

User Involvement in Primary Care: A case study examining the work of one Patient Participation Group attached to a primary care practice in North London

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Abstract

The involvement of patients and the public in the planning of health care is high on the political agenda. However, user involvement in health care remains under-researched and there are few models on which to draw. This case study examined a Patient Participation Group attached to one primary care practice in North London at a time when the transition was being made to Primary Care Groups and Trusts. A combined approach using both quantitative and qualitative research was used to evaluate the work of the group. The usual problems with representativeness were identified, together with the difficulty of attracting new members to the group. The Patient Participation Group members felt that they functioned better when the practice was fund-holding and had difficulty identifying with the concept of the Primary Care Group with its wider remit.

Key words: Patient participation, user involvement, primary care.

Introduction

Democracy has always implied participation in public life, but recently there has been a concerted drive to promote such participation. Croft and Beresford (1996) identified three particular developments over the last 30 years that form examples of attempts to involve people in issues that affect them. Firstly, within the field of urban regeneration in the 1960s, public participation took place concerning land-use planning. Secondly, community development initiatives in the 1970s involved local people in effecting neighbourhood change. Thirdly, the 1980s saw the emergence of user-involvement in public services, initially as a result of self-help groups related to specific services, and new social movements set up by marginalised groups like people with mental illness and with disabilities (Croft and Beresford, 1996).

This article looks particularly at user involvement in the National Health Service (NHS) and describes a study which evaluated the work of a Patient Participation Group (PPG) attached to a General Practice in North London, against the background of a dynamic policy infrastructure.

Literature Review

Traditionally, the National Health Service has provided a system of health care where there has been little public participation (Berridge, 1999); the

role ascribed to users being a passive one with little or no opportunity to exercise 'voice' in the planning of services or 'choice' in treatment (North, 1997). Indeed, Klein (1984) has described the NHS as a 'monument to enlightened paternalism' (p.17).

During the 1970s this approach was challenged when, according to Baggott (1998), attempts were made to improve accountability and patient representation within the NHS through the creation of Community Health Councils and the Health Service Commissioner. However, since the late 1980s there has been a general growth of consumer awareness, supported by the concern of the successive Conservative governments over the lack of choice that was available to consumers of health services. The growth of user-involvement in health services thus has to be considered in the context of government policy and legislative change which has emphasised the role of the consumer (Barnes and Walker, 1996), but also reflected the renewed concern with issues of citizenship and its attendant rights and responsibilities (Beresford and Croft, 1993). A key feature of public services is that they should be accountable to citizens and this increased interest in citizenship took place within the context of a perceived need for service improvement and democratic renewal (Barnes et al, 1996; Prior, Stewart and Walsh, 1995). The publication of *Working for Patients* (DoH, 1989), the *Patient's Charter* (DoH, 1991) and the passage of the NHS and Community Care Act in 1990 all served to emphasise the need to consult with, and involve, service users regarding the level and nature of

services available to them. During the 1990s, a series of initiatives aimed to involve the users of health services much more in their planning and delivery. In particular, in 1992, health authorities were urged to consult users in planning and monitoring services in the document *Local Voices* (NHSME, 1992) in order to help make services more responsive to local needs. While Cooper et al (1995) acknowledge that health authorities did employ a wide variety of methods, including postal surveys, opinion polls, focus groups, and community panels, they argue that Local Voices initiatives were used to consult the public, rather than to enable them to participate more actively in decision making. They claim that there was little shared understanding of the public's dual role as both patient/consumer and as citizens. By 1993, Beresford and Croft were able to claim that it was no longer a case of whether people should have a voice in local life and service, but how this was to be achieved.

The importance of greater public and patient involvement in decision-making in the NHS was further reinforced in the NHS Executive guidance document *Patient Partnership: Building a Collaborative Strategy* (NHSE, 1996). This document proposed that work needed to be undertaken in the areas of information for health service users, helping users to develop the necessary skills for working in partnership, supporting staff in achieving partnership and evaluation of effective mechanisms for patient partnership (McIver, 1998). McIver describes two main justifications for involving the public in service development issues: firstly, as taxpayers, they have a right to have a say in how their money is spent and secondly, lay people bring a unique and valuable perspective. For example, Tranter and Sullivan (1996) describe the assessment of need for palliative care in a rural area during which it was identified that professionals were concerned with the structure, e.g. beds and buildings, while users and carers were concerned with process issues, e.g. access, information and support groups.

The desire to involve the public has spanned changes in government (Brown, 2000; Milewa, Dowswell and Harrison, 2002) and Barnes and Evans (1998) claim that one of the overarching aims of the present Labour government is to

rebuild confidence in public services: action is being taken to open up decision-making processes and find new ways of including citizens in the planning and provision of public services. This led Harrison, Dowswell and Milewa (2002) to describe public and user involvement in the NHS as a "central plank" of government policy with the intention that the voices of patients are heard through every level of the service, promoting change and improvement. The White Paper, *The New NHS Modern, Dependable* (1997), described the changes that were to be made to bring this into effect.

The purpose and vision of the *NHS Plan* (2000) includes a health service 'designed around the patient' (p.10). According to this plan, patients are to be given new powers and influence in their care and the development of local services. This will be operationalised by various initiatives extending from advocates in every hospital, to representation throughout the NHS, for example, with a local advisory forum in each Health Authority area and increased lay membership on professional regulatory bodies.

The focus on user involvement has been given further expression in a series of government documents. For example, *Shifting the balance of power within the NHS* (Department of Health, 2001a) is the programme of change that aims to empower frontline staff, who understand patients' needs and concerns, and patients and local communities, by creating a new culture in the NHS that puts patients first. A main feature of this document has been to give Primary Care Trusts (PCTs) the role of running the NHS and improving health in their areas. These PCTs will have Patient Forums. *Involving patients and the public in healthcare: a discussion document* (Department of Health, 2001b) addresses the progress made towards creating a 'patient-centred NHS'. Proposals are also made to enshrine the Government's patient empowerment agenda in law (via the Health and Social Care Act 2001) and create new bodies for patient representation.

Drawing on the experience of social work, Barnes and Walker (1996) describe two models of user involvement: firstly the consumerist model which offers users a choice between products.

Conservative policies towards user-involvement without doubt pursued a consumerist approach. As Greenwell (1996, p142) points out, under the 'consumerist' model there is *'no duty of active involvement laid on the consumer of health services, other than to obtain for themselves the best provision'*. Secondly the empowerment model involves users in the development, management and operation of services as well as in the assessment of need. New Labour, arguably, has adopted a more democratic approach. According to Greenwell, in a democratic partnership model, *'there is an implied responsibility given to the patient, and to the community of potential patients, to contribute to the partnership as a citizen willing to sustain adequate service provision'*. So, while rights of citizenship were initially presented as rights of individual consumers (Prior, Stewart and Walsh, 1995), under New Labour and Third Way politics, the rights of citizens are balanced by obligations amid the desire for a more active civil society. However, Banks (2001) argues that current government policy is still very much about patients rather than wider citizen involvement.

User involvement and general practice

General practice forms the central point of activity of first level health services in the United Kingdom (Brown, 1999). Patient Participation Groups have a long history within general practice (Banks, 2001), the first PPGs having been initiated by doctors in the early 1970s in different parts of England and Wales (Wood, 1984; Brown, 2000). From their commencement, these groups have taken many different forms and have had different aims and activities (Wood, 1984; Brown, 2000), though Banks (2001) claims these activities tend to focus on fundraising, patient education and the day-to-day operation of the practice. The idea common to all such groups is that a group of patients should meet together regularly with the doctors and other practice staff with the aim of improving communication and services (Wood, 1984). The intention has also been that the group of patients should be representative of all the patients registered with the practice. The National Association of Patient Participation Groups was formed in 1978 and the numbers of such groups have grown (Wood, 1984). Brown (1999) describes a survey of all known PPGs carried out by Richardson and Bray in 1985. These

researchers found that the groups tended to be associated with larger practices and were mostly initiated by a doctor; participants in the groups pointed to the difficulties of widening participation beyond the usual members; it was found that most patients were probably unaware of the existence of the groups. Brown (2000) carried out his own study of the level and type of activity used to involve the public in general practice in a city district in the north of England. The study revealed that levels of activity were generally low and only a small minority of general practice teams had undertaken a range of activities to involve the public. Pressures of existing workload, lack of resources and public apathy were given as among the main obstacles by respondents.

Aim of the Study

The aim of this study was to evaluate user involvement in a North London General Practice, which had a longstanding Patient Participation Group. Primary research questions were based on the model of Barnes and Wistow (1992):

- Which users were involved?
- How were users involved?
- What was the outcome of involving users?

Methods

A case study with a combined quantitative and qualitative approach to data collection was undertaken in order to acquire breadth and depth of information.

Data Collection

Practice database

The demographic characteristics of the patients registered with the practice, in terms of gender and age, were identified from the practice database.

Survey

A postal survey of 500 patients, selected by a process of random sampling, sought to examine:

- Levels of awareness of the existence of the user group
- Levels of awareness of communication systems within the practice

- Perceptions of the role of the user group
- Levels of willingness to become involved in the user group
- Factors influencing the likelihood of becoming involved in the user group

The data were analysed using the SPSS package.

Non-participant observation

Two researchers attended a user group meeting. An observation schedule was drawn up in advance, based on what the literature suggested might be 'user group' activities. Throughout the meeting the two researchers worked independently and recorded each time one of the group members undertook a pre-defined activity.

Semi-structured interviews

The interview schedule was constructed around key themes identified in the literature on user involvement, and the local issues that emerged during the non-participant observation. Semi-structured interviews were conducted with seven involved users, drawn from PPG members. The twelve members of the PPG were all asked if they would participate in the study and seven agreed to be interviewed. Of these seven volunteers, three were men and four women; six were between the ages of 46 and 65 years and one was over the age of 65 years. A purposive sample of seven key informants was selected from the practice staff, and all agreed to participate in the study. The sample was chosen to include medical, nursing and administrative staff and to include the Senior GP and the Practice Manager, who had been involved with the PPG since its inception; some of the other informants were more recently employed by the practice. These interviews allowed the exploration of several key issues related to the involvement of users:

- The roles and responsibilities of users
- Relationships between professionals and users
- Relationship between involved and non-involved users

The proposed interview guide was initially piloted on one selected member of the PPG and of the practice staff. The interviews were carried out by members of the research team who were not known to the interviewees. All interviews were

audiotaped and fully transcribed. Miles and Huberman's (1994) systematic approach was utilised as a framework for content analysis of the interview transcripts. In order to demonstrate methodological rigour (Sandelowski, 1986; Bowling, 1997) it was recognised that such an explicit and systematic method of data analysis was required. Two main strategies to ensure credibility and dependability were used:

- The interview schedule was peer reviewed
- Content analysis of the interview transcripts was carried out independently by three researchers

Ethical Issues

The Local Research Ethics Committee approved the research. Confidentiality and anonymity of the practice population database was maintained in accordance with the Data Protection Act (1998) utilising the following strategy:

- A member of the practice administration team, with access to the database, was employed to provide administrative support to the research team.
- The random sample of the practice population was drawn, by the practice staff member, from the database and a mailing list constructed.
- The research team prepared and packaged the questionnaire, research information sheet, and return stamped addressed envelope into a blank stamped envelope to which the practice staff member attached the mailing label, thus ensuring that no member of the research team outside of the practice had access to information held on the practice population.

Results

• Which users were involved?

The Practice database was used in order to assess how well the members of the PPG represented the practice population. A profile of the members of the group was compared with the demographic characteristics of the practice population. In terms of gender the PPG adequately represented the practice population with there being slightly more females than males. However, when looking at age

distribution of the practice population it is clear that it is not fully represented by the PPG, whose members were over 46 years old, in contrast to the practice population, in which the largest group are aged between 26 and 45 years of age. It was not possible to describe the ethnic profile of the population as only patients registered in recent years had their ethnic background recorded.

- **How were users involved?**

A postal survey of 550 randomly selected patients registered with the practice resulted in the return of 175 completed questionnaires (35% response rate). This was achieved by a second mailing of the questionnaire to all respondents. This low response places limitations on the results of this study. Forty eight per cent of the respondents were male and fifty two per cent were female; these percentages are similar to those of the wider practice population. All age groups were represented in the respondents, though there were fewer responses from the younger age group (18 – 25 year olds), and the older age group (65 + years old) was over-represented (see Figure 1).

Figure 1: Ages of respondents and practice population

Age group	Percentage of practice population	Percentage of survey respondents
18 – 25 years	19%	8%
26 – 45 years	39%	34%
46 - 65 years	27%	30%
65 + years	15%	28%

All socio-economic groups were represented with the largest group drawn from the intermediate class. Seventy four per cent of respondents identified themselves as British, with the remaining twenty six per cent identifying themselves as belonging to a range of minority ethnic groups. However, as the practice database did not include information on socio-economic group or ethnicity it was not possible to compare the survey respondents to the practice population in respect of these variables. Further, as the initial sample for the survey was identified by the practice staff it was not possible to make comparisons between the sample and the respondents.

Awareness of the existence of the PPG

Respondents were asked about their awareness of the existence of the PPG. Fifty-eight (33%) respondents acknowledged awareness of the existence of the PPG with no detectable patterns of awareness according to gender, class or ethnicity. None of the respondents were members of the PPG. Most of these patients who knew of the existence of the group gained their information from either the notice board in the medical centre or from the newsletter circulated by the PPG.

Perceptions of the role of the PPG

Respondents were asked what would encourage them to become involved in the PPG and multiple choices were offered. Eighty-seven (50%) indicated that it would be useful to represent the patients' view, 69 (39%) saw it as an opportunity to influence change, 61 (35%) to have an opportunity to learn how the practice works, 48 (27%) because they would have a say in decision making, 42 (24%) to be able to help others. Seven (4%) provided other reasons which included making patients feel they matter and to provide more help for staff.

Factors preventing involvement

Respondents were then provided with a list of factors that might prevent their involvement with the PPG and were asked to indicate those that applied. Eighty-three (47%) indicated that paid work was the main reason for lack of involvement with the PPG. Sixty-four (35%) gave family commitments as their reason, 35 (20%) indicated that they felt they had not much to offer, 18 (10%) indicated a lack of interest and 8 were too busy due to voluntary work.

Role of PPG

Various themes concerning the role of the PPG were identified:

- **Benefits of PPG for patients**

The PPG was seen as a forum where patients' views could be presented to the practice, as way of improving communication between patients and doctors and as a way for patients to gain understanding about how the practice operates, and as a way of implementing change.

- **Benefits of PPG for practice**

The PPG was seen as a way of raising doctors' awareness of patients' needs, as improving the management of the practice, as a way of improving communication between doctors and patients and as a way of making patients more tolerant.

- **Non-participant observation of PPG**

Two researchers observed a bi-monthly evening meeting of the PPG. Seven members attended, six lay members (including the Chair of the group) and a practice representative. Issues were raised by members of the group and these included items arising from the PPG members' direct experience of care, a decision to record all patient consultations on a computer and the availability of services. There was some comment on the issue of communicating with the wider practice population, the focus of this being mainly via a newsletter produced by the group. All matters were directed at the practice representative who responded at length, and had a good relationship with the lay PPG members. Only one issue was raised which derived from the wider practice population and this was raised by the practice representative.

- **What was the Outcome of Involving Users?**

Three main themes emerged from the semi-structured interviews with members of the PPG and practice staff, the same interview guide being used for both groups of informants.

- **Evolution of the group over time**

The interviews revealed that both group members' and practice staff's perceptions of the purpose of the PPG had changed over time. The introduction of GP fundholding had required GPs to involve patients more in delivery of health services through user participation groups. This was perceived by the PPG to be the time when the aims and purpose of the group were most clearly focused. With the change to Primary Care Groups and Primary Care Trusts the purpose of the group changed and came to be perceived by both user group members and practice staff as lacking in direction and clarity. Areas of participation and involvement in the practice were thought to have receded with the removal of fundholding status, motivation had consequently decreased, also any sense of power. The following quotation from a member of the

practice staff summarises the situation:

"So I think its changed a bit because when fundholding was in they had a lot more areas they were covering. But now it seems to have dwindled to a more elderly sort of patients' group."

(Staff member 2A)

- **Engagement difficulties**

Group members and practice staff stressed the difficulties encountered in engaging the wider practice population, both in actual participation in the group and in giving feedback on current group activity. This particularly relates to people from minority ethnic groups and the younger members of the practice population, as captured by one of the members of the PPG:

"The younger generation, like 30s, you need more people to get feedback from them ... which would have been nice but you don't know how to get them, how you get them into these things."

(Group member 2B)

"You find the same people work tirelessly."

(Staff member 7A)

- **Benefits of involvement**

Both practice staff and members of the PPG identified a number of ways in which involvement in the group was beneficial. Members of the PPG claimed to have enhanced their knowledge and understanding of how the NHS works through involvement with the group, as well as personal satisfaction; some expressed a sense of altruism in being able to "put something back into the community" (Group member 6B).

"I felt that I was giving my spare time perhaps to encourage other people to benefit from the group."

(Group member 4B)

Both PPG members and practice staff were able to identify positive contributions to practice in terms of fundraising and a means for bringing users' views to the attention of the staff. This had notably been achieved when users' views were elicited in relation to the design and planning of the new

surgery and also contributed to a review of the appointment system which had made access to services more user friendly. The practice staff saw this as a valuable means of communication with the practice population:

“So patients could their voice could be heard. Their views would be brought and discussed and heard by that team.”

(Staff member 1A)

Discussion

Representativeness

The members of the PPG were not representative of the practice population in terms of age and the group members raised this concern themselves, as well as the need to engage members of minority ethnic groups. One of the problems of attempting to involve users of services in their planning and delivery is that of representativeness. Jewkes and Murcott (1998) take up this issue in the context of seeking representatives for ‘Health for All’ steering groups. ‘Community representatives’ were often drawn from people of higher income, education level and occupation group than average. Beresford and Croft (1993) argue that it is essential to make specific provision to involve members of minority ethnic groups in such activities as they are unlikely to respond to general initiatives. Anderson et al’s (2002) research into user involvement in primary care organisations found that initiatives to engage ‘hard-to-reach’ groups involved a variety of activities ranging from targeted outreach to interpreters.

Coulter (2002) raises questions concerning the representativeness of the proposed Patient Forums as many of the existing patient groups represent patients with specific diseases. However, Barnes and Evans (1998) claim that it might be preferable for multiple user groups to be involved when decisions are made about different services. Coulter (2002) further warns that while patients want providers to listen to their views, the scope for active participation might be small. This issue is taken up by Litva et al (2002) whose study looked at the public’s preferences for being involved in particular types of participation. Their informants indicated that the public should be involved in decision-making but only in terms of informing the decisions made by professionals,

with a reluctance to share the responsibility for decision-making.

Pattison (2001) claims that some users will find ‘user groups’ unattractive due to discontent both with process and outcome and concern has been expressed (Coulter, 2002) that Patient Forums may be too close to Trust management. Rowe and Shepherd (2002) note that responsibility for acting in the public’s interest has shifted from medical professionals to health service managers. The providers of health services are charged with the responsibility of providing services that reflect their patients’ needs and at the same time the responsibility of increasing efficiency and cost-effectiveness. Public participation might thus serve the purpose of management (Rowe and Shepherd, 2002). Harrison and Mort (1998) suggest that health authorities appropriated the language, and implemented the mechanisms of public participation, in order to legitimise their decisions. While managerial and professional respondents were in favour of user involvement in general, some questioned the legitimacy of user groups: all managers and professionals employed tactics to ignore the outcomes of user involvement, yet some made use of their opinions to support one or other manager’s or professional’s preferred course of action against that of another. Harrison and Mort concluded that the local managers remain in control and that user groups may have an important function in informing, education, influencing, even in improving accountability, but have not yet been successful in changing, determining or shaping policy. A study of user involvement in Primary Care Groups (PCGs) and Primary Care Trusts (Milewa, Dowswell and Harrison, 2002) suggests that health service managers and practitioners continue to exercise considerable influence in comparison to that of patients and citizens.

Engaging people in the work of the PPG

There was a general lack of awareness of the existence of the PPG. Paid work was a factor in preventing people from becoming involved in the work of the PPG. This points to the need for resources identified by other authors (Beresford and Croft, 1993; Brown, 2000). People need time as well as space, skill and support in order to become ‘involved’ users of services.

Conclusion

Banks (2001) notes that PPGs have traditionally confined their activities to fundraising, patient education and the daily activities of the practice. Such findings were echoed in this study. As the focus for providing health care shifted from the fund-holding practice to a PCG, PPG members lost their motivation and were unable to identify with the PCG. Primary Care Groups were required to have a lay member on their boards, hold open meetings and develop forms of public involvement. Brown (2000) has identified the challenges faced by PCGs in developing public involvement. Noting this challenge, Anderson et al (2002) have considered the activities of six London primary care organisations in relation to involving the public. They found that public involvement is not easy and refer to a lack of resources with a continuing focus on short-term initiatives rather than long-term support. These authors warn that PCTs are in danger of becoming distant corporate bodies, remote from local people, though they are required to have Patient Forums. The remit of PCTs is no longer limited to practice based patient participation but now involves local communities. Harrison, Dowswell and Milewa (2002) claim that there is a distinction between current service users (consumers or patients) and the general public (citizens), who are likely to have different interests. There is a need to work towards facilitating the sense of loyalty that PPG members felt towards their practice within the wider scope of the local community, also to foster the sense of altruism, and also a sense of power, that some of these members expressed. It is also clear that resources are necessary, such as time and training, if public involvement is to move beyond informing decision makers to devolving power to local communities.

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