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Developing a Patient and Public Involvement Agenda in  
Patient Safety and Quality: Learning Lessons from other  
Sectors.

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## **Introduction**

The current drive to create greater patient and public involvement (PPI) in health over the last ten years and more recently in patient safety, is now a widely stated aim of the current government's agenda to modernise the National Health Service. This aspiration has been seen as central to creating services that are 'Fit for Purpose' in the 21<sup>st</sup> Century, as well as able to respond to and fulfil the needs of patients (DOH 2000:51). This paper focuses primarily on user involvement in public sector service delivery, although it also looks at participation in risk governance. In exploring developments in this context, some of the broad-ranging arguments that have driven this discourse across the public services are analysed, as well as the available evidence for the impact of user involvement. These arguments are then considered in the context of quality and patient safety. In exploring these issues, we argue that much can be learned from the development of user involvement in sectors other than health, although there is much less evidence of its impact, and user involvement appears to be underdeveloped in the area of patient safety. A research agenda is proposed which both addresses the issue of how to develop user involvement in the governance of patient safety and contributes to the evidence base on its impact.

## **The Discourse on User Involvement**

The debate about achieving user involvement in public services has been driven by a number of different critiques. Several of these have highlighted the way in which certain groups in society have been disenfranchised, and their struggle to achieve broader citizenship, welfare rights and access to services that genuinely meet their needs (Croft and Beresford 1989; Taylor 1989; Williams 1989; Beresford 2003; Cowden and Singh 2007; Tritter and Lester 2007). Others have focussed on issues relating to the dominant role of professionals and a loss of public confidence in their expertise (Illich, Zola et al. 1977; Schon 1983). This has occurred at the same time as other authors have suggested that there is a 'democratic deficit' in society, that has excluded the active participation of citizens in the planning of public services and decision-making (Milewa, Valentine et al. 1999; Florin and Dixon 2004; Davies, Wetherall et al. 2006). This has raised questions about the legitimacy

of western liberal democracies and their modes of governance (Daemen and Schaap 2000; Smith 2005 cited in Barnes, Newman et al. 2007; Irwin 2006) and the need for new forms of participation to address this vacuum (Fiorino 1990:228).

In the United Kingdom these arguments have led to considerable developments in involving service users in public services such as social work, health, housing, education, local authority work etc. These developments can also be associated with parallel international campaigns that have led to the emergence of user involvement in public services in many other Western countries (Feldberg and Vipond 1999; Tritter and McCallum 2006).

The period of the late 1970s and throughout the 1980s has been identified as particularly significant in Britain. This saw a series of campaigns by disenfranchised groups and communities take place around welfare services (Williams 1989; Ahmad 1990; Rogers and Pilgrim 1991; Johnson 1992; Knight 1993; Shakespeare 1993; Dominelli 1997; Hogg 1999). In analysing these struggles, Cowden and Singh (2007) argue that the 'post-war welfare State was based essentially on a series of *'assumptions about entitlements'* (Cowden and Singh 2007:7) which can be understood 'structurally as expressions of relations between genders, classes and 'racial'/ethnic groups' (Cowden and Singh 2007:7). From the 1970s, a disjuncture is seen to have emerged in welfare provision between professionals and non-professionals (citizens, clients, users, activists etc), and on the other hand, about the assumptions underpinning the type of society post-war Britain had become..These assumptions it is argued, increasingly came to be challenged by the emergence of new social movements: Black and anti-racist, feminist, lesbian and gay and disability rights movements, who 'had broad agendas for social change' (Cowden and Singh 2007:8).

In the context of health, this saw a number of health social movements (HSMs) emerge, which acted as an important political force for achieving broader social change (Brown and Zavestoki 2004). Groups connected to a wider women's health movement raised major concerns about issues such as the medicalisation of childbirth (Oakley 1976; Donnison 1977; Tew 1990).

Disability, mental health and Black and Minority ethnic (BME) groups also produced critiques rejecting a medical model as a source of oppression and called for an alternative 'social' model of disability (Shakespeare 1993). These groups were vocal in challenging a wide range of oppressive behaviour and discrimination that led to campaigns in many other parts of the public services.

In parallel to these challenges from user groups and social movements, a number of related sociological arguments emerged during this period. Critics of biomedicine argued that it was vital to recognise that lay people had their own valid interpretations of health and illness and that understanding these was essential to the process of treatment and healthcare. Other concerns focussed on the way in which some groups experienced poorer and unequal access to healthcare (Townsend and Davidson 1982; Acheson 1998). Sociologists also highlighted concerns about the very nature and disabling effects of the professions and their role in healthcare iatrogenesis (Illich 1974; Illich, Zola et al. 1977; Schon 1983). These issues, and wider concerns about healthcare relating to rising costs, litigation, the influence of the pharmaceutical industry and growing protest from patient groups, were seen to provide the basis for curbing the autonomy of the medical professions and addressing the traditional imbalance of power between doctors and patients (Freidson 1970; Blane 1991).

Public and service user participation in current welfare services has therefore emerged as a response to a number of competing claims. First, to progressive demands for the democratisation of services aimed at securing the participation of citizens in improving the quality of public services and the legitimacy of decision-making in a range of public bodies, but also in response to demands for market efficiency and the involvement of the private sector (Cowden and Singh 2007). These claims have also led to calls for new types of medical relationships in which the individual patient is more active (Gabe, Bury et al. 2005) and which embrace more informed and shared models of treatment and decision-making (Freidson 1970; Charles, Gafni et al. 1999; Rutter, Manley et al. 2004).

## **Theories Shaping Participation**

To understand further the considerable momentum for greater participation in public services, it is also useful to look at some of the underlying theoretical and philosophical drivers that have shaped participation processes.

When looking at the public services, two distinct conceptual models or approaches to participation can be identified. These can be characterised as consumerist/managerialist and democratic, which have predominated since the 1990s (Beresford 2002:97). These approaches have been linked with the degree and type of user involvement implemented in organisations (Hickey and Kipping 1998:88), although there appears to be no single underlying conceptual framework underpinning involvement (Wait and Nolte 2006:152) in practice.

The managerialist/consumerist approach is associated with the thinking of the 'new right' and the values of the market. Beresford has argued that methods of involvement related to this approach have been framed mainly in market research terms of 'improving the product' and that they operate through market testing and feedback, based upon data collection methods and consultation designed to improve service provision on the basis of consumer or customer intelligence (Beresford 2003:41). With the democratic approach, the emphasis has been on the involvement of users directly in the decision-making process and with broader democratisation at a community level (Hickey and Kipping 1998:84). Beresford (2003) has argued that this approach focuses on people having more say in organisations that impact upon them and on being able to exert more control over their lives. McKnight's (1977) distinction between consumers and citizens highlights the difference in power which either group is able to exert over decision-making between the two approaches. This is because a consumer as an individual becomes a judge of the benefits of a service, but in essence accepts the service ideology so that their role is merely evaluating outputs. In contrast, the user as citizen decides the content of a service (Hickey and Kipping 1998:85).

Other writers contributing to this debate such as Tritter and McCallum (2006), argue that whilst the justification for user involvement in public services can be seen to occupy a continuum between these two approaches, there is also a need for a more nuanced approach to achieving involvement. This new model they argue needs to go beyond Arnstein's ladder of citizen participation (1969) which acts as a metaphor in setting out different levels of participation in relation to levels or access to power. This model is seen as too one-dimensional based upon service user power to be helpful in formal-decision-making processes. Martin (2008) also challenges the usefulness of trying to test how far public involvement conforms to democratic and technocratic ideals. He points to the need to 'move to how in practice these and other rationales are put to discursive effect, how individuals' characteristics develop through the involvement process, and with what material consequences for those involved and not involved in public-participation processes' (Martin 2008:51).

These critiques, combined with arguments about a lack of evidence of impact and effectiveness in involving users (Florin and Dixon 2004; Rothstein 2004; SCIE 2004; Coulter and Ellins 2006; Rothstein 2007), suggest there is a considerable need for an assessment framework for evaluating the processes of involvement and its outcomes.

In the next section consideration is given to how user involvement has emerged in other parts of the public services such as social care, mental health, education and risk governance. These sectors have been chosen because user involvement has often developed at faster rates than in healthcare more generally and in patient safety in particular (although it is also recognised that considerable developments in user involvement have also occurred in areas such as local government that has not been covered in this paper). The sectors outlined above are therefore explored to identify what some of the barriers have been to participation, what strategies have emerged to address difficult issues and whether these might provide some good practice examples for governor and member participation in patient safety and quality.

## **User Involvement and Social Care**

The area of social work has a long history of debating issues associated with user involvement and empowerment. This can be traced to challenges in the 1970s to the way that social work and social welfare had individualised social problems affecting a range of social groups, that were ultimately linked to wider issues of political and structural inequalities in society (McLaughlin 2005:284).

Whilst early critiques in social work concentrated on class and challenges to the pathologising of the poor, by the 1980s and 1990s the focus had shifted to how a number of groups were oppressed in society. This saw the emergence first of anti-racist, Black perspective and anti-oppressive critiques (Ahmad 1990; Braye and Preston-Shoot 1995; Dominelli 1996; Macey and Moxon 1996; Dominelli 1997; Dominelli 2002). These were later followed by anti-discriminatory practice critiques in areas such as disability (Oliver 1984; Oliver 1990), sexuality (Lees 1983; Brown 1998) and age discrimination (Quinn and Tomita 1986). An important feature of these arguments was the way in which discrimination and oppression in society had disadvantaged certain groups, making them more likely to be clients of social work. The social work profession was then seen as compounding these experiences through negative treatment in the provision of service delivery.

Social work critiques of oppressive practice have subsequently led to considerable developments to involve service users in a wide range of areas across the 'social care landscape' (Braye (2000:9). Beresford has argued, however, that whilst the social work and social care professions are certainly more advanced than other related academic disciplines and areas of professional activity, they still have a long way to go (Beresford 2000:496). McLaughlin has been even more critical by arguing that the development in social work of anti-racist and anti-oppressive practices, whilst once radical measures, have now become institutionalised and lost much of their original meaning (McLaughlin 2005:283).

With regards to the development of good practice in this area, Hasler (2008) points to some examples from the social care field that would be transferable to health, for example long-standing traditions of co-opting users onto Social Services committees and special sub committees and the funding of user-led services. Social work and social care can also be seen as providing a range of theoretical and practice frameworks (anti-racist, anti-discriminatory and anti-oppressive practice, the social model of disability) for working with groups who have traditionally been excluded and ways of tackling the barriers to their participation. These frameworks have been reinforced by models for achieving effective user participation that draw upon a whole systems approach (Wright, Turner et al. 2006). Recent research by the Social Care Institute for Excellence (SCIE) also provide a number of examples of good practice concerning user involvement in the governing bodies set up to regulate service, workforce, education and training standards in social care. This is particularly relevant to developing the role of governors and members in patient safety. A key conclusion from this research was that whilst user participation was not necessarily typical of user involvement generally (given that participation was taking place at senior levels in boards), what was encouraging, was the fact that the organisations involved were found to be listening to and learning from the users on their boards (SCIE 2003:5).

### **User Involvement and Mental Health**

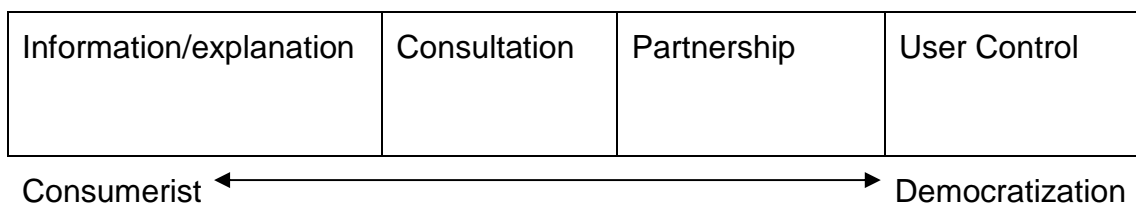
In the area of mental health, the 1970s has also been cited by a number of writers as marking a key turning point in the emergence of a movement of mental health service users. These groups have been seen as active in deploying collective action to challenge traditional ways of thinking and achieve changes to service provision and to the wider society (Rutter, Manley et al. 2004). This process also occurred in a number of other countries (Rogers and Pilgrim 1991:130).

These developments have led Peck, Gulliver et al (2002) to argue that a more favourable climate for user involvement has now emerged in mental health. But, they point out, whilst this may be the case, there appears to be remarkably little published research exploring the impact of involvement and what does exist points to a range of barriers that still operate as a deterrent to

any meaningful participation of users in mental health services. Findings from their research and others (Rutter, Manley et al. 2004; Campbell 2005; Tait and Lester 2005) indicate that involvement mainly takes the place of consultation and information giving, rather than ‘power-sharing’.

In exploring the concept of user involvement in mental health, Hickey and Kipping (1998) have developed a model for evaluating a range of different user activities that also address the disparity between consumerist and democratisation approaches to user involvement, discussed earlier. This is illustrated through the use of a ‘participation continuum’ (see below). This shows with the first two positions, ‘information/explanation’ and ‘consultation’, the activities that are more closely associated with the consumerist approach because they do not transfer any control over decision-making to the user. The ‘partnership’ and ‘user control’ positions reflect a democratisation approach because power is transferred from the service provider to service user (Hickey and Kipping 1998:85). This model could easily be applied more broadly in health settings, in conjunction with other useful typologies which we have identified, relating to the degree and type of user participation (Involve & togetherwecan 2005; McIver 2006).

**The participation continuum**



Source: (Hickey and Kipping 1998:85).

Stickley (2006) also points to what she calls a number of excellent examples that illustrate the democratic approach to user involvement in mental health (relating to involvement in both health research and practice). This includes the work of the Service User Research Enterprise (SURE) at the Institute of Psychiatry; projects led by the Sainsbury Centre for Mental Health such as user-focused monitoring; strategies for Living at the Mental Health

Foundation; and a growing number of other user initiatives such as Shaping Our Lives (Stickley 2006:575).

In the next section, lay participation in the governance of schools appears to provide a particularly relevant example that could be used in developing the role of Foundation Trust governors and members in patient safety and quality.

### **Governor Involvement and Education**

In England, governing bodies have had a significant role in the governance of education since the mid-1980s, when the 1986 Education Act reconstituted governing bodies to include parental, teacher and community representation (Farrell 2005:89). There are now about 350,000 school governors, who are all volunteers (the largest number in any public sector organisation), who are said to 'make a substantial and high quality contribution to the work of schools' (University of Bath 2008: 4). Their central responsibilities relate to providing strategic direction, critical friendship and accountability (Ofsted 2002), as well as providing an operational function in terms of overseeing the work of schools (University of Bath 2008:24). However, despite the input of such a large number of volunteers, recent research suggests that major problems exist when it comes to recruiting enough governors for schools because the role is complex and governing bodies are responsible for too much, with not enough promotion of the benefits of being involved. Approximately 40,000 vacancies exist at any one time, with schools struggling to recruit those with suitable skills, especially in urban areas (University of Bath 2008).

Specific barriers to participation in school governance have particularly been identified for under-represented groups. These relate to issues such as the costs of taking part, lack of financial reimbursement, a lack of confidence and self-esteem amongst potential volunteers, and negative feelings about previous experiences of schooling and barriers created by the recruitment process (Ellis 2003). Ranson, Arnott et al in a study of 19 schools in five areas of the UK, found that school governors were generally 'White, middle aged, middle class, middle income, public/community service workers' (Ranson, Arnott et al. 2005:360). They concluded that schools could not sustain

educational improvement whilst remaining independent of the communities they were embedded in. Dean, Dyson et al (2008) have also argued that whilst reforms to school governance are necessary, they cannot be divorced from a wider debate regarding the governance of public services and the nature of democracy in disadvantaged areas.

In the field of education, some general recommendations to address the problems of the recruitment of school governors have emerged that may also be relevant when looking at the role of Foundation Trust governors and members. These relate to the need to raise the public profile of school governing and the established benefits of this process, recruit members of groups currently under-represented in governing bodies, establish compulsory training for governors which should be quality assured, and find ways of maintaining high quality relationship with communities where recruitment of governors could be built and developed (University of Bath 2008:6).

In terms of developing the effectiveness of school governing bodies, Farrell (2005) has noted that despite the creation of these bodies since 1986, this has not led to governors having a significant level of strategic involvement in schools. Her research found that 'governing bodies are only involved in approving decisions taken by professionals within schools – the lowest level of participation' (Farrell 2005:108). Earley has argued that for governing bodies to become more effective and professional, greater emphasis needs to be given to strategy and accountability. He points to the need for training for governors to 'ask the awkward questions' about the school and its performance and for them to be given more strategic information to perform their role based upon a more shared leadership between the head teacher and the governing board (Earley 2003:365). Evidence suggests that the most useful approach a school governing body can adopt is to scrutinise and agree relevant aspects of school management and to provide a forum for discussion of strategy and policy matters. This is seen as helping to deliver both effective performance and to bring about improvement (University of Bath 2008).

## **Participation and Risk Governance**

Lastly, the area of risk governance provides an important area to consider in the context of developing greater participation, particularly in the governance context of patient safety. Risk governance covers many areas of government policy associated with hazards to health, safety, and the environment, which during the past several decades 'have become increasingly contentious' (National Research Council 1996:11). In this context, three main rationales can be identified as a basis for participation in risk decisions which are classified as normative, substantive and instrumental (Fiorino 1990). A normative approach is concerned with the value dimension of policy considerations and the right of the public to participate and have a say in the process as part of a commitment to democratic ideals. A substantive approach emphasises the ability of lay or non-technical experts to contribute important knowledge that experts may miss in solving policy problems, thus improving the quality of decision-making. Lastly, an instrumental approach focuses on the way in which effective lay involvement helps legitimise and builds trust leading to less conflict and more efficient results. In the context of managing environmental risk this has raised the possibility this approach may 'reduce the probability of error' (Fiorino 1990:228).

However while these rationales reflect different philosophical justifications for developing participation, a number of criticisms have emerged about the limitations of these arguments in guiding practice. This has led to calls for a more coherent framework for making the difficult judgements about implementing different types of involvement (Perhac 1998) and how 'to distinguish between relative success and failure in different dimensions' (Rothstein 2007:604). In areas such as environmental risk management, Fiorino (1990) has also called for the development of institutional policy analysis that relates particular participatory mechanisms to addressing different kinds of policy problems, whilst Perhac (1998) has argued that a key challenge in developing appropriate modes of involvement, is to do this without re-writing scientific fact. The failure to achieve this balance he notes, 'can threaten the protection of public health and the ecosystem, which must

be grounded in science even if judgements that transcend science come into play as well' (Perhac 1998:238).

### **User Involvement in Health: The Policy Context**

It is therefore within this broader context of the development of user involvement in welfare and public services that the policy imperative for user participation in health should be viewed. The late nineties marked a distinct shift in the language of user involvement in health with the emergence of a policy and later legal imperative in 2001, emphasising the importance of PPI in healthcare as part of New Labour's NHS modernisation agenda. A key emphasis driving developments has been to stress the importance of participation as an important way of improving the performance of healthcare services (Baggott 2005:545), which can also enhance democratic principles (Rutter, Manley et al. 2004). In practice, this statutory commitment to user involvement has come considerably later than in other parts of the public services and therefore suggests that health can benefit considerably from drawing on lessons from other sectors.

The development of a PPI agenda in health was also given greater momentum by evidence of serious clinical and service failings highlighted by high profile inquiries, often fought for by harmed patients, such as the Bristol Inquiry (2001). The Bristol Inquiry has been followed by a number of other NHS inquiries (Royal Liverpool Children's Inquiry 2001; Department of Health 2004a; Department of Health 2004b; Department of Health 2005; The Shipman Inquiry 2005; Healthcare Commission 2008; Healthcare Commission 2009). These inquiries have reinforced demands for greater accountability from health services and regulatory bodies such as the General Medical Council (Irvine 2004).

The Bristol Report (2001) in particular highlighted the need for PPI in the new systems being set up around patient safety. This was seen as the only way to move beyond a culture of continuing secrecy, anonymity and paternalism, to create a better quality health service, giving patients a much greater degree of ownership over their own healthcare, based upon patient empowerment. Central to this concept was the idea that bodies set up within the NHS to give

patients and the public a voice lacked real power and that individuals working within the NHS had to be ready for a shift in power, to enable PPI in decision-making to be more than about tokenism (Bristol Royal Infirmary Inquiry 2001)

This context has therefore led to a bewildering array of initiatives in the area of PPI, especially since the 1990s (see table Appendix A), but key questions nonetheless remain about the coherence and effectiveness of these developments (Hogg 2007). In order to assess how well trusts currently engage patients and the public, the Healthcare Commission (HCC) (now the Care Quality Commission (CQC)) carried out a national evaluation study published in March 2009. This noted that no national data currently exists on how well people are engaged in health services or which allows the performance of different trusts to be compared across the country. The main findings of the study were that whilst the majority of trusts had strategies in place and plans for improvement, there was limited evidence that trusts used people's views routinely to plan or improve the delivery of services. They found that those in the poorest health, in vulnerable circumstances or experiencing a patient safety incident (PSI), or discrimination, often found it the hardest to engage (Healthcare Commission 2009).

### **Assessing the Evidence for the Impact of Involvement in Healthcare**

In examining the research evidence concerning the impacts of involvement in health, Picker Institute Europe (Coulter and Ellins 2006), on behalf of the Health Foundation, have carried out the most comprehensive review in this area to date. The review looked at the effectiveness of PPI strategies and their impact on healthcare quality, examining over 150 systematic reviews published between 1998 and 2006, plus a number of other studies. The research was an attempt to respond to increasing criticism about the lack of an evidence base for involvement. Patient-focused interventions were defined as 'those that recognise the role of patients as active participants in the process of securing appropriate, effective, safe and responsive healthcare' (Coulter and Ellins 2006:142). Patients/citizens were viewed as contributing to quality improvement at both an individual and collective level, with patient focused interventions seen generally as aimed at one or more of the following seven quality improvement goals: improving health literacy; clinical decision-

making; self-care; patient safety; access to health advice; the care experience and service development.

Regarding PPI in service improvement and development, most of the evidence related to seven published qualitative research reviews (Simpson and House 2002; Crawford et al 2003; Rose et al 2003; Simces et al 2003; Carr 2004; Farrell 2004; Involve & togetherwecan 2005). This research identified a scarcity of reliable and detailed evidence of involvement and suggested that studies therefore tended to assess only the overall impact of involvement, rather than focus on the outcomes of involvement by method used. In addition, the Picker Review also looked at a number of individual studies in this area, which they grouped under three sections: consultation and deliberative methods; participation groups and forums; and lay representation.

The main conclusions of the research review were that ample evidence exists that the public generally likes being involved and think local people should have a say in how services are run, although recruitment to this process is difficult. Little evidence was found on the benefits and costs of involvement. Most evidence existed on the process of involving lay people in decision-making. This identified a number of factors that can promote or hinder public involvement such as people feeling unclear about their role and what was expected of them, resistance from healthcare staff and managers, a shortage of resources and concerns about representation. Citizens' juries were identified as effective in overcoming the shortcomings of other methods of participation but were found to be expensive and other approaches still provided little evidence on what worked best. For the future, the review argued that more research was needed to develop an agreed evaluation framework for public involvement that identified how outcomes should be defined and reasonably measured (Coulter and Ellins 2006).

In drawing together the best objective evidence on the outcomes of patient-focussed interventions, concerning what worked and what did not, the Picker Review argued that in the future, robust research evidence is required to

underpin any discussion of policy and practice in this area in healthcare (Coulter and Ellins 2006).

A number of studies also reveal the benefits of wider community involvement in health. These have shown that bringing people together through encouraging the formation of networks, leads to benefits in terms of increased confidence, transferable skills and increased friendships (Cooper, Arber et al. 1999; Berkman and Glass 2000). Research by the Joseph Rowntree Foundation however, questions the prevailing orthodoxy in this area. They investigated key factors influencing community participation in governance processes and how this was connected to the creation of social capital in communities. Social capital has been defined by Putnam as 'features of social life – networks, norms, and trust –that enable participants to act together more effectively to pursue shared objectives....Social capital, in short refers to social connections and the attendant norms and trust' (Putnam 2000:664-5). The Rowntree research found that the social capital created by community involvement in governance processes, tended to be concentrated in the hands of a small group of people. This meant that there was no guarantee that the wider community would feel the benefit of this social capital because formal governance structures were not embedded in the everyday informal spaces of community life. The way forward was seen as 'to try to find the points where stronger and more effective connections can be made between formal participation by a small group of insiders and the more informal, everyday social networks in which a much bigger group of citizens spend a significant part of their lives' (Skidmore, Bound et al. 2006:xi).

### **The Patient Safety Context**

Given the current considerable debate about user involvement in health, it is therefore interesting to see how these developments have emerged within the context of the patient safety movement over the last ten years.

There is now a widespread consensus on the need to address patient safety in modern healthcare systems and for many countries this has now become 'the key issue in terms of healthcare quality and risk management' (NAO 2005:1). Whilst the debate about tackling patient safety concerns is now

relatively well developed as part of the policy and political agenda, with some progress made in creating a patient safety culture (NAO 2005), significant concerns remain (House of Commons 2006; DOH 2006). The majority of studies on the numbers of adverse events (AEs) in healthcare mainly cover hospital settings. There is still little comprehensive data on the situation in primary care (House of Commons 2009), despite the fact that most people's health needs are treated in this sector.

Reliable information that does exist suggests that medical harm is widespread in health and a recurring phenomenon in caring for patients. It is generally agreed that about 10% of hospital admissions result in an adverse incident, about half of which are preventable (IOM 1999; DOH 2000; NAO 2005). The NAO (2005) study found that few trusts included hospital acquired infections in their data, which they estimated could increase patient safety incidents by around 300,000 (around 30 per cent of which may be preventable). Other studies show that hospital acquired infections on their own are likely to kill as many as 5000 patients every year (NAO 2004). In addition, the study found a significant under-reporting of deaths and serious incidents. Some 2,181 deaths due to PSIs were recorded in their survey of trusts, whilst it was noted that other published estimates of deaths suggested a range from 840 to 34,000. In reality the NHS simply does not know the true figures relating to PSIs (NAO 2005).

### **Developing a Patient Safety Culture: Systems and Governance**

In the patient safety context, a number of the inquiries (mentioned earlier) into serious failings of clinical care since the late nineties, have focused on the issue of governance as central to addressing issues of safety and quality of patient care in NHS organisations. More generally it has now been recognised that governance and accountability are central to the performance of health systems (WHO 2008) and an important influence on safety and quality of care (Braithwaite, Healy et al. 2005). 'Organisational governance' can be seen as referring to the systems within an organisation which ensure it is effectively managed (Fulop, Chamberlain et al. 2008).

The Government's response to the Bristol Report firmly identified the issues of deficiencies in organisational culture and system failure as major factors in preventing the development of a patient safety culture. The Bristol Inquiry report subsequently led to the report *An organisation with a memory* (DOH 2000). This represented a major turning point in tackling PSIs, and provided the first comprehensive look at the way that the NHS managed adverse incidents when they occurred. The implication was that NHS organisations needed to learn from these incidents and develop a culture and infrastructure to support that learning. This thinking marked the start of a considerable debate within healthcare about how to develop a patient safety culture that went beyond a focus on the individual actions of doctors and healthcare professionals as constituting the main cause of medical errors. In this respect, writers such as Reason (1990) and Perrow (1984) have pointed to the importance of looking at the role of systems and their design in causing error, rather than focusing on error occurring in organisations through the unsafe acts of individual employees.

As far back as the 1970's, sociologists such as Freidson (1970) have criticised a biomedical approach focused on the individual body as the prime unit of analysis in terms of explaining illness and disease. He argued that medical practice, organised in this way, systematically encouraged the average doctor to give indifferent medical care in a climate where the pressures of the system were directed toward increasing the number of services and decreasing the professional quality of those services. In devising solutions to this situation, Freidson advocated both the development of regulatory systems of accountability that monitored a doctor's performance, as well as measures that empowered patients in the doctor-patient relationship. This dual approach was designed to address issues relating to the imbalance of power, recognised as implicit in the doctor-patient relationship. In the context of patient safety, Inquiry reports such as Shipman and Bristol have addressed these issues by focussing on the importance of good governance arrangements.

In the NHS, there are multiple inter-linked strands of governance which include not only clinical governance arrangements, but also corporate and financial governance as well as numerous other governance instruments concerning risk management and controls assurance. An integrated approach to dealing with these processes has therefore been set out in the *Integrated Governance Handbook*. This defines integrated governance as ‘systems, processes and behaviours by which trusts lead, direct and control their functions in order to achieve organisational objectives, safety and quality of service and in which they relate to patients and carers, the wider community and partner organisations’ (Department of Health 2006:10). In patient safety however, a range of reports (DOH 2006; Health 2006; House of Commons 2006; The Secretary of State for Health 2007) suggest that progress in developing a systems approach and how issues of governance are managed, still have a long way to go. It is within the broader debate about achieving good governance in patient safety, that a strong emphasis has also been placed on the importance of developing greater patient and public engagement. This agenda is discussed in more detail below.

### **Patient and Public Involvement in Patient Safety**

The importance of developing a PPI agenda as a central feature in developing a patient safety culture was firmly addressed by the Bristol Inquiry Report. The Report viewed increasing the participation of patients, parents and the public in health as vital to developing a safety culture, which might also prevent the occurrence of errors and ameliorate the effects of harm (Bristol Royal Infirmary Inquiry 2001). Post-Bristol, Kennedy expanded upon this view by arguing that patients and doctors were both experts in their own fields and so should work in partnership together (Kennedy 2003). This thinking has subsequently been reinforced by a number of other writers. Vincent and Coulter have noted that the most remarkable feature of the multi-faceted patient safety movement is ‘the lack of attention paid to the patient’ (Vincent and Coulter 2002:76). More recently, David Colin-Thome’s report (2009) on the events at Mid Staffordshire NHS Foundation Trust, has argued that patient engagement and empowerment should be a central part of the processes for delivering safety and quality in healthcare.

In reinforcing the need for further culture change in this area, Sir Liam Donaldson, the Chief Medical Officer, has pointed out that whilst the NHS in the past was characterised by paternalism, 'tomorrow's patients will not be willing to accept the role of grateful and passive recipients of care. Recognizing and acting on the part that they and the public can play in shaping the NHS is vital. The quality and safety of care in the future depends on it' (Donaldson 2008:341). Whilst this statement may appear to be contradicted by evidence that indicates that about three-quarters of patients rate their satisfaction with NHS care as excellent or very good, in recent years there has also been 'a growing concern among the general public about safety in healthcare' (The Health Foundation 2007:65). Evidence from NHS patient surveys show that patients generally want more safety related information, particularly in areas to do with the side effects of medicine and in understanding test results (Picker Institute Europe 2007:148).

Whilst there is little in the literature on the views of harmed patients, the evidence that does exist suggests that these patients have strong opinions about the medical profession, safety and changing the system (Ocloo 2007; Ocloo 2008). Allsop, Jones et al (2004) have pointed to what they call 'protest groups' who have formed as a result of adverse clinical events. She found that these groups were more likely than other health consumer groups to 'view medical practices as paternalistic and oppressive and to see health professionals as people who withheld information and close ranks against patients when questioned' (Allsop, Jones et al. 2004:751). Other evidence suggests that in addressing patient safety concerns, issues relating to accountability are seen as important by the public (Davies and Shields 1999).

Therefore the issues emerging from harmed patients appear to bring to the debate concerns that are very different to dominant perspectives shaping the current patient safety reforms. They can also be viewed as part of the broader struggle highlighted earlier, by groups who have been disenfranchised by health services, who are seeking changes to the way those services are provided, which are also about more democratic governance, citizenship and human rights.

Post-Bristol, a number of inquiry reports (DOH 2006; HM Government 2007) have continued to emphasise the importance of involving patients and the public in new organisational arrangements. Yet eight years after the publication of the Bristol Report (2001), growing evidence about practice on the ground suggests a lack of progress in developing PPI in the patient safety agenda. In 1999, the document 'Clinical Governance: in the new NHS' (*National Health Service Executive 1999*), set out clear expectations for NHS Trusts in developing PPI in this area. However, evidence from two National Audit Office (NAO 2003; NAO 2007) reports looking at implementation of clinical governance arrangements in the NHS in primary care and the hospital sector, found that progress in developing PPI was limited. Little evidence is provided in these reports about the barriers to involvement. Findings from a two-year pilot initiative, the Patients for Patient Safety (PfPS) project, also found a number of problems. A key finding was that whilst patients and the public were willing to work in partnership with NHS organizations, they faced substantial barriers to real involvement (Ocloo 2008).

As mentioned above, Picker Institute Europe (Coulter and Ellins 2006) provide the most systematic review of the literature when looking at evidence concerning involvement in the patient safety agenda. They have concluded that, 'The UK has had a major programme to improve patient safety since 2001, but with little recognition of patients' potential to take an active role' (Picker Institute Europe 2007:6). They note that historically the patient safety movement has overlooked the role of the patient and tended to view patients in a passive way as simply the victims of errors. In practice this has meant disregarding the various ways in which patients already contribute to their care (Coulter and Ellins 2006). The review noted that whilst research in this area was still in its early stages, successful partnerships with patients on safety and in reducing error, could only take place in environments where patient involvement was both valued and supported. The extent to which patients could contribute to patient safety improvement was seen to depend on various factors such as demographic characteristics, perceived vulnerability to harm and confidence in challenging health professionals. However these initiatives were seen as complimentary to and not a substitute

for action aimed at changing professional behaviour and addressing systemic problems. An important issue also highlighted was that patients wanted greater openness and honesty from healthcare professionals that included full disclosure of medical errors and incidents that had affected them (Coulter and Ellins 2006).

The main areas where patients were thought to have the potential to make the most difference in ensuring the safety of their care and to prevent the occurrence of errors was through making informed choices about providers; helping to reach an accurate diagnosis; sharing decisions about treatments and procedures; contributing to safe medication use (in this area various strategies for improving patient adherence to treatment had shown that the most effective involved simplifying dosing regimes); participating in infection control initiatives; checking the accuracy of medical records; observing and checking care processes; identifying and reporting treatment complications and adverse events; practising effective self-management, including treatment monitoring; and shaping the design and improvement of services.

Other interventions relating to patient education, information and counselling were noted to have produced less conclusive results. Educational interventions and information provision were found unlikely to be effective on their own, although issues of health literacy were viewed as needing to be addressed before information about safety and risk could be effectively communicated to patients and acted upon by them. Other data provided mixed evidence for the role of patient safety information in adverse event prevention. For example little is known about the impact of patient reporting of adverse incidents and there is evidence that patients do not always comply with respect to marking the correct surgical site when involved in surgical procedures (Coulter and Ellins 2006:143).

Overall they conclude, along with others (Vincent and Coulter 2002), that far more needs to be known about the particular ways that safety improvements can be enhanced through patient involvement and the benefits of patients becoming more active in the safety of their care. Given the sensitivity and complexity of patient safety, innovative strategies were seen as required, to support patients and health professionals to work in partnership. These they

argue 'will need to be subjected to formal evaluation so that best practice can be identified and applied across settings' (Coulter and Ellins 2006:172). This evidence is particularly important given the concerns raised by some writers such as Lyons (2007) that PPI is not always a good thing because patients and/or their families do not possess the requisite biomedical clinical training and knowledge to contribute to meaningful involvement in patient safety.

Despite the lack of research in this area, writers such as (Vincent and Coulter 2002; Entwistle 2007) make a number of suggestions for involving individual patients in the safety agenda. But with regards to successful strategies to promote more collective or strategic involvement in patient safety, little evidence is available. Pickard, Marshall et al (2002) in investigating the involvement of users in clinical governance activities within Primary Care Groups (PCGs) and Trusts (PCTs), found that 'despite an acknowledgement of an organisational commitment to lay involvement in practice very little has occurred' (Pickard, Marshall et al. 2002:187). Davis, Jacklin et al (2007) however in reviewing a range of safety and healthcare literature, have developed a conceptual framework illustrating the known and putative factors that could affect the participation of the patient in safety issues and their own healthcare (see table Appendix B). Patient participation in safety is seen to depend on a complex interplay of these factors that need to be considered in developing a strategy for involvement.

The authors conclude that there is a pressing need for more empirical research to investigate more fully the relative impact/importance of the various factors identified within the conceptual framework and the interactions between them in determining involvement. Some qualifying factors with regards to involvement were that patients should only be seen as having responsibility for safety concerns, when they wanted and felt able to perform this role, but that responsibility for patient safety must ultimately remain with healthcare professionals. They also question whether 'adopting a 'one size fits all' approach will be successful in facilitating patient involvement in safety' (Davis, Jacklin et al. 2007:266).

## **Research Study: Foundation Trust Governor and Member Involvement**

Having looked at the wider context for PPI in the public services in this paper, the aim of the research to be conducted will be to look specifically at the role of Foundation Trust governors and members in the governance of patient safety and quality. This will be considered within the wider context of the legal duty in health concerning patient and public involvement. This duty is set out in Section 11 of the Health and Social Care Act 2001 (s242(1B) of the consolidated NHS Act 2006).

In the NHS, patient and public involvement have traditionally been linked together to describe the various ways in which members of the public can shape service improvement. A common definition used by practitioners is that PPI can take place at:

- The **individual** level – how patients and carers can have a say in their own care and treatment and the extent to which they share in decision making about options; and
- The **collective level** – how patients, carers and the public can have a say in service delivery and policy and planning.

In this research the emphasis will be more on the collective level or what has also been referred to as public involvement. The research will not look at the much wider area of patient involvement in their own treatment that is covered by a substantial body of literature (not reviewed in this paper).

### **Background: Foundation Trusts**

NHS Foundation Trusts (FTs) were established under the Health and Social Care (Community Health and Standards) Act that came into force in November 2003. This legislation ushered in a new type of NHS organisation, modelled on mutual aid and co-operative traditions. But whilst they remain part of the NHS, they can be seen as unique and distinct from other NHS Trusts in their governance arrangements in three main ways.

Foundation Trusts operate governance arrangements that give local stakeholders, patients and the public the opportunity to be involved in the strategic management of these trusts. This occurs through a duty to consult and engage with an elected Board of Governors made up of patients, staff,

and members of the public and other key stakeholders. Governors in turn are held to account by the voting members recruited to the trust (patients, carers, staff and members of local communities), who are also able to stand for elections to the governing board. Foundation Trusts have greater freedom and flexibility than other NHS trusts to manage their affairs and whilst they must continue to meet the same standards and targets as other trusts, they are not subject to any powers of direction by the Secretary of State nor are they performance managed by Strategic Health Authorities. The Boards of Directors as free standing entities therefore have much greater autonomy both to access capital and invest surpluses in developing new local services for the communities they serve (DOH website – NHS foundation trusts 2008; (Department of Health 2005).

Foundation Trusts also have a new regulator, Monitor, which is responsible for monitoring performance and standards of care. Monitor ensures trust compliance with their 'Terms of Authorisation' through a risk based ratings approach to regulation. This is designed to allow well governed, high performing trusts the discretion to use the freedoms they have, whilst trusts experiencing problems are monitored more intensively.

### **Foundation Trusts: Institutional Factors Shaping Participation**

The literature on the governance of Foundations Trusts is still fairly limited. Research is currently being carried out by the NIHR Service Delivery and Organisation programme investigating the governance of Foundation Trusts. Early critiques have also emerged about these organisations in meeting their stated aims, as have results from a survey commissioned by Monitor.

Research looking at the work of Homerton Foundation Trust, found that after a year of being involved, the council of governors had made little tangible impact on the running of the hospital and strategic decision-making (Lewis 2003; Lewis and Hinton 2005). This situation was partly explained by the lack of knowledge and skills and the 'experience gap' of governors, that were still developing and ambiguity over governors' roles and rights. The transfer of power into the hands of members' (Lewis 2003:9) and developing the right type of support mechanisms for new members 'to take on their rights and

responsibilities effectively' (Lewis and Hinton 2005:13), was seen as crucial. These findings were reflected in a wider survey of governor opinion in a straw poll carried out by the King's Fund in January (Lewis 2005).

Writers such as Mills also highlight the importance of governors acting as 'the conduit' between local people expressing their needs about services and how they should be delivered and those making decisions about service delivery (Mills 2007:7). This has been reinforced by Gorsky (2006) who argues that in order to avoid the historical limits to localism that existed in hospital governance before the NHS, major efforts will be required to encourage 'membership community' involvement, with clear ground rules for enabling 'popular influence on policy' (2006: 1). Day and Klein (2005) note in their review of the governance of Foundation Trusts that a number of different models of governance exist in practice. They argue that the challenge for the future will be to identify how well these work and how 'to devise explicit criteria for choosing between them' (Day and Klein 2005:29).

More recently a survey carried out by Monitor on Foundation Trusts has been more positive about how governors are carrying out their roles and statutory responsibilities. Key findings indicated that the majority of governors were clear about their role, had good relationships with their executive board and were using their statutory powers to make a difference. Areas identified for improvement focused on the need for better information for new governors, improved operation of the board of governors and better interaction with Boards of Directors and developing relationships with members. Monitor also identified a need to provide further guidance to governors on understanding and discharging their statutory duties (Monitor 2008a; Monitor 2008b). This evidence however appears to be somewhat contradicted by unpublished research commissioned by the NHS Confederation. This suggests that Foundation Trust staff governors feel unclear about their role, disempowered and lack the skills to hold boards to account (Santry 2009).

What also appears to present an issue in terms of the transparency and openness of Foundation Trusts and public involvement, are the findings from a recent poll by the *Health Service Journal* of Foundation Trusts. This found

that just 'seven of 30 foundation trusts questioned allowed the public to attend even a part of their directors' meetings' (West 2009:1).

Overall this evidence on the governance arrangements of Foundation Trusts, provide some pointers in considering how a strategy for involving governors and members in patient safety and quality might be delivered. In the section below, key evidence about barriers to involvement in other sectors identified earlier is also important.

### **Some Strategies for Involvement**

This evidence about barriers in the context of health has revealed issues about a lack of clarity about role, resistance from healthcare staff and managers, a shortage of resources and concerns about representation. With regards to patient safety, the issues identified by the PfPS project and the framework developed by Davis, Jacklin et al (2007) are important to consider. The former highlights fears from staff concerning the involvement of PPI in patient safety, and calls from patients and the public for more support in relation to being given information about involvement opportunities and for proper reimbursement of expenses and training on key specialist areas. With Davis, Jacklin et al the emphasis has been on the complex interplay of factors that need to be considered in developing a strategy for involvement. In developing an intervention they suggest that those 'targeted carefully to specific patient groups and which employ a "multi-modal" approach are probably more likely to engage patients successfully' (Davis, Jacklin et al. 2007:266).

More broadly, some of the experiences emerging from other parts of the public sector may also be especially relevant in developing good practice on involvement in the patient safety agenda. These areas highlight issues concerning dealing with power inequities involving users in different areas of governance and in the design and delivery of services.

In mental health, Rutter, Manley et al's (2004) research particularly highlights the disparities in power in decision-making between health professionals and users. In looking at these issues, they note that 'the health and psychiatric literature, may be relevant to policy in many different organizational contexts

characterized by a diversity of stakeholders, and great inequities of power' (2004:1982). Peck, Gulliver et al also highlight trends in the 1990s coinciding with the empowerment of mental health service users in society that could usefully be transferrable to the area of patient safety. These relate to the influence of theories such as social constructionism, postmodernism and consciousness raising in challenging professional narratives on the nature of mental distress and in influencing ideas for social change particularly in professions such as social work (Peck, Gulliver et al. 2002:441-2). The literature in social work and social care also offers a range of theory and practice about how to engage with diverse user groups disadvantaged by oppressive and paternalistic service provision and excluded as a result of discrimination at the personal, cultural and institutional level.

With regards to involvement in governance processes, education and social care provide a number of useful pointers. This is illustrated by the practice of governor involvement in education and in social care regulatory bodies, which can provide useful exemplars in the research proposed into the role of governors and members in patient safety and quality. The area of risk governance also provides some pointers for tackling barriers to participation which highlight issues concerning power inequities. Fiorino (1990), drawing upon participation theory, outlines criteria for evaluating institutional mechanisms as democratic processes, that might help develop participatory processes in practice. These relate to how mechanisms allow for the direct participation of amateurs in decisions; how citizens are enabled to share in collective decision-making; how mechanisms provides a structure for face-to-face discussion over a period of time; and how opportunities can be provided for citizens to participate on some basis of equality with professional/technical experts.

### **Key aims of the Research**

In developing research on governor/member involvement the key aim will be to develop and evaluate models to facilitate involvement at the collective level. This raises issues both about good governance and the improvement of service delivery. The principal research question to be addressed is:

- Are governors/members able to be involved in the governance context of patient safety and quality and influence service planning and provision?

Secondary research questions are:

- What factors facilitate or hinder the involvement process?
- How can the level and quality of involvement be improved and what different models can be used to achieve this?
- How do health care staff (professionals, managers etc) relate to the involvement process in terms of support for or resistance to it and what assistance do they require to support involvement processes?
- What metrics provide a useful way of measuring the process and impact of involvement?

## **Conclusion**

Overall this paper suggests that whilst there has been a debate about PPI in patient safety for at least the last eight years, there is still a lack of concrete evidence about how to achieve greater levels of participation in the patient safety agenda. The lack of evidence concerning successful involvement at a strategic level in NHS trusts is particularly acute. What is also clear in developing this agenda more broadly, is that a framework is needed for evaluating both different types of participation and their impact.

The idea of PPI in patient safety is clearly an area that is just beginning to emerge, in line with the emergence of a wider patient safety movement. However the slow pace at which this is occurring seems out of place with developments in other parts of the public services. It would therefore appear that in order to develop this agenda further, much more use needs to be made of the broad range of experiences and knowledge that exist outside of patient safety.

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## Appendix A

### The Development of Key User Involvement initiatives in Health

<b>Establishment of Key Bodies</b>	
The Community Health Councils 1973 (abolished 2003).	UI becomes a central component of NHS policy.
The establishment of the Commission for Patient & Public Involvement in Health (CPPIH) and the Patient and Public Involvement Forums (PPIFs) in 2003.	Set up to give patients /public a voice on health matters mainly through the PPIFs.
Patient Advice & Liaison Services (PALS) 2003.	Set up within hospital trusts to provide info & resolve patient concerns.
Independent Complaints & Advocacy Service (ICAS) 2003.	Set up to provide support to patients who have formal complaints against the NHS.
The Overview & Scrutiny Committees (OSCs) 2003.	Made up of local councillors with the power to scrutinise & improve health services.
CPPIH & the PPIFs were abolished by the Local Government & Public Involvement in Health Act 2007. This Act set up the Local Involvement Networks (LINKs).	
<b>Key Policy Documents</b>	
Patients Charter 1991	Set out standards the public were entitled to in the delivery of health services.
Local Voices 1992	Set out plans stressing the need to make services more responsive to patient need.
Changing Childbirth 1993	Stressed the importance of women-centred care & involvement in childbirth.
Patient & Public Involvement in the new NHS 1999	Further emphasised the benefits of PPI in own care & planning of services.
The NHS Plan 2000	A ten-year plan for modernising the NHS with patients at its centre.
Strengthening Accountability 2003	This outlined the stat duties created by Section 11 of the Health and Social Care Act 2001 (cited below).
The NHS Improvement Plan 2004	Supported the ongoing commitment to a 10-year process of reform in the NHS
A stronger local voice 2006	Set out the govt's plans for the future of PPI in health and social care
World class commissioning 2007	Sets out aims to transform dramatically the way services commissioned in health and care services
High quality care for all: NHS Next stage Review 2008	Sets out a vision for an NHS with quality at its heart
NHS Community Care Act 1990	First piece of UK legislation to establish duty to involve users in service planning.

The Health & Social Care Act 2001 (now S242(1B) of the consolidated NHS Act 2006)	Placed a legal duty on NHS trusts to involve & consult patients/public.
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**Appendix B**

**Factors Influencing Patient Participation and Engagement**

Patients' Demographic Characteristics	Illness related (e.g. illness severity)	Health care Professionals' Knowledge and beliefs	Health care setting-related (e.g. primary or secondary care)	Task related (e.g. whether the required patient safety behaviour challenges clinicians' clinical abilities).
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