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Wait, S; NOLTE, E (2006) Public involvement policies in health: Exploring their conceptual basis. *Health Economics, Policy and Law*, 1. pp. 149-62. DOI: <https://doi.org/10.1017/S174413310500112X>

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# Public involvement policies in health: Exploring their conceptual basis

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## **ACKNOWLEDGEMENTS:**

Suzanne Wait and Ellen Nolte are supported by a research fellowship from the Nuffield Trust on International Benchmarking. The authors are grateful to John Wyn Owen, Professor Martin McKee and Professor Dame Sandra Dawson for their comments on earlier versions of this paper.

*Key words: public, involvement, participation, health, policy.*

# Public involvement policies in health: Exploring their conceptual basis

## **ABSTRACT**

Despite its obvious appeal, the concept of public involvement is poorly defined and its rationale and objectives are rarely specified when applied to current health policy contexts. This paper explores some of the underlying concepts, definitions and issues underpinning public involvement policies and proposes a set of criteria and questions that need to be addressed to allow for the evaluation of public involvement strategies and their impact on the health policy process. It aims to further our understanding of the role that public involvement may play in contributing to health systems that are responsive to the needs and priorities of the public, and, ultimately, providing better health and health care services to the community at large.

*Key words: public, involvement, participation, health, policy.*

## **BACKGROUND**

Over the past decade, governments have increasingly advocated public engagement as a necessary means to increase health systems' responsiveness to the legitimate expectations of the population. For example, the Council of Europe advocated that governments should promote policies that foster citizen participation on the basis that the rights of patients and citizens to help determine healthcare goals and targets was an integral part of any democratic society (Council of Europe, 2000).

Public involvement is a central pillar of the health policy process in the UK, Canada and Australia (Department of Health 1999; Health Canada, 2000; National Resource Centre for Consumer Participation in Health, 2005). Different countries have experimented with initiatives such as public consultation to guide priority-setting (Kitzhaber 1993), regional or community health councils (Frankish *et al.*, 2002), lay involvement in health boards and citizen juries (Lenaghan *et al.* 1996; Mooney and Blackwell 2004). In the current policy context dominated by concerns about quality and accountability, the incorporation of public views into policy-making is perceived as a means to restore trust, improve accountability and secure 'cost-effective decision-making' within health care systems (Church *et al.* 2002). Yet the evidence to support these assumptions remains scarce, partly because many of the current public participation initiatives in place are fairly recent. Also, their objectives and rationale are rarely stated.

This analysis aims to explore some of the key questions, issues and conceptual frameworks underpinning public involvement policies in health care, on the basis that this understanding is essential if one wishes to evaluate the contribution of public involvement to the improvement of health system performance (Church *et al.* 2002). Our ultimate aim is to propose an evaluative framework that may be used to assess the impact of public involvement policies within different health care systems. This paper represents a first step in this endeavour. Based on a pragmatic review of the literature, we explore definitions, concepts and issues arising from public involvement, drawing on examples from different initiatives where appropriate.

## DEFINING TERMS

### *Who is 'the public'?*

The term 'public' is often used interchangeably with notions of 'citizen', 'consumer', 'lay (person)', '(service) user', or 'patient'. Florin and Dixon (2004) distinguish between public involvement, defined as "the involvement of members of the public in strategic decisions about health services and policy at local or national level", and patient involvement, which refers to "the involvement of individual patients, together with health professionals, in making decisions about their own health care."

Yet in practice, citizens or 'the public' may assume different roles at different times depending on their interaction with the health care system. Thus, Lomas *et al.* (1997) defines the roles of citizens (or residents) in three distinct areas of decision-making. First, there is the citizen-taxpayer who is concerned by how health care services are financed and what services will be offered. Secondly, there is the citizen-collective decision-maker, concerned by the range of services (or choice) that will be offered within his/her community setting. Finally, there is the citizen-patient, whose concerns will be that the appropriate and most effective services are delivered to meet his and other patients' clinical and individual needs (Lomas *et al.* 1997). Charles and DeMaio (1993) emphasise the notion of 'lay participants' who may adopt different roles as patients, advocates, tax payers, fund raisers, volunteers or policy makers.

Again, though these distinctions are helpful, in practice the distinction between individuals as patients or potential patients but members of the public may be more opaque. Along these lines, Coulter (2002) suggested that the 21<sup>st</sup> century patient is at once "a decision-maker, a care manager, a co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers". Little is known about how individuals' expectations or motivations may change as they navigate between these different roles.

### ***What is involvement?***

Notions of ‘involvement’, ‘engagement’ and ‘participation’ are often used alongside each other with little agreement about what they are meant to specify in the context of health policy. Thus, (public) participation involves “taking part in the process of formulation, passage, and implementation of public policies [through] action by citizens which is aimed at influencing decisions which are, in most cases, ultimately taken by public representatives and officials” (Parry et al. 1992). Similarly, involvement may be considered as “a local attempt to include organized groups of service users in the planning, and occasionally the management, of such services” (Harrison and Mort 1998). Either definition is, however, considered distinct from the notion of consultation, with Contandriopoulos (2004) for example noting that “participation encompasses all possible ways in which the public can influence a decision [whereas] consultation usually describes a situation in which the public can voice its opinion without any direct possibility of decision in the end.”

A further concept is that of empowerment, with community empowerment advocated, for example, as a key driver of population health by the WHO (WHO Ottawa Charter 1986). The Council of Europe outlines four different levels of empowerment: i) the ability to influence the administration of the health care system and participate in decision-making processes; ii) the ability to further particular interests through citizen or patient interest groups, iii) representation in governance structures and (iv) direct influence over care provision through the exercise of choice. (Council of Europe, 2000). These tie into the areas for public involvement, described in a later section of this paper

The term participation appears to be the preferred heading of much of the work on public involvement undertaken in the 1960s through to the 1980s (e.g. Arnstein 1969; Maxwell and Weaver 1984), possibly because participation implies a less passive and more specific activity than involvement (Lupton et al. 1997). Thus, Arnstein for example dismisses the notion of citizen involvement as an “innocuous euphemism” as opposed to citizen control, which she considers as a “categorical term for citizen power” (Arnstein 1969). More recently the terms participation and involvement have been used much more

interchangeably (e.g. Donovan and Coast 1996; Lupton et al. 1997; Harrison and Mort 1998; Litva et al. 2002) although research undertaken in Canada almost exclusively uses the term participation (e.g. Charles and DeMaio 1993; Abelson et al. 2004; Contandriopoulos 2004).

For the purposes of this paper, the term *involvement* will be considered as a generic term that encompasses the notions of participation, consultation and engagement. The *public* is considered along the lines defined by Florin and Dixon (2004).

### **WHY INVOLVE THE PUBLIC?**

There appears to be no single underlying conceptual framework underlying public involvement. Two important perspectives that emerge are the democratic and the consumerist perspective, which we will briefly examine in turn.

#### ***The democratic perspective***

Stemming from political science, this perspective assumes that greater public involvement will lead to more democratic decision making and, in turn, enhanced accountability (Florin and Dixon 2004). It relates to people or 'the public' in their capacity as citizens and tax-payers with rights to use public services and duties to contribute and participate in society (Lupton *et al.* 1997). It emphasises the importance of equity and empowerment and is based on two principles: (i) public participation should be encouraged since it is beneficial to maintaining a strong democracy and helps people fulfill the obligations of citizenship and (ii) the diversity of interests and allegiances in society should be represented in the political process.

This perspective is founded on the idea that democracy has an educative and development function, a view first advanced by the likes of Jean-Jacques Rousseau and John Stuart Mill. Through participation in policy decisions, citizens may develop a more realistic understanding of what health care systems can and cannot provide, which has the potential for empowering the public to use the system effectively (Cayton 2003).

The push for public involvement policies assumes that citizens want to engage in ‘active citizenship’ or ‘deliberative democracy’ (Redden 1999) and participate in health policy decisions. This assumption may be presumptuous, however, as it depends on how accountable members of the public feel for their health care system beyond their own personal health, how politically engaged they may wish to be, and how empowered they feel to actually have some impact on results.

### ***The consumerist perspective***

Economists have long advocated public involvement as a necessary route to correcting for the inherent failures in health care markets including information asymmetry, difficulties relating to product evaluation, and the high cost of error. Consumer preferences are viewed as the lever to enhance competitiveness between providers and, in doing so, reaffirm the rights of users to information, access, choice and redress in relation to a specific service or product (Lupton *et al.* 1997). The notion of information asymmetry underlies the agency model, which is used to describe the relationship between patients, providers and the state (LeGrand 2003). According to this model, consumers choose to delegate decision-making authority to physicians (Arrow 1963). However, with increasing public access to health care information, the public may be less willing to relinquish decision-making authority and demand more transparent accountability from health providers and the state.

Another notion central to economic theory is that of patient choice. Saltman (1994) suggests that choice of provider and setting of care, when added to granting patients influence over treatment decisions and actual budgetary allocation, allows for the direct participation of the citizenry in governing ‘what is ostensibly *their* health system’. In health care systems that are centred on the principles of solidarity and equity, there may appear to be a trade-off between patient choice and the principle of equity of access and service. However, one may argue that the onus on such health care systems is to allow for patient choice within the limitations of budgets of service provision, as opposed to



forcing consumers to opt out of the public system and exercise their choice within the private system of health care (Saltman 1994).

### **SPECTRUM OF PUBLIC INVOLVEMENT**

There is little evidence of a discernible dominating pattern of public involvement in health policy (North and Werkö 2002). Arnstein (1969) elaborated a ‘ladder of participation’ which categorises levels of power available to citizens. This framework ranges from manipulation and therapy, through information, consultation and conciliation, to partnership, power and control. Charles and DeMaio (1993) collapsed these categories into three levels of participation: consultation, partnership and lay domination. Borrowing somewhat from Arnstein’s framework, Brager and Specht developed a ladder of community participation, depicted in Figure 1. Also focusing on the individual level but taking a more socio-political perspective, Lomas *et al.* (1997) distinguish policies that harbour citizen input from those that allow for citizen governance. These frameworks are rooted in the democratic model and define involvement in terms of the individual’s influence on decision making and, particularly, resource allocation.

[Insert Figure 1 here]

### **AREAS FOR PUBLIC INVOLVEMENT**

A key question relates to the actual areas in health policy the public ought to be involved in, with three possible areas being described in the literature: priority-setting, the planning of services (including resource allocation) and the delivery of services, including treatment decisions and patient choice (Charles and DeMaio 1993). The following discussion focuses on priority-setting and the delivery of services, with the planning of services being subsumed under the former.

#### ***Priority-setting***

Most often, the impetus for involving the public in priority-setting decisions comes from the central government in response to budgetary pressures, as opposed to from the public. The stated purpose of such initiatives is most often that of distributional equity (Redden 1999). Lomas *et al.* (2003) suggests that one of the greatest challenges to involving the public in priority-setting exercises is to ensure that the process for gathering public input is transparent, impartial and truly reflects the values of users. There is substantial debate about the appropriate methods for eliciting preferences from the public to involve them in priority-setting decisions. Some authors suggest that indirect input (via mediating institutions) is more feasible and appropriate than direct public input, which may result in hyper-democratic questioning of a wide range of stakeholders (Tenbensen 2002). In any case, the chosen approach for eliciting public input will inevitably involve a compromise between transparency of process and complexity and richness of the information gathered.

### ***Service delivery***

Several countries have experimented with or have already institutionalised the involvement of lay representatives of the public in service delivery decisions, be it at the level of a community hospital, primary care centre or local government body. To take the example of England and Wales, a Citizens' Council has recently been added to the National Institute for Clinical Excellence (NICE) governance structures to represent the views of the public. This is in addition to the key role of patient representatives as stakeholders in health technology appraisals and in the formulation of clinical guidelines. Patient and Public Involvement Forums (PPIFs) are an integral part of the governance structures of hospitals and Primary Care Trusts and members of the public will be involved in the running of new NHS foundation trusts (Department of Health 2002). In the UK and elsewhere, patient groups, particularly in the area of chronic disease, are an ever more powerful voice in shaping treatment guidelines and in other key health policy decisions (Department of Health, 2001).

### **DOES THE PUBLIC WISH TO BE ENGAGED?**

Policy documents advocating public involvement seem to suggest that just as patients are known to and are now expected to take on a greater role in charting the course of their care (e.g. notions of shared decision-making and involved patients), these same individuals as citizens have greater expectations from the health care system as a public service, and are thus expected to be more involved, or concerned, by the quality of services and budget allocation decisions within their health care system.

This apparently seamless link between individuals as patients and individuals as citizens should not, however, be taken for granted. Klein (1984) has cautioned against the assumption that “there is a dammed-up demand for greater participation, only waiting for the institutional changes needed to open the floodgates of public involvement”. Economic theory suggests that the public has less incentive to participate in key decisions than managers and providers, given the imbalance of interests as well as information within health care markets (Marmor and Marone 1980). The fact that individuals’ contact with the health care system is usually involuntary, sporadic and unplanned supports this view.

For individuals to wish to be engaged in public involvement initiatives, they must trust that the mechanisms put in place take their views into account. Surveys from Canada and Australia suggest that citizens generally feel more confident in government decisions which seek out public opinion, yet their trust in public officials remains low (Abelson *et al.* 2004). A public opinion survey in the UK found that a significant minority of individuals would not use any feedback system in existence because they lacked confidence in the responsiveness of the NHS (Entwistle *et al.* 2003). Other evidence suggests that the public wishes for better communication about the process and desired outcomes of public involvement initiatives (Rutter *et al.* 2004). Specifically, they wish to see how public involvement mechanisms fit into the wider decision-making process (Abelson *et al.* 2004).

In addition, the willingness of members of the public to participate in decision making may depend on the actual level of decision being considered. Several studies have pointed to the public’s reluctance to take on the role of rationers (Lomas 1997; Mossialos

and King 1999). Litva *et al.* (2002), for example, observed a strong desire for the public to be involved in decisions that were related to aspects of funding or distribution of particular services but a reluctance to decide on issues relating to individual-level decisions, for example choosing between two patients in terms of treatment.

Related to this is the observation that the achievement of effective public involvement will also depend on the public's understanding of, and interest in health and health services, as it relates to them as potential users and to others as members of their community. The pivotal role of health literacy in patient involvement in treatment decisions is apparent (Parker *et al.* 2003); its role in motivating individuals to become involved in public-level health care decision-making is less so. For example, the public may feel uncomfortable in making choices if they feel that they lack the expertise required for the task (Lomas *et al.* 1997). Several surveys of individuals involved in public involvement mechanisms suggest that individuals often feel the need for significantly more information about the issues concerned to be able to contribute effectively (Lenaghan *et al.* 1996; Abelson *et al.* 2004). A distinction is needed between the 'literal public', who may not have any special knowledge of health or health care, and the 'idealised public', which is well-informed and highly motivated to engage in health policy decisions (Harrison *et al.*, 2002).

This brings us to the key issue of representation and equity. Several authors have cautioned that a majority view might obscure the needs of minorities or "less glamorous services" in public involvement policies (Donovan and Coast 1996). Klein (1984) observed the emergence of an *inverse law of participation* where those in greatest need to further their interests often had the least capability to do so. Indeed, those vulnerable groups who are least likely to be able to assert their own self-interest, for example the elderly, the mentally ill, refugees, and who are most deprived in terms of health care (e.g. unskilled, poorly educated) are least likely to participate (Klein 1984). Better public representation repeatedly emerges as a concern of participants of public involvement mechanisms (Abelson *et al.* 2004).

## **WHAT IS THE IMPACT OF PUBLIC INVOLVEMENT?**

Public involvement – like democracy – is often viewed as an intrinsic good (Florin and Dixon, 2003). Some authors have suggested that its outcome is mainly therapeutic or symbolic (Arnstein 1969). Others suggest that it is an instrument to inform decision making rather than as a process that actually devolves power to local communities (Rowe and Shepherd 2002). Others go further still and interpret public involvement as a "legitimation" strategy – or "social technology" - by which the decisions and activities of decision-makers in health care can be justified (Harrison and Mort, 1998). They suggest that public involvement initiatives may be used by governments to contain criticism and unrest, thereby deflecting some of the "political heat" and giving legitimacy to otherwise unpopular policy decisions, especially in the field of rationing (Redden 1999; Church *et al.* 2002; Lupton *et al.* 1997). Recent research, however, provides a more optimistic view, suggesting that public involvement models have evolved away from the "top-down, paternalistic efforts to extract information from participants" of the past and that they do contribute to improving accountability within health care systems (Abelson *et al.* 2004; Department of Health 2004; National Resource Centre for Consumer Participation in Health 2005).

Yet the impact that public involvement policies remains difficult to evaluate, partly because many policies are short-lived or very recent. Usually, no timeframe or evaluative framework is specified for their assessment. In a systematic review reported by Crawford *et al.* (2002) on the effects of involving users (here: patients) in the development and planning of health care, only 42 studies (12%) of the 337 studies complying with inclusion criteria for the study period (1966-2000), actually described the impact of involvement. These 42 studies generally showed that involving users did contribute to changes in the provision of a range of services including the production of new or improved sources of information for patients, the commissioning of new services or the modification of plans to close hospitals. However, the effect of involvement strategies on the quality and effectiveness of services could not be ascertained from any of the reports (Crawford *et al.* 2002).

## DISCUSSION

This paper has explored some of the conceptual underpinnings of current public involvement initiatives. It is based on a pragmatic review of the published literature and it is critical to note that most of this literature comes from Australia, England and Canada. It is not possible, based on our findings, to judge whether this ‘Anglo-Saxon bias’ in the literature is due to a lack of a discussion of public involvement in other countries or a mere lack of *published* discussion. It is however worthwhile noting that England, Canada and to a certain extent Australia are characterised by tax-funded health care systems and it may well be hypothesised that the experience of public involvement may be different in insurance-based health care systems, let alone in private health care markets, or indeed in any country where the policy environment is not dominated by the themes of accountability, devolution, patients’ rights or rising consumerism. We recently undertook a review of public involvement initiatives in different European countries which appears to support this assumption and has made evident that social and political values play a crucial role in shaping public involvement policies within different health care contexts (Nolte and Wait, under review).

This review raises some important questions for future research on public involvement policies in the health sector. There is considerable lack of clarity on how ‘public involvement’ is defined in current policy contexts. Whilst the literature offers some helpful distinctions between ‘patient’ and ‘public’ involvement, this distinction is rather opaque in many policy documents and current initiatives. It is also somewhat paradoxical in practice. In theory, ‘lay people’ are meant to not have been subject to socialization or training (for example, medical training) and represent the views of the ‘general’ public (Hogg *et al.* 2001). In practice of course, all of us are, or have been, patients at some point of our lives and this experience is bound to affect our views on the health system.

From a research perspective, we need further understanding of whether and how individuals assume the different roles of active citizen, user and potential user and how

individual expectations and motivations for involvement may be influenced by the structure of the health care system, social and political values and health literacy levels.

The underlying conceptual framework for current public involvement policies is also poorly defined. Many initiatives described in the literature appear to be rooted in the democratic, rather than the consumerist, perspective on public involvement. Yet how this conceptual framework marries with some concurrent reforms aimed at increasing patient choice and enhancing ‘choice and exit’ for service users is unclear.

The issues raised here also have important ramifications for the evaluation of public involvement as a policy tool. A clear definition of the objectives and desired outcomes of public involvement policies is needed, as is further observation of the dynamics between patients, the public, professionals and other players within health care systems to ascertain whether public involvement can achieve these objectives. If implemented in earnest, public involvement policies may lead to a significant departure from the paternalistic model of governing health care systems and involve fundamental shifts in the responsibilities of patients, professionals, the government and society (Blalock 1999; Church *et al.* 2002). Hence the question raised by one of the founding architects of public involvement in the UK: ‘[are we] engaged in a radical rethinking of the relationship between health care providers and the people who pay for them or are we just trying to use patient [and public] compliance to manage the system better?’ (Cayton 2003).

Thus the success of public involvement is contingent on policy-makers’ genuine willingness to yield power to the public and the public’s genuine engagement in the health policy process. Many public involvement initiatives have been criticised for assigning to the public a reactive rather than a proactive role. Ultimately, managers and policy-makers still hold the power to decide how to incorporate the public’s input into decision-making (Milewa *et al.* 2002). In most health care settings, we are far from the stated ideal of citizen empowerment. Also, engagement of the public should not be taken for granted just because the system opens a window allowing the expression of voice. Nor should we take for granted that involving the public is necessarily warranted within

all areas of the policy process. Scepticism about how the more recent incarnations of public involvement differ from their predecessors may be expected from the public, health professionals and managers alike. Further clarity is needed about how public involvement initiatives fit into the overall decision-making process for the sake of all those involved. For example, in one Canadian province, legislation was recently changed to require health authorities to clearly demonstrate how the input from community health boards is used in its business plan development (Abelson *et al.* 2004).

In conclusion, public involvement is a central theme of health policy reforms in many countries. Despite its obvious appeal, it is important to keep a clear and honest perspective of what public involvement policies aim to achieve and what health system changes may be needed to allow for their full implementation. Developing an evaluative framework to assess the impact of these policies may be a helpful start. This research aims to contribute to improving our understanding of the role that public involvement may play towards making our health systems more responsive to the needs and priorities of those who use them and pay for them, and, ultimately, producing better health and health care services for the community at large.



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FIGURE 1. A ladder of participation

Degree of control	Participant's action	Illustrative mode
<p><b>HIGH</b></p> 	Has control	Organisation asks community to identify the problem and to make all the key decisions on goals and means. Willing to help community at each step to accomplish goals.
	Has delegated control	Organistaion identifies and presents a problem to the community, defines the limits and asks community to make a series of decisions, which can be embodied in a plan it can accept.
	Plans jointly	Organisation presents tentative plan subject to change and open to change from those affected. Expect to change plan at least slightly or perhaps more subsequently.
	Advises organisation	Organisation presents a plan and invites questions. Prepared to modify plan only if absolutely necessary.
	Is consulted	Organisation tries to promote a plan. Seeks to develop support to facilitate acceptance or give sufficient sanction to plan so that administrative compliance can be expected.
	Received information	Organisation makes a plan and announces it. Community is convened for information purposes. Compliance is expected.
	<b>LOW</b>	none

*Adapted from Brager and Sprecht, 1973; building on Arnstein (1969)*