Rising to the challenge: a study of patient and public involvement in four primary care trusts

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As new organizations with responsibility for the health and health care of their local populations, primary care trusts (PCTs) need to engage with patients and the wider public. This paper identifies the challenges faced by PCTs in implementing patient and public involvement and reports on a qualitative study of four PCTs in one health district. Findings from two pieces of data collection are reported on: an audit of community involvement activity and 16 semi-structured interviews with individuals working in the PCTs. The findings show that organizational capacity for undertaking patient and public involvement activities increased considerably over an 18 month period. The PCTs were found to be engaging with individuals and groups from the community and voluntary sector through a range of different structures and processes. Considerable commitment to patient and public involvement was reported but there were concerns over implementation. A number of influencing factors were identified including national policy, organizational factors, leadership, workload, access to experienced involvement workers and the pattern of local community activity. The paper discusses the implications for the development of patient and public involvement in PCTs including the importance of cultural change and the need for organizational development. The potential for PCTs to be involved in a range of participatory activities and to work with other partner organizations in localities is also discussed. The paper concludes that, despite challenges, progress can be made in implementing patient and public involvement as a mainstream activity in PCTs.

Key words: communities; organizational development; patient and public involvement; primary care trusts

Over recent years there have been huge changes in the organization and accountability structures in primary care in the UK, most notably the creation of primary care groups (PCGs) and primary care trusts (PCTs). These are organizations with responsibilities for the healthcare needs of local populations, led primarily by health professionals but with some lay representation (Secretary of State for Health, 1997). In 2001, the Department of Health in *Shifting the balance of power within the NHS* (Department of Health, 2001a) made PCTs the lead NHS organizations for planning and

commissioning services with responsibilities for health improvement. Decentralization in the NHS is seen as bringing decision making and planning closer to the people – 'Devolving power and responsibility to PCTs offers real opportunities to engage local communities in the decisions that effect their local health service' (Department of Health, 2001a: 13). A strong reform agenda around increasing patient and public involvement throughout the NHS accompanies these changes (Department of Health, 2001b).

Community and patient involvement in primary health care is not, of course, a new idea. Community participation, in conjunction with a reorientation of health services, is recognized as necessary to deliver more equitable, accessible health care (Godinho *et al*., 1992; World Health Organization,

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1978) and these ideas have been reflected in some of the community based approaches seen in UK practice (Heritage, 1994). There is a history of attempts to increase patient involvement in general practice, through methods such as patient participation groups and surveys, however the spread of involvement activities has tended to be patchy, and sustainability has been a problem (Brown, 1999; 2000; McIver, 1999).

Although the value of patient and community involvement in primary health care has been recognized, what is new is the impetus for reform driven by national policy. In 1999 a health service circular *Patient and public involvement in the new NHS* (NHS Executive, 1999) gave PCGs and PCTs specific responsibilities for patient and public involvement. The government's commitment to increasing patient and public involvement in health was later endorsed by the NHS Plan (Secretary of State for Health, 2000) which proposed changes to make the health service more 'patient centred', including the establishment of patient forums. Developments in the NHS are paralleled by initiatives to tackle health inequalities and social exclusion which also stress the importance of community involvement (Judge *et al.*, 1999; Social Exclusion Unit, 2001).

PCTs undoubtedly face a significant challenge in building involvement into planning and decision making processes and some have suggested that public influence may remain weak (North and Peckham 2001; Rowe and Shepherd, 2002). Early studies indicate that some progress on patient and public involvement has been made and PCG/Ts were beginning to develop and initiate a range of public involvement activities including surveys, public events and newsletters (Alborz *et al.*, 2002; Milewa and Harrison 2001). However the National Tracker Survey (Wilkin *et al.,* 2000) found that PCGs were less successful at involving the public than other groups of stakeholders. In another study, chief executives and chairs perceived that the public and service users had less influence on decision making than any other group (Smith *et al.,* 2000a).

PCG/Ts have been responding to the mandate set by national government in the context of major organizational and structural changes in primary health care and there are issues around their capacity to involve the public and patients. Lack of time, resources and expertize have been identified as major barriers to public involvement (Florin and Anderson, 2000; Smith *et al.*, 2000a).

A survey of PCGs in south and west region found that there was a 'lack of preparation for taking forward public participation and uncertainty about how to begin to engage patients and the public' (Shepherd, 2001: 32).

The literature highlights some pertinent issues but conclusions about the extent of patient and public involvement have to be tentative as PCTs are emerging organizations whose development is likely to be rapid. The majority of early studies were based on questionnaires to key individuals such as chairs and chief executives. The aims of this paper are to present the results of a qualitative study that investigated the development of patient and public involvement in four PCTs within one health district and to discuss the implications for practice.

The study context

The study was carried out in one UK city, with four PCTs which had all achieved PCT status in November 2000. The PCTs covered populations from 92 000 to 150 000. The number of practices within each PCT ranged from 19 to 43. One PCT covered an inner city area with a large minority ethnic population, while another covered a wide geographical area with three distinct localities.

There was significant poor health in the district and there were areas of deprivation in all the PCTs. The district had become a Health Action Zone (HAZ) in 1998 and commitment to achieve greater community and service user involvement in health and healthcare led to the establishment of a HAZ Community Involvement Team in 1999. The focus of the team's work was to build organizational capacity and support the PCG/Ts in the process of engaging with local communities. The team consisted of four workers, each attached to a PCT, and a team manager. An evaluation of the team was set up and funded through the HAZ.

Methods

The evaluation adopted a qualitative orientation and multiple methods were used in order to investigate social processes and develop an in-depth understanding of the development of community involvement in the four PCTs (South and

Green, 2001). The findings presented in this paper are drawn from two major pieces of data collection undertaken for the evaluation: an audit of community involvement activity and semi-structured interviews with PCT managers and members.

The audit of community involvement activity was undertaken for the period November 2000 to October 2001, the PCTs' first year of operation. An earlier audit had been conducted for the baseline assessment covering PCG activity, April 1999– March 2000. A structured form was used in both audits to collect data on community involvement activity and aspects of organizational capacity to allow comparison over time. The repeat audit was completed by the community involvement leads in each PCT and the HAZ Community Involvement Team members. The information was then collated and compared to the baseline audit.

Semi-structured interviews were undertaken to investigate whether patient and public involvement was being routinely built into the planning and activities of the PCTs. Purposive sampling was used to draw up a sample of individuals to include two managers or Professional Executive Committee (PEC) members from each PCT who had direct operational experience of patient and public involvement and two PEC members from each PCT who did not have a major role. Eighteen individuals were contacted and two refused.

An interview guide was prepared with a mix of topics to be covered and some specific open ended questions. Semi-structured interviews were conducted from March to August 2001. In all interviews, detailed notes were taken by hand, typed up and then returned to the interviewees for validation and additional comments. A thematic analysis of all interview data was then carried out. Themes and influencing factors were mapped for each PCT using matrices. Diagrams were used to develop ideas, continually returning to the data to refine the analysis (Riley, 1990).

Findings: Audit of PCT community involvement activity, 2000–1

Policy development

It was found that policy development had advanced considerably in the 18 months following the baseline audit. Whereas only one PCG had achieved a patient and public involvement strategy,

action plan and agreed budget by March 2000, by November 2001 all PCTs had strategies and action plans, and were in the process of implementation. Patient and public involvement was also included in business plans, communication policies and equality and diversity strategies. In all the PCTs, patient and public involvement targets had been set for general practices either through the Personal Medical Service (PMS) contracts or through clinical governance quality standards.

Resources

All the PCTs had budgets in place and there had been a considerable increase in core PCT money directed to patient and public involvement compared with the earlier audit. Budget allocations ranged from £42 000 to £150 000 and included both resources for supporting PCT-led activities as well as funding for community based and community initiated projects. The amounts allocated to local projects were in some cases quite significant. One PCT had funded 29 community involvement projects and was in the process of developing a commissioning model to support projects aimed at PCT priority areas which would also ensure community needs were reflected.

Training and staff development

A lack of knowledge and experience around patient and public involvement had been identified as an influencing factor in the early work and initially there had been little or no training input. The repeat audit found that all the PCTs now regarded training and skills development as very important. One PCT audit stated 'equipping staff with skills to operate in the new environment is seen as a key priority'. Experience of community involvement was a component of job descriptions for groups of staff in two of the PCTs. Compared to the earlier audit, training opportunities were hugely increased and these included presentations to board and committee meetings, use of protected learning time for seminars on patient and public involvement, and staff attendance at community events.

Community involvement activities

The audit asked respondents to list the main PCT community involvement activities over the past year and to categorize them using one of five levels of participation (Wilcox, 1994). Wilcox's model

uses a broad definition of community involvement that includes partnership working with communities and support to community activities through to consultation and provision of information. The earlier audit had shown that although links were being made between the PCGs and local community groups, activities were predominately clustered around consultation for PCT status and information. The repeat audit found that the range of involvement activities had increased over the past 18 months, in some cases quite dramatically. PCTs were involved in a greater range of consultation activities and there was evidence of patient and/or public involvement in some decision making processes. Two PCTs had health improvement groups with wide community and voluntary sector representation and all four PCTs were working with a broad range of partners from small community groups to district organizations.

The audit asked for information on measures to involve minority ethnic communities and people from groups often excluded from planning processes, such as people with learning disabilities. Earlier evidence had shown that although there were intentions to develop work in those areas, very little had been done. The repeat audit found that all the PCTs had since taken measures to involve marginalized groups, including those from minority ethnic communities. These included efforts to ensure public events were inclusive and to get some marginalized communities participating in decision making. For example, one PCT had involved organizations representing minority ethnic communities, learning disabilities, domestic violence support and mental health advocacy, on a group looking at improving access.

Findings–Interviews

Sixteen interviews were conducted with individuals covering a range of responsibilities and different professional backgrounds (see Table 1). Length of time working in the PCT varied, 11 had been involved in the PCG, while five had become involved after PCT status was granted. The results are presented below. To protect the anonymity of individuals, no names or positions that might identify participants are given. Quotation marks are used in the text to indicate when statements or phrases were recorded verbatim.

Table 1   Interviewees' main job

Interviewees	
PCT manager	5
General practitioner (GP)	5
Nurse manager	2
Practice manager	2
Public health facilitator	2

Community influence

All interviewees were asked to identify ways in which patient and public involvement took place and their perceptions of community influence. A range of mechanisms for involving patients and the public were identified and later grouped (Table 2). Although each PCT was utilising broadly similar mechanisms, the development of new participatory structures was found to vary. In addition to the use of formal structures, ad hoc contact and informal dialogue was reported to be taking place and this was recognized as an important aspect of involvement. Interviewees described their PCTs participating in existing partnerships and initiatives external to their organization that had community represen-

Table 2   Mechanisms for community involvement identified by PCT interviewees

Mechanisms for patient and public involvement	Examples
PCT based	Health forums in localities, open to the public PCT health improvement group with community representation Whole system events/community conferences
Structures external to PCT	Neighbourhood forums Healthy living centre groups Single regeneration bids
Primary health care services	Community nurses in touch with community needs Patient participation groups
Informal processes	Dialogue with local community projects funded by HAZ or PCT Ad hoc contact with community groups Contact through community involvement workers

tation, such as the local authority forums at ward level and regeneration initiatives. One PCT had a large number of such initiatives on their patch and this was seen as a particularly useful mechanism for engaging with communities.

Many of those interviewed identified the importance of GPs and primary health care staff acting as advocates for their patients and this was seen as one of the key mechanisms for getting community views into planning processes. However patient participation activities were reported to be variable, dependent on the motivation and interest of individual general practices.

Perceptions of community influence varied. In two of the PCTs, interviewees reported a transfer of ideas from the community into their PCT and there was evidence of some planning being shaped by community views. In the other two PCTs, structures were still developing at the time of the interviews and there was reported to be little community input into decision making, although dialogue with communities was taking place. A number of those interviewed were able to give examples of user involvement in specific clinical areas, such as mental health or diabetes. Overall there were beginning to be channels open for community views to be fed in but there was little evidence that communities and service users were having a significant influence on decision making across the full range of PCT activities.

Commitment

The study wanted to examine whether the principles of patient and public involvement were central to the way the PCTs functioned as organizations. All interviewees were asked a question on their perception of the level of commitment to involving patients, communities and the wider public in the PCT. There was reported to be a strong commitment in all the PCTs, with a high level of support in boards, among senior officers and in the Professional Executive Committees (PECs). There was recognition that due to national policy, patient and public involvement was no longer optional. One PCT manager commented that people had signed up to the idea and understood the importance of it.

Although there was evidently commitment to patient and public involvement, reservations were expressed about moving from the vision to implementation and the extent of change required.

One manager spoke of the road in PCTs being 'paved with good intentions'. In terms of commitment in general practice, some interviewees thought that there was little awareness or that it was not seen as a priority, while others considered that there was a moderate level of commitment. One interviewee was typical in saying that they were committed at practice level but there was some 'nervousness' about it.

Developing shared ownership of the patient and public involvement agenda and the importance of integrating it into all aspects of PCT business were seen as important While some interviewees identified the need for a radical culture change in primary health care, others perceived that a culture more oriented to community involvement was beginning to grow. In one of the PCTs it was reported that there was an ethos supportive to community involvement and a high level of awareness amongst all staff.

Influencing factors

Interviewees were asked to identify any factors that had influenced the work around patient and public involvement. Not surprisingly a whole web of factors were revealed, some considered more significant than others. National policy was identified as a major driver for change, however it was reported that patient and public involvement could slip from the agenda as other priorities were deemed more urgent. One GP described the PCT as 'lurching from one thing to another' as they needed to respond to different initiatives with the result that patient and public involvement tended to be put on the 'back burner' at times.

Factors related to the functioning of the PCT as an organization were reported to have had a significant impact on the work. The management structure and the allocation of responsibility for patient and public involvement were considered important by several of those interviewed, as was good communication in the organization. The presence of individuals who could champion the patient and public involvement agenda, the culture of the organization, and the leadership shown by PCT chairs, chief executives and other key individuals were all significant factors. Time constraints and the workload were seen as major constraining factors in PCTs and general practices. Many spoke of the huge agenda faced in primary care, the pace of change, and the information overload. Lack of

experience and knowledge was also identified as a barrier.

HAZ status was generally seen as positive as it had raised awareness of community involvement and provided resources. The extent to which interviewees had contact with HAZ Community Involvement team members varied but the majority valued their contribution, indeed some considered it essential to the progress made. The involvement workers' role in networking and building links between local communities and PCTs was acknowledged as particularly valuable. They were regarded as a resource for PCTs, in terms of expertize and skills for patient and public involvement.

The nature of each PCT's 'patch' was also perceived to be a major factor shaping the approaches taken and impacting on the progress made. The realities of implementing patient and public involvement in the context of time constraints, low community capacity, and social exclusion, led to PCTs tending to deal with established groups. There were concerns raised by many interviewees about their PCT's ability to involve the wider public and marginalized groups. There was also some discussion in the interviews over what degree of power sharing was appropriate and this was voiced particularly by the GPs interviewed. The potential for patient and public involvement to raise expectations that could not be met out of current resources were reported to be genuine concerns in primary care.

Discussion

The study sought to gain an indepth understanding of the context and approaches to patient and public involvement in a group of PCTs. Semi-structured interviews allowed a range of individuals with differing roles and responsibilities to explore connections and influencing factors. While the views and experiences of those interviewed cannot be considered representative, common themes did emerge. The two audits allowed changes in organizational activities to be assessed over a period of time and provided additional data to the interviews, strengthening the validity of the findings. Many of the organizational aspects and influencing factors identified through the study were context specific and, as with any qualitative research, the results

cannot be generalized. Nonetheless the study gave a valuable insight into how PCTs in one area have responded to the challenge of implementing patient and public involvement. In this section, key themes are discussed and the implications for practice drawn out (see Figure 1).

The patient and public involvement agenda proposes radical change for primary health care organizations (Brooks, 2001; Scottish Association of Health Councils *et al.*, 1999) and the capacity of PCG/Ts to deliver on this agenda has been questioned (Anderson, 2001; North and Peckham, 2001). This study has shown that despite the ambitious nature of the agenda and the presence of significant barriers in the context of major organizational change, a group of PCTs were able to foster organizational commitment to patient and public involvement, to implement activities involving their local communities and to develop infrastructures to support the work. Using (Crisp *et al.*'s 2000) measures for assessing changes in organizational capacity in health, there was evidence of change in all four areas: policy development; resource allocation; organizational implementation; and sanctions/incentives for compliance. Patient and public involvement was increasingly regarded as a mainstream activity with its inclusion in PCT business plans, PMS contracts and clinical governance standards. This can be seen as a significant finding given that patient and public involvement has generally been found to be a peripheral activity in primary care in past studies (Brown, 2000; McIver, 1999).

Although the PCTs were evidently investing in an infrastructure supporting patient and public involvement, a key question for the study was whether different communities were actually participating and whether there was any subsequent impact on decision making. PCTs were in fact engaging with different communities, including existing service user and community groups, practice patients and members of the general public. What was perhaps more interesting was that a huge range of different mechanisms and methods, both informal and formal, were identified. Alborz *et al.* (2002) also found that in the absence of formal structures PCGs were developing a mix of activities. Community and user involvement, of course, encompasses a broad range of approaches and methods (McFayden and Farrington, 1997; Wilcox, 1994) and purposes can vary according to the

Building patient and public involvement in PCTs: key findings

- Focus on organizational development as a key building block;

- Champions can drive the agenda and senior level support is important;

- A shared commitment to patient and public involvement can be fostered within the organization;

- Patient and public involvement can be linked into other areas of work such as clinical governance;

- A range of mechanisms are needed to involve patients and the wider public – formal structures and informal processes can be used;

- PCTs need to know what community and voluntary activity is happening in the local area. There is potential to link with other initiatives involving local communities.

Figure 1 Building patient and public involvement in PCTs: key findings

context and underlying values. The findings of this study indicate that PCTs will need to develop a range of mechanisms and utilize different approaches simultaneously as they seek to work with different types of communities, in addition to fulfilling statutory responsibilities to develop patient forums. There appears to be good potential for PCTs to link with other initiatives and partnerships with community representation, such as Healthy Living Centres. PCTs have much to gain from working with other partner organizations in terms of drawing on resources and expertize (Florin and Anderson, 2000). The implication for the development of patient and public involvement is that PCTs need to know what is going on in their local area and be prepared to participate in local initiatives.

Although involvement activities were being developed in the four PCTs, patients and the general public were not routinely and systematically inputting into key planning and decision making processes, although there were many areas where community influence had been felt. This finding could be interpreted as reflecting the scale of changes required and the early stage of development but the issue of translating activity into influence was clearly pertinent. There were genuine concerns raised by interviewees in terms of representation and ensuring that marginalized communities were heard, as well as anxieties about what power sharing would mean for front line staff. These concerns are in effect where debates on the purpose of involvement and issues of power and influence are linked to what actually happens in practice. The potential for these concerns to act as barriers to community involvement has been identified by other studies (McIver, 1999; North *et al.,* 1999). PCTs were set up to represent 'natural communities' but in reality they cover large areas with different localities, ethnic populations and

communities of interest. In addition, there are potential tensions between a community and practice focus (Peckham, 2000). The findings suggest that those working to implement patient and public involvement need to acknowledge the potential problems around representation, and have clarity over the level of participation offered, in order to convince PCT and primary health care staff of its value. There is evidently scope for supporting the extension of community development approaches in primary care (Crowley, 2000; Fisher and Gillam, 1999; O'Keefe and Hogg, 1999) to ensure genuine participation, particularly in communities where social deprivation exists.

A strong theme to emerge from the study was the impact of organizational factors on the implementation of patient and public involvement. The organizational development agenda in PCTs as new health organizations has been enormous and lack of time, resources and infrastructure were clearly having a negative effect as found in other studies (Rowe and Shepherd, 2002; Smith *et al*., 2000a). However, having leaders and other key individuals prepared to support and champion patient and public involvement, subgroups to share responsibility for implementation, and developing good internal communication, as well as a shared vision, were all seen as significant enabling factors despite the presence and pull of other priorities. Attention to organizational development can be seen to be an essential component in building community involvement (Scottish Consumer Council, 1998; Smithies and Webster, 1998). PCTs need to build organizational infrastructure and gain high level support as a prerequisite for patient and public involvement activity. Cultural change is equally important: 'Public involvement cannot be viewed as an add-on to existing work. It must be integral to the ethos of the organization, built into the culture and responsive to both the public's needs and those of the organization' (Scottish Association of Health Councils *et al.,* 1999: 14). Brown (1994; 2001) has argued that the culture and ethos of individual general practices are related to their approach to involvement activities. This study supports the view that organizational responses to the patient and public involvement agenda need to incorporate an attempt to win over 'hearts and minds' as well as implementation of structural changes as the two aspects are linked.

Patient and public involvement requires new skills and many groups of health professionals lack experience of dealing with community groups and members of the public in the context of participatory processes. Lack of expertize and skills have been identified as significant barriers to involvement (Shepherd, 2001; Smith *et al*., 2000b). This study was conducted as part of the evaluation of a team of community involvement workers. Although the role of the team has been discussed more fully elsewhere (South and Green, 2002), it is important to note that access to involvement workers was regarded a valuable resource for the development of the work. Elsewhere some PCG/Ts have employed community involvement workers although specific roles vary (Smith *et al*., 2000a; Wykurz, 2000). While the evidence does point to the need to address support needs, there is insufficient research to draw conclusions as to the relative effectiveness of different approaches. In this context community involvement workers were undoubtedly of great value and PCTs are now employing them from their mainstream funds.

Conclusion

The current patient and public agenda proposes a radical cultural shift in the way the health service operates – 'towards a new model where the voices of patients, their carers and the public are heard through every level of the service, acting as a powerful lever for change and improvement' (Department of Health, 2001b: 2). Whilst this remains a challenging agenda for primary health care, this study has shown that PCTs can make progress in implementing patient and public involvement as a legitimate and significant activity for primary health care organizations. The context was unique but the study has highlighted a number of pertinent issues. The importance of organizational development as a key building block in achieving mainstream change, developing a culture that values the input of different communities and access to sources of expertize are all important. Given the size and diversity within and between PCT areas a range of approaches and mechanisms for patient and public involvement will need to be utilized. Issues of representation, particularly of marginalized communities, are important if PCTs are to engage with all the communities on their patch. While there is no blueprint of how to do

patient and public involvement – there is much to be gained by PCTs sharing good practice and learning.

Acknowledgements

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