Public participation in health policy in high income countries – why, who, what, which, and where?

Edited by Tim Tenbensel, University of Auckland

This Virtual Special Issue on public participation in health policy contains thirteen key articles drawn from Social Science & Medicine over the period 2002-2009. This collection provides a way of tracking the emphases, commonalities, key differences and trends in this area of literature, in which contributors to this journal have made a substantial contribution.

In selecting articles for this issue, a broad definition of public participation was adopted. Each of the search terms ‘public’ and ‘community’ was combined with each of the terms ‘participation, engagement, deliberation and involvement’ published between 2002 and 2009. From the 126 articles found, articles selected were those that:

a) had an explicit focus on health policy, (we ruled out, for example, articles on community-based health promotion as beyond the scope of this particular Virtual Special Issue) and

b) had public participation as a major focus, rather than something incidentally touched on

c) focused on high-income countries – there is a related literature on public engagement in low and middle income countries that deals with a different range of concerns

The introduction to this Virtual Special Issue is organised around a series of questions about public participation that are addressed directly or indirectly by the contributors:

(i) Why is public participation in health policy of interest?

(ii) Who constitutes ‘the public’?

(iii) What health policy issues are canvassed in exercises of public participation?

(iv) Which techniques of public participation are studied?

(v) Where to from here in public participation practice and research?

Why is public participation in health policy of interest?

Broadly speaking, we can readily identify two distinct, albeit frequently intertwined, rationales for greater public involvement, both of which are well-established. The first rationale is primarily concerned with the democratic legitimacy of policy processes in general, or health policy in particular. If health policy is conducted within a democratic context, public participation is essential if health policy processes are to be accountable and transparent to the general public. The second rationale is more focused on the contention that public input produces better, more intelligent health policy decisions. The articles in this Virtual Special Issue form a solid basis for reviewing what is new in academic understandings of the legitimacy and rationality of public participation in health policy in the past decade.

The first decade of the 21st century has seen a maturation of health policy scholarship that draws from the wellsprings of late 20th century democratic theory to demonstrate how citizen engagement enhances the legitimacy of health policy processes. Most prominent here are ideas of participatory,
deliberative and discursive democracy which share an emphasis on dialogue between citizens. Abelson, Forest, Eyles, Smith, Martin and Gauvin’s (2003) contribution provides a very useful overview of this rationale, emphasising that ‘(c)ollective “problem-solving” discussion is viewed as the critical element of deliberation, to allow individuals with different backgrounds, interests and values to listen, understand, potentially persuade and ultimately come to more reasoned, informed and public-spirited decisions’ (Abelson et al. 2003: 241). In line with this emphasis, a number of articles in this collection explore varieties of deliberative techniques (see the ‘how’ section below).

However, some contributions also identify some possible boundaries and limits that circumscribe the legitimate scope of public participation and engagement. The title of one article – ‘the public is too subjective’ (Litva, Coast, Donovan, Eyles, Shepherd, Tacchi, Abelson and Morgan 2002) highlights misgivings that some members of the public have about the legitimacy of public input into health priority-setting, particularly within particular health services and programmes. In investigating a similar question, however, the findings of Wiseman, Mooney, Berry and Tang (2003) indicate significantly less reluctance on the part of members of the public.

The second type of justification is that public engagement is desirable for its contribution to policy-relevant knowledge. Academic scholarship on public engagement in health policy seeks to answer the question that Lehoux, Daudelin, Demers-Payette and Boivin (2009) ask: ‘what do we want to know from publics?’ By the end of the 1990s, the predominant argument was that citizen input helps to shape and define the key values that can then underpin policy decisions, and indeed that knowledge about values was the key component of the public’s ‘expertise’. However, a number of the articles in this collection demonstrate that a more nuanced understanding of the relationship between values, public participation and health policy is required.

As Lehoux et al (2009) argue in their paper, it is highly misleading to think that citizens and publics only contribute knowledge about values which can then be integrated with the factual information provided by technical experts. Contrary to this ‘demarcationist’ view, lay members of the public constantly synthesise facts and values. Facts and values have an iterative relationship, and experts bring values (often unacknowledged) while publics make use of research findings to modulate and moderate their value judgements. A number of other articles in this collection give credence to this argument.

For some of the articles in this collection, the question of why public participation is important in health policy is very much an open one. Both Frankish, Kwan, Ratner, Wharf-Higgins and Larsen (2002) and Martin (2008) emphasise the variety of perspectives from participants in health policy processes, and identify some important tensions and conflicts between multiple rationales for public participation. Taking this further, Contandriopoulous (2004) argues that the ‘why’ of public participation needs to be answered quite differently in different policy contexts. In his review of public participation in Quebec health policy, the strongest rationale public participation was grounded simply in a sense of grass roots dissatisfaction with the status quo.

A number of articles in this collection place the study of public participation alongside a broader range of theoretical concerns. The piece by Callaghan and Wistow (2006) connects the topic to discussions of governance drawing on the work of Bob Jessop (2003) and demonstrates how participation takes quite different forms depending on whether health services are steered in a hierarchical or a heterarchical manner. Other contributions also develop important connections to
broader sociological literature including the sociology of knowledge (Lehoux et al 2009), and the work of Bourdieu (Contandriopoulos 2004).

**Who constitutes the public?**

Literature on public participation in health policy has drawn upon a wide range of conceptualisations of who constitutes the public and who is entitled to ‘represent’ it in policy processes ranging from randomly selected citizens, health service users, patient advocacy groups, and elected representatives on public bodies.

In this collection, all these manifestations of the public are present. The most common the way the public is constructed, however, is as citizens – accounting for nearly half the articles in this issue (Litva et al. 2002; Abelson et al. 2003; Bates, Lynch, Bevan and Condit 2005; Abelson, Forest, Eyles, Casebeer, Martin and Mackean 2007; Bennett and Smith 2007; Secko, Preto, Niemeyer and Burgess 2009). The concept of citizens is closely tied to notions of the ‘disinterested’ public. That is to say, when members of the public participate as citizens, they put aside their particularistic preferences (which may be based on age, gender, location, health condition), and participate for the common good and are therefore closely tied to the deliberative turn in democratic theory.

However, this collection also contains some rather more distinct and sometimes quite particularistic characterisations of the public. Martin (2008) focuses on health service users, while other contributors take a more pragmatic approach to identifying publics, recruiting general practice patients (Wiseman et al 2003), and audiences at theatre performances (Cox, Kazubowski-Houston and Nisker 2009) as their ‘slice’ of the public.

**What health policy issues are canvassed in exercises of public participation?**

What are the specific health policy issues and domains that have prompted research on public participation in health policy, and have these changed over time? Based on the articles in this Virtual Special Issue, we can see four prominent clusters of health policy areas in which public participation is typically sought and/or researched.

The first common domain is strategic planning which is undertaken by local, public sector health authorities (Frankish et al. 2002; Contandriopoulos 2004; Callaghan and Wistow 2006; Abelson et al. 2007). The second, sometimes closely related arena is health service rationing and prioritisation (Litva et al 2002; Wiseman et al 2003). The third arena is health technology assessment (Milewa 2006; Lehoux et al. 2009), which is a more specific strand of the broader literature on health priority-setting. These articles, however, focus on quite specific organisational settings, notably organisations such as England and Wales’s National Institute of (Health) and Clinical Excellence (NICE). These health policy domains (regional planning, priority-setting, technology assessment) illustrate significant continuity with literature on public engagement in health policy published in the 1990s. With the exception of the Bates et al (2005) study of public attitudes to genetic research in the US, each of these articles draws from research in the context of health systems that are predominantly tax funded, and therefore strongly coupled with regimes of public accountability.

The final health policy domain consists of a broad range of issues involving genetic research, technologies and related services (Bates et al 2005; Bennett & Smith 2007; Cox et al 2009; Martin

The increased prevalence of genetic issues in recent years constitutes a new development which could well be indicative of a significant sea-change in the focus of public participation research in health policy. It is also possible that the shift into this area reflects a recognition that these are policy areas where imperatives for public involvement are that much stronger as governments begin to ‘puzzle’ over these issues characterised by a high degree of ethical complexity.

**Which techniques of public participation are studied?**

In this collection, techniques of eliciting public input vary widely. This partly reflects a range of research agendas. Some contributors are simply looking to examine ‘actually existing’ practices of public engagement which are made possible by specific, government-initiated mechanisms. These include participation in regional health sector governance (Frankish et al 2002; Callaghan & Wistow 2006) and lay representation on health technology assessment bodies (Milewa 2006). Understanding of how these mechanisms operate is vital to broader understandings of public participation, and these authors certainly flesh out the specific limitations and possibilities of each of these channels of public engagement. Milewa demonstrates how power relations serve to curtail the influence of citizen representatives in NICE decision-making, while Frankish et al (2002), provide a sobering account of the democratic possibilities of electoral mechanisms. But we should be wary of drawing too firm conclusions about the implications of particular technologies of public participation. As Callaghan and Wistow (2006) show, the same platform for public participation can lead to quite a difference in the quality of engagement and to quite different results in different settings.

Another group of contributors are more concerned to actively develop and monitor innovative techniques (Abelson et al 2007; Bennett & Smith 2008; Cox et al 2009), through projects that have been partly initiated by academic researchers. Abelson et al (2007) are concerned that deliberative exercises in health policy are too rarely evaluated, and that more rigorous evaluation should enable us to identify which public participation techniques are better able to deliver on their democratic potential. Perhaps the most interesting and innovative technique reported in this Virtual Special Issue is the use of theatrical productions as a way of stimulating public debate and deliberation (Cox et al 2009). While this approach may be more vulnerable than others on grounds of legitimacy (those participating were disproportionately older, more educated and female), it certainly shows promise as a powerful and practical way of presenting multiple perspectives relevant to a health policy issue, while also having many practical advantages over the resource intensive techniques such as citizens’ juries.

Three of the studies in this collection probe in depth the processes of deliberative reasoning. Bennett & Smith (2008) show that deliberative processes are capable of clarifying and developing normative orientations of citizens, they also serve to transcend the distinction between expert and
laity, emphasising that members of the public move iteratively between normative criteria and specific contextual information, exactly as Lehoux et al (2009) suggest. Bates et al (2008) also give weight to the argument that the public’s reasoning is important and robust because it integrates normative reasoning with lay experience as patients and taxpayers.

Two contributions (Bennett & Smith 2008; Secko et al 2009) add valuable insights to our understanding of the possibilities of deliberative processes, particularly regarding the changes in public perceptions that occur in citizens’ juries. Secko et al’s (2009) research showed how citizen perspectives on the withdrawal of previously agreed consent were significantly altered through deliberative processes, indicating that normative views change when citizens are presented with information about the practicality of different policies and procedures. In this case, the deliberative process served to lessen the divergence between citizen and expert perspectives. Bennett & Smith’s (2008) citizens’ jury, which was given the task of choosing between explicit policy alternatives, showed that deliberative processes can clarify which values are the most important (in this case, the value of ‘fairness’), although this did not mean that they led to a consensus around a preferable policy option. As the authors state, ‘there was a normative impulse driving debate and a recognition among jurors that being agreed as to ‘ends’... neither dictates the appropriate means, nor guarantees agreement over these’ (Bennett & Smith, 2008: 2496). Each of these case studies supports a more contingent understanding of the possibilities of deliberative processes. While deliberative exercises may ably fulfil some democratic functions (e.g. civic education) these examples cast doubt on both the feasibility and perhaps even the desirability of consensus as an outcome of deliberative processes. As Milewa notes ‘democratic deliberation does not necessarily amount to deliberative democracy’ (2006: 3110).

Where to from here in public participation practice and research?

One clear conclusion that can be drawn from this collection of articles is that there is now less concern to justify public participation in health policy, or the need to research it. It is now a well-established field of research in health policy. For the vitality of research in this area, it is imperative that public participation in health policy remains a domain of enquiry informed by diverse questions, theoretical impulses and practical policy concerns.

The growing sophistication in both the design of participatory mechanisms and interpretation of what they produce is something that should continue over the next decade. But perhaps the key challenge for those who research and write about public participation is to understand which areas of health policy are the most amenable to the use of such ‘emerging technologies’. What are the health policy issues in which the use of participatory techniques can make a strong and discernible contribution to policy decisions and outcomes? Here, the shift towards complex ethical issues such as genetics may well represent a better opportunity for integrating public input in a sophisticated and meaningful way, and ultimately produce more fruit than the more ‘traditional’ domains of health service planning and prioritisation.


