' policies over the past decade in developed health systems including in Australian jurisdictions. There is likely more to be gained than lost in doing what CEC proposes, and there is considerable risk in not engaging with the community, given CEC's mission and charter. One question is how CEC engages, and is seen to engage, with a wider group of citizens (as opposed to a smaller, more expert group such as the one envisaged). The NICE model, with a sample of 30 citizens drawn from the community, might offer an extensive range of experiences and perspectives. Perhaps this might be the next stage in CEC's thinking, after evaluating the proposed council's role, operation and contribution over a period of time.

On this latter matter, it is a crucial consideration that CEC measures the effectiveness of the council, or indeed any public participation strategy. Evaluation normally is conducted in two modes: formative, to facilitate improvement, and summative, to measure the extent of improvement. We suggest an evaluation of the council's effectiveness through a design which formulates performance indicators for council and then formatively and summatively assesses its progress against these indicators, perhaps over a two year period.

## 5 CONCLUSION

The participation of the public at all levels of health services has gained increasing momentum since its introduction in the 1970s. The core questions appear, however, to remain the same across time. Changes in the names of the people to be involved (patients, clients, consumers, citizens) have not changed the central issue: are they to be involved as individuals, as members of the public, or as formal representatives of their communities?

The literature suggests that there are three major reasons why the public should be involved in health services. The first is because it is part of the philosophy and policy if not the practice, of most developed health systems. Secondly, consumer participation appears to be beneficial, although not unproblematic, for both the health services and the consumers and communities, themselves. Finally, it may add to the transparency, accountability and acceptability of health service plans, priorities and decisions.

A variety of models for participation has developed, ranging from the incorporation of individuals into existing organisational structures and hierarchies (such as a single consumer or member of the public on a management committee or advisory board) through to advisory boards made up of local community members (such as in Area Health Services in NSW) to independent structures intended to monitor the work of the service (such as in the UK's Community Health Councils) to forums where 12 average citizens can meet to debate the issues which directly or indirectly affect their or their family's health care (as in citizen's juries). Many other forms of consultation and feedback are currently in use. The key to the method of participation appears to be not just in the appropriateness of the mechanism, but in the perception, by the community, that the mechanism is more than tokenistic and that the public's input will have a positive effect, even if, in the short term, it can sometimes be a perturbing one for the agency or health service.

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## 7 CITATIONS AND ABSTRACTS

Abbott, J. and H. Mercer (2000). "A course of action." Nursing Standard 14(41): 25.

Community health councils are best known for their A&E snapshot surveys, but their role as healthcare watchdogs is just as important.

Abelson, J. (2001). "Understanding the role of contextual influences on local health-care decision making: case study results from Ontario, Canada." Social Science & Medicine 53(6): 777-93.

Approaches to involving the public in local health care decision making processes (and analyses of these approaches) have tended to treat participation and publics uniformly in search of the ideal method of involving the public or providing the same opportunities for public participation regardless of differing socio-economic, cultural, institutional or political contexts within which decisions are made. Less attention has been given to the potential for various contextual factors to influence both the methods employed and the outcomes of such community decision-making processes. The paper explores the role that context (three sets of contextual influences more specifically) plays in shaping community decision-making processes. Results from case studies of public participation in local health-care decision making in four geographic communities in Ontario are presented. During the study period, two of these communities were actively involved in health services restructuring processes while one had recently completed its process and the fourth had not yet engaged in one. Several themes emerge from the case studies regarding the identification and role of contextual influences in differentially shaping participation in local health care decision-making. These include the propensity for communities with different social and structural attributes to engage in different "styles" of participation; the importance attached to "community values" in shaping both the qualitative and quantitative aspects of participation: the role of health councils, local government and inter-organizational collaboration as participation "enablers"; and the politicization of participation that occurs around contentious issues such as hospital closures.

Abelson, J., J. Eyles, et al. (2003). "Does deliberation make a difference? Results from a citizens panel study of health goals priority setting." Health Policy 66(1): 95-106.

How to involve the public in setting health and health care priorities is a constant challenge for health system decisions. Policy maker interest in involving the public in increasingly complex and value-laden priority setting processes has led to the use of deliberative public involvement methods designed to promote discussion and debate among participants with the objective of obtaining more informed and consensual views. These methods have not been evaluated rigorously using controlled designs with pre- and post-test measurements. We examined, using a controlled design, the effects of introducing different opportunities for deliberation into a process for obtaining public input into a community health goals priority setting process. Our findings indicate that deliberation does make a difference to participant views. As more deliberation is introduced, participant views may be more amenable to change.

Deliberation also offers the potential for views to become more rather than less entrenched. While we are beginning to understand the difference deliberation makes to participant views, we are still at an early stage in understanding the process through which these differences come about and what difference deliberation makes to broader outcomes such as civic competence, civic engagement and health policy decisions.

Abelson, J., P.G. Forest, et al (2001). Deliberations about deliberation: issues in the design and evaluation of public consultation processes (Working paper 01-04) Hamilton, Ontario, McMaster University Centre for Health Economics and Policy Analysis Research.

Abelson, J., P.G. Forest, et al. (2004). "Will it make a difference if I show up and share? A citizens' perspective on improving public involvement processes for health system decision-making." Journal of Health Services & Research Policy 9(4): 205-12.

INTRODUCTION: Health policy decision-makers are grappling with increasingly complex and ethically controversial decisions at a time when citizens are demanding more involvement in these decision processes. OBJECTIVES: To assess and revise a set of guiding principles for the design of public involvement processes generated from a synthesis of public participation design and evaluation frameworks that can be used to inform the design and evaluation of future public participation processes in the health sector. METHODS: Six focus groups held in five Canadian provinces comprising citizens with considerable experience of public participation processes. RESULTS AND DISCUSSION: Our findings suggest that citizen participants are highly critical of, and discerning about, their public participation experiences. Yet, they are optimistic and determined to contribute in meaningful ways to future public policy processes. They are clear about where improvements are needed and give top priority to what information is shared, and how, among participants and decision-makers. The views of experienced citizens mapped well onto most of the prior principles of public involvement with a few modifications. First, participants gave greater emphasis to the content and balance of information for the purposes of building trust and credibility between citizens and decision-makers. Second, participants viewed themselves, as well as decision-makers, as sources of information to be shared through the consultation process. Finally, participants stressed the importance of getting the information and communication principles right over addressing all other principles.

Abelson, J., P.G. Forest, et al. (2003). "Deliberations about deliberative methods: issues in the design and evaluation of public participation processes." Social Science & Medicine 57(2): 239-51.

A common thread weaving through the current public participation debate is the need for new approaches that emphasize two-way interaction between decision makers and the public as well as deliberation among participants. Increasingly complex decision making processes require a more informed citizenry that has weighed the evidence on the issue, discussed and debated potential decision options and arrived at a mutually agreed upon decision or at least one by which all parties can abide. We explore the recent fascination with deliberative methods for public involvement first by examining their origins within democratic theory, and then by focusing on the experiences with deliberative methods within the health sector.

In doing so, we answer the following questions "What are deliberative methods and why have they become so popular? What are their potential contributions to the health sector?" We use this critical review of the literature as the basis for developing general principles that can be used to guide the design and evaluation of public involvement processes for the health-care sector in particular.

Abelson, J. and J. Lomas (1996). "In search of informed input: a systematic approach to involving the public in community decision making." Healthcare Management Forum **9**(4): 48-52.

Given the task of distributing scarce resources, decision makers are faced with the question of how to involve an increasingly threatened and disenfranchised public in decisions affecting their communities. This article introduces a systematic approach to public involvement in community decision-making and identifies key elements in the design of institutional driven public participation exercises. Examples are drawn from the health care system restructuring experiences of three Ontario communities.

Abram, M. B. and S. M. Wolf (1984). "Public involvement in medical ethics." New England Journal of Medicine **310**(10): 627-32.

When Congress in 1978 created the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, the federal government claimed unprecedented power over ethical issues in medical practice. The commission's term has recently expired, and proposals for a successor body are being considered. The question is whether the government should be making pronouncements on medical ethics and if so, how. This article argues for a government role of limited scope and evaluates the mechanism Congress chose, the independent advisory commission, against others recently proposed. We conclude that the alternatives will not fulfill a proper government role and that the temporary independent advisory commission is the most appropriate model.

Agazade, N. (1998). "Setting up the Caspian Mental Health Association." Mental Health Reforms **3**(1): 3-4.

The Caspian Mental Health Association (CMHA) was established by a group of Baku psychiatrists in March 1995 and registered at the Ministry of Law of Azerbaijan in October 1996. The association presently has over 100 members, including psychiatrists, sociologists, psychologists, nurses and consumers. The association's president is responsible for external relations and policy initiatives, the general director has executive and coordinating responsibilities, and the board of the association is responsible for making all major decisions. The board is represented by all sectors of mental health, including patients and their relatives, psychosocial rehabilitation centers, nurses and psychiatrists. The advisory council incorporates leading specialists and community representatives from all mental health institutions.

Agnew, B. (1998). "NIH embraces citizen's council to cool debate on priorities." Science **282**(5386): 18-19.

Agnew, T. M., J. Baker, et al. (1990). "Informed consent: Discussion paper by the New Zealand Health Council's working party." New Zealand Medical Journal **103**(894): 348-351.

Ainsworth, S. (1998). "Community health councils." Health Service Journal **108**(5618): 23.

Ainsworth, S. (1999). "NHS reorganisation." Health Service Journal **109**(5648): 20-1.

The 1974 reorganisation of the NHS was the most radical to date. It abolished the involvement of local authorities in health, set up community health councils, introduced area health authorities and changed the management of family doctor services. The changes increased the power of hospitals.

Alborz, A., D. Wilkin, et al. (2002). "Are primary care groups and trusts consulting local communities?" Health and Social Care in the Community **10**(1): 20-7. (25 ref).

Primary care groups and trusts (PCG/Ts) in the English NHS were established in 1999 and have responsibility for providing and commissioning health-care for around 100 000 people. PCG/Ts are dominated by health professionals, but are responsible for representing the interests of the local community. This paper assesses how they have informed and consulted local communities and the perceived impact of this consultation on decision-making. The paper uses evidence from the National Tracker Survey of PCG/Ts, a longitudinal survey of 72 (15%) of the PCG/Ts in England, using data from telephone interviews with chairs and chief officers, and postal questionnaires to lay board members and representatives of Community Health Councils (CHCs). Eighty-one per cent of PCG/Ts had public involvement working groups. Methods of consulting the community included consulting CHCs (87%), holding public meetings (75%) and consulting local patient groups (67%). Only 31% of chairs felt they were effective at consulting. Ninety-two per cent of CHC representatives attended all board meetings. Most CHC representatives reported that there had been little or no consultation with the CHC in areas such as commissioning, service development or clinical governance. Only 14% of CHC representatives rated PCG/T consultation with the public as effective. Eighty-seven per cent said that local communities were largely unaware of the existence of PCG/Ts, and 70% commented on the weaknesses in PCG/T efforts at public consultation. Public participation is being taken seriously by PCG/Ts, but most are struggling to develop effective ways of involving local communities. Efforts to involve the public may become little more than token gestures. The proposed abolition of CHCs may make it more difficult for PCG/Ts to obtain a lay perspective. Effective consultation requires the development of new methods and adequate resources, but a stronger lay voice in the governance structures of PCG/Ts is needed.

Allsop, J. and K. Jones (2002). "Patient involvement." Health Service Journal **112**(5798): 28-9.

The government's proposals for public and patient involvement in the NHS seem more robust than the current structures. They involve a greater degree of accountability. They represent some consensus among health consumer groups.

Allsop, J., R. Baggott et al. (2002) "Health consumers groups and the National Policy Process", in Henderson S., Petersen, A. (eds) Consuming health: the commodification of health care. London, Routledge.

Anderson, E., M. Shepherd, et al. (2006). "'Taking off the suit': engaging the community in primary health care decision-making." Health Expectations **9**(1): 70-80.

**OBJECTIVE:** To explore the process of public involvement in planning primary health care. **BACKGROUND:** Recent policy in the UK promotes public involvement in planning health but there have been difficulties in engaging communities in the process. Surveys of health service organizations have found that there has been a failure to adapt to new approaches. It has become important to understand why this has occurred if policy initiatives to encourage involvement are to succeed. **DESIGN:** Qualitative study. Data collected through individual interviews and focus groups. **SETTING:** Two new primary healthcare developments in deprived areas in Bristol and Weston-Super-Mare. **PARTICIPANTS:** Thirty-six professionals and 23 local residents in Bristol; six professionals and three local residents in Weston-Super-Mare. **RESULTS:** Three themes were identified: process, partnership and power. The main findings were that exceptional people with a shared commitment to public involvement were necessary to motivate others and develop partnerships. Local people were drawn into the process and with increased confidence became powerful advocates for their community. Creative and varied methods to involve the public were important in achieving balance between professionals and lay people. However, conflicts over practical decisions arose from a lack of clarity over who had power to influence decisions. **CONCLUSION:** Most of the participants were enthusiastic about their experience of public involvement in planning primary health care. Features crucial to sustainable involvement included a commitment from leaders within statutory agencies, support over a long period to build the confidence of local people, willingness to use informal approaches that are in tune with local culture, and a recognition of the concerns of both service users and providers.

Anderson, R. (1979). "Public awareness and interest in community health councils." Health & Social Service Journal **89**(4633): C29-31.

Community health councils were set up four years ago. They were an institutional innovation, with a remit to represent local community interests in the health services to those responsible for managing them and to facilitate communication between management and (potential) users of the health service. The cover of one CHC's annual report explains the service offered: 'We can make sure that the consumer's point of view is heard. We can help people who need information about the NHS and those who have a complaint about something which has gone wrong'. They might have added, as a caveat, that to do all this effectively, 'we need you'. This paper presents some information, from a recent national study of general practice (Cartwright and Anderson), about public awareness of an interest in community health councils.

Anderson, W. (2000). "Public involvement in primary care groups." British Journal of Community Nursing **5**(7): 316.

Anderson, W., Florin, D., Gillam, S., Mountford, L. (2002) Every voice counts: primary care organisations and public involvement, London, King's Fund.

Andersson, N., J. Matthis, et al. (2004). "Social audit of provincial health services: Building the community voice into planning in South Africa." Journal of Interprofessional Care **18**(4): 381-390.

Social audits of health services in three South African provinces (Limpopo 2001, Gauteng 2003 and Eastern Cape 2001) demonstrated a fusion of participatory research, qualitative data collection, epidemiological surveys and analysis, and socialising of evidence for action. The social audit in each province involved the community in covering eight principles of service delivery. In the particular case of Gauteng province, householders answered a questionnaire on public perceptions of government health services. In each sentinel community, the results were returned for discussion in focus groups, made up of a sample that had answered the household questionnaire. Institutional reviews of health facilities and interviews with health workers in those facilities gave the government side of the story. Five actions came from the community-based focus groups, all accepted by the provincial government. Firstly, redesigned communication strategies will aim to reach those with lower levels of education. The second set of actions involves rebuilding the culture of care. Thirdly, the public knowledge of ways to complain was closely related to levels of public satisfaction. Leadership in the health services turned out to be a fourth area for development. And finally, related to this, is the longer-term challenge of establishing and reinforcing community consultation mechanisms. copyright Taylor & Francis Ltd.

Anya, I. (2004). "Public involvement in health care: Process needs to be transparent and open." British Medical Journal **328**(7437): 462-b-.

Anonymous (1973). "Community health councils." Lancet **1**(7799): 357-8.

Anonymous (1975). "Community health councils." Health Visitor **48**(6): 197.

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Anonymous (1980). "Community health councils: a chance to take stock." Lancet **2**(8186): 130-1.

Anonymous (1980). "Health consumers at the crossroads: which way to go?" Consumer Health Perspectives **6**(8): 1-2.

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Anonymous (1994). "Federal agency can still appoint special ethics advisory boards." Human Research Report **9**(7): 6.

Anonymous (1998). "Pew Commission calls for ongoing competency assessment of health professionals, greater say for public on regulatory boards." American Journal of Health-System Pharmacy **55**(23): 2454.

Anonymous (2000). "The Hepatitis C Prevention, Support and Research Program: Health Canada initiatives on hepatitis C." Canadian Journal of Public Health (91 Suppl 1): S27-9.

In September 1998, Health Minister Allan Rock announced new federal hepatitis C funding of +50 million over five years for initiatives relating to community-based support, research, and disease prevention. Since then, broad cross-country consultations have taken place with individuals and their caregivers who are infected, or affected, by this disease; non-governmental organizations; provinces and territories; and health care professionals.

The result is a relevant, compassionate and targeted new Health Canada Hepatitis C Program with a four-point action agenda, that encompasses five components--prevention; community-based support; care and treatment support; research; and ongoing management, evaluation and public involvement.

Anonymous (2000). "UKCC agrees strategy for greater public involvement." Journal of Nursing Management **8**(6): 369.

Anonymous (2001). "CHCs still to go despite protests." Nursing Standard **15**(41): 6.

Anonymous (2001). "NICE seeks citizens council members." Pharmaceutical Journal **267**(7176).

Anonymous (2001). "UKCC public involvement strategy and information leaflets show the way forward for professional regulation." Journal of Nursing Management **9**(1): 59.

Anonymous (2002). "NICE citizens council selected." Pharmaceutical Journal **269**(7224).

Anonymous (2002). "Patients' forums to replace CHCs." British Journal of Nursing **11**(2): 80.

Anonymous (2003). "Community Health Councils to be abolished - Lammy." News Review **149**: 10

Anonymous (2003). "New era in patient and public involvement." Scottish Nurse **7**(7): 5.

Anonymous (2003). "NICE should not ask if illness is 'self-induced' - Citizens council." Pharmaceutical Journal **270**(7230).

Anonymous (2003). "Public involvement in new forums." Pharmaceutical Journal **271**(7264): 256.

Anonymous (2004). "Patient and public involvement in disarray, warns King's Fund." Nurse 2 Nurse **4**(7): 7.

Anonymous (2004). "Spending boost will depend on public involvement." Pharmaceutical Journal **273**(7309): 104.

Anonymous (2005). "GMC review launched in wake of Shipman Inquiry." Pharmaceutical Journal **274**(7335).

Anonymous (2005). "JCAHO officials provide guidance on new patient safety goals." Biomedical Instrumentation & Technology **39**(1): 39-40.

Anonymous (2005). "Society and PSNC oppose DoH patient pack plan." Pharmaceutical Journal **275**(7379).

Anya, I. (2004). "Public involvement in health care: process needs to be transparent and open." British Medical Journal **328**(7437): 462.

Ard, C. F. and M. R. Natowicz (2001). "A seat at the table: membership in federal advisory committees evaluating public policy in genetics." American Journal of Public Health **91**(5): 787-90.

**OBJECTIVES:** This study examined who participates in federal government advisory committees regarding public policy in human and medical genetics, what parties they represent, and to what extent the general public is meaningfully represented. **METHODS:** Analysis focused on 7 federal government documents published from January 1990 to February 1995. Advisors were categorized into 4 groups based on the professional affiliations that were listed in the publications. After a search of several references and data-bases, the study examined whether these individuals also had other affiliations not listed in the government publications. **RESULTS:** Individuals whose principal affiliations were with academia (n = 32; 44%) or industry (n = 19; 26%) represented nearly three fourths of the sample, followed by government employees (n = 13; 18%) and consumer advocates (n = 8; 11%). At least 16% of the advisors serving on the federal committees, mostly members of academia, had a dual affiliation. **CONCLUSIONS:** These data indicate that the public has modest representation on key federal advisory committees making policy recommendations regarding human genetics technology and clinical practice and that there is ample room for additional public participation.

Armour, A. (1995) "The citizens' jury model of public participation: a critical evaluation", in Renn, O., Webler, T., Wiedemann, P. (eds). Fairness and competence in citizen participation: evaluating models for environmental discourse. Dordrecht: Kulwer Academic Publishers.

Arnstein, S. (1969) "A ladder of citizen participation", Journal of the American Planning Association, **35**(4): 216-244.

Arora, S., A. Davies, et al. (2000). "Developing health improvement programmes: Challenges for a new millennium." Journal of Interprofessional Care **14**(1): 9-18.

This paper describes a rapid appraisal undertaken by the King's Fund to explore the process of developing some of the first Health Improvement Programmes (HImPs) in London. HImPs were introduced by the new Labour Government in 1997. They are three-year action plans, developed in each health authority district, aimed at improving the health of the local population. The first HImP documents, setting out local strategies for health improvement, were completed by April 1999. The purpose of the study was threefold: to examine what could be learnt from the first round, what worked well and what problems had arisen. The study found that HImPs are currently generating enthusiasm at local level, but a number of key challenges were identified by respondents. Six challenges are discussed. These are: policy overload, changing roles and responsibilities, interagency partnership, resources, public involvement and measuring progress. The paper concludes that these challenges will need to be addressed if enthusiasm is to be maintained and if HImPs are to be an effective means of reducing health inequalities and delivering better health for all.

Au, D. K. (1999). "Constructing options for health care reform in Hong Kong." Journal of Medicine & Philosophy **24**(6): 607-23.

The Harvard Report, published in April 1999 for public consultation in Hong Kong, proposed a fundamental restructuring in its health care delivery and financing systems. The Report claims to be evidence-based in its approach (Hsiao et al., 1999a). While 'evidence' has been widely collected by the consultancy team through surveys, consultations and focus groups, the recommendations put forth are not value-free. They carry clear ideological preferences. The value assumptions and ethical presuppositions underlying the report are discussed in this paper. The Harvard consultancy study is in favor of a positive government role in regulation and control, a single central body to administer compulsory health insurance for all citizens, and a purchaser-provider split to induce competition. Such preference is based on pre-existing ideology and generic health care management concepts, which are still in the experimental phase internationally. While value and ideology are inevitable factors in any policy choice, the challenge is to lay these values open for reflection and public debate. For Hong Kong, the challenge is also to take on local substantive issues in health care and deal with them head-on, rather than putting hope in a universal, generic solution.

Baggott, R. (2005). "A Funny Thing Happened on the Way to the Forum? Reforming Patient and Public Involvement in the NHS in England." Public Administration **83**(3): 533-551.

Bal, R., W. E. Bijker, et al. (2004). "Democratisation of scientific advice." British Medical Journal **329**(7478): 1339-41.

Barcelo Aparicio, M. L., E. Martinez Reche, et al. (1992). "Health Councils: assessment after 1 year of functioning." Atencion Primaria **9**(2): 73-8.

OBJECTIVE. Analysis of the experience from creating and developing Health Committees in the areas of Santa Maria de Gracia and La Nora (Murcia) throughout more than one year in operation (1989-90), as bodies for community participation. DESIGN. Participative research which has meant the transformation of existing reality, and which in the process has been a source of knowledge. LOCATION. Clinic Centres, at community level, in two basic health areas, one rural and one urban. PARTICIPANTS. E.A.P., education officers, pharmacists, various associations, mayors, the Government, Department of Socio-health Sciences of the Faculty of Medicine, and the community in general. INTERVENTIONS. The analysis of developing the participative dynamics. MAIN RESULTS. The content of the Minutes of the meetings were analysed in order to give an objective, systematic and quantitative view of what has occurred, 22 variables were identified which were grouped and cross grouped. CONCLUSIONS. Everyone is invited to the Committees and the large majority attend. Citizens and professionals speak and express their views. The meetings are democratic and agreements are reached, objectives established, health problems are resolved and the only instrument used being participation. This has all been stable throughout the year of operation.

Barnes, M. (1999) "Users as citizens: collective action and the local governance of welfare." Social Policy and Administration **33**(1): 73-90.

Barnes, M. (2002) "Brining difference and deliberation? Disabled people, survivors and local governance." Policy and Politics **30**(3): 319-331.

Barnes, M., J. Newman, et al. (2003). "Constituting 'the public' in public participation." Public Administration **81**(2): 379-399.

Barr, H. (2005). "Six of the best." Journal of Interprofessional Care **19**(1): 1-2.

Baum, F. (1998). The new public health: an Australian perspective. Buckingham, Oxford University Press.

Baum, F., C. Sanderson. (1997) "Community participation in action: and analysis of the South Australian Health and Social Welfare Councils." Health Promotion International **12**(2): 125-34.

Beard, J. and H. Birden (2004). "The role of the public in the management of public health risks." Australian & New Zealand Journal of Public Health **28**(5): 415-7.

OBJECTIVE: To critique current models of public involvement in the management of public health risks. METHODS: Two case studies are used to highlight the challenges of contemporary practice. RESULTS: Current models often result in affected communities having perceptions of risk that conflict with those responsible for risk management. This can lead to ineffective decision making. CONCLUSIONS: Involving the public throughout the risk assessment and risk management process may lessen conflict and result in better decisions. IMPLICATIONS: Those responsible for responding to public health risks should aim for transparent processes that highlight assumptions and uncertainties, and involve the public wherever possible.

Bell, R. J. (1986). "Ontario's DHCs, 13 years later." Health Management Forum **7**(4): 72-8.

Black, N. (1981). "How many divisions has the Pope? Community medicine and community health councils." Community Medicine **3**(4): 314-9.

Blackman, R. (1992). "Senior partners." Healthcare Alabama **5**(6): 9-11.

Both hospitals and seniors groups will be among the prominent players when health reform discussions heat up. In the spirit of cooperation and greater understanding, the two have teamed up to form the Senior Citizens Advisory Council.

Bochel, D. and M. MacLaren (1979). "Local health councils--representatives of the consumer?" Hospital & Health Services Review **75**(5): 164-8.

Bochel, D. and M. MacLaran (1979). "Representing the interests of the public?: the case of the local health council in Scotland." Journal of Social Policy **8**(4): 449-72.

The statutory function of local health councils in Scotland (and of community health councils in England and Wales) is to represent the interests of the public in the health service. This article, based on data from a four-year research project financed by the Scottish Office, examines official and participants' assumptions and claims about the legitimacy of health councils, as at present constituted, to carry out this function. Clarification of the basis of their legitimacy would assist, it is argued, in the resolution of a central dilemma: How are councils to represent the interests of the public? The conclusion is reached that inadequate thought was given to developing theoretically sustainable arrangements. Several interpretations of representation are admixed in the rationale for the present system and they cannot be aggregated to produce a coherent defence of it.

Bostwick, M. (1999) "Twelve angry citizens: can citizens' juries improve local democracy in New Zealand?" Political Science **52**(4): 615-33

Bowling, A., B. Jacobson, et al. (1993). "Explorations in consultation of the public and health professionals on priority setting in an inner London health district." Social Science & Medicine **37**(7): 851-857.

The methodology for eliciting the public's priorities for health services is in its infancy. The paper presents the results from a series of exploratory exercises on priorities in City and Hackney. The authors surveyed the opinions of members of community groups and tenants' associations, and compared their responses with those of a random sample of the public as well as general practitioners, consultants and public health doctors. This revealed some disagreement on priorities between these groups.

The public, in consistency with the results from other studies, prioritised perceived life saving technologies as high, in contrast to community services and services for people with mental illnesses, which they prioritised as medium to low, in contrast to all the samples of doctors; the public also prioritised health education and family planning as fairly low, as did the GPs and consultants, in contrast to the public health doctors who prioritised them as high. Before DHAs embark on these studies as part of priority setting, they must answer the question: "what will they do if they disagree with the results?"

Boyle, A. (2005). "Can age discrimination ever be appropriate?" Geriatric Medicine **35**(5): 11.

The National Institute for Clinical Excellence was hit by controversy again this month with the publication of its consultation document Social Value Judgements prepared by the institute's citizen's council, which has sparked outrage with age care charities and healthcare practitioners alike. Alison Boyle reviews the document, which states that 'where age is an indicator of benefit or risk, age discrimination may be appropriate'.

Bradney, D. (1979). "Community health: watchdogs that give you a say in keeping health services up to scratch." Health & Social Service Journal **89**(4623): 16-7.

Although community health councils have been with us since reorganisation, author feels knowledge of them and their workings is lacking. He sets out to explain their statutory and wider functions.

Brittain, I., B. Taylor, et al. (2002). "Public involvement." Health Service Journal **112**(5803): 30-1.

A joint project involving a community health council, primary care trust and GPs identified more than 100 people keen to become involved in local services. The venture has led to a shadow patients' forum being set up. GPs and practice managers have proved important in involving the local population.

Broadbent, B. (1998). "Open to question." Health Service Journal **108**(5596): 30-1.

Have trust boards really welcomed the public to their meetings in the new spirit of openness required by Frank Dobson? Former trust non-executive Barbara Broadbent carried out an informal survey in her area.

Brogren, P. O. and M. Brommels (1990). "Central and local control in Nordic health care: the public organisation spectrum revised." International Journal of Health Planning & Management **5**(1): 27-39.

One of the distinguishing characteristics of national health care systems is the degree of public involvement in service provision, funding and policy making. In international comparisons the Nordic countries are usually seen as a uniform group.

Yet, the countries do have important differences, and a descriptive model was sought to demonstrate these, and, at the same time, to differentiate the concept of public control. Using the central-local dichotomy, differences within the public framework were demonstrated between the countries, e.g. in methods of funding, financial regulation, formal planning instruments, and control of resource allocation. Financial control and planning were identified as two distinct components of public control. An analysis of the degree of centralisation along both dimensions separated the Nordic countries, which are otherwise homogenous as to public sector dominance.

Brown, I. (2000). "Involving the public in general practice in an urban district: levels and type of activity and perceptions of obstacles." *Health and Social Care in the Community* 8(4): 251-9. (46 ref).

This paper reports on a study of the level and type of activity used to involve the public in general practice in a city district in the north of England. The association of these activities with features of the general practice organisation and environment were studied. Service providers' perceptions of obstacles were also studied. Data were collected in a survey of all general practice organisations in the district using a postal questionnaire completed by a practice manager. Interviews were conducted with health service managers responsible for primary care development in the district. The study showed that the district had a good track record for innovation in primary care development and in giving emphasis to developing public involvement. However, it also showed that it was difficult to translate policy rhetoric into practical initiatives at the general practice level without evidence of models of best practice, and with limited resources. The survey had a high response of over 84%. It showed that levels of activity were low across the district and only a small minority of general practice teams had undertaken a range of activities to involve the public. The socio-economic environment did not appear to be a factor, but small practices (one or two partners and/or practice population under 3000) were much less likely to develop activities. Pressures of existing workload, lack of resources and public apathy were given as among the main obstacles by survey respondents. The study indicates the challenges faced by Primary Care Groups in developing strands of public involvement. Primary care teams need a clear strategic framework, models of best practice, and adequate resources to manage, change and develop initiatives.

Brown, I. (2001). "Organizational values in general practice and public involvement: case studies in an urban district." *Health & Social Care in the Community* 9(3): 159-67.

A multiple case study design was used to explore dimensions of organizational values in general practice with respect to developing public involvement. The study was undertaken in an urban district in England with data collected through in-depth individual and focus group interviews with service providers and service users. Four general practice organizations were randomly selected for study after sorting all in the district according to their record of developing involvement activities.

The case studies provide evidence of how organizational values can differ markedly in general practice in relation to ideas of public involvement, with consequences for the quantity and quality of activities for involving local people and service users. The differences manifest themselves in the beliefs and attitudes of service providers about the purpose of the organization and the types of relationships that are appropriate with service users and local people. Service users appear to be very perceptive to the underlying ethos and purpose to their practice organization and this affects their responsiveness to initiatives for their involvement. The dimensions of the different values found in the study appear to be essentially the same as a number of established empirical findings of variations in values in general practice: an orientation to a narrow medical role and to general practice as a business are associated with a low valuation of involvement; an orientation to teamwork and to a broader social role appear more congruent with the development of involvement. Power is a critical issue in this setting with evidence in the study of the dominance of the medical practitioners in establishing organizational values and the nature of public involvement activities.

Buchanan, D., E. Mathieu, et al. (2001). "The Holyoke Community Health Planning Commission: a model of academic-practice-community collaboration in Massachusetts." Public Health Reports **116**(5): 499-502.

Buck, D. S., D. Rochon, et al. (2004). "Involving homeless persons in the leadership of a health care organization." Qualitative Health Research **14**(4): 513-25.

Consumer advisory boards (CABs) are a way of involving patients in their health care. To engage the homeless in the administration of a health care organization for the homeless, a service agency formed such a board comprising homeless and formerly homeless individuals. The purpose was to integrate experiences of homelessness into programmatic design and research efforts of the organization, and to promote participatory research among the homeless. A content analysis and member checking revealed four distinct themes relating to committee goals, identity definition, power, and issues and needs of the homeless. Findings indicate that participatory research provided a useful structure in which the CAB could improve self-sufficiency and self-efficacy, and contribute to the direction of the health care agency.

Buckley, J. and T. Hutson (2004). "User involvement in care: avoiding tokenism and achieving partnership." Professional Nurse **19**(9): 499-501.

Public involvement in health care has increased in recent years, and patients now expect to have greater input into the care and services they receive. This paper describes an initiative in one trust in which patients with cancer were able to take a lead in improving services. The evolution of the group into a cancer patients' forum offers an example of good practice.

Burke, A. (2000). "The NHS Plan: stifling the patient's voice?" British Journal of Community Nursing **5**(11): 528.

Burke, M. M. (1984). "The Nova Scotia Commission on Drug Dependency: public involvement in a public health problem." Medicine & Law **3**(3): 273-86.

Burkeman, S. (1980). "Community Health Councils--building a constituency." Royal Society of Health Journal **100**(5): 157-60.'

Butler, C. and F. Khavarpour (1999). "The context for community participation in health action in Australia." Australian journal of Social Issues **34**(3): 253-265.

Cagan, E. R., T. Hubinsky, et al. (2001). "Partnering with communities to improve health: the New York City Turning Point experience." Journal of Urban Health **78**(1): 176-80.

Concurrent with the New York City Department of Health's reorganization efforts, the Robert Wood Johnson and W.K. Kellogg Foundations launched Turning Point, a national initiative designed to strengthen the nation's public health system. The Turning Point initiative has emphasized broad-based partnership building and planning as key prerequisites for improving public health practice. In response to the foundations' request for proposals, the department formed a New York City Public Health Partnership, which in turn applied for and was granted a Turning Point planning grant. This funding allowed New York City Turning Point to initiate a public health planning process, part of which involved convening forums in each of the five boroughs. With over 1,100 community participants, these forums provided both a starting point for establishing public health priorities and an interactive setting for sharing health and demographic data. Included among the issues that emerged as priorities were: access to care, environmental health, mental health, housing, asthma, education, and dietary issues. Building on the forum outcomes, the New York City Public Health Partnership developed a public health system improvement plan. The goals delineated in this plan are: (1) to create and support public health partnerships at the community, borough, and citywide levels; (2) to identify community health concerns and develop strategies responsive to these concerns; and (3) to develop policies to support and sustain a community health approach to improve health status. This article also discusses possible roles for local health departments in promoting a community health approach to address public health concerns.

Calltorp, J. (1999). "Priority setting in health policy in Sweden and a comparison with Norway." Health Policy **50**(1-2): 1-22.

The development of priority setting policies has been an important part of the national agenda for health services in Sweden and Norway during the past 10 years. Both countries have health systems with a pronounced public character and a declared emphasis on equity and solidarity. Both countries have also had National Priority Commissions that have developed general documents providing advice, but not very detailed guidelines, on how to set priorities. Resource constraints and the rapid restructuring of the health care system were important characteristics forming the background for the National Priority Commission in Sweden (1995). In Norway, the starting point for the first-ever Priority Commission in the world (1987) was how to set limits for health care in a society with rapidly increasing wealth. The second Norwegian Commission (1997) critically reviewed the effects of the general principles for priority setting that have been put forward, and demonstrated the importance to link them to steering tools within health care services.

Calman, K. C. (1994). "The ethics of allocation of scarce health care resources: a view from the centre." Journal of Medical Ethics **20**(2): 71-4.

Resource allocation is a central part of the decision-making process in any health care system. Resources have always been finite, thus the ethical issues raised are not new. The debate is now more open, and there is greater public awareness of the issues. It is increasingly recognised that it is the technology which determines resources.

The ethical issues involved are often conflicting and relate to issues of individual rights and community benefits. One central feature of resource allocation is the basing of decisions on the outcomes of health care and on their subsequent economic evaluation. The knowledge base is therefore of great importance as is the audit of results of clinical treatment. Public involvement is seen as an integral part of this process. For all parts of the process, better methodologies are required.

Calman, K. C. (1995). "Certification in postgraduate medical education." Medical Education **29 Suppl 1**: 100-2.

This paper sets out some of the issues relating to certification of specialists. It first defines the purpose of certification as assuring the public of the level of competence of specialist practice. It then describes some of the issues involved, which include the assessment of competence, the need for public involvement, the issue of re-certification, and the problem of dealing with poor doctors. It concludes with a challenge to doctors to seize the opportunities and to enhance the quality of teaching and research in medical education.

Calman, K. C. (2000). "Postgraduate specialist training and continuing professional development." Medical Teacher **22**(5): 448-451.

Specialist education and continuing professional development are likely to change considerably over the next 20 years. This will reflect the context within which medicine is practised. This will include changes in disease patterns, population structure, medical advances, information technology and, perhaps most powerfully, public involvement. In speciality education there will be a need to define more clearly both the role of the specialist, and the competences to be achieved. CPD is the longest period of education and, as such, it is the phase during which there is likely to be greatest change in clinical practice. There is a need to develop mechanisms to assure the public that doctors continue to practice up-to-date medicine, and that there is confidence and trust in the process.

Calnan, M. (1997) "Citizens, users and health care." European Journal of Public Health **7**: 1-2.

Carlsson, P. (2004). "Health technology assessment and priority setting for health policy in Sweden." International Journal of Technology Assessment in Health Care **20**(1): 44-54.

This article describes the development of health technology assessment (HTA) in Sweden, its influence on decision making, and its link with priority setting. Sweden has a well established governmental HTA body, the Swedish Council on Technology Assessment in Health Care (SBU), and an increasing number of regional/local HTA organizations. HTA has had an impact on clinical practice and is used to some extent in policy decisions. Several initiatives have now been taken to develop processes for open priority setting of health-care services. With the establishment of a new agency to undertake reimbursement decisions on pharmaceuticals, and greater patient and public involvement in decision making, it seems inevitable that HTA will play a more important role in priority setting in the near future.

Casterline, R. (1978). "A process for plan development under P. L. 93-641" American Journal of Health Planning **3**(1): 24-35.

P.L. 93-641, the National Health Planning and Resources Development Act, specifies that health planning focus on health status as well as cost containment. It also specifies the integration of technical analysis with public involvement and political decision making. This paper suggests one planning process which can embody these difficult concepts. The process can be visualized as a series of four Decision Points at which the Governing Body of a Health Systems Agency takes action. Each Decision Point is supported by a staff Analysis which provides the decision makers with the best possible information about the area's health status and health system.

Cayton, H. (2004). "Patient and public involvement." Journal of Health Services & Research Policy **9**(4): 193-4.

Chapman, L. (2002) "Involving patients in the new NHS." Primary Health Care **12**(2): 10.

Leslie Chapman summarises the current state of play in the planning and implementation of Patient and Public Involvement targets in primary care and highlights the experiences of one London PCT project.

Charles, C., DeMaio, S. (1993). "Lay participation in health care decision making: a conceptual framework". Journal of Health Politics Policy and Law **18**(4): 881-904.

Chesney, J. D. (1984). "Citizen participation on regulatory boards." Journal of Health Politics, Policy & Law **9**(1): 125-35.

This article examines the relationship between regulatory board function and citizen participation. The research indicates that public members generally prefer advisory boards, while provider members prefer quasi-judicial bodies. Implications of these findings for structuring citizen participation in the regulatory process are examined.

Chess, C. (2000). Improving public participation in solving environmental health problems. Journal of Environmental Health **63**(1): 24-27.

Ciesla, J. R., M. E. Samuels, et al. (1992). "The role of the Medical Care Advisory Committee in the administration of state Medicaid programs." Evaluation & the Health Professions **15**(3): 282-98.

Every state Medicaid program has a Medical Care Advisory Committee (MCAC). MCACs are required by federal regulations to have representation from state human service agencies, health care providers, and Medicaid consumers. Survey data presented in this study show the make-up of MCACs by representative group. Other data presented show meeting frequencies, subcommittee structure, and information about MCAC activities. Comparisons are made from historical MCAC data showing long-term trends of their composition and structure. It is argued that MCACs can be useful to state Medicaid agencies in policy development but have not been structured to do so. Recommendations are given to make MCACs more useful.

Clough, C. (2003). "Involving patients and the public in the NHS." Clinical Medicine **3**(6): 551-4.

Involving patients and the public in the NHS is a new strategic initiative by the Department of Health. Over time it will make a significant change to how services are designed and delivered. Doctors need to be aware of this new legislation and the change in the patient/clinician dynamic it embraces. In the clinical setting a change of culture is required so that doctors move to working in partnerships with their patients. Within trusts, hospital or otherwise, structures must be in place to ensure appropriate patient/public involvement. Health service workers and the public will need to understand the skills required from both sides for a constructive partnership to emerge. It is hoped that the prioritising of health service resources in the future will be the result of a more democratic process involving patients, public and health service workers.

Coleman, A. J. and C. Glendinning (2004). "Local authority scrutiny of health: making the views of the community count?" Health Expectations **7**(1): 29-39.

Collier, A., K. Johnson, et al. (2005). "A win-win proposition: fostering US health care consumer involvement in the Cochrane Collaboration Skin Group." Journal of the American Academy of Dermatology **53**(5): 920-1.

Collins, B. (1992). "CHCs: independent but working in partnership." Health Services Management **88**(1): 19-20.

Coleman, A. J. and C. Glendinning (2004). "Local authority scrutiny of health: making the views of the community count?" Health Expectations **7**(1): 29-39.

Consumer advisory boards (CABs) are a way of involving patients in their health care. To engage the homeless in the administration of a health care organization for the homeless, a service agency formed such a board comprising homeless and formerly homeless individuals. The purpose was to integrate experiences of homelessness into programmatic design and research efforts of the organization, and to promote participatory research among the homeless. A content analysis and member checking revealed four distinct themes relating to committee goals, identity definition, power, and issues and needs of the homeless. Findings indicate that participatory research provided a useful structure in which the CAB could improve self-sufficiency and self-efficacy, and contribute to the direction of the health care agency.

Condit, C. (2001). "What is 'public opinion' about genetics?" Nature Reviews Genetics **2**(10): 811-5.

Every biotechnology success story increases the number of decisions that the lay public must make about genetics. But vibrant public discussion about these far-reaching changes has been rare, and research on the public's understanding of genetics has barely scratched the surface. This article reviews what we know about the public's attitudes towards genetics, proposes some concepts for thinking about public involvement and indicates some future lines of research.

Contandriopoulos, D. (2004). "A sociological perspective on public participation in health care." Social Science & Medicine **58**(2): 321-330.

This paper presents conclusions drawn from a comparative analysis of three qualitative case studies of participation processes at the regional level in Quebec's healthcare system in Canada. Our objective is twofold: primarily, to draw on our observations to elaborate and discuss a sociological framework for the analysis of public participation; and secondarily, to use our data to criticise many pervasive but questionable preconceptions in the scientific literature on public participation. The framework used applies the social theory of P. Bourdieu in conjunction with the representation framework of H.F. Pitkin to demonstrate how any form of participation will imply some implicit or explicit delegation. The significance of the analysis is its focus on the social operations implied in these acts of delegation and in the use of the concept of symbolic struggles to understand the conflicts arising when the intrinsic legitimacy of the public is appropriated.

Conway, T., T. C. Hu, et al. (1997). "Setting health priorities: community boards accurately reflect the preferences of the community's residents." Journal of Community Health **22**(1): 57-68.

Setting priorities remains an important part of healthcare planning and program management. Local community input is often sought in government or publicly sponsored programs. Community policy/advisory boards are a common vehicle to represent the community's interests in program decisions and direction. Questions remain whether community boards accurately represent their communities' views. As part of a planning effort within Chicago and Cook County, Illinois, local District Health Councils (DHCs) have been created to provide assistance and leadership in systemization and improvement of the healthcare in communities with the poorest health status in the region. We sought to discover how closely the perceptions of health priorities of DHC members agreed with those of community members. A structured five-point Likert scale questionnaire of 22 of the most common diseases and conditions known to impact health were used for a random digit dialing telephone interview with a sample of 286 households from three under-served communities. The same interview was repeated with all DHC members (n = 80) representing those communities. Sociodemographic profiles and health-related behaviors were also collected. The results of this interview indicate a close and substantial agreement in priorities between community members and DHC members. Psychosocial conditions such as violence and substance abuse were ranked as the highest priorities by both groups. In contrast, sociodemographics and healthcare behavior differed significantly between DHC members and community's residents. This study demonstrates that these community policy/advisory boards can closely reflect the views of the communities they represent. Attention to their differences in sociodemographics and healthcare experiences with the community may strengthen their role even more.

Cook, D. (2002). "Consultation, for a Change? Engaging Users and Communities in the Policy Process." Social Policy and Administration **36**(5): 516-531.

Cookson, R., P. Dolan (2000) "Priority setting in health care." British Medical Journal **321**: 954.

Cooper, T. L. (1979). "The hidden price tag: participation costs and health planning." American Journal of Public Health **69**(4): 368-74.

The citizen participation program of the Los Angeles County Health Systems Agency represents one of the most ambitious efforts at implementing the public involvement provisions of PL 93-641. The first year of this program is discussed and analyzed through a participation costs theoretical framework. Specific costs which are inherent in the organizational design and introduced by the implementation procedures adopted are identified and discussed. Levels of participation after one year of operation are examined and found consistent with the high cost of participation in this program.

Cortis, J. D. and A. E. Lacey (1996). "Measuring the quality and quantity of information-giving to in-patients." *Journal of Advanced Nursing* **24**(4): 674-81.

Community health councils (CHCs) were set up in the United Kingdom in 1974 as part of the reorganization of health care delivery. They were intended to have a 'watch dog' function, monitoring the quality of health care in their own district and acting as a link between the providers of care and the public, who are the health care consumers. This paper describes a year-long survey undertaken by one CHC to monitor the quality of information-giving in acute hospital care. A large sample of 1500 discharged patients were sent questionnaires relating to satisfaction with information-giving, and a good response rate was achieved. Results indicate a generally high level of satisfaction, particularly relating to information about surgical and other technical procedures. Information was less satisfactory about non-technical aspects of care and about administrative procedures.

Covey, D. (2001). "Briefing." *Mental Health & Learning Disabilities Care* **4**(6): 212. (1 ref).

The NHS Plan will introduce a whole new national system of patient advocacy and representation, replacing the current Community Health Councils.

Craig, A. (2004). "Public involvement in health care: every voice counts, not just that of patients." *British Medical Journal* **328**(7437): 462.

Craig, A., P. M. Lapsley, et al. (2004). "Public involvement in health care." *British Medical Journal* **328**(7437): 462-463.

Crawford, M. J., D. Rutter, et al. (2002). "Systematic review of involving patients in the planning and development of health care." *British Medical Journal* **325**(7375): 1263-.

OBJECTIVE: To examine the effects of involving patients in the planning and development of health care. Data sources: Published and grey literature. STUDY SELECTION: Systematic search for worldwide reports written in English between January 1966 and October 2000. DATA EXTRACTION: Qualitative review of papers describing the effects of involving patients in the planning and development of health care. Results: Of 42 papers identified, 31 (74%) were case studies. Papers often described changes to services that were attributed to involving patients, including attempts to make services more accessible and producing information leaflets for patients. Changes in the attitudes of organisations to involving patients and positive responses from patients who took part in initiatives were also reported.

**CONCLUSIONS:** Evidence supports the notion that involving patients has contributed to changes in the provision of services across a range of different settings. An evidence base for the effects on use of services, quality of care, satisfaction, or health of patients does not exist. **WHAT IS ALREADY KNOWN ON THIS TOPIC:** Involving patients in planning and delivering health services is recommended as a means of improving the quality of services. Methods for engaging with patients have been considered in depth, but the effects of involving patients are less clear. **WHAT THIS STUDY ADDS:** Few studies have explored the effects of involving patients. Involving patients has contributed to changes in service provision, but the effects of these on quality of care have not been reported

Culliton, B. J. (1977). "Science, society and the press." New England Journal of Medicine **296**(25): 1450-3.

Apprehension about federal support of and public involvement in research has prompted the biomedical community to adopt an accommodating--some would say, enlightened--attitude toward the press during the past several years. However, it is not uncommon for investigators to see reporters as a potential extension of themselves, whose job it is to "educate" the public so that it will appreciate and, therefore, support the scientific enterprise. With the distinction between "educating" and "informing" in mind, it is simply the duty of the press to inform the public about developments in science--particularly those that have implications for public health and safety--but not necessarily to speak for the biomedical community. As the recombinant-DNA controversy shows, the essence of the important issues between science and society will be that they have no obvious, easy answers, and that they cannot be resolved by a "scientific" analysis of the "facts."

Culyer, A. J. (2005). "Involving stakeholders in healthcare decisions--the experience of the National Institute for Health and Clinical Excellence (NICE) in England and Wales." Healthcare Quarterly **8**(3): 56-60.

Appeal to "stakeholders" and involving them in decisions and the processes through which decisions are made are becoming touch stones of "best practice," both clinical and managerial, in health care. Few organizations have sought to integrate stakeholders, especially patients and their caregivers, more completely than the National Institute for Health and Clinical Excellence (NICE) in England and Wales. This article outlines the circumstances in which NICE was created (1999) and the means through which it has created truly effective involvement of its many stakeholder groups. Key messages are that client involvement in decision-making is possible and can work well, but it demands commitment from the entire organization, specific managerial arrangements and, depending on the circumstances, it can be costly. Trust is an important ingredient of success.

Dabbs, C. (1999). "Community health councils." Health Service Journal **109**(5655): 22-3.

CHCs have changed little since 1974. There are huge variations in their effectiveness. National policy is needed to set out their remit and lines of accountability.

Daniels, K. and K. Taylor (1993). "Formulating selection policies for assisted reproduction." Social Science & Medicine **37**(12): 1473-80.

This paper addresses one of the most important problems in the area of assisted reproduction, namely the selection policies used by the providers of the services. Some of the difficulties involved in formulating policies in this area are outlined. The paper concludes that public involvement in decision making in this area is vital, and that to facilitate this the issues must be opened up to public scrutiny and debate. Such a debate would be a significant first step towards the implementation of policies which reflect the opinion of the entire community rather than just the professionals who provide the service, or sectional groups who manage to influence the professionals.

da Silva, M. A. and F. C. Lana (2004). "How do nurses perceive their role on health councils?" Revista Brasileira de Enfermagem **57**(1): 26-30.

This study is part of a Master's thesis on the participation of nurses on Health Councils and aims to analyze the perception nurses have of their role in these forums. A qualitative approach is used with a theoretical referential of Discourse Analysis. The subjects are nurses who have been members of Local and Municipal Health Councils in Goiania, Goias State, since 1995. The perceptions expressed are related to their concerns about not monopolizing the councils, about councils--especially local ones--being used for party political purposes, about avoiding corporate positions, about council autonomy, lack of infrastructure, political interference, lack of preparation on the part of professionals and the necessity of training for political quality, the contributions that they can make to discussion, reflection, group analysis, interventions and technical support. Hopeful perspectives refer to continued change in order to qualify a greater number of councilors, to the growing emancipation of people for citizenship and to the reliability of present administrations.

Davidson, N. (1979). "Opening doors to meet the needs of the people served." Health & Social Service Journal **89**(4641): 566-9.

Does the patient have an effective say in health service decisions that directly affect him? Community health councils have been with us since 1974 but how representative are they and how much influence can they exert on health authorities? Concluding our series on the Royal Commission, author examines these questions and outlines the views of patient organisations and health administrators on the proposal for electing rather than appointing members to AHAs.

Davidson, S. M., T. E. Herold, et al. (1984). "The Medical Care Advisory Committee for state Medicaid programs: current status and trends." Health Care Financing Review **5**(3): 89-98.

Each State Medicaid program is required by Federal Regulations to have a Medical Care Advisory Committee ( MCAC ) which includes provider, consumer, and government representatives and which participates in policy development and program administration. Data are presented about the composition of these committees, their structure, the administrative and financial support they receive, and the nature of their activities. It is argued that they can play an important role in policy formulation and implementation, but that they need to be reformed in order to exploit that potential.

Davies, C., M. Wetherell et al. (2005) Opening the box: evaluating the Citizens Council of NICE Milton Keynes, The Open University.

de Selincourt, K. (1992). "Power to the patients." Nursing Times **88**(33): 18.

DePompei, P. M., K. M. Whitford, et al. (1994). "One institution's effort to implement family-centered care." Pediatric Nursing **20**(2): 119-21.

A children's hospital in the midwest initiated widespread changes in care delivery to provide care that is truly family-centered in practice. The role of nurses, from nursing administration to the staff nurse level, has been a key element in initiating and implementing the institution's move to family-centered care. A Family Advisory Council, composed of hospital personnel and families, identifies family needs and recommends new programs and approaches. Participants in a nursing leadership retreat designated family-centered care as a priority and piloted several innovative programs. Nursing commitment has encouraged other disciplines and departments to initiate family-centered practices as well.

Deber, R. B., N. Kraetschmer, et al. (2005). "Patient, consumer, client, or customer: what do people want to be called?" Health Expectations **8**(4): 345-351.

Dickinson, E. Deighan, M. (1999) "Collaboration and communication- the millennium agenda for clinical improvement?" International Journal for Quality in Health Care **11**: 279-281

Dolan, P., A. Tsuchiya, et al. (2003). "NICE's citizen's council: What do we ask them, and how?" Lancet **362**(9387): 918-919.

Donaldson, K. and C. Moss (2002). "Believe me, public involvement does work - Honest!" British Journal of General Practice **52**(478): 427.

Doult, B. (2001). "Compromise will not save community health councils." Nursing Standard **15**(23): 9.

Drake, L. (2000). "Abolition of community health councils a blow to user participation." Nursing Standard **15**(13-15): 30.

Draper, M. (1997). Involving consumers in improving hospital care: lessons from Australian hospitals. Canberra, AGPS.

Duffin, C. (2000). "More than a survey." Nursing Standard **14**(41): 12-3.

Community health councils are best known for their A&E snapshot surveys, but their role as healthcare watchdogs is just as important.

Duncan, D. (1980). "Community health councils: to be or not to be." British Medical Journal **280**(6215): 719-20.

Dunham, P. and S. Smith (1993). "The changing role of CHCs (community health councils)." Health Services Management **89**(5): 14-5.

Peter Dunham and Sally Smith have experienced at first hand the changing role of community health councils and the opportunities that exist for collaborative working arrangements. Here, they define the progress that can be made in a relatively short period of time when empathy and trust exists between a CHC and its local health authority.

Dzur, A. W. and D. Levin (2004). "The "nation's conscience:" assessing bioethics commissions as public forums." Kennedy Institute of Ethics Journal 14(4): 333-60.

As the fifth national bioethics commission has concluded its work and a sixth is currently underway, it is time to step back and consider appropriate measures of success. This paper argues that standard measures of commissions' influence fail to fully assess their role as public forums. From the perspective of democratic theory, a critical dimension of this role is public engagement: the ability of a commission to address the concerns of the general public, to learn how average citizens resolve moral issues in healthcare, and to monitor public opinion on the topics addressed in the commission. Such a public forum role is supported by the critical literature within bioethics, which has deemed some commissions successful, supported more generally by the history of bioethics as a reform discourse that has brought socially important values into the medical domain, and supported more generally still by the example of the great social issues commissions of the 1960s.

Eagar, K., P. Garrett, et al. (2001). Health planning: Australian perspectives. Crows Nest, Allen & Unwin.

Elston, J. and N. Fulop (2002). "Perceptions of partnership." Public Health 116(4): 207-13.

Health Improvement Programmes (HImPs) are at the heart of the UK government's partnership agenda for the National Health Service (NHS). This paper assesses the nature of HImP partnerships in England by analysing 50/99 first-round HImP strategies (randomly selected). The documentary analysis quantifies the structures and mechanisms of partnership, the degree of inter-sectoral participation and the extent of voluntary sector involvement. Three-quarters of responding health authorities (37/50) appear to have set up formal partnership structures to produce the HImP, or are planning to do so. After health authorities, local authorities (47/50) appear to be most involved in contributing to the HImP, particularly social services departments. Within the NHS 'family', acute and community trusts (43/50) appear to be the most involved, with Primary Care Groups (PCGs) contributing less (39/40). Community Health Councils (CHCs) appear to be similarly involved (40/50). The voluntary sector appear to be involved in all but four HImPs, mainly through umbrella organisations represented on strategic partnership boards (34/50). User and carer and community groups appear to participate far less. Lack of endorsement of HImPs by partner organisations, poor delineation of responsibilities and absence of transparency in resource allocation suggest that ownership of, and commitment to HImPs may be weak. HImPs appear to have focused on creating structures rather than developing aspects of partnership process. If levels of inter-sectoral involvement and voluntary sector participation are to be maintained or increased in future, Primary Care Trusts (PCTs) will need to develop a strategic approach to partnership.

Emanuel, E. J. and L. L. Emanuel (1997). "Preserving community in health care." Journal of Health Politics, Policy & Law 22(1): 147-84.

There are two prominent trends in health care today: first, increasing demands for accountability, and second, increasing provision of care through managed care organizations. These trends promote the question: What form of accountability is appropriate to managed care plans? Accountability is the process by which a party justifies its actions and policies.

Components of accountability include parties that can be held or hold others accountable, domains and content areas being assessed, and procedures of assessment. Traditionally, the professional model of accountability has operated in medical care. In this model, physicians establish the standards of accountability and hold each other accountable through professional organizations. This form of accountability seems outdated and inapplicable to managed care plans. The alternatives are the economic and the political models of accountability. In the economic model, medicine becomes more like a commodity, and "exit" (consumers changing providers for reasons of cost and quality) is the dominant procedure of accountability. In the political model, medicine becomes more like a community good, and "voice" (citizens communicating their views in public forums or on policy committees, or in elections for representatives) is the dominant procedure of accountability. The economic model's advantages affirm American individualism, make minimal demands on consumers, and use a powerful incentive, money. Its disadvantages undermine health care as a nonmarket good, undermine individual autonomy, undermine good medical practice, impose significant demands on consumers to be informed, sustain differentials of power, and use indirect procedures of accountability. The political model's advantages affirm health care as a matter of justice, permit selecting domains other than price and quality for accountability, reinforce good medical practice, and equalize power between patients and physicians. Its disadvantages include inefficiency in decision making, capture by extremists or experts, intractable value conflicts, fragmentation of community, and oppression of minorities. The political model is the model we should endorse. Its disadvantages can be minimized by proper institutional design. In addition, recent research on managed care plans suggests that the political model may be the best for a competitive marketplace because it can ensure that tough allocation decisions are addressed and improve health through changes in nonmedical aspects of community life.

Emanuel, E. J. and K. Titlow (2002). "Evaluating Community-Based Health Initiatives: Identifying the Characteristics of Successful Initiatives and Evaluations." Journal of Health Politics Policy and Law **27**(1): 105-108.

Epstein, S. (1995). "The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials." Science Technology & Human Values **20**(4): 408-37.

Erikson, J. (1995). "Breast cancer activists seek voice in research decisions." Science **269**(5230): 1508-9.

Eyre, R., R.Gauld. (2003) "Community participation in a rural community health trust: the case of Lawrence, New Zealand." Health Promotion International **18**(3): 189-97.

Farrell, C. (2004) Patient and public involvement in health: the evidence for policy implementation London, Department of Health.

Felvus, J., C. Riley, et al. (1991). "The policy practice interface in Wales." Health Services Management **87**(5): 208-11.

The National Health Service in Wales, through the work of the Welsh Health Planning Forum (WHPF), has developed a new and exciting way of planning and managing its services. This encourages consumers to exert influence from the individual right through to the national level. Furthermore, managers are required to seek out and involve people, and to take advice from consumer-led groups. In this paper, Jeremy Felvus and colleagues describe briefly this new way of working and give practical examples of its impact on strategy development at all levels.

Florin, D. and J. Dixon (2004). "Public involvement in health care." British Medical Journal **328**(7432): 159-161.

Forrest, E. (2004). "Patient-public involvement." Health Service Journal **114**(5923): 26-7.

The Royal Liverpool Children's trust is determined to move on after the organ retention scandal. New forums for parents, staff, carers and children have been set up. A newly formed communications team stresses openness and transparency.

Frankish, C. J., B. Kwan, et al. (2002). "Challenges of citizen participation in regional health authorities." Social Science & Medicine **54**(10): 1471-80.

Citizen participation has been included as part of health reform, often in the form of lay health authorities. In Canada, these authorities are variously known as regional health boards or councils. A set of challenges is associated with citizen participation in regional health authorities. These challenges relate to: differences in opinion about whether there should be citizen participation at all; differences in perception of the levels and processes of participation; differences in opinion with respect to the roles and responsibilities of health authority members; differences in opinion about the appropriate composition of the authorities; differences in opinion about the requisite skills and attributes of health authority members; having a good support base (staff, good information, board development); understanding and operationalizing various roles of the board (governance and policy setting) versus the board staff (management and administration); difficulties in ensuring the accountability of the health authorities; and measuring the results of the work and decisions of the health authorities. Despite these challenges, regional health authorities are gaining support as both theoretically sound and pragmatically based approaches to health-system reform. This review of the above challenges suggests that each of the concerns remains a significant threat to meaningful public participation.

Fraser-Lee, N. J., P. J. Macdonald, et al. (1993). "The hopes and hazards of health goals development." Canadian Journal of Public Health Revue Canadienne de Sante Publique **84**(6): 419-22.

As part of the Edmonton Board of Health's centennial celebrations, health goals and objectives were developed for the city. The intensely collaborative process used to develop the goals and objectives is reviewed and critical activities such as communication, media and community involvement, committee membership, and implementation are discussed. It is hoped that the information will be useful for others who are developing health goals and objectives at the municipal level.

Freedman, D. B. (2006). "Involvement of patients in Clinical Governance." Clinical Chemistry & Laboratory Medicine **44**(6): 699-703.

Clinical Governance is a framework through which the National Health Service (NHS) organisations in the UK are accountable for continuously improving the quality of their services and safeguarding high standards by creating an environment in which excellence in clinical care will flourish. The NHS has moved on from being an organisation that simply delivered services to people, to being a service that is totally patient-led and responds to their needs and wishes. There are numerous national drivers and initiatives for patient involvement, including the NHS Plan 2000, Involving Patients and public in healthcare 2001 and, more recently, Creating a patient-led NHS 2005 and Patient choice 2005. There is also an independent public body funded by the Department of Health, the Commission for Patient and Public Involvement in Health (CPPIH), which supports and enables patient involvement in local decisions about delivery of healthcare. At Luton & Dunstable Hospital NHS Trust, patients and carers are seen as a valuable resource and there are formal mechanisms for recruiting patient representatives to sit on hospital committees and to be involved in service provision, including Clinical Governance arrangements. copyright 2006 by Walter de Gruyter.

Friele, M. B. (2003). "Do committees ru(i)n the bio-political culture? On the democratic legitimacy of bioethics committees." Bioethics **17**(4): 301-18.

Bioethical and bio-political questions are increasingly tackled by committees, councils, and other advisory boards that work on different and often interrelated levels. Research ethics committees work on an institutional or clinical level; local advisory boards deal with biomedical topics on the level of particular political regions; national and international political advisory boards try to answer questions about morally problematic political decisions in medical research and practice. In accordance with the increasing number and importance of committees, the quality of their work and their functional status are being subjected to more and more scrutiny. Besides overall criticism regarding the quality of their work, particular committees giving political advice are often suspected of being incompatible with democratic values, such as respect for affected parties, representation of diverse values and transparency in the decision-making processes. Based on the example of the German National Ethics Council, whose inauguration caused a still ongoing debate on the aims and scopes of committees in general, this paper discusses: (1) the requirements of modern democratic societies in dealing with complex scientific-technical problems; (2) the composition and organisation of committees working as political advisory boards; and (3) the appointment procedures and roles of laymen and experts, and here in particular of ethicists, who may legitimately be taken on by a committee. I will argue that bioethics committees do not necessarily endanger democratic values, but can considerably improve their realisation in democratic decision-making procedures--if, and only if, they do not act as substitutes for parliamentary processes, but help prepare parliamentary processes to be organised as rationally as possible.

Galea, S., S. H. Factor, et al. (2001). "Collaboration among community members, local health service providers, and researchers in an urban research center in Harlem, New York." Public Health Reports **116**(6): 530-9.

The Urban Research Center at the Center for Urban Epidemiologic Studies brings together community members and researchers working in Harlem, New York. A Community Advisory Board (CAB) composed of community members, service providers, public health professionals, and researchers was formed to assist the Center's research and interventions and to guide community partnerships. Through a collaborative process, the CAB identified three public health problems—substance use, infectious diseases, and asthma—as action priorities. To deal with substance use, the Center created a Web-based resource guide for service providers and a "survival guide" for substance users, designed to improve access to community services. To deal with infectious diseases, the Center is collaborating with local community-based organizations on an intervention that trains injection drug users to serve as peer mentors to motivate behavior change among other injection drug users. To deal with asthma, the Center is collaborating with community child care providers on an educational intervention to increase asthma awareness among day care teaching staff, enhance communication between staff and families, and improve the self-management skills of children with asthma. The Center's experience has demonstrated that active communities and responsive researchers can establish partnerships that improve community health.

Gallagher, E. M. and G. Hodge (1999). "The forgotten stakeholders: seniors' values concerning their health care." International Journal of Health Care Quality Assurance Incorporating Leadership in Health Services **12**(2-3): 79-86.

Within the context of health care reform and its evaluation, a major gap exists in relation to our understanding of the values which seniors hold regarding their health care. This paper reports on a modified participatory, ethnographic study of such values, using transcribed interviews with ten seniors from across Canada. Members of the National Advisory Council of Canada, most of whom are themselves seniors, participated in designing the study, carrying out the interviews and interpreting the results. Clusters of values were identified concerning health care services, service providers and the overall health care system. While the numbers involved in this study preclude generalizing to the population, a number of recommendations emerged from the study which could impact on future research and begin to influence health policy at local and national levels.

Gastil, J. (2000) "Is face to face citizen deliberation a luxury or a necessity?" Political Communication **17**: 357-361.

Genovich-Richards, J. and J. V. Wyzkiewicz (2002). "Consumers: from perceptions to participation." Journal for Healthcare Quality **24**(6): 39-41.

As Winston Churchill once said, "Personally, I am always ready to learn, although I don't always like being taught." In behavioral health, consumers can make important contributions to the design and evaluation of programs and services. As demonstrated by this case study, progress can be made in incremental steps, over several years. Another reason for BABH's success was progression from very concrete projects to an ongoing organizational structure that consumers could identify as providing a role in policy and procedure development, program evaluation, strategic planning, and programmatic changes.

Performance improvement professionals, through their contributions to the organizational design of committees and communication structures, are in ideal positions to promote the full participation of consumers across all healthcare settings. Just imagine what could be achieved in understanding how to design systems if current issues and recent research results were routinely explored--such as those by Harrington et al. regarding Medicare beneficiary complaints (2001) and Gines et al. (2001) on chronic care and satisfaction with managed care--with a consistent group of consumers. Consider adding consumer participation as a new exciting goal in the next edition of your performance improvement and strategic plans!

George, C. (2005) "Talk to the hand." Mental Health Today Jul-Aug; 8-9.

Changes to the NHS patient and public involvement structure could have serious consequences for mental health service users. Chris George reports.

Gerschman, S. (2004). "Municipal Health Councils: activity and representation of grassroots communities." Cadernos de Saude Publica 20(6): 1670-81.

This article was based on the results of research concerning health policy in municipalities that achieved the most extensive development of decentralization and innovation in the State of Rio de Janeiro, Brazil. The study applied a questionnaire for health system users' representatives in Municipal Health Councils. The central issues were: the Councils' political role; social control by the Councils, viewed as surveillance by organized society over government actions; the nature of social representation exercised by the Council members; and the type of mandate they serve. Community representatives in the Councils reinforce aspects pertaining to the exercise of representation in unequal societies. There is a predominance of a differentiated elite consisting of older males with more schooling and higher income than the community average. The notion of "social control" as the basis for the Councils is difficult for the members to grasp. Exercise of representation is diffuse, occurring by way of designation by community associations, election in assemblies, or designation by institutional health policy agencies.

Gherzi, D. (2002). "Making it happen: approaches to involving consumers in Cochrane reviews." Evaluation & the Health Professions 25(3): 270-83.

The core work of the Cochrane Collaboration is the conduct of systematic reviews dealing with important health care questions. It is the policy of the Collaboration to involve consumers in all stages of the review process: from refining and prioritization of research questions through protocol design, to review conduct and ultimately dissemination of results. It has been difficult to achieve consumer involvement across all parts of the Cochrane Collaboration. Different approaches have been tried and different levels of success have been achieved. This article discusses consumer involvement in the Cochrane review process in relation to the 10 key principles that guide the work of the Cochrane Collaboration: collaboration, building on the enthusiasm of individuals, avoiding duplication, minimizing bias, keeping up to date, striving for relevance, promoting access, ensuring quality, continuity, and enabling wide participation.

Gilbert, D. (2003). "Nothing about us without us: what patient and public involvement means to CHI." Quality in Primary Care 11(1): 61-5. (14 ref).

Gillespie, R., D. Florin, et al. (2004). "How is patient-centred care understood by the clinical, managerial and lay stakeholders responsible for promoting this agenda?" Health Expectations 7(2): 142-8.

**AIMS AND OBJECTIVES:** This study explores how the term patient-centred care is understood, particularly by those who are involved in translating the concept from a theoretical idea into a practical application. It examines the ways in which intermediate level stakeholders such as health service managers, educationalists, professional leaders and officers of patient bodies understand and promote patient-centred care among health professionals actually delivering patient care. **DESIGN:** Qualitative interview study. **SETTING AND PARTICIPANTS:** Interviewees were drawn from groups and organizations from four categories: health agencies and regulatory bodies, Royal Colleges and other professional bodies, educational institutions, patient and user groups and consumer organizations. **MAIN VARIABLES STUDIED:** The meanings and understandings of patient-centred care, commitment to implementing patient-centred care and barriers and opportunities to implementation. **RESULTS AND CONCLUSIONS:** Patient-centred care covers a range of activities from patient involvement in individual care to public involvement in health policy decisions. Current Department of Health policy has made patient-centred care a priority, but has not clarified exactly what it means. Thus, health professionals, educationalists, managers and patient representatives have all developed different meanings of patient-centred care to reflect their own particular backgrounds and roles. The individual aspects of patient-centred care have been neglected in policy terms and important research findings have not been incorporated into policies to change the attitudes and behaviours of health professionals. Developing a shared understanding of patient-centred care which encompasses all its components is an important role for the new Commission for Patient and Public Involvement.

Gillon, R., R. Higgs, et al. (2001). "Wanted: a social contract for the practice of medicine." British Medical Journal 323(7304): 64.

Glasser, M. A. (1980). "Assuring professional competence in medicine: expectations of the public." Health Policy & Education 1(2): 187-95.

A trend toward increased public involvement in assuring professional competence in medicine has resulted as an outgrowth of the consumer movement, the public disenchantment with many traditional institutions, including professions, and broad social acceptance of the concept of health care as a basic human right. Expectations of consumers and the public include a broader definition of professional competence which includes caring and ability to communicate as aspects of curing. Knowledgeable consumers are concerned that inadequate safeguards exist to preclude physicians from practicing beyond their scope of competence and to assure continued competence of a physician over time. While assuring competence is the responsibility of the medical profession, it serves a public function and must be held accountable to public and consumer interests. Consumers should be involved more directly in the process. They can bring valuable judgment to the human questions relating to competence. They can bring a more holistic and humanitarian view to the process. Involvement of consumers, particularly in relation to hearing grievances, would serve to increase public confidence in certifying institutions. They can help assure that public, not merely professionals, interests are served.

To assure that consumer representation makes a significant contribution, consumer members of certifying bodies should be provided with adequate orientation, continued training and direct staff assistance to aid in understanding technical issues and evaluating technical recommendations.

Goggin, M. L. and et al. (1984). "The life sciences and the public: is science too important to be left to the scientist?" *Politics & the Life Sciences* **3**(1): 28-75.

Goldfarb, J. (1995). "Accessing patient care advisory committees: preparing the clinical nurse as a patient advocate in this forum." *Maryland Nurse* **14**(4): 13.

Gollust, S. E., K. Apse, et al. (2005). "Community involvement in developing policies for genetic testing: assessing the interests and experiences of individuals affected by genetic conditions." *American Journal of Public Health* **95**(1): 35-41.

Because the introduction of genetic testing into clinical medicine and public health creates concerns for the welfare of individuals affected with genetic conditions, those individuals should have a role in policy decisions about testing. Mechanisms for promoting participation range from membership on advisory committees to community dialogues to surveys that provide evidence for supporting practice guidelines. Surveys can assess the attitudes and the experiences of members of an affected group and thus inform discussions about that community's concerns regarding the appropriate use of a genetic test. Results of a survey of individuals affected with inherited dwarfism show how data can be used in policy and clinical-practice contexts. Future research of affected communities' interests should be pursued so that underrepresented voices can be heard.

Goold, S. D. (1996). "Allocating health care: cost-utility analysis, informed democratic decision making, or the veil of ignorance?" *Journal of Health Politics, Policy & Law* **21**(1): 69-98.

Assuming that rationing health care is unavoidable, and that it requires moral reasoning, how should we allocate limited health care resources? This question is difficult because our pluralistic, liberal society has no consensus on a conception of distributive justice. In this article I focus on an alternative: Who shall decide how to ration health care, and how shall this be done to respect autonomy, pluralism, liberalism, and fairness? I explore three processes for making rationing decisions: cost-utility analysis, informed democratic decision making, and applications of the veil of ignorance. I evaluate these processes as examples of procedural justice, assuming that there is no outcome considered the most just. I use consent as a criterion to judge competing processes so that rationing decisions are, to some extent, self-imposed. I also examine the processes' feasibility in our current health care system. Cost-utility analysis does not meet criteria for actual or presumed consent, even if costs and health-related utility could be measured perfectly. Existing structures of government cannot creditably assimilate the information required for sound rationing decisions, and grassroots efforts are not representative. Applications of the veil of ignorance are more useful for identifying principles relevant to health care rationing than for making concrete rationing decisions. I outline a process of decision making, specifically for health care, that relies on substantive, selected representation, respects pluralism, liberalism, and deliberative democracy, and could be implemented at the community or organizational level.

Gray, R. and L. McAnespie (2004). "Consulted or excluded?" Learning Disability Practice **7**(6): 30-2.

To enable people with learning disabilities to take up their right to public involvement the process must be meaningful. Rosemary Gray and Lucie McAnespie describe how, by using an inclusive communication approach, they helped people with a range of disabilities to have their say.

Gregory, G. and J. Humphreys (1997). "National rural health policy and the role of the National Rural Health Conferences." Australian Journal of Rural Health **5**(3): 169-73.

The biennial National Rural Health Conference has become an essential feature on the calendar of events for rural and remote health professionals, researchers, public servants and consumers. Since the first conference held in 1991, attendance has grown significantly, factors hindering the achievement of optimal health for all rural and remote Australia have been clearly identified, and recommendations for action have been endorsed by the broad rural health constituency. These recommendations have provided valuable input to the National Rural Health Strategy and many programs and policies of Commonwealth and State departments of health. Significantly, too, the first four conferences have facilitated greater collaboration among rural and remote health professionals and provided a major catalyst in fostering cooperation between consumers, health workers, service providers and governments.

Griffiths, R. (1982). "The community health councils of the future." Royal Society of Health Journal **102**(1): 3-6.

Gulland, A. (2001). "Community health councils temporarily reprieved." British Medical Journal **322**(7296): 1199.

Gulland, A. (2002). "NICE proposals for citizens council condemned by patients." British Medical Journal **325**(7361): 406.

Gupta, S. and S. Sinha (2005). "Establishing national advisory group for neonatal transport." Journal of Neonatology **19**(4): 332-335.

Gutteridge, F., Z. Bankowski, et al. (1982). "The structure and functioning of ethical review committees." Social Science & Medicine **16**(20): 1791-800.

Hale, E. O. (1993). "Successful public involvement." Journal of Environmental Health **55**(4): 17-19.

One of the cornerstones of environmental health is public education and involvement environmental health issues and programs. Unfortunately it seems many agencies have wed their public involvement process to rely almost exclusively on the public hearing process that is required by law in many areas. Realizing the inadequacy of the hearing system, the health districts in Idaho wished to identify a more effective public involvement method for a state wide solid waste plan being developed in 1990. This paper examines the available social science literature and identified a workable system of involvement based on a committee system supported by public opinion survey.

This paper also identifies the underlying attitudes of both the public and agencies that are likely to determine the success failure of any type of public involvement system.

Hall, D., J. Farrell, et al. (2001). "A voice for good?" Nursing Standard **16**(5): 22.

The government has announced another body to give patients a say. Voice -- the Commission for Patient and Public Involvement in health -- will replace community health councils. We asked our readers panel if they thought it would improve NHS service.

Halpern, J. (1995). "Can the development of practice guidelines safeguard patient values?" Journal of Law, Medicine & Ethics **23**(1): 75-81.

Ham, C. (1980). "Promoting consumer participation: the case for collaboration between community health councils and community physicians." Community Medicine **2**(2): 144-7.

Ham, C. (1986). "Health authority members." Health Service Journal **96**(5027): 1551.

Hanna, K. E., R. M. Cook-Deegan, et al. (1994). "Bioethics and public policy: still seeking a forum." Politics & the Life Sciences **13**(1): 102-5.

Harman, C. G. and K. R. Harman (1982). "District Health Councils: should their mandate be broadened?" Health Management Forum **3**(1): 50-5.

Harris, T. (1995). "Community health councils." British Journal of Hospital Medicine **53**(8): 413-4.

Community health councils (CHCs) are the local 'patients' watchdogs' for the NHS. CHCs were set up by the Government in 1974 to monitor and review the NHS and to recommend improvements. They are independent of local health authorities and trusts and are concerned with all aspects of the NHS.

Harris, T. (1996). "Perspectives." Nursing Standard **10**(41): 19.

As the Association of Community Health Councils meets for its annual conference this week, its director Toby Harris says a good NHS complaints system benefits everyone.

Harrison, S., G. Dowswell, et al. (2002). "Guest editorial: public and user 'involvement' in the UK National Health Service." Health & Social Care in the Community **10**(2): 63-6.

Hart, J. T. and A. P. Haines (1975). "Letter: Representation of community health councils in health-centre management." Lancet **1**(7906): 571.

Hatch, J. (1978). "The role of individuals and communities." Annals of the New York Academy of Sciences **310**: 49-56.

Hemingway, D. and T. MacLeod (2004). "Living north of 65 years: a community-based process to hear the voices of northern seniors." Rural Social Work. **9**: 137-46.

In an effort to hear the health concerns and needs of senior citizens, the Northern Interior Regional Health Board initiated a community-based participatory process amongst older adults from eight communities across northern British Columbia, Canada.

Rather than relying exclusively on the services of researchers at the Health Unit or the University to initiate this consultative process, a more community-controlled route involving eight regionally based Community Advisory Committees (CACs) and a Task Force on Seniors' Health (each composed of seniors and trusted allies) was adopted. The CACs were the mainstay of the nearly two-year long collaborative process and approved each aspect of the work which included: hosting a local community forum; drafting, revising, piloting and distributing a survey instrument (entitled "Living North of Sixty-Five Years"); organizing a regional seniors' consultative forum; analyzing survey and forum data; identifying the key findings; and, ultimately, presenting recommendations to the Health Board. Successes and limitations of this community-based process are examined along with its potential implications for policy development, service delivery and social work practice with older adults in smaller northern and rural communities.

Henry, C. J., M. S. Moses, et al. (1997). "The need for policy and risk analysis--the Department of Energy experience." *Toxicologic Pathology* **25**(1): 27-31.

Reduction of major risks to the public and workers is a top priority of all federal agencies. Given current and future budget realities, agencies cannot attempt to address all risks simultaneously nor to address certain relatively lower risk activities as rapidly as some would like. The assumptions and judgments inherent in using risk analysis in the absence of data, however, have to be clearly stated. What is needed is an integrated risk assessment and management process that meets the current and future needs of the government, as well as of stakeholders. Yet there have been many questions raised regarding risk assessment: our ability to define the risks on a specific substance or site basis and in a systematic way; methodology questions about identifying and assessing diverse hazards and risks as well as uncertainties in the estimates, data gaps, and concern over the quality of information; and the fact that "who" performs the risk assessment matters. Knowing these controversies surrounding risk and the use of risk-based approach, the Department of Energy (DOE) requested the National Academy of Sciences-National Research Council to determine whether and how risk and risk-based decisions could be incorporated into a major federal program, the DOE's Office of Environmental Management. The report identified the major obstacles, issues, and barriers to implementing a risk-based management approach. The report concluded that the use of risk-based approach could help compare outcomes, build consensus, and gain early public involvement to include cultural, socioeconomic, historical, and religious values, if its purposes and limitations are well defined. A status of the DOE's ability to implement the recommendations presented in the report on the use of risk assessment in a major federal program and the adoption of principles for using risk analysis will be given.

Heywood, D. (2004). "Payments to service users: what is the solution?" *A Life in the Day* **8**(3): 14-7.

The issue of paying people for user involvement activities is one that affects every NHS trust in the country. This is an exploration of how one NHS trust has used the conflicting information from the various agencies to implement a system that meaningfully involves service users in the planning and delivery of services in line with the Department of Health directives on patient and public involvement -- and pays them for their work and time.

Higgins, J. (2003). "The Patient Information Advisory Group and the use of patient-identifiable data." Journal of Health Services & Research Policy **8** (Suppl 1): S1:8-11.

Patient confidentiality has been a matter of concern in the English National Health Service (NHS) for many years. A number of recent events have triggered the demand for a more concerted programme of change to eliminate the use of patient-identifiable data and to devise more acceptable alternatives. The Caldicott Committee, in 1997, set out the case for change and legislation in 1998 (the Data Protection Act and Human Rights Act) and emphasised the need for urgent action. A number of public inquiries into failures of care in the NHS (at Bristol Royal Infirmary and Alder Hey Hospital) pointed to the failure to seek consent as a major issue for the NHS. Whilst accepting the need for change, the Government, in drafting the Health and Social Care Act 2001, allowed for the fact that some organisations and individuals would need time to move towards anonymisation of data (reversible or irreversible) or to obtain patient consent. Under Section 60 of the Act it established the Patient Information Advisory Group (PIAG). PIAG advises government ministers on circumstances in which the continued use of patient-identifiable data should be permitted, as a temporary measure. PIAG faces a number of challenges as it develops its programme of work: how to maintain the pace of change towards anonymisation, how to ensure compliance with the law, how or whether to share information across organisational boundaries in the interests of citizens, how consent should be obtained and how to achieve 'joined up' working across those organisations that are charged with promoting confidentiality and privacy.

Hill, W. Y., I. Fraser, et al. (1998). "Patients' voices, rights and responsibilities: on implementing social audit in primary health care." Journal of Business Ethics **17**(13): 1481-97.

Hiller, E. H., G. Landenburger, et al. (1997). "Public health policy forum." American Journal of Public Health **87**(8): 1280-8.

OBJECTIVES: State newborn-screening programs collectively administer the largest genetic-testing initiative in the United States. We sought to assess public involvement in formulating and implementing medical policy in this important area of genetic medicine. METHODS: We surveyed all state newborn-screening programs to ascertain the screening tests performed, the mechanisms and extent of public participation, parental access to information, and policies addressing parental consent or refusal of newborn screening. We also reviewed the laws and regulations of each state pertaining to newborn screening. RESULTS: Only 26 of the 51 state newborn-screening programs reported having advisory committees that include consumer representation. Fifteen states reported having used institutional review boards, another venue for public input. The rights and roles of parents vary markedly among newborn-screening programs in terms of the type and availability of screening information as well as consent-refusal and follow-up policies. CONCLUSIONS: There is clear potential for greater public participation in newborn-screening policy-making. Greater public participation would result in more representative policy-making and could enhance the quality of services provided by newborn-screening programs.

Hird, M. (2001). "Patient and public involvement." Professional Nurse **16**(5 Suppl): S9.

Hodgson, I. (2004). "Patient and public involvement (PPI) in HIV care: innovation or tokenism -- reflections." HIV Nursing **4**(4): 11-3.

Hogan, M. F. (2003). "The President's New Freedom Commission: recommendations to transform mental health care in America." Psychiatric Services **54**(11): 1467-74.

Hogg, C. (1999) Patients, power and politics: from patients to citizens UK, Sage.

Hogg, C. and C. Williamson (2001). "Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees." Health Expectations **4**(1): 2-9.

Hogg, C. and F. Winkler (1990). "Community health councils." Health Services Management **86**(4): 171-3.

Christine Hogg and Fedelma Winkler review the major and varied changes being introduced in the management of community health councils by different regional health authorities in the wake of the NHS Bill. This piecemeal approach may lead to more variations in the standards of service that individual CHCs offer the public and they argue that there needs to be a coherent policy about the role of CHCs and evaluation and monitoring of their functions.

Hohenemser, L. K. and B. D. Marshall (2002). "Utilizing a youth development framework to establish and maintain a youth advisory committee." Health Promotion Practice **3**(2): 155-65.

There is a growing trend to involve young people in a range of advisory roles. As a research institution focused on healthy adolescent development, the Johns Hopkins Center for Adolescent Health recognizes its need for youth input on applied research activities as well as its ability to contribute to the positive development of the young people who serve in this capacity. Due to the lack of a tested theoretical model for establishing and maintaining a youth advisory committee, the Center's Youth Advisory Committee is examined through the lens of a youth development frame-work that includes opportunities and supports for adult-youth relationships, youth participation, youth as resources, and program flexibility. Challenges and facilitating factors in the development and maintenance of a youth advisory committee are also discussed.

Hubbard, G. and M. Themessl-Huber (2005). "Professional perceptions of joint working in primary care and social care services for older people in Scotland." Journal of Interprofessional Care **19**(4): 371-385.

The purpose of this paper is to report health and social care professionals' perceptions on joint working for the care of older people in Scotland. Semi-structured interviews were conducted with 34 primary care and social care professionals. These professionals emphasised that joint working requires a fundamental change in thinking and a scrutiny of professional roles and identities and is influenced by the given geographical and organisational infrastructure. In order to facilitate sustained joint working knowledge and models of care bespoke to joint working need to be developed. This requires health and social care organisations to focus on the co-creation and generation of new knowledge by health and social care professionals as well as the communication and exchange of existing knowledge between services. However, joint working also needs to be based on patient views to guarantee a whole systems perspective. copyright 2005 Taylor & Francis Group Ltd.

Human Genetics Advisory, C. (1999). "Consultation rejects human reproductive cloning." Human Reproduction & Genetic Ethics: An International Journal **5**(2): 21-3.

Humphery, K. (2003). "Setting the rules: the development of the NHMRC guidelines on ethical matters in Aboriginal and Torres Strait Islander health research." New Zealand Bioethics Journal **4**(1): 14-9.

From 1986 to 1991 the Australian National Health and Medical Research Council in close consultation with Australian Indigenous organisations embarked on a process of formulating ethical guidelines for the conduct of Aboriginal and Torres Strait Islander health research. These guidelines were drafted under the direction of the National Aboriginal and Islander Health Organisation, reviewed by an NHMRC appointed Aboriginal Working Party, and eventually published--though not formally ratified--as the interim NHMRC Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research, 1991. This article briefly documents this lengthy and sometimes difficult process, offering an account of the events and actions that led to the release of the 1991 interim guidelines. In doing so, the paper illustrates some of the ways in which the process and politics of 'Western' health research have been debated and confronted within the context of Indigenous/non-Indigenous relations in Australia.

Jackson, C. (2005). "Patient and public involvement." Mental Health Today: 5.

Jaffe, G. A. (1989). "Institutional ethics committees." Journal of Legal Medicine **10**(3): 393-431.

James, R. (2004). "Patient and public involvement (PPI) as an employment opportunity for patients." HIV Nursing **4**(4): 8-9. (3 ref).

Johnson, A., K. Skilburn. (2000) "Community and consumer participation in Australian health services: an overview of organisational commitment and participation processes." Australian Health Review **23**(3): 113-21.

Johnson, P. T. "How I turned a critical public into useful consultants." Harvard Business Review **71**(1): 56-60.

When Peter Johnson was an executive in the private sector, he viewed conflict with company outsiders as, at best, an annoyance. But when Johnson became the administrator of Bonneville Power Administration in Portland, Oregon, he realized that outsiders had the power to bring the organization down. To survive, BPA had to listen to the people affected by the agency's decisions--BPA's harshest critics. BPA had long been respected, but by the time Johnson arrived in 1981, the agency was reviled. People were put off by BPA's father-knows-best approach to decision making, whereby the agency first made decisions and then explained them. So Johnson took what many thought was an unimaginable risk. Despite the warnings of attorneys and his own deep apprehensions, he opened up BPA's decision making to the public. The first attempts to involve BPA's critics were full of fireworks, but thanks to BPA's rock-solid commitment to public involvement, success soon followed. Experiences early on proved to Johnson that involving the public in BPA's decision making was a practical alternative to litigation. Moreover, BPA's stakeholders--once the agency's adversaries--became BPA's partners in making better decisions, and the agency gained authority and legitimacy.

Johnston, C., N. Smethurst, et al. (2005). "Should people with a history of an eating disorder work as eating disorder therapists?" European Eating Disorders Review **13**(5): 301-310.

Much recent attention has focused on the fitness to practise of health professionals. Patients expect their care to be provided by therapeutic staff who can give support and guidance without unhelpful subjective influence. On the other hand, those recovered from health problems expect their employment prospects to be free of discrimination. Eating disorder services increasingly encourage patient and public involvement in service design and monitoring but reservations are sometimes expressed about employing staff who have themselves suffered with an eating disorder. This survey canvassed the views of patients, carers and professionals on the suitability of employing people with a history of an eating disorder as therapists in the same field. With some reservations (mainly from professionals), there was a widespread belief that those who had recovered would have therapeutic advantages as a result of their experience. Therapists with a current eating disorder, however, were thought to lack objectivity and to be vulnerable. Current UK policies on employment appear unnecessarily discriminatory and stigmatizing. Copyright copyright 2005 John Wiley & Sons, Ltd and Eating Disorders Association.

Jones, B., P. Litzelfelner, et al. (2003). "The value and role of Citizen Review Panels in child welfare: perceptions of citizens review panel members and child protection workers." Child Abuse & Neglect **27**(6): 699-704.

Jones, A., J. May (1994). Working in human service organisations. Melbourne Longman-Cheshire.

Jones, D. G. and B. Telfer (1990). "National bioethics committees: developments and prospects." New Zealand Medical Journal **103**(884): 66-8.

Jones, M. and B. Salter (2003). "The governance of human genetics: policy discourse and constructions of public trust." New Genetics & Society **22**(1): 21-41.

The collection of practices now commonly understood as 'biotechnology' poses a challenge to traditional mechanisms of regulating science and technology, just as it challenges traditional practices of science. The task of regulation is to reconcile the often conflicting political demands of protecting science, economy and the public interest. Public trust is the key measure of political success or failure. The purpose of this paper is to use policy discourse analysis as a vehicle for exploring the politics of the relationship between human genetics governance and public trust. An analysis of 30 policy documents produced six identifiable discourse streams relevant to public trust. These findings will be discussed, and an analysis of their impact on effective governance presented in conclusion.

Jones, M. R. (1995). "Establishment of a community advisory committee at a major teaching hospital." Physician Executive **21**(12): 39-41.

With the advent of continuous quality improvement and the '90s focus on patient or customer satisfaction, hospitals have started to try to identify what their patients or customers want. Hospitals serve communities of one sort or another, whether local communities or statewide communities for highly specialized procedures. They need to consult at least their local communities as part of a quality improvement process and also to help determine future directions.

Austin Hospital in Australia decided to establish a formal advisory committee in order to accomplish this consultation. Although there have been minor deficiencies in the arrangement, the advisory committee has largely fulfilled the promise for which it was created more than seven years ago.

Kashefi, E. and M. Mort (2004). "Grounded citizens' juries: a tool for health activism?" Health Expectations 7(4): 290-302.

Involving the public in decision-making has become a bureaucratic pre-occupation for every health agency in the UK. In this paper we offer an innovative approach for local participation in health decision-making through the development of a 'grounded' citizens' jury. We describe the process of one such jury commissioned by a Primary Care Group in the north-west of England, which was located in an area suffering intractable health inequalities. Twelve local people aged between 17 and 70 were recruited to come together for a week to hear evidence, ask questions and debate what they felt would improve the health and well-being of people living in the area. The jury process acted effectively as a grass-roots health needs assessment and amongst other outcomes, resulted in the setting up of a community health centre run by a board consisting of members of the community (including two jurors) together with local agencies. The methodology described here contrasts with that practiced by what we term 'the consultation industry', which is primarily interested in the use of fixed models to generate the public view as a standardized output, a product, developed to serve the needs of an established policy process, with little interest in effecting change. We outline four principles underpinning our approach: deliberation, integration, sustainability and accountability. We argue that citizens' juries and other consultation initiatives need to be reclaimed from that which merely serves the policy process and become 'grounded', a tool for activism, in which local people are agents in the development of policies affecting their lives.

Kasperson, R. E. (1986). "Six propositions on public participation and their relevance for risk communication." Risk Analysis 6(3): 275-81.

New societal obligations for communicating risk information are emerging in a variety of contexts. This article draws upon the lengthy societal experience with citizen participation programs to identify how risk communication efforts may be effectively structured and implemented. Six major propositions address such themes as means/ends differences in expectations, the timing of the program, the role of credibility and trust, the need for technical and analytical resources, differing thresholds of public involvement, and limitations upon current understandings. Key conclusions for the design of risk communication programs are set forth.

Kelson, M. C. (1999). "Consumer collaboration, patient-defined outcomes and the preparation of Cochrane Reviews." Health Expectations 2(2): 129-135.

Kenkel, P. J. (1992). "Consolidations in Minnesota help bring about the demise of state's health coalition." Modern Healthcare **22**(24): 32.

Recent consolidations by healthcare purchasers and providers in the Minneapolis area have contributed to the demise of the Minnesota Coalition on Health, the 12-year-old consortium of provider, business and consumer groups that was a pioneer in educating healthcare consumers about cost-control strategies. Observers said much of the responsibility for analyzing healthcare services, costs and outcomes is now moving to the marketplace.

Kennedy, J. F. (2000). "Public involvement." Health Bulletin **58**(2): 145-7.

Keywood, O. (1978). "The NHS and the consumer." Nursing Times **74**(5): 180-1.

King, P. A. (1996). "Credibility, persuasiveness, and effectiveness." Kennedy Institute of Ethics Journal **6**(3): 313-7.

Kitzhaber, J. A. (1993). "Prioritising health services in an era of limits: the Oregon experience." British Medical Journal **307**(6900): 373-7.

How do we decide who should receive the benefits that medical science has to offer? One approach to this decision process, that used by the state of Oregon, is described: who and what are covered, and how health care is financed and delivered, are considered. Oregon's priorities were set on the basis of broad consensus. The objective of health care reform, it was agreed, is to improve, maintain, or restore health--not universal coverage, access to health care, or cost containment. A Health Services Commission was created to consider clinical effectiveness and, through public involvement, to attempt to integrate social values into the priority list. Oregon's legislature can use the list to develop an overall health policy which recognises that health can be maintained only if investments in several related areas are balanced.

Klein, R. (1990). "Looking after consumers in the new NHS." British Medical Journal **300**(6736): 1351-2.

Klein, R. (1990). "New lamps for old." Health Service Journal **100**(5211): 1110-1.

Kmietowicz, Z. (2001) "Reform of NICE needed to boost its credibility." British Medical Journal **323**: 1324.

Lakhani, M. (2001). "Patient and public involvement in quality improvement." Journal of Clinical Governance **9**(4): 165-6.

Langridge, C. (1977). "Community Health Councils-watchdogs or lapdogs?" Nursing Mirror **145**(15): 42-3.

Lapsley, P. M. (2004). "Public involvement in health care: public involvement is needed at highest level." British Medical Journal **328**(7437): 462.

Le May, A. (2003). "A new year, a new commission: the commission for patient and public involvement in health." Journal of the Royal Society of Health **123**(1): 10.

Learmonth, M. (1995). "Consulting users." Health Service Journal **105**(5474): 31.

Legge, D. (1986). "Quality assurance: what is the consumers' role?" Australian Clinical Review **6**(23): 190-6.

We commenced with the question: what is the "proper" role for consumers in quality assurance? Quality assurance has been discussed as encompassing three phases: clinical review, linkage and drive. We have discussed a range of mechanisms which can contribute to expressing a consumer perspective or the consumers' interest in each of these phases of quality assurance. It is clear that the consumers' experience is a useful and legitimate input to clinical review. It is clear that mechanisms for listening more carefully to the consumers' perspective could be introduced more widely. It is clear that greater consumer understanding of an involvement in the whole quality assurance cycle is practicable and, from the point of view of many consumers, highly desirable. Whilst more detailed answers have not been brought forward, a useful framework for considering how to proceed from here has been presented.

Lenaghan, J., B. New, et al. (1996). "Setting priorities: is there a role for citizens' juries?" British Medical Journal **312**(7046): 1591-3.

Citizens' juries are an attempt to meaningfully involve members of the public in decisions which affect them in their own communities. The Institute for Public Policy Research and Cambridge and Huntingdon Health Authority have recently piloted the first jury in the United Kingdom. Sixteen jurors sat for four days, hearing evidence from a number of expert witnesses. The jurors were asked to consider how priorities for health care should be set, according to what criteria, and to what extent the public should be involved in this process. This pilot was also an attempt to assess the process itself, and our initial evaluation indicates that, given enough time and information, the public is willing and able to contribute to the debate about priority setting in health care.

Levin, L.S. (1995) "Public participation in healthcare quality". Journal of Epidemiology and Community Health **49**(4): 163-172.

Lewing Group (2002). Community participation can improve America's public health systems. Battle Creek, Michigan, W.K. Kellogg Foundation.

Lewis, J. M. and M. Considine (1999). "Medicine, economics and agenda-setting." Social Science & Medicine **48**(3): 393-405.

The filtering of potential policy issues from a large range of possibilities to a relatively small list of agenda items allows the organisation of power and influence within a policy sector to be examined. This study investigated power and influence in health policy agenda-setting in one State of Australia (Victoria) in the years 1991, 1992 and 1993. The actors seen as influential were predominantly medically trained and working in academia, health bureaucracies and public teaching hospitals. This research supports an elite model of health policy agenda-setting, in which outcomes are dependent on the structured interests within the policy field. However, while the corporate elite of the profession is influential, the frontline service providers are not, as indicated by the location of influentials in large and prestigious organisations. Politicians and professional associations and unions are less well represented, and consumer and community groups are virtually absent. In 1993 there was a sharp increase in economists being nominated as influentials, with a subsequent decrease in influentials with medical training. This relates to a (perceived or real) shift in influence from the medical profession to senior health bureaucrats.

Economic concerns appear to be shaping the visible health policy agenda, through an increased number of influentials with economics training, but also through an apparent ability to shape the issues that other influentials are adding as agenda items. The corporate elite of medicine remains powerful, but their range of concerns has been effectively limited to cost containment or cost reduction, better planning and efficiency. This limiting of concerns occurs within an international policy context, where the general trends of globalisation and an emphasis on neo-liberal economics impact on the direction of health policy in individual countries.

Lewison, H. (1994). "Power at local level." Modern Midwife 4(11): 14-6.

Helen Lewison explains the rationale for Maternity Services Liaison Committees and suggests that they could become a useful forum for change in the maternity services.

Lim, M. K. (2004). "Quest for quality care and patient safety: the case of Singapore." Quality & Safety in Health Care 13(1): 71-5.

Quality of care in Singapore has seen a paradigm shift from a traditional focus on structural approaches to a broader multidimensional concept which includes the monitoring of clinical indicators and medical errors. Strong political commitment and institutional capacities have been important factors for making the transition. What is still lacking, however, is a culture of rigorous programme evaluation, public involvement, and patient empowerment. Despite these imperfections, Singapore has made considerable strides and its experience may hold lessons for other small developing countries in the common quest for quality care and patient safety.

Lipley, N. (2001). "Government presses ahead with abolition of CHCs." Nursing Standard 15(21): 7.

Lipley, N. (2002). "Clocking off." Emergency Nurse 10(4): 5.

The latest Casualty Watch survey was the last ever undertaken by community health councils in England. Nick Lipley reports.

Litva, A., J. Coast, et al. (2002). "'The public is too subjective': public involvement at different levels of health-care decision making." Social Science & Medicine 54(12): 1825-37.

There are a number of impulses towards public participation in health care decision making including instrumentalist, communitarian, educative and expressive impulses and the desire for increased accountability. There has, however, been little research looking systematically at the public's preferences for being involved in particular types of rationing decisions, nor indeed, has there been a critical examination of the degree of involvement desired by the public. The research reported here uses findings from focus groups and in-depth interviews to explore these questions. Eight focus groups were conducted with a total of 57 informants, four amongst randomly selected members of the public and four with informants from health and non-health related organisations. Nineteen interviews were conducted to allow the elaboration of focus group comments, to probe views more deeply and to pursue emerging themes.

The findings show variations in the willingness of members of the public to be involved in health care decisions and consistency across the different forms of the public as represented by the focus groups with randomly selected citizens and pre-existing organisations. There was a strong desire in all the groups for the public to be involved both at the system and programme levels, with much less willingness to be involved at the individual level. At the system and programme levels informants generally favoured consultation, without responsibility for decisions, but with the guarantee that their contribution would be heard and that decisions taken following consultation would be explained. At the patient level informants felt that the public should participate only by setting criteria for deciding between potential beneficiaries of treatment. The public has much to contribute, particularly at the system and programme levels, to supplement the inputs of health care professionals.

Lowden, S. "Abolition? It's nothing personal." Health Service Journal **115**(5944): 18-9.

The Commission for Patient and Public Involvement in Health was the victim of a 'political decision' and was not given the opportunity to prove itself, according to chief executive Steve Lowden. He also defended the 'courageous' decision to set up a network of not-for-profit forum support organisations, which some criticised for under funding forums themselves.

Lloyd, P. "Working partnerships: engaging communities and consumers." In Harris, M. (ed) Managing health services: concepts and practice Sydney, MacLennan & Petty.

Luciani, S. and N. J. Berman (2000). "Status report." Chronic Diseases in Canada **21**(1): 23-5.

The Canadian Strategy for Cancer Control is a stakeholder-driven initiative, led by a partnership between the Canadian Cancer Society, National Cancer Institute of Canada, Canadian Association of Provincial Cancer Agencies and Health Canada. The planning process began in January 1999 and currently involves more than 130 health professionals and community representatives who are volunteering their time, experience and expertise. A crucial aspect of the strategy's successful implementation is early participation of the provincial/territorial ministries of health in the planning process. Working groups are addressing 11 areas of the cancer continuum: prevention, screening, diagnosis, treatment, supportive care/rehabilitation, palliative care, pediatric cancer, research, human resource planning, surveillance and informatics/technology. Two stakeholder conferences will engage all cancer stakeholders in helping develop recommendations and establishing priorities for cancer control in Canada.

Lupton, D. (1997). "Consumerism, reflexivity and the medical encounter." Social Science & Medicine **45**(3): 373-81.

Lupton, C., S. Buckland, et al. (1995). "Consumer involvement in health care purchasing: the role and influence of the community health councils." Health and Social Care in the Community **3**(4): 215-26.

Recent reforms in the National Health Service (NHS) place great emphasis on the importance of the "voice of the consumer" in the provision of health care. Health purchasers are now required to adopt the role of "champion of the people", traditionally that of the Community Health Councils (CHCs).

In turn the CHCs have been encouraged to become more closely involved in the purchasing process. This paper draws on a national investigation of the operation of CHCs in order to examine the response of both the Councils and local purchasers to these developments. For many CHCs pressures for greater involvement may clash with their concern to retain an independent stance. This paper examines how closely CHCs are currently working with local purchasers and explores the central question of whether those prepared to work more collaboratively with their Health Authorities (HAs) are likely to have greater impact on purchasing decisions. The paper concludes that, while some CHCs are more closely involved than others, few perceive that they exert much real influence over the decision-making process. Councils share a general view that major purchasing decisions are increasingly being made without the opportunity for scrutiny by them or the wider public.

Lussing, F. J. and G. N. Zalot (1985). "Health planning in Ontario." Hospital & Health Services Administration **30**(6): 118-27.

Stephen C. Hanson's article, "Health Planning: The Fourth Generation," (Hospital and Health Services Administration 27/4, 1982, pp. 55-65) comments on the possible "downsizing" of Health System Agencies (HSAs) because of severe budget cuts. Hanson suggests that they shift from regulatory to planning agencies. A relatively recent development in Ontario, Canada, involves the establishment of area-wide planning agencies known as district health councils (DHCs) which may provide a model for HSAs of the future. Although DHCs operate in a government-sponsored healthcare system and are advisory rather than regulatory in nature, the DHC concept can be adapted to HSAs in order to become true planning agencies. This article outlines the salient features of the Ontario DHC Program and compares its similarities and differences with Hanson's "Fourth Generation" model of HSAs. While Hanson proposes a model, Ontario's experience for which comparisons and insights are offered has gone beyond the conceptualization stage and has been operating for over ten years. The DHC Program is still evolving, tentative in some areas, and searching for the most appropriate role and means in other areas. As HSAs will be transformed out of necessity, a close look at the Ontario DHC program may prove to be both instructive and timely.

Lyons, M., Smuts, C., Stephens, A. (2001) "Participation, empowerment and sustainability: (how) do the links work?" Urban Studies **38**(8): 1233-1251.

Macfarlane, D. (1996). "Citizen participation in the reform of health care policy: a case example." Healthcare Management Forum **9**(2): 31-35.

MacKeith, J. S. (1996). "Customers and contractors in the new NHS." International Journal of Health Care Quality Assurance 9(5): 45-8.

Presents the results of a study in the former Yorkshire region to discover the effect of the changes in the NHS on relationships between Community Health Councils (CHCs) and health service authorities. Respondents were asked to comment on how the changes had affected these relationships in six aspects; interaction with the public, accountability, independence, effectiveness, representativeness and prioritization of work.

Identifies a number of questions about the relationships which can be grouped under four headings: CHCs' identity problem; the effect of the greater discretion which health service authorities have in their relationships with CHCs; the balance between independence and co-operation in these relationships; and the influence of superior bodies on the relationships. Suggests that answers to these questions will help to release the potential of CHCs to contribute to the quality and effectiveness of the NHS, in accordance with the priority given in the reforms to obtaining the views of the public.

MacKinney, A. C. and B. R. Wolfman (1996). "Is accreditation in the public interest?" Journal of Health Administration Education 14(1): 17-23.

The relationship of accreditation to the public interest has been a topic of discussion in the media as well as in higher education circles as the topic has been politicized. This article examines the historical evolution of public involvement in the accreditation process as well as the reasons for public representation on accreditation bodies and in decision making. The links between accreditation and quality control are discussed and assessed.

Macklin, R. (1996). "Disagreement, consensus, and moral integrity." Kennedy Institute of Ethics Journal 6(3): 289-311.

The Advisory Committee on Human Radiation Experiments experienced some disagreements among its members in the course of its work. An epistemological controversy over the nature and degree of evidence required to draw ethical conclusions pervaded the Committee's deliberations. Other disagreements involved the proper role of a governmental advisory committee and the question of when it is appropriate to notify people that they were unknowing subjects of radiation experiments. In the end, the Committee was able to reach consensus on almost all of its findings and recommendations through a process that preserved the integrity of its members.

Mandrich, M. L. (2000). "Family councils contribute to quality." Provider 26(4): 39-40.

Marre, L. (1977). "Community Health Councils - a personal view." Community Health 8(3): 164-7.

Marston, P. (1993). "Patients' complaints: Community health councils advise patients." British Medical Journal 307(6916): 1427.

Martin, D. K., J. Abelson, et al. (2002). "Participation in health care priority-setting through the eyes of the participants." Journal of Health Services & Research Policy 7(4): 222-9.

**OBJECTIVES:** The literature on participation in priority-setting has three key gaps: it focuses on techniques for obtaining public input into priority-setting that are consultative mechanisms and do not involve the public directly in decision-making; it focuses primarily on the public's role in priority-setting, not on all potential participants; and the range of roles that various participants play in a group making priority decisions has not been described. To begin addressing these gaps, we interviewed individuals who participated on two priority-setting committees to identify key insights from participants about participation. **METHODS:** A qualitative study consisting of interviews with decision-makers, including patients and members of the public.

**RESULTS:** Members of the public can contribute directly to important aspects of priority-setting. The participants described six specific priority-setting roles: committee chair, administrator, medical specialist, medical generalist, public representative and patient representative. They also described the contributions of each role to priority-setting. **CONCLUSIONS:** Using the insights from decision-makers, we have described lessons related to direct involvement of members of the public and patients in priority-setting, and have identified six roles and the contributions of each role.

Marwick, C. (1998). "Bill of rights' for patients sent to Clinton." Journal of the American Medical Association **279**(1): 7-8.

Maxwell, J., S. Rosell, et al. (2003). "Giving citizens a voice in healthcare policy in Canada." British Medical Journal **326**(7397): 1031-1033.

Maynard, C. A. (1995). "Stakeholders in the political process: nurses' role in MinnesotaCare." Nursing Policy Forum **1**(5): 18-25. (9 ref).

ISSUE. In 1992, the Minnesota State Legislature first passed bipartisan legislation to reform the state's health care delivery system. Currently under debate is whether efforts to simplify the health care system have instead become very complicated and bureaucratic. Indeed, it appears the complex nature of health care itself impedes the pace of reform. Consumers tend to respond or react to specific issues and personal experience but rarely understand the whole reform process. To ensure that individuals have the opportunity to voice their concerns, the MinnesotaCare Act created several commissions and committees, as well as six regional coordinating boards (RCBs). Each advises the legislature and the commissioner of health during all phases of reform. Members of these groups are chosen from a diverse cross-section of volunteers who share equal responsibility, thus empowering all stakeholders in the political process. IMPLICATIONS. Minnesota nurses have been instrumental in directing change and influencing decision-making within commissions, advisory committees, and RCBs. Whether appointed by the governor or through the Minnesota Nurses Association (MNA), they use their knowledge of the health care delivery system to assist in clearly identifying public health and private sector roles. By encouraging interdisciplinary collaboration, empowering consumers, and advocating for a continuum of care, these dedicated providers not only develop policy that promotes the health and welfare of the state's citizens, but also help to define the nature of their profession for years to come. Clearly, all nurses can be empowered through the political process -- a testament to the profession's role as a valuable asset in reform. Locally, nurses can become active in public policy by supporting their professional associations, sharing professional expertise with colleagues and legislators, lobbying on behalf of specific reforms, or presenting testimony on such issues as nurse staffing and primary care. Today, nurses have the opportunity to move beyond grassroots activities and evolve into powerful players -- indeed, policymakers -- in their own right.

Mays, N. (1982). "Community Health Councils " Royal Society of Health Journal **102**(1): 21-3.

McCallum, J. (1979). "Community health councils, consultation, and planning." British Medical Journal **1**(6180): 1798.

McCormick, S., J. Brody, et al. (2004). "Public involvement in breast cancer research: an analysis and model for future research." International Journal of Health Services **34**(4): 625-46.

Public involvement in health program planning has been taking place for many years, and has provided a precedent for the emergence of public involvement in research conducted since the early 1990s. Such involvement is now widely seen in breast cancer research, due to the large public concern and major social movement activity. This article reviews current practices and general models of public involvement in research and constructs a prototype. The authors interviewed researchers, program officers, and laypeople in order to understand the obstacles, processes, and benefits. They conclude that public involvement has major ramifications for the democratization of science and the construction of knowledge by teaching lay people about science and sensitizing researchers to concerns of the public. There is growing support on the part of scientists and government agents for public involvement.

McClure, L. F. and L. G. DePiano (1983). "School advisory council participation and effectiveness." American Journal of Community Psychology **11**(6): 687-704.

This study presents a preliminary framework of the variables of effective citizen participation on mandated school advisory councils and systematically investigates the relative effects of participant-type (e.g., parent, teacher), council power, leadership style, and social climate on council member satisfaction and involvement with their councils. A group of 149 school principals and 505 of their council members provided data for the study. The major findings revealed that increased satisfaction, feelings of involvement, and actual number of activities engaged in by council members are related to higher degrees of council member power, more support from the principal for member involvement, clearer role and responsibility definition, and a person-oriented leadership style of the principal. It was also found that principals and teachers are less satisfied with council effectiveness than parents. Theoretical and intervention implications of the results are discussed.

McDonald, E. (2002). "Consumers first: participating in the system." New South Wales Public Health Bulletin **13**(7): 165-6.

McInerney, J. D. (1984). "Public involvement in medical ethics." New England Journal of Medicine **311**(4): 264.

McIver, S. (1998). Health debate? An independent evaluation of citizens' juries in health settings. London, Kings Fund.

McIver, S. (1999). "Focus." NT Research **4**(4): 245-56. (24 ref).

The focus of healthcare is changing to primary care in many countries, including the UK. One aspect of this development is a community orientation, which can be defined in a number of different ways. This paper examines community involvement in the UK, and reports some of the findings of a survey of public participation in primary care, discussing the implications for primary care groups. The survey findings and discussion concentrate on three main issues: methods and approaches to public participation; difficulties identified and ways of addressing them; achievements and outcomes of public participation.

McIver, S. and N. Brocklehurst (1999). "Public involvement: working for better health." Nursing Standard **14**(1): 46-52.

In this article, the authors explore the concept of public involvement in health service development, what it means and what techniques are being used to increase it.

McNicol, M. W. (2004). "Public involvement in health care: Some things do count." British Medical Journal **328**(7437): 462-3.

Merkens, B. J. and R. G. Emmerson (1995). "Local healthcare planning in rural southwestern Ontario." Leadership in Health Services **4**(4): 12-6.

In rural areas, local health and social services are often planned and developed by members of the community, the hospital and community agencies acting together. This system is a web of informal ties that, relying heavily on volunteer commitment, provides programs that aptly fit the local situation. In this article, the authors show how this functions in the Ontario community surrounding Palmerston and District Hospital, and offer a suggestion for the improved support of this system.

Milewa, T. and M. Calnan (2000). "Primary care and public involvement: achieving a balanced partnership." Journal of the Royal Society of Medicine **93**(1): 3-5.

Milewa, T., Dowswell, G. Harrison, S. (2002). "Guest editorial: public and user involvement in the UK National Health Service". Health and Social Care in the Community **10**(2): 63-66.

Milewa T., J. Valentine, M. Calnan (1999) "Community participation and citizenship in British health care planning: narratives of power and involvement in the changing welfare state." Sociology of Health and Illness. **21**(4): 445-465.

Milewa, T., Dowswell, G. Harrison, S. (2002). "Partnerships, power and the "new" politics of community participation in British health care planning: narratives of power and involvement in the changing welfare state". Social Policy and Administration **36**(7): 796-809.

Milewa, T. and S. Harrison (2001). "Consultation." Health Service Journal **111**(5752): 32-3.

A telephone survey of primary care groups and trusts revealed that visits to community groups are the most favoured form of public involvement. There was some evidence of plans having been changed in response to public involvement. It is too early to say whether PCG/Ts will be more successful in involving the public in planning care than health authorities.

Milewa, T., S. Harrison, et al. (2002). "Citizens' participation in primary healthcare planning: Innovative citizenship practice in empirical perspective." Critical Public Health **12**(1): 39-53.

The British National Health Service has been the focus of sustained political rhetoric in favour of greater public and patient involvement in decision making. The creation of Primary Care Groups-organizations based on local groups of general practitioners-has thus been accompanied by a requirement that they involve users and the public.

This article reports on a study of Primary Care Groups (n = 167) to address two questions. First, how have the groups responded to this requirement? Second, can user and public involvement activities be related to broader changes with regard to the roles and expectations of citizens? The study indicated significant activity around public and patient involvement but also a tendency among informants to rationalize these activities in terms of a professional commitment to quality and responsiveness (rather than in relation to the expressed preferences of local citizens). In terms of the second question the results provide some, contestable, evidence of realignments in the values, priorities and assertiveness of individuals and communities of interest with regard to the state. The impact of such phenomena is, though, highly dependent upon how managers and clinicians in Primary Care Groups choose to prioritize the views of local service users and residents in relation to professional judgement, operational requisites, planning constraints and limited resources.

Mitton, C., S. Patten, et al. (2005). "Priority-setting in health authorities: moving beyond the barriers." *Healthcare Quarterly* 8(3): 49-55.

The objective of this study was to identify key issues relevant to the development and implementation of a macro-level priority-setting framework (i.e., across broad service areas) within the Calgary Health Region. We used rigorous qualitative methods, including focus groups, meeting observations and interviews to identify views of decision-makers.

Key issues relevant to macro-level priority-setting included: application of evidence, incentives, physician involvement, public involvement and application of values. Detailed insight into each of these issues was derived, including how best to handle related barriers to priority-setting in health organizations and important lessons for framework development. These lessons learned should provide insight for similar activity in other jurisdictions.

Momeyer, R. W. (1990). "Philosophers and the public policy process: inside, outside, or nowhere at all?" *Journal of Medicine & Philosophy* 15(4): 391-409.

Three standard tasks undertaken by applied ethicists engaged in the public policy process are identifying value issues, clarifying concepts and meanings, and analyzing arguments. I urge that these should be expanded to include making specific moral judgments and advocating positions and policies. Three objections to philosophers/ethicists' engagement in the formation of public policy are advanced and evaluated: philosophers necessarily do public policy badly, doing it at all compromises one's integrity as a seeker after truth, and frequently participation is in the service of a repressive status quo that is structured simultaneously to preclude radical change and to co-opt ethicists. Finally, however, I argue that those who would be 'applied ethicists' cannot avoid all participation in some form of a public policy process; that engagement holds the hope as well for improved ethical theory; that the preferred form of participation is frequently from outside of establishment bodies; and that wherever philosophers do involve themselves in policy formulation, this is best done in the expanded sense urged at the outset.

Mongoven, A. M. (2003). "Duties to stakeholders amidst pressures from shareholders: lessons from an advisory panel on transplant policy." *Bioethics* 17(4): 319-40.

The distinction between stakeholders and shareholders frequently employed in business ethics can illuminate challenges faced by a bioethics advisory panel. I use the distinction to reflect back on the work of an advisory panel on which I served, a panel on US transplant policy. The panel hearings were akin to a shareholders' meeting, with many stakeholders absent. In addition to 'hearing out' the shareholders who were present, the panel had duties to absent stakeholders to insure their interests were included in public discussion. While panel efforts to include stakeholder perspectives rightfully framed its report, such duties should have framed its operating procedures more robustly. The stakeholder/shareholder distinction also offers a critical prism on the actual evolution of organ allocation policy, which the panel failed to influence. Current policy embodies a compromise among shareholders that obscures major stakeholder interests. This results in under-attention to likely medical benefit of transplant, compared to other allocation criteria. Recognition of duties to stakeholders amidst pressures of shareholders complicates the notion of 'consensus' for an advisory panel. Consensus framed on terms defined only by shareholders, not stakeholders, may be an inadequate measure of public interest.

Morgan, L.M. (2001) "Community participation in health: perpetual allure, persistent challenge." Health Policy and Planning **16**(3) 221-30.

Morone, J. A. and E. H. Kilbreth (2003). "Power to the People? Restoring Citizen Participation." Journal of Health Politics Policy and Law **28**(2-3): 271-288.

This article investigates a lost ideal--citizen participation in health policy. We begin by mapping the different types of participation. We then suggest what direct citizen action has achieved in the past, why it ought to be restored today, and how we might go about reviving it. A changing social environment--marked by globalization, immigration, a culture war, and managed care--could be addressed by robust, local, democratic health reforms. Finally, we contrast the top-down health sector with education and crime policies that take communities far more seriously.

Morris, J. (1993). "The First Nations and the planning process." Health Law in Canada **13**(4): 237-8.

Mower, M. (2000). "Health authorities." Health Service Journal **110**(5721): 26-7.

A survey of 25 health authorities found user groups, professional forums, newsletters, complaint scheme, roadshows and focus groups the most extensive means of consultations. The majority of health authorities had identified the parties to be consulted over strategic planning. The results suggested that consultation is being used more for service planning than strategic purposes. Many health authorities plan to include police and fire services, the media, unions and the private sector and schools in consultations.

Mullally, S. (2002). "Just listen here." Nursing Standard **16**(20): 23.

England's chief nursing officer Sarah Mullally argues that community health councils will be replaced with a better system.

Mullen, P. (1977). "Community Health Councils--planning and health care planning teams." Royal Society of Health Journal **97**(2): 85-8.

Mullen, P. M. (1999). "Public involvement in health care priority setting: An overview of methods for eliciting values." Health Expectations **2**(4): 222-234.

There is increasing interest, in the UK and elsewhere, in involving the public in health care priority setting. At the same time, however, there is evidence of lack of clarity about the objectives of some priority setting projects and also about the role of public involvement. Further, some projects display an apparent ignorance of both long-standing theoretical literature and practical experience of methodologies for eliciting values in health care and related fields. After a brief examination of the context of health care priority setting and public involvement, this paper describes a range of different approaches to eliciting values. These approaches are critically examined on a number of dimensions including the type of choice allowed to respondents and the implications of aggregation of values across individuals. Factors which affect the appropriateness of the different techniques to specific applications are discussed. A check-list of questions to be asked when selecting techniques is presented.

Murie, J. (2001). "Public involvement in primary care: Time to turn good intentions into practice." British Journal of General Practice **51**(462): 73.

Murie, J. and G. Douglas-Scott (2004). "Developing an evidence base for patient and public involvement." Clinical Governance: An International Journal 9(3): 147-54.

This paper summarises five years' experience of patient and public involvement in primary care, citing examples from the Lanark practice and Clydesdale Local Health Care Co-operative (LHCC) in Lanarkshire, Scotland. Strategic development and models which align primary care structures within a framework for patient and public involvement are described, along with barriers to implementation. Examples derived from clinical governance, health promotion and needs assessment include patient and carer involvement in significant event analysis and audit, joint training and patient-held record cards.

Positive outcomes reported are effective dialogue between health professionals, patients and the public, service developments and quality improvements. The success of initiatives is retrospectively assessed against the Audit Commission's critical success factors.

Nellis, M., S. Navagh, et al. (1998). "How to develop a parent advisory council -- and why." Contemporary Pediatrics 15(10): 179-80.

A parent's group that collaborates with the hospital staff can do much to ease the concerns of patients' families. This account of the early life of one such group reflects the different perspectives of professionals and parents.

Neuberger, J. and R. Tallis (1999). "We do need a new word for patients?" British Medical Journal 318(7200): 1756-1758.

In these days of public involvement and active participation, has the term 'patient' become an offensive anachronism or does it capture what is positive about the special relationship between health workers and ill people? A former chairman of the Patients' Association and a clinician argue for and against 'patients'.

Newell, C. (2003). "Disability: a voice in Australian bioethics?" New Zealand Bioethics Journal 4(2): 15-20.

The rise of research and advocacy over the years to establish a disability voice in Australia with regard to bioethical issues is explored. This includes an analysis of some of the political processes and engagement in mainstream bioethical debate. An understanding of the politics of rejected knowledge is vital in understanding the muted disability voices in Australian bioethics and public policy. It is also suggested that the voices of those who are marginalised or oppressed in society, such as people with disability, have particular contribution to make in fostering critical bioethics.

NSW Health (2001). Partners in health: sharing information and making decisions together. North Sydney, NSW Health.

Nixon, E. (2004). "The argument for patient and public involvement (PPI) as an innovation." HIV Nursing 4(4): 10-1. (6 ref).

Norlander, L. and E. Ratner (2004). "Formation and operation of a statewide commission on end-of-life care in Minnesota." Journal of Palliative Medicine 7(6): 839-45.

BACKGROUND: Innovative approaches to improving end-of-life care are needed. One strategy involves government/community partnerships to improve care. OBJECTIVE: Engage health care provider and health care consumer communities in the State of Minnesota to improve end-of-life care. DESIGN: The Minnesota Commission on End of Life Care was formed to make recommendations that would be used by public and private policy makers to improve care in the state. RESULTS: An innovative selection process brought together a broad group of people to identify, prioritize, and make recommendations regarding end-of-life care in the state. Carefully selected leadership, good planning, and organization ensured a successful process that kept all appointed commission members engaged throughout the 18-month project. Using a consensus process, the Commission endorsed a framework for end-of-life care and made specific recommendations for improving access, education and public policy. This paper describes the process of developing and implementing the Commission, the challenges, successes, and lessons learned.

North, N. and S. Werko (2002). "Widening the debate? Consultation and participation in local health care planning in the English and Swedish health services." International Journal of Health Services **32**(4): 781-98.

In both English and Swedish health care, there is currently much interest in encouraging public consultation and participation in public service planning in order to improve quality, enhance local accountability, and help to inform and legitimize difficult decisions about health care priorities. This article explores the progress of local budget holders for health services in the two countries--primary care groups/trusts in England and county councils and municipalities in Sweden--in developing consultative and participative processes. Using secondary and primary research methods, the study identified much activity among English primary care groups/trusts, although with less certainty of outcome. In Sweden, initiatives were limited to a few county councils, were more distinctive, and in the case of one county council, resulted in the sustained channeling of citizens' views. In comparing and contrasting the approaches in the two countries, the authors note the importance of political cultures and institutional arrangements as well as, more generally, the complexities and challenges of consultation and participation in health care planning.

O'Dowd, A. (2002). "Eyeing up the experts." Nursing Times **98**(35): 13.

Is the creation of a Citizens Council for the National Institute for Clinical Excellence a boost for patient power or a scam to deflect criticism of difficult decisions? Adrian O'Dowd reports.

O'Keefe, E. and C. Hogg (1999). "Public participation and marginalized groups: The community development model." Health Expectations **2**(4): 245-254.

Objectives: To develop ways of reaching house-bound people and enabling them to give their views in planning and monitoring health and social care. Strategy: HealthLINK - a project based in a community health council - explored ways of involving older house-bound people in the London Borough of Camden, in planning and monitoring health and social care using community development techniques. Results: HealthLINK set up an infrastructure to enable housebound people to have access to information and to enable them to give their views. This resulted in access for health and local authorities to the views of house-bound older people and increased the self esteem and quality of life of those who became involved. Conclusions: Community development approaches that enable an infrastructure to be established may be an effective way of reaching marginalized communities. However, there are tensions in this approach between the different requirements for public involvement of statutory bodies and of users, and between representation of groups and listening to individual voices.

Ong, B.N. (2000). "Assessing the context for partnerships between communities and the National Health Service in England." Critical Public Health **10**(1): 343-351.

Organisation for Economic Co-operation and Development (OECD) (2001). Citizens as partners: Information, Consultation and Public Participation in Policy-making. France, OECD Publications. Accessed 6 July, 2006 from <http://www1.oecd.org/publications/e-book/4201131E.PDF>

Organisation for Economic Co-operation and Development (OECD) (2001). Citizens as partners: OECD Handbook on Information, Consultation and Public Participation in Policy-making. France, OECD Publications. Accessed 6 July, 2006 from <http://www1.oecd.org/publications/e-book/4201141E.PDF>

O'Rourke, A., N. Fox, et al. (2001). "A survey of education and training for clinical governance leads and Caldicott Guardians in primary care in Trent Region." Journal of Clinical Governance **9**(3): 137-142.

Objectives: To survey all clinical governance leads and Caldicott Guardians for PCGs and PCTs in the Trent NHS Region about their participation in a workshop programme offered by NHSE Trent and a virtual conference offered by the WISDOM Centre; to explore barriers to participation, benefits of these initiatives and aspirations for future training and education for these roles. Method: Postal questionnaire. Results: Those who attended the workshops scored them highly. Requests for future sessions include clinical governance in PCTs and increasing public involvement. There was low use of the email group and the Internet resources.

The main barriers to fuller participation in the programme were time and, for the discussion group, access to email and confidence about using it. Conclusion: In an area the size of Trent it is difficult for leads on Caldicott and clinical governance to attend a single regional workshop. More training and encouragement is needed to develop a learning network through technologies such as email and dedicated websites: simply providing and advertising such networks does not lead to participation.

O'Rourke, T. W. and M. Forouzesh (1981). "The readability of HSAs' plans--implications for public involvement." Health Law Project Library Bulletin **6**(1): 23-6.

Orr, S., C. Mayer, et al. (2001). "A select few." Nursing Standard **16**(3): 21.

The Bristol Inquiry report called for public involvement in the selection of health professionals, with nationally agreed criteria. We asked our readers panel for their views.

Orriss, H. D. (1974). "Community health councils." Nursing Times **70**(24): 928-9.

Otway, H. and D. von Winterfeldt (1992). "Expert judgment in risk analysis and management: process, context, and pitfalls." Risk Analysis **12**(1): 83-93.

The regulation and management of hazardous industrial activities increasingly rely on formal expert judgment processes to provide wisdom in areas of science and technology where traditional "good science" is, in practice, unable to supply unambiguous "facts." Expert judgment has always played a significant, if often unrecognized, role in analysis; however, recent trends are to make it formal, explicit, and documented so it can be identified and reviewed by others. We propose four categories of expert judgment and present three case studies which illustrate some of the pitfalls commonly encountered in its use. We conclude that there will be an expanding policy role for formal expert judgment and that the openness, transparency, and documentation that it requires have implications for enhanced public involvement in scientific and technical affairs.

Packham, H. (1980). "Community Health Councils: time to give the public more responsibility." Nursing Mirror **150**(3): 30-1.

Packham, H. (1981). "Community health councils: forward thinking." Nursing Mirror **153**(18): 27-8.

Parker, E. Margolis, L.H., Eng, E., Henriques-Roldan, C. (2003). "Assessing the capacity of health departments to engage in community-based participatory public health." American Journal of Public Health **93**(3): 472-476.

Parkinson, J. (2004). "Hearing Voices: Negotiating Representation Claims In Public Deliberation." The British Journal of Politics and International Relations **6**(3): 370-388.

Pathak-Sen, E. and R. Turner (2003). "Voices from a wide a community as possible: A closer look at the Citizens Council." Journal of Clinical Excellence **4**(3): 369-370.

Pear, R. (1997). "Panel meets to consider bill of rights for patients." New York Times: A19.

Pearce, L. (2001). "Power struggle." Nursing Standard **15**(52): 14-6.

Community health councils are fighting back after the threat of abolition. Over the next few pages we examine their role and how Australia is protecting its patients' interests. First, Lynne Pearce reports on the battle to save CHCs

Pearce, L. (2003). "Power to the people." Nursing Standard **18**(11): 12-3.

Patient and public involvement forums come on stream this month to replace community health councils. But will they work? Lynne Pearce investigates.

Peck, E. (1998). "Integrity, ambiguity or duplicity? NHS consultation with the public." Health Services Management Research **11**(4): 201-10.

Recent guidance from the Department of Health and National Health Services (NHS) Executive has stressed the importance of public involvement in the NHS. This paper places this guidance in the historical context of public consultation in the NHS and explores, through a detailed case study, the traditional approach to consultation that the guidance is seeking to change. The paper concludes with some reflections on the challenges that will need to be addressed in order for the guidance to be put into practice.

Peckham, S. (1994). "Community health councils." Health Service Journal **104**(5391): 37.

Perry, D. (2004). "A voice for research, a voice for patients." Plos Biology **2**(6): e182.

Peterson, A. and D. Lupton (1996). The new public health: health and self in the age of risk. Sydney, Allen & Unwin.

Pickard, S. (1998). "Citizenship and Consumerism in Health Care: A Critique of Citizens' Juries." Social Policy and Administration **32**(3): 226-244.

Pickard, S., M. Marshall, et al. (2002). "User involvement in clinical governance." Health Expectations **5**(3): 187-198.

**OBJECTIVES:** To investigate the involvement of users in clinical governance activities within Primary Care Groups (PCGs) and Trusts (PCTs). Drawing on policy and guidance published since 1997, the paper sets out a framework for how users are involved in this agenda, evaluates practice against this standard and suggests why current practice for user involvement in clinical governance is flawed and why this reflects a flaw in the policy design as much as its implementation. **DESIGN:** Qualitative data comprising semi-structured interviews, reviews of documentary evidence and relevant literature. **SETTING:** Twelve PCGs/PCTs in England purposively selected to provide variation in size, rurality and group or trust status. **PARTICIPANTS:** Key stakeholders including Lay Board members (n = 12), Chief Executives (CEs) (n = 12), Clinical Governance Leads (CG leads) (n = 14), Mental Health Leads (MH leads) (n = 9), Board Chairs (n = 2) and one Executive Committee Lead. **RESULTS:** Despite an acknowledgement of an organizational commitment to lay involvement, in practice very little has occurred. The role of lay Board members in setting priorities and implementing and monitoring clinical governance remains low. Beyond Board level, involvement of users, patients of GP practices and the general public is patchy and superficial.

The PCGs/PCTs continue to rely heavily on Community Health Councils (CHCs) as a conduit or substitute for user involvement; although their abolition is planned, their role to be fulfilled by new organizations called Voices, which will have an expanded remit in addition to replacing CHCs. **CONCLUSIONS:** Clarity is required about the role of lay members in the committees and subcommittees of PCGs and PCTs. Involvement of the wider public should spring naturally from the questions under consideration, rather than be regarded as an end in itself.

Piette, D. (1990). "Community participation in formal decision-making mechanisms." Health Promotion International **5**(3): 187-197.

This article deals with the formal mechanisms of population participation: with any sort of institutional form of participation aimed at decision-making concerning health in the community. A case study concerning Community Health Councils (England and Wales) and the fluoridation of the water supply illustrates the following points: (i) the defensive or protester role of the population in decision-making: the population may want to share power without changing the rules of the game or may wish to change the norms and values put forward by the authorities; (ii) the lay versus the expert approaches of those professionals mandated to represent the population; (iii) the democratic representation of a heterogeneous population within a health service. Results show that a health committee may participate effectively, even in an advisory capacity, and that conflicts may be seen as an indicator of the reality of participation. Implications for the development of population participation include the distinction between expertise and decision-making, the need for the community to develop networking of sub-groups and organizations, and the shift from a democratic representation of the population to a polyarchy system (the rule of minorities).

Poindexter, C. C. and T. S. Lane (2003). "Choices and voices: participation of people with HIV on Ryan White Title II Consumer Advisory Boards." Health & Social Work **28**(3): 196-205.

This article presents an assessment of the functioning and training needs of consumer advisory boards in Massachusetts (CABs) who advise the Massachusetts agency and the consortia funded through Title II of the Ryan White Comprehensive AIDS Resources Emergency Act. The study found that the stage agency and the CABs valued the role of consumers in policy making, but the mechanisms for translating this goal into reality were not always clear or available. The CABs wanted more opportunities to interact with HIV/AIDS Bureau staff and with one another. The CAB members expressed need for ongoing training and technical assistance for themselves and for consortia staff. This project was an example of action research, for the purpose of change and mobilization.

Porter, E. (1980). "Community health councils." British Medical Journal **280**(6215): 720.

Pratchett, L. (1999). "New fashions in public participation: towards greater democracy?" Parliamentary Affairs **52**(4): 616-33

Preston, T. "The need for public involvement in medicine: the national economy and the public interest necessitate increased consumer activity in monitoring medical practices." Biomedical Communications **10**(6): 9-11.

Price, D. (2000). "Choices without reasons: citizens' juries and policy evaluation." Journal of Medical Ethics **26**(4): 272-6.

Citizens' juries are commended as a new technique for democratising health service reviews. Their usefulness is said to derive from a reliance on citizens' rational deliberation rather than on the immediate preferences of the consumer. The author questions the assertion of critical detachment and asks whether juries do in fact employ reason as a means of resolving fundamental disagreements about service provision. He shows that juries promote not so much a critically detached point of view as a particular evaluative framework suited to the bureaucratic idiom of social welfare maximisation. Reports of jury practice reveal a tendency among juries to suppress by non-rational means the everyday moral language of health care evaluation and substitute for it a system of thought in which it can be deemed permissible to deny treatment to sick people. The author concludes that juries are chiefly concerned with non-rational persuasion and because of this they are morally and democratically irrelevant. Juries are no substitute for voting when it comes to protecting the public from zealous minorities.

Quennell, P. (2001). "Getting their say, or getting their way? Has participation strengthened the patient "voice" in the National Institute for Clinical Excellence?" Journal of Management in Medicine **15**(3): 202-19.

Examines the interaction of patient organisations with the National Institute for Clinical Excellence (NICE) during the first two years of its existence. In particular, it considers the intersection of two policy areas prominent in the Labour Government's health reforms--patient participation and evidence-based medicine. Data has been obtained from unstructured interviews with patient/carer representatives from NICE's committees and patient/carer groups with an interest in NICE's technology appraisals, supplemented by observation of NICE's Board and Partners' Council meetings, and analysis of documentary evidence.

The paper focuses on "formal" and "informal" involvement of patient groups in NICE's structures and appraisals process. Most interviewees felt that the patient voice had been strengthened in these areas, though there was concern about the relative weights of patient and scientific evidence. Thus NICE illustrates two paradoxes in Labour's policy objectives--centralisation/participation and evidence-based medicine/patient perspective--which may become problematic.

Ramsay, S. (1998). "UK public consulted on ethics of human cloning." Lancet **351**(9100): 427.

Raper, M. (2003). "A fond farewell." Nursing Standard **18**(9): 20-1.

Community health councils are to be abolished next month. Maureen Raper looks back on a rewarding role.

Rawlings, M.D., Lipman, T. et al (2001) "The failings of NICE: reply from the Chairman of NICE." British Medical Journal **322**: 489-495

Rawlings, M.D. Culyer, A.J. (2003) "National Institute for Clinical Excellence and its Value Judgements" British Medical Journal **329**, 24 July, 224-227.

Redondo, J., C. Lluch, et al. (1994). "Health council: conclusions after 3-year experience." Atencion Primaria **14**(9): 1047-50.

**OBJECTIVE.** To evaluate the Health Council from 1990 to 1993. To find out what is the knowledge and opinion of the Community about Health Council. **DESIGN.** Observational, descriptive and crossover study. **SITE.** Health Council in El Higuero Health Center. Rural population. Cordoba. **PARTICIPANTS.** Social agents and professionals who had participated in the Health Council's meetings during the three last years. Community of our suburb. **MEASUREMENTS AND MAIN RESULTS.** The records from three years ago have been analysed. A questionnaire was developed and answered in the community. Three focal groups, which had been done with social agents and health professional, have been analysed as well. Two groups of activities have been discussed: in relation to health problem of the community and in relation to Health Center's working. The 70% of them were carried out. Social agents took the initiative in 36%. Questionnaire: 92% of community think they must participate in the health's problems; 40% of community know the Health Council. Focal groups: Health Council is useful for improving the relation between Health Center and Community or for getting the Community to participate in this subject. **CONCLUSIONS.** It is important to remain and increase its utilization. It is necessary to divulge the Health Council and its function.

Reiling, J. G., B. L. Knutzen, et al. (2004). "Enhancing the traditional hospital design process: a focus on patient safety." Joint Commission Journal on Quality & Safety **30**(3): 115-24.

**BACKGROUND:** In 2002 St. Joseph's Community Hospital (West Bend, WI), a member of SynergyHealth, brought together leaders in health care and systems engineering to develop a set of safety-driven facility design principles that would guide the hospital design process. **DESIGNING FOR SAFETY:** Hospital leadership recognized that a cross-departmental team approach would be needed and formed the 11-member Facility Design Advisory Council, which, with departmental teams and the aid of architects, was responsible for overseeing the design process and for ensuring that the safety considerations were met. The design process was a team approach, with input from national experts, patients and families, hospital staff and physicians, architects, contractors, and the community. **OUTCOME:** The new facility, designed using safety-driven design principles, reflects many innovative design elements, including truly standardized patient rooms, new technology to minimize falls, and patient care alcoves for every patient room. The new hospital has been designed with maximum adaptability and flexibility in mind, to accommodate changes and provide for future growth. The architects labeled the innovative design. The Synergy Model, to describe the process of shaping the entire building and its spaces to work efficiently as a whole for the care and safety of patients. **CONCLUSION:** Construction began on the new facility in August 2003 and is expected to be completed in 2005.

Rhodes, P., A. Nocon, et al. (2002). "A service users' research advisory group from the perspectives of both service users and researchers." Health & Social Care in the Community **10**(5): 402-9.

Much has been written about the importance of involving service users in the research process. Far less is available about the experience of involvement from the perspective of service users themselves. The present paper is a joint account by service users and researchers of a service users' advisory group set up to support and advise a project to evaluate diabetes services in Bradford, UK. The establishment of a separate advisory group for service users is, to our knowledge, an innovative approach to lay involvement within mainstream National Health Service (NHS)-based research. Factors that contributed to the group's success included personal contact, continuity of membership and integration into the management structure of the project. Also valued were the confidence in numbers which membership of the group gave, and the opportunity to meet and discuss issues away from the formal and somewhat intimidating atmosphere of the project's steering group. Aside from the personal value to participants and any impact on the quality of research outcomes, wider benefits included the ability to share knowledge with others and gain greater intercultural understanding.

Richardson, A. (1983). Participation. London, Routledge & Kegan Paul.

Richardson, A., M. Charny, et al. (1992). "Public opinion and purchasing." British Medical Journal **304**(6828): 680-682.

OBJECTIVES: To explore the use of a questionnaire to obtain representative public opinions on health services. To examine residents' priorities, knowledge, and views on the public's role in decision making. DESIGN: Self administered postal questionnaire. POPULATION: Random sample of 1500 residents in Bath District Health Authority, drawn from electoral registers. MAIN OUTCOME MEASURES: Levels of agreement or disagreement with statements provided and degree of importance given to services and aspects of services. RESULTS: 704 questionnaires were returned unopened. Completed questionnaires were returned by 704 (49.2%) of the 1430 remaining residents. Kidney dialysis was thought very important to 559 (87%) respondents and family planning by only 58 (9%). Public priorities did not seem to reflect value for money. Clear information about treatment was rated as very important by 530 (76%) and comfortable waiting areas by 70 (10%). 372 (53%) of respondents said that they would definitely travel to a hospital outside the district to reduce their wait for surgery. Knowledge of the services provided by the authority and the money available to it was poor. 446 (65%) respondents wanted greater public involvement in decision making. CONCLUSIONS: A postal questionnaire can provide useful information about public priorities and perceptions about the services provided. More information about health services and their costs and benefits should be given to the public to assist greater public participation in decision making.

Richardson, R. and C. Waddington (1996). "Allocating resources: community involvement is not easy." International Journal of Health Planning & Management **11**(4): 307-15.

Resources for health care are limited in all societies; decisions have to be made about who gets what health care. A case study is discussed. Jaymee Bowen was a British child whose Health Authority refused to provide free treatment for her advanced leukaemia. The media advertised her case and public opinion was mobilized in favour of treating her with public funds. Cost-effectiveness can be used to identify treatments that provide value-for-money.

The public can express an opinion on what kinds of care are wanted--for example, what are the relative benefits of preventing morbidity or mortality, or of helping children rather than young people? Rational criteria can be developed with public involvement--in the case of Jaymee Bowen, the proposed treatment really did not appear to offer value-for money. But some individual cases that contradict the 'rational' criteria for the population as a whole will always be able to attract public sympathy and interest.

Rifkin, S.B. (1996) "Paradigms lost: toward a new understanding of community participation in health programmes". *Acta Tropica* **61**(2): 79-92.

Roberts, J. H. (1999). "Coalition building and public opinion." *International Journal of Technology Assessment in Health Care* **15**(1): 15-21.

The process of technology assessment is evolving. The process of policy development for technology is the least understood in the cycle of technology assessment. The process of policy development, which should involve extensive consultation and a broad-based research and evaluation program, is often fraught with difficulties and can cause further analysis or the assessment process to come grinding to a halt. This article reviews some social, political, and ethical issues and the role of civil society in influencing the technology assessment process for new reproductive technologies in Canada. It is written from the perspective of one of the Deputy Directors of Research and Evaluation for the Royal Commission on New Reproductive Technologies and highlights the strengths and difficulties of technology assessment when civil society and technology assessment come face to face. A brief update by a policy analyst in Health Canada on the current situation of legislation on new reproductive technologies has been provided and is included at the end of this article.

Roberts, T., S. Bryan, et al. (1999). "Public involvement in health care priority setting: an economic perspective." *Health Expectations* **2**(4): 235-44.

**BACKGROUND:** Public involvement in health care decision making and priority setting in the UK is being promoted by recent policy initiatives. In 1993, the British Medical Association called for public consultation where rationing of services was to be undertaken. The approach to priority setting advocated by many health economists is the maximization of quality adjusted life years (QALYs). Typically, for a particular health care programme, the QALY calculation takes account of four features: (1) the number of patients receiving the programme, (2) the survival gain, (3) the gain in quality of life and, (4) the probability of treatment success. Only one feature, that relating to quality of life, is based upon public preferences. If the QALY is to be used as a tool for health care resource allocation at a societal level then it should incorporate broader societal preferences. **METHODS:** This study used an interview-based survey of 91 members of the general public to explore whether the traditional QALY maximization model is a good predictor of public responses to health care priority setting choices. **RESULTS AND CONCLUSIONS:** Many respondents did not choose consistently in line with a QALY maximization objective and were most influenced by quality of life concerns. There was little support for health care programmes that provided a prognostic improvement but left patients in relatively poor states of health. The level of respondent engagement in the survey exercise was not sensitive to the provision of supporting clinical information.

Romanow, R. J. (2002). Building on values: the future of health care in Canada. Ottawa, Canadian Government Publishing.

Rosen, A., P. McGorry, et al. (2004). "Australia needs a mental health commission." Australasian Psychiatry **12**(3): 213-9.

OBJECTIVES: The present paper aims to: (i) describe how the Mental Health Commission in New Zealand works and has contributed to the substantial enhancement of mental health resources and services; (ii) determine whether mental health reform policies will ever be implemented properly without an independent monitor with official influence at the highest levels of government; and (iii) demonstrate how variants on this model work in other Western countries and how it can be adapted to the Federated system in Australia. CONCLUSIONS: It is recommended that the Australian National Mental Health Plan 2003-2008 should be complemented by a long-standing national mental health commission (or similarly constituted body), which is also able to report independently from and to the government, with direct access to the Prime Minister, Premiers and Australian Health Ministers. Its aims would be to monitor service effectiveness and identify gaps in service provision, training and performance of the work force, management and government. It would be informed by consumer, carer and provider experience, and by reviews of evidence-based research regarding health needs and cost-effective services. It should accurately cost such service gaps, and advise government on a strategy for implementing them. It could also promote and advise formally on enhancing community awareness, decreasing stigma and discrimination and improving workforce recruitment and retention.

Rowe, G. and L. J. Frewer (2000). "Public participation methods: a framework for evaluation." Science, technology & human values **25**(1): 3-29.

Rowe, G. and L. J. Frewer (2004). "Evaluating Public-Participation Exercises: A Research Agenda." Science Technology Human Values **29**(4): 512-556.

The concept of public participation is one of growing interest in the UK and elsewhere, with a commensurate growth in mechanisms to enable this. The merits of participation, however, are difficult to ascertain, as there are relatively few cases in which the effectiveness of participation exercises have been studied in a structured (as opposed to highly subjective) manner. This seems to stem largely from uncertainty in the research community as to how to conduct evaluations. In this article, one agenda for conducting evaluation research that might lead to the systematic acquisition of knowledge is presented. This agenda identifies the importance of defining effectiveness and of operationalizing one's definition (i.e., developing appropriate measurement instruments and processes). The article includes analysis of the nature of past evaluations, discussion of potential difficulties in the enactment of the proposed agenda, and discussion of some potential solutions.

Rowe, R. and M. Shepherd (2002). "Public Participation in the New NHS: No Closer to Citizen Control?" Social Policy and Administration **36**(3): 275-290.

Ruelas, E. (2006). "Citizens' quality councils: an innovative mechanism for monitoring and providing social endorsement of healthcare providers' performance?" Healthcare papers **6**(3): 33-7; discussion 58-61.

In recent years, under the influence of continuing improvement and total quality strategies, efforts to improve the quality of healthcare have been generated from within each healthcare organization. External mechanisms, such as accreditation, that drive quality improvement from without, have existed for much longer. However, these accreditation systems incorporated the need to demonstrate the existence of continuing improvement processes as a standard barely 10 years ago; thus, the external mechanism included the development of internal processes as yet another requirement. As Dobrow, Langer, Angus and Sullivan state in the lead article, the existence of a whole evidence-based culture that has spread the concern about quality is beyond doubt; I would add that it has also intensified this concern. Several factors have contributed to this trend, which now seems irreversible. On the one hand, as the paper points out, one of these factors is the growing requirement to allocate resources according to performance. On the other, there is the growing evidence of errors committed by health systems that cause harm to patients. The latter has created increasing demand for reliable information, conceived not only to allow the detection of these situations, but also to invest greater reliability in the health systems in the eyes of patients and general public. In both cases, however, the question remains: Who defines and who measures quality levels in such a way that the information is credible?

Russell, E. and C. Smith (2003). "Whose health is it anyway?: enabling participation." J Epidemiol Community Health **57**(10): 762-763.

Ryan, N. (2001) "Reconstructing citizens as consumers: implications for new modes of governance." Australian Journal of Public Administration **60**(3): 104-9.

Sadler, J. Z. and B. Fulford (2004). "Should patients and their families contribute to the DSM-V process?" Psychiatric Services **55**(2): 133-8.

The authors consider arguments for and against the formal inclusion of mentally ill patients and their families in the deliberative processes leading to DSM-V. These discussions involve six key issues: the scientific status of psychiatric classifications; public policy and political considerations; the practical implications of widening the review process; the capacities of lay members of the workgroups; freedom of expression and the openness of the review process; and the uniqueness of consumer perspectives. The authors conclude that involving patients and families in the DSM review process is supportable on both scientific and public policy grounds.

Samuels, B. and D. Sherr (1979). "From SAC's to DAC's--will consumers' voices be muted?" Health Law Project Library Bulletin **4**(4): suppl 2-3.

Sanders, L. (1997) "Against deliberation" Political Theory **25**: 347-476.

Sang, B. (2004). "Choice, participation and accountability: assessing the potential impact of legislation promoting patient and public involvement in health in the UK." Health Expectations **7**(3): 187-90.

Recent legislation enabling increased patient and public involvement in health decision-making will increasingly interact with the maturing independent patient movement to open up accountability systems across healthcare. Lay people will develop new roles, building on learning from the independent advocacy sector, self management, and wider active participation. Inevitably, this means a profound cultural challenge for healthcare organizations, and for citizens, as they begin to understand the implications of the new policies, including patient choice.

Santos, S. L. and C. Chess (2003). "Evaluating citizen advisory boards: The importance of theory and participant-based criteria and practical implications." *Risk Analysis* **23**(2): 269-279.

The role of risk communication and public participation in environmental and public policy decision making has significantly increased over the last 15 years and remains an important social policy issue. In spite of this emphasis, government officials and participants in the process continue to struggle with what makes for 'good' public participation. This study used two frameworks - one theoretical and one participant-based - to evaluate two U.S. Army Restoration Advisory Boards (RABs). The theoretical framework explores the extent to which the RABs facilitate Habermas's idealized conditions of speech as related to fairness. Not surprisingly, we found that the two RABs do not consistently foster the idealized aspects of fairness suggested by Habermas. The participant-based criteria were elicited through interviews with participants from the various stakeholder groups represented on the RAB, direct observation of RAB meetings, and a review of RAB-related documents. We found that participants' value outcomes (the results of participatory processes) and not just the process itself, which is the focus of the theoretical framework. We also found that participants in the various stakeholder groups had different perceptions of the goals of the participatory process, which were closely related to their notions of success. Our results illustrate both the complexity and importance of using multiple frameworks for evaluating participatory efforts and the need for more systematic evaluation.

Sato, H., A. Akabayashi, et al. (2005). "Public appraisal of government efforts and participation intent in medico-ethical policymaking in Japan: a large scale national survey concerning brain death and organ transplant." *BMC Medical Ethics* **6**: E1.

**BACKGROUND:** Public satisfaction with policy process influences the legitimacy and acceptance of policies, and conditions the future political process, especially when contending ethical value judgments are involved. On the other hand, public involvement is required if effective policy is to be developed and accepted. **METHODS:** Using the data from a large-scale national opinion survey, this study evaluates public appraisal of past government efforts to legalize organ transplant from brain-dead bodies in Japan, and examines the public's intent to participate in future policy. **RESULTS:** A relatively large percentage of people became aware of the issue when government actions were initiated, and many increasingly formed their own opinions on the policy in question. However, a significant number (43.3%) remained unaware of any legislative efforts, and only 26.3% of those who were aware provided positive appraisals of the policymaking process.

Furthermore, a majority of respondents (61.8%) indicated unwillingness to participate in future policy discussions of bioethical issues. Multivariate analysis revealed the following factors are associated with positive appraisals of policy development: greater age; earlier opinion formation; and familiarity with donor cards. Factors associated with likelihood of future participation in policy discussion include younger age, earlier attention to the issue, and knowledge of past government efforts. Those unwilling to participate cited as their reasons that experts are more knowledgeable and that the issues are too complex. CONCLUSIONS: Results of an opinion survey in Japan were presented, and a set of factors statistically associated with them were discussed. Further efforts to improve policy making process on bioethical issues are desirable.

Saunders, M. (1980). "Would community health councils be missed?" Nursing Focus 1(7): 278-80.

Seifert, M. H. (1984). "Patient advisory council cuts malpractice costs." Patient Education Newsletter 7(5): 1-2.

Shepherd, M. (2001). "Primary care groups." Health Service Journal 111(5742): 32-3.

A survey of primary care groups in the South West region found a lack of expertise in involving the public. Respondents saw the main obstacles as lack of time, expertise and money. If the NHS plan's ambitious agenda for public involvement is to be achieved the shortage of expertise must be addressed.

Shepherd, M. (2001). "Voice recognition." Health Service Journal 111(5742): 32-3.

Simces, Z (2003) Exploring the link between public involvement/citizen engagement and quality healthcare: a review and analysis of current literature Ottawa, Health Canada.

Slachtova, H. (2002). "Theoretical framework for risk perception and risk communication." Hygiena 47(1): 32-40.

At the beginning of the nineties the process of environmental health risks assessment and reduction was initiated which at present is developing into the process of risk management and risk control. Health risks assessment and their subsequent control is one of the duties of the hygiene service laid down in Act 258/2000, i.e. the Act of public health protection. A part of the process of risk communication and risk management is also involvement of public. It is important to assess how people evaluate risks they encounter in everyday life. It is important to know which risks they consider important and whether they are able and willing to resolve them. Knowledge of the mechanism of risk perception is an essential prerequisite for public involvement in the process of technological risk management. The article provides theoretical framework needed to understand basic principles of risk perception and risk communication.

Sloane, T. (2005). "Citizen reformers." Modern Healthcare 35(10): 42.

Smith, R. (2000) "The failings of NICE" British Medical Journal 321: 363-4.

Smith, T. (2003). "Towards a more responsive health system?" Quality and Safety in Health Care 12(2): 156-158.

Smith, E., F. M. Ross, et al. (2005). "Developing a service-user framework to shape priorities for nursing and midwifery research." *Journal of Research in Nursing* **10**(1): 107-20. (29 ref).

Many people believe, and government policy recommends, that service users should be involved more in research agenda setting. This paper helps to provide a way of undertaking this, drawing on the approach used in a national research priority setting exercise for nursing and midwifery service delivery and organisation. A framework of service-user expectations for nursing and midwifery services was developed through a process of focus group discussions. Thirty-two participants were recruited from Community Health Councils (CHCs) because of their formal role in linking to health providers and as advocates of local communities. Discussions focused on the main gaps in nursing and midwifery services, priority areas for improvement and ways of involving service users in these developments. Nine broad expectations for nursing and midwifery services were identified and were used as a framework for the alignment of professional stakeholder data and literature and policy analysis. This enabled five priority areas for research to be identified that were important to all of these groups. Targeted sampling, information giving prior to the focus groups, careful explanation of confidentiality and the purpose of the exercise and facilitation skills were important for developing a framework that covered the wide breadth of the topic area. The process also raised important questions for nursing and midwifery research. Conceptual difficulties about balancing service-user control and researcher influence, and the authenticity of the data in representing diversity, were limitations of the approach. A final report is available at [www.sdo.lshtm.ac.uk/nursingandmidwifery](http://www.sdo.lshtm.ac.uk/nursingandmidwifery).

Sofaer, S. (1999). "Challenges for the public in negotiating the health system in the 21st century." *Journal of Urban Health* **76**(2): 211-28.

This paper addresses the challenges and opportunities that face the public in negotiating the health care system (both medicine and public health) in the 21st century. It addresses three issues: how consumers exercise choice, with special attention to the choice of health care coverage; how patients and communities interact with clinicians and public health professionals; and whether and how the public's "voice" is heard as health policy decisions, at the societal and institutional levels, are made. With respect to each of these issues, the paper describes the current status of public influence and articulates a vision for the future. These three related visions are (1) that empowered, informed, supported consumers make decisions about health plans, clinicians, treatments, and their own behavior; (2) that clinicians and public health professionals, working as partners with patients and communities, are in a position to "standardize the customization of care" so that all aspects of care are tailored to the needs of the individual, family, or community in question and social, economic, and cultural factors are taken into account in the day-to-day practice of medicine and public health; and (3) that the ability and willingness of the public to negotiate and shape the health care environment is supported by an independent infrastructure that permits enhanced public involvement in health policy making and governance. The paper identifies key elements of this vision, discusses challenges to pursuing and achieving each vision, and identifies opportunities that may support the pursuit of the vision.

Spitzer, R. L. (2004). "Good idea or politically correct nonsense?" *Psychiatric Services* **55**(2): 113.

Steinberg, M. (1979). "The relative emphasis upon physician practice and organizational affairs of a consumer council in a prepaid group practice health plan." Journal of Community Health 4(4): 312-20.

This paper examines the topics of interest to a consumer advisory council in the Health Insurance Plan of Greater New York, a prepaid group practice. Data are derived from observations of consumer council meetings. Topics considered by the council dealt with (a) health plan services, (b) health plan structure, and (c) consumer council structure, process, and organizational role. The council was primarily interested in retaining and expanding existing services, facilitating utilization of services by enrollees, and achieving broader enrollee representation on the board of directors. These interests are directed toward the organizational context within which care is provided and do not relate to physician-patient encounters. Individual enrollees in prepaid group practice may be concerned with the physician-client relationship but consumer representatives are concerned only with the organization-client relationship.

Stevenson, R. and M. Hegarty (1994). "Consumer audit." Health Service Journal 104(5430): 22-4.

Strauss, R. P., S. Sengupta, et al. (2001). "The role of community advisory boards: involving communities in the informed consent process." American Journal of Public Health 91(12): 1938-43.

Ethical research involving human subjects mandates that individual informed consent be obtained from research participants or from surrogates when participants are not able to consent for themselves. The existing requirements for informed consent assume that all study participants have personal autonomy; fully comprehend the purpose, risks, and benefits of the research; and volunteer for projects that disclose all relevant information. Yet contemporary examples of lapses in the individual informed consent process have been reported. The authors propose the use of community advisory boards, which can facilitate research by providing advice about the informed consent process and the design and implementation of research protocols. These activities could help reduce the number of individual informed consent lapses, benefiting study participants and the scientific integrity of the research in question.

Sweeney, G., B. O'Hagan, et al. (2005). "The Patients Accelerating Change project: does it make any difference?" Clinical Governance: An International Journal 10(1): 72-83.

**PURPOSE:** The purpose of this survey was to evaluate the impact and experience of the Patients Accelerating Change (PAC) project from the perspective of 28 people who were closely involved in the project. **DESIGN/METHODOLOGY/APPROACH:** Data were collected by telephone interview with 28 individuals from nine acute NHS Trusts which piloted the PAC project. **FINDINGS:** PAC was seen to make a positive impact in terms of improving communication and information, helping patients feel valued and listened to, providing real direction as a result of listening to feedback from patients, and improving processes and procedures in the participating Trusts. The PAC project raised the profile of the Patient and Public Involvement Agenda within the NHS Trust organisations that participated in the project.

RESEARCH LIMITATIONS/IMPLICATIONS: The PAC project was still in its infancy at the time of data collection for this study, and over half of the sample was likely to have been composed of enthusiasts for the process: this may have contributed to a positive bias. PRACTICAL IMPLICATIONS: The PAC project works on a "staggered approach" in terms of realising short- and then long-term improvements in the patient's experience. By the end of the project it was expected that some "quick wins" could be identified and the PAC organisers acknowledged that more time is needed in order to realise longer-term improvements. ORIGINALITY/VALUE: This survey provides useful information to patients and staff at NHS Trusts who may be considering how best to involve patients in planning and improving the quality of care that they receive.

Tai-Seale, T. (1999). "Policy theory and social issues." International Quarterly of Community Health Education **19**(4): 363-73.

Mass public involvement in community health planning has been the dream of health planning agencies for decades. The Alma Ata Declaration announced that people have the right and duty to participate and most community health planning models agree that community involvement is essential if significant, lasting, and appropriate progress is to be made in health promotion and disease prevention. Progress toward this goal, however, has not been remarkable. This article argues that the slow progress is attributable to the way community has been defined and to deficiencies in the traditional community development models used by health planners. It advances a radical alternative to conventional methods of involving community in health planning and sets forth steps through which masses can become involved in meaningful planning.

Tarlton, S. (2001). "Public involvement in science and decision making?" Health Physics **81**(6): 730.

Taylor, D. and C. Downer (1997). "Toward a women-centered health care system: women's experiences, women's voices, women's needs." Health Care for Women International **18**(4): 407-22.

In this report we describe the results from 19 focus groups of nearly 250 women held in 1993 and 1994, in which diverse groups of women were asked to respond to a model health care delivery system. This project, sponsored by the Women's Health Advisory Committee of the San Francisco Department of Public Health, solicited focused input from diverse groups of women as they reviewed the draft of an "ideal" women's health care service model. Women's responses to an ideal system revealed some of the problems inherent with the current "nonsystem" of health care delivery. These responses were categorized into general themes and are presented here to demonstrate the range of women's experiences with their current health care, from their perspective and in their voices.

Taylor, J., D. Wilkinson. (2006) "Is it consumer or community participation? Examining the links between 'community' and 'participation'." Health Sociology Review **15**(1): 38-47.

Tee, S. (2002). "Promoting patient and public involvement in primary health care: part 1 -- literature review." MCC: Building Knowledge for Integrated Care **10**(3): 39-46.

Primary care groups are required to demonstrate that patients and the public are involved in the planning, delivery and evaluation of the services they provide. However, a review of the literature suggests that managers' ability will be greatly tested if they are to achieve meaningful progress in this area. Some suggestions are made to assist managers in this important role. In the next issue of MCC, Part 2 reports findings from a locality case study.

Tee, S. (2002). "Promoting patient and public involvement in primary health care: part 2 -- local case study." MCC: Building Knowledge for Integrated Care **10**(4): 41-8.

Primary care groups (PCGs) and primary care trusts (PCTs) are required to ensure that patient and public involvement underpins all activity. In Part 1, the literature review revealed many challenges to implementing this important measure of performance that would test those with responsibility for achieving a meaningful outcome for all stakeholders. Part 2 reports on a local study that used qualitative data from key stakeholders to examine how one PCG was responding to the involvement agenda. The findings revealed cynicism and doubt among board members about the purpose and value of involvement, despite which some progress had been made in engaging with local voluntary groups. However, the experience of involvement among local patients had not always been a positive one. It is suggested that issues of power and organisational culture will need to be tackled through greater investment in clinical and managerial staff development.

Tenbenschel, T. (2002). "Interpreting public input into priority-setting: the role of mediating institutions." Health Policy **62**(2): 173-94.

Discussions about public participation in health priority-setting have tended to assume that the best type of information about public values is that in which the public 'speaks for itself'. However, wherever public input has been used in priority-setting, the way in which it is used is far from transparent. Those jurisdictions that have initiated priority-setting processes have been characterised by the substantial involvement of 'mediating bodies' i.e. bodies such as the Oregon Health Services Commission or the New Zealand National Health Committee, that take on the role of interpreting information about public values. The information that they interpret is usually presented in a highly ambiguous form and most definitely does not 'speak for itself'. In the priority-setting literature, however, little attention has been paid to the role of these bodies and the way in which they interpret and digest information about public values. This article argues that these bodies are essential, but that their decision-making processes are necessarily opaque and should not be judged according to the criterion of transparency.

Thompson, A. (1999). "New millennium, new values: citizen participation as the democratic ideal in health care." International Journal for Quality in Health Care **11**(6): 461-464.

Thompson, C. A. (2005). "Safety advisory group gets mixed marks from members." American Journal of Health-System Pharmacy **62**(3): 236.

Topliss, E. (1975). "The role of Community Health Councils." Royal Society of Health Journal **95**(6): 299-301.

Trappenburg, M. (2005). "Fighting sectional interests in health care." Health Care Analysis **13**(3): 223-37.

In the 1970s policy making in The Netherlands took place in sectoral networks, consisting of professional interest groups and like minded civil servants, advisory councils, MP's and departmental ministers. In this article the author examines whether such a sectoral policy network still exists in Dutch health care by comparing past and present data on the background of civil servants, MP's and departmental ministers. Next she describes the political fight against the health care sectoral network, which has gone on for decades. She concludes that the health care sectoral network has been severely weakened, although it remains to be seen whether this will lead to a substantial reduction of health care costs, which was one of the main reasons why politicians fought against sectoral interests in the first place.

Traulsen, J. M. and A. B. Almarsdottir (2005). "Pharmaceutical policy and the lay public." *Pharmacy World & Science* **27**(4): 273-7.

Almost every national and supranational health policy document accords high importance to the need to listen to and 'empower' patients. The relationship between pharmaceutical policy and the lay public is not direct but mediated by several actors, including health care workers, patient organisations, industry and, most recently, the media. Although the overall aim of health and pharmaceutical policy is to address the needs of all citizens, there are only a few, well organised groups who are actually consulted and involved in the policymaking process, often with the support of the industry. The reasons for this lack of citizen involvement in health and pharmaceutical policymaking are many, for example: there is no consensus about what public involvement means; there is a predominance of special interest groups with narrow, specific agendas; not all decision makers welcome lay participation; patients and professionals have different rationalities with regard to their views on medicine. Because the lay public and medicine users are not one entity, one of the many challenges facing policy makers today is to identify, incorporate and prioritise the many diverse needs. The authors recommend research which includes studies that look at: lay attitudes towards pharmaceutical policy; lay experiences of drug therapy and how it affects their daily lives; the problem of identifying lay representatives; the relationship between industry and the consumers; the effect of the media on medicine users and on pharmaceutical policy itself. The authors acknowledge that although lay involvement in policy is still in its infancy, some patient organisations have been successful and there are developments towards increased lay involvement in pharmaceutical policymaking.

Tuler, S., T. Webler, et al. (2005). "Competing perspectives on public involvement: planning for risk characterization and risk communication about radiological contamination from a national laboratory." *Health, Risk & Society* **7**(3): 247-66.

Public involvement is increasingly emphasized as part of government agencies' responses to environmental health hazards, including risk characterization and risk communication. For example, there is a growing body of literature on health and risk communication proposing best practices and evaluating processes, yet there has been little attention to the ways that preferences for process features and criteria for evaluating success may vary among stakeholders and between stakeholders and government agency staff.

This paper reports on a study into how participants associated with an effort to address public health risks from the distribution of plutonium contaminated sewage sludge in Livermore, California, think about the most appropriate way to conduct a process integrating public involvement. Using Q method this paper identifies five perspectives about what constitutes a good collaborative process in this case. The lessons for organizers and participants of risk characterization and risk communication efforts when people subscribe to different (sometimes competing) perspectives about process are discussed.

Valdiserri, R. O., G. M. Tama, et al. (1988). "The role of community advisory committees in clinical trials of anti-HIV agents." Irb: a Review of Human Subjects Research **10**(4): 5-7.

van Wersch, A. and M. Eccles (2001). "Involvement of consumers in the development of evidence based clinical guidelines: practical experiences from the North of England evidence based guideline development programme." Quality in Health Care **10**(1): 10-6.

BACKGROUND: Consumer involvement in clinical guidelines has long been advocated although there are few empirical accounts of attempts to do so. It is therefore not surprising that there is a lack of clarity about how and when to involve consumers and what to expect from them within the process of guideline development. METHODS: The North of England evidence based guideline development programme has used four different methods of consumer involvement. RESULTS: When individual patients were included in a guideline development group they contributed infrequently and had problems with the use of technical language. Although they contributed most in discussions of patient education, their contributions were not subsequently acted on. In a "one off" meeting with a group of patients there were again reported problems with medical terminology and the group were most interested in sections on patient education and self management. However, their understanding of the use of scientific evidence in order to contribute to a more cost effective health care remained unclear. In a workshop it was possible to explain the technical elements of guideline development to patients who could then engage with such a process and make relevant suggestions as a consequence. However, this was relatively resource intensive. A patient advocate within a guideline development group felt confidence to speak, was used to having discussions with health professionals, and was familiar with the medical terminology. CONCLUSIONS: Consumers should be involved in all stages of guideline development. While this is possible, it is not straightforward. There is no one right way to accomplish this and there is a clear need for further work on how best to achieve it.

Walsh, P. (2001). "Community health councils." Health Service Journal **111**(5779): 26-7.

The government's decision to abolish community health councils in England does not appear to be the result of public consultation. A survey of councils for voluntary service in England suggests that most are in favour of strengthening and reforming CHCs. The government's handling of the issue does not bode well for future consultation in the NHS.

Warner, M. M. (1980). "Health care in the 1980s: consumer contamination or purposeful planning?" Health Management Forum **1**(1): 57-70.

Watts, R. J. Rhetoric or reality: a critical analysis of public involvement in the Western Australian health care system. (UNIVERSITY OF COLORADO HEALTH SCIENCES CENTER) \*\* 1991; PH.D.

The purpose of this study was to critically analyze the socio-political process of public involvement in the Western Australian health care system. An action research design, set within the critical, praxis-oriented paradigm and informed by theories of democratic process, was used to address this purpose. Contextual, experiential, and action-related data were obtained from public documents, 10 respondents, and 17 participating communities of interest. These groups were drawn from existing community and health provider organizations within the state of Western Australia. Data were gathered by interviews, small group discussions, and workshops. Analysis of contextual, experiential, and action-related data proceeded through four stages: familiarization with the data; structural analysis; interpretive analysis; and critical reflection. Data analysis revealed a number of themes and counterthemes related to public involvement in health care. Modifications to the a priori theory were indicated by the process of critical reflection. The following themes were identified from the experiential data: definition of the term "community"; functions of public involvement, both ideal and instrumental; power strategies; reasons for the existence of disempowerment; and factors affecting involvement. The contradictions revealed by the analysis of the contextual, experiential, and action-related data fell into three categories: ideology, provider-community relationships, and goal and process. From the latter grouping three sub-categories of contradictions were derived: primacy of goals, guiding model of health, and management process. The experiential data were not supportive of the major tenets of the contemporary theory of democracy. These data were congruent, however, with the contrasting theory of participatory democracy. Modifications to several aspects of this theory were suggested by the data, for example the nature of representation. Critical reflection on the data and a priori theory provided the basis for informed action. A model was developed of formal public involvement designed for inclusion in the organizational structure of the Health Department of Western Australia. Implications for nursing and other health care provider groups in terms of practice, education, and research were indicated within this model. Three of the participating groups continue to implement action plans developed from their involvement in the study.

Wendhausen, A. and S. Caponi (2002). "Dialogue and participation in a local health council in the State of Santa Catarina, Brazil." *Cadernos de Saude Publica* **18**(6): 1621-8.

Although we are accustomed to believing that dialogue must involve participation, actual practice shows that it can occur in different ways. In this study, conducted in a municipal health council in the State of Santa Catarina, Brazil, the discursive mechanisms and strategies that appear as "obstacles" to this dialogue were analyzed, based on the minutes from 39 council meetings. Dialogue remained absent even though the council was intended as a forum for participation. Among the strategies, certain expressions which Umberto Eco refers to as "hypercodifications" were identified. Such expressions apparently act to block any debate in the council. The hypercodifications identified in this study were expressions of technical, administrative, and political jargon. Through these discursive strategies, the authors observed that language is used as a ruse, closing off possibilities for democratic interlocution, effectively cutting off dialogue. Thus, there is little transitivity in the power wielded by various segments in the council, which ended up concentrating primarily in the government sector.

White, D. G. (1994). "Medical school-community dialogue: a survey of current initiatives in Canada and the United States." *Academic Medicine* **69**(7): 588-90.

BACKGROUND. Medical schools are being challenged to respond to societal needs and to engage in dialogue with the public, but there are few empirical data on the extent and nature of such efforts. METHODS. In early 1992, the associate deans for medical education at all accredited medical schools in the United States and Canada were surveyed regarding public involvement in their schools. Their descriptive responses were analyzed by computer search for key words, and correlations were determined between response categories and the schools' characteristics. RESULTS. Of the 95 responding schools (66%), 59 (62%) regularly involved members of the public in administrative bodies, usually those related to research, admission, hospital boards, and undergraduate education. Community-based schools were more likely to involve the public. Sixty schools (63%) had taken steps to identify community needs, and these schools showed evidence of greater public involvement in administration. The respondents perceived public involvement as beneficial primarily for building commitment between a school and its community. CONCLUSION. In contrast to concerns about declining trust between medical schools and the public, the impressions of the 95 respondents about public involvement in their schools were positive. The survey results suggest that such involvement builds mutual understanding and represents a direct and constructive response to declining trust.

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American Health Decisions is a developing social movement that aims to work at the grassroots level to educate people about issues and problems in health care and to promote public involvement in decision making about health policy. The movement offers nurses opportunities to expand their traditional commitment to involving people in decisions about their health. By promoting the development of the movement, nurses can contribute to the creation of a structured process of direct public participation in policy decisions related to health care. Nurses may have a special role to play in the movement by promoting the participation of low-income people.

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Williamson, C. (1998). "The rise of doctor-patient working groups." British Medical Journal **317**(7169): 1374-7.

Willson, J. A. (1997). "Criteria for identifying regulatory issues and the role and responsibility of council members of health regulatory bodies." Health Law in Canada **18**(1): 23-9.

Wiseman, V. (2005). "Comparing the preferences of health professionals and members of the public for setting health care priorities : experiences from Australia." Applied Health Economics & Health Policy **4**(2): 129-37.

**INTRODUCTION:** This article reports on a priority-setting exercise involving members of the general public and health professionals. The aim is to compare the healthcare priorities of these two groups, as well as their attitudes towards public involvement in priority setting. **METHODS:** A convenience sample of 373 members of the public attending two central Sydney, Australia, medical clinics were asked to complete a structured, interviewer-administered questionnaire. Forty-four purposively sampled healthcare professionals working in central Sydney completed the same questionnaire. Both groups were asked whether the preferences of the public should inform priority-setting decisions. They then had to allocate an additional (but fixed) amount of healthcare resources across competing programmes, medical procedures and population groups and their preferences were compared. **RESULTS:** The health professionals and members of the public strongly supported using public preferences to inform priorities in healthcare. Both groups expressed a slightly stronger preference for using public preferences to inform priorities across healthcare programmes and population groups than for medical interventions. **DISCUSSION/CONCLUSION:** Considerable uniformity of preferences was revealed between the health professionals and the members of the public. However, it is argued that, even where the preferences of health professionals are consistent with and representative of those of the wider community, public involvement is important in terms of procedural justice, as it helps to legitimise both the process and the resultant priorities.

Witchell, L. (2003). "Patient and public involvement." Ophthalmic Nursing: International Journal of Ophthalmic Nursing **6**(4): 3.

Woods, D. (1976). "District health councils: health care for the people or just another layer of bureaucratic fat?" Canadian Medical Association Journal **115**(9): 928-32.

Woodward, S. (2005). "Seven steps to patient safety." Revista de Calidad Asistencial **20**(2): 66-70.

It is now well recognised that incidents in healthcare systems are a serious problem which requires urgent attention. This paper outlines the work of the National Patient Safety Agency (NPSA), presents an overview of the 7 key steps required to achieve a safer organisation. The first 3 steps introduce the concepts, methods, research and practical tools in relation to developing a safety culture (step 1), establishing a strong focus on patient safety throughout the organisation (step 2) and integrating risk management systems (step 3). The following steps describe national and local reporting requirements (steps 4), patient and public involvement in safety (step 5), the root cause analysis approach to incident investigation (step 6) and transferring lessons to solutions (step 7). Every day more than a million people are treated safely and successfully in the NHS. However the advances in technology and knowledge in recent decades have created an immensely multifaceted healthcare system. Patient safety is such an important concept that taking this agenda forward might seem daunting in any area of the NHS. It is vital that healthcare staff can progress towards delivering this safety agenda. The 7 steps provides a guide to help them achieve this.

World Health Organisation (1978). The Declaration of Alma-Ata. Geneva, World Health Organisation (WHO).

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Zalot, G. N., S. Elson, et al. (1990). "Setting community health goals: one District Health Councils experience." Healthcare Management Forum **3**(2): 34-8.

The Niagara District Health Council has embarked on a strategic planning exercise to develop health goals, objectives and preliminary targets for action. This process was approached in three phases: establishment of a Health Goals Task Force and adoption of the five goals developed by the Premier's Council on Health Strategy; planning and implementation of a Health Goals Consultation Day to involve community members in the identification and priority ranking of objectives; and development of measurable and realistic preliminary targets through consultations with expert groups and individuals. This process is a practical planning tool applicable across sectors and communities.

Zukoski, A. P. and S. M. Shortell (2001). "Keys to building effective community partnerships." Health Forum Journal **44**(5): 22-5.

A four-year study of 25 community health partnerships reveals the six characteristics that help partnerships succeed. Managing size and diversity, addressing coalition conflict, and recognizing life cycles are among the primary behaviors differentiating the strong from the weak.