Breaking Down the Barriers

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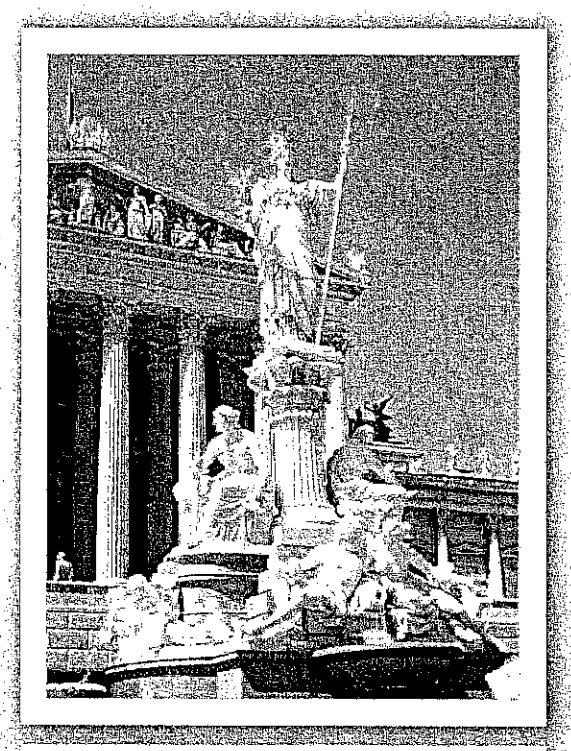

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From Rhetoric to Reality: Breaking Down the Barriers. To What Extent Are Service Users Collaborating in Decision Making Processes within the NHS?

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Introduction.

Embroiled in the notion of `social inclusion` that lies at the heart of New Labour's `third way` politics, the government have fostered the way for collaborative working in health and social care. Within this framework public, patient and service user involvement in how local services should best be delivered is a central wheel in the cog of collaboration. The White Paper The New NHS Modern and Dependable (1997) and subsequent legislation (1999) (2000) (2006) and more recently The Local Government and Public Involvement in Health Act (2007) has set the agenda for greater public participation in how local health services should best be delivered. However, the implementation of such a task is fraught with difficulties and highly problematic to implement. Medical and managerialist dominance of health care, lack of public knowledge and agreed definitions of what constitutes an appropriate level of health care for all service users are just some of the issues which need to be addressed, if the rhetoric of strong democratic public participation in the decision making process is to become a reality within the NHS. This paper draws on past and present empirical research to highlight the difficulties of transforming policy proposals for greater public and service user involvement in decision making into practice within the NHS. The paper will conclude by offering for debate a number of suggestions, which may foster greater equitable public participation and collaboration in health care planning and delivery of service.

Defining Participation

Given a lack of agreed definition of what 'participation' means and the catalogue of models which highlight different levels of 'participation' in the literature, it is hardly surprising that inclusion of the public in the decision making process within health services has been difficult to implement in practice. Approaches to the notion of public 'participation' in state planning processes are considerably varied. A vast amount of literature regarding this subject appears to offer no clear agreement of the meaning of 'participation'. (Harrison, et al 2000: 3) Two of the many definitions, which dominate the literature, are offered by Bracht and Tsouros 1990 and the World Health Organisation 1991. Bracht and Tsouros for example, view 'participation' as, "the social process of taking part (voluntarily) in formal or informal activities, programmes and/or discussions to bring about a planned change or improvement in community life, services and/or resources". (Bracht and Tsouros 1990, in Harrison 2000: 3) Similarly, the World Health Organisation outlines its key indicator for 'community participation' in health service planning as the, "Existence of mechanisms for involving lay members of the community in the implementation of national health strategies and in the delivery of health services at local and regional levels, including responsibility for allocation and/or use of funds" (World Health Organisation Regional Office For Europe 1991 in Harrison et al 2000: 3) A number of frameworks for measuring levels of participation have also been developed. For example, Hirgcham 1970, Hoggett 1992, Harrison (2000) and the now classic Arnstein's 'ladder' of participation 1969. Arnstein prefers the term 'participation' rather than involvement because of its precise emphasis on interaction. Arnstein outlines a range of eight different levels of participation and then presents them in the form of a 'ladder'. The first two rungs on the ladder equate to non participation in decision making, rungs three to five outline differing degrees of tokenism and rungs six to eight show degrees of citizen participation.

8 Citizen Controls	}	Degrees of citizen power
7 Delegated power		
6 Partnerships		
5 Placation	}	Degrees of tokenism
4 Consultation		
3 Informing		
2 Therapies	}	**Non-participation**
1 Manipulation		

Figure 1. Arnstein's ladder of citizen participation. 1969.
Source: (Lupton et al 1998: 47)

Therefore, given the complexity of the definitions and the various levels of 'participation' outlined, the continuing trend of minimal public participation in NHS decision-making is inevitable. Without a clearly defined working definition, which can be understood by all concerned parties, that is, politicians, NHS professionals and the public, proposals for greater public participation in decision making processes within the NHS is likely to remain an empty piece of political rhetoric, rather than becoming reality in practice.

Theoretical Approaches To Public and patient Participation.

Historically, the National Health Service has applied two theoretical approaches for including patients and the public in health policy decision-making, the 'democratic' and 'consumerist' models. (Hunter and Harrison 1997) Firstly, the democratic approach views citizens and taxpayers as having rights not only to access health services but also to participate collectively in managing such services. This approach is built on the principles of social equity and citizen empowerment and was incorporated in strategies such as the now disbanded Community Health Councils and Citizens' Juries. Both strategies have however been highly criticised for their lack of a broader inclusion of underrepresented sections of society in the decision making process. As Rudolf Klein points out,

"Why should such a small number of people be trusted to represent and influence the decisions that will affect the many thousands of citizens who make up a given community? Moreover the process of randomly selecting jury

members may lead to the under representation of minority group interest" (Klein 1998: 18)

Despite the criticism of the democratic approach, the consumerist approach to public participation in NHS decision-making has also encountered its fair share of critics. For example, see, (Grinson 1998; Harrison and Pollitt 1994 Klein 1995). The consumerist approach models itself on the consumer / supplier relationship found in the private commercial market and was the preferred model of the previous new right conservative government, made evident in the 1990 NHS quasi-market Reforms. The Major government's Patients' Charter 1992 amended in 1995 are also clear examples of a consumerist approach. The 1992 Patients' Charter was the archetypal example of a consumerist driven health policy, setting out a number of 'rights' and 'Standards' which appeared to mimic the expectations of consumer / supplier relationships in a commercial market. For example, service users were given individual 'rights' to 'shop around' and choose their own GP; expect open information regarding availability and standards of services and 'rights' to complaints procedures. (Grinson 1998) As Klein suggests,

"It would appear that Working For Patients (1989) and the preceding Patient Charter, amended in 1995 has led to a fundamental change in health policy, redefining the notion of 'citizenship' as defined by T.H. Marshall as a 'social right' to one of ' customer' relationships between the individual and the state." (Klein in Grinson 1998: 232)

A review of New Labours health policy documentation, for example, The New NHS Modern & Dependable 1997 The NHS Plan 2000, The Health and Social Care bill 2000 and the more recent Local Government and Public Involvement in Health Act 2007 appears to neither lend itself whole heartedly to either the democratic approach or the consumerist approach as a means to facilitating greater public participation in local health care decision making. In keeping with its 'Third Way' agenda New Labour have utilized elements of both democratic and consumerist approaches, casting service users in the role of democratic citizens with 'social rights' and individual consumers of local health care services. (Grinson 1998) Proposals from the Health and Social Care bill 2000 show specific examples of this collaborative approach.

"The Bill will provide: a statutory duty on all NHS organisations to consult with and involve patients and the public... new independent support for patient complaints, scrutiny of local NHS by elected councillors. New independent Patient forums will be set up in every Trust and Primary Care Trust in England to give patients and the public a voice in shaping their local service – with patients being represented at the very top, on every Trust board. The forums will be made up of representatives from patients groups, voluntary groups and individuals..." (DOH. 21.12.2000: 1)

How New Labour's 'coupling' of the democratic and consumerist approach has enhance greater public participation in policy decision making processes Within the NHS is however highly debatable and problematic to implement in practice.

From policy into practice

Regardless of New Labour's claim for greater public and patient participation, historically, there has been a weak tradition of public or patient inclusion in decision making within the NHS. Despite the abundance of rhetoric since the early 1990s, at both the political and institutional level little has changed in practice. As Lupton points out, there has been little public involvement in UK general practice services and "the central form of the public's contract with general practice has remained the doctor – patient interaction". (Lupton et al 1998:105) Moreover, an evaluation of early GP commissioning pilots also showed little evidence of commissioning groups involving patients or the public in planning services. In Regan's view, " Neither patients, the public or the now disbanded Community Health Councils (CHCs) in their role of service users 'representatives' had little influence on the decision making power of the commissioning pilots." (Regen et al 1999: 60) A number of studies to date concerned with public and patient participation in decision making processes within the NHS would appear to highlight a continuing trend. (Garliardi et al 2008; Lewis and Hinton 2008 Cowder and Singh 2007 Brooks 2006) Galliards qualitative study 2006 undertaken in two teaching hospitals highlights barriers to public and patient participation in decision making processes. Health professionals and managers within the study "thought patients should have an opportunity to voice their opinion or provide feedback, but should not be

involved in making decisions. As the professionals questioned pointed out, "I do think the final decision rests with health professionals" (surgeon) "Consumers can't have the final decision...it's such a complex system."(Nurse) "Final decisions are made by health professionals." (Manager) (Galiardi 2008:14) Brooks' 2008 ethnographic study of a patient and public council in an acute hospital found that public and patient involvement in decision making was limited by agendas of managerialism and professional norms. So despite a policy drive for public and service user participation in the decision making process within the NHS it would appear that professionals are still finding it difficult for the reasons cited to implement this participatory paradigm into practice.

The impact of State Governance on public and patient participation.

Governance theory of the late twentieth century according to Newman and Clarke was preoccupied with the 'hollowing out' of the state. (Newman and Clarke 2009) The state was viewed as having ceded power to a range of bodies, private sector, regional and local levels of governance and in this instance hospital authority, NHS Trusts, Primary care Trusts etcetera. According to Rhodes (1997) this hollowing out of the state suggests a displacement of the nation state as the sovereign authority. (Rhodes in Newman 2009) This shift in governance it is argued has led to such concepts as 'participatative governance' or 'empowering or partnership state' (Newman and Clarke 2009 104) Within this shifting paradigm of governance it could be suggested as indeed it is noted in many government policies for example The Local Government and Public Involvement Act (2007) that the public would play a more central role in participating in decision making processes regarding delivery of services. Nevertheless despite central government devolvement and the rhetoric of public participation in decision making, as Newman and Clarke point out the given government of the day still maintains overall power in the decision making process.

When considering the public as lay participants in the decision making process within the NHS it is important to look at what forms of knowledge and

expertise are valorised in governance. (Newman and Clarke 2009) Culter and Waine (1997) suggest there is a 'generic management' practice within organisational governance. Such practices need further consideration when discussing the issue of public participation within organisational governance within the NHS. 'Generic management' practices within organisational governance according to Newman and Clarke highlight important questions about "forms of knowledge and expertise that are valued in governance and the forms of knowledge that is devalued and demobilised". (Newman and Clarke 2009 105) According to 'generic management' theory managers in all organisations including the NHS share common characteristics and universal principles (Culter and Waine 1997). Those recruited into governance roles within the NHS have certain attributes, organisational knowledge and expertise, financial and legal knowledge and expertise, financial and legal knowledge and business acumen. Whilst 'ordinary people' with lay knowledge of everyday experience may be recruited to governance bodies within the NHS without characteristics that fit the generic management model they could easily become marginalised in the business of governance. (Newman and Clarke 2009) Therefore without appropriate training of lay people to equip them with the necessary management knowledge and attributes to participate in the decision making process, public and patient participation will it could be suggested remain tokenistic.

Conclusion

Traditionally Britain has had a weak track record in public participation in decision making within the NHS. Despite the various political approaches and policies to assist greater public participation it would appear from the evidence cited that there is still a fair way to go before we witness what Arnstein refers to as true degrees of citizen participation, delegated power or true partnerships. In order to improve public and patient decision making within the NHS a number of issues need to be addressed. Firstly, there needs to be a clear definition of 'participation' in government documentation that can be easily identified and understood by those using and providing NHS services.

Secondly, the public need better informing of their rights to participate in decisions that effect local delivery of services within the NHS. Thirdly, there is a need for managers to concede power and be better trained in sharing decision making processes. Fourthly, if true democratic public participation is to come to fruition not only the most vocal but marginalised groups such as the homeless, ethnic minorities and older people need to be included in the decision making processes as to how services should best be delivered in the NHS. Without a concerted effort from the government, NHS managers, medical and nursing staff the proposals for greater public and patient participation in decision making will remain an empty piece of political rhetoric.

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This document presents papers and abstracts from the 13th International Research Conference on Dilemmas in Human Services. The aims of the conference are to provide a forum for new and experienced researchers to present papers exploring a variety of organisational, policy and service issues which impact upon public service delivery, their staff and clients. The conference also aims to work in a collegial and supportive manner which encourages innovative ideas to be explored in an open forum.

The theme of this conference were the problems experienced in human services by the barriers to effective delivery of services and the efforts to overcome such barriers.

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