Involving Patients in Primary Care: Lessons for Primary Care Organisations

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Abstract

This article reports the results of a national postal questionnaire to Chief Executives of Primary Care Organisations (PCOs) in England and two in depth case studies of public involvement in decision making in primary care organisations. The case studies took place in Trent Region. The study is placed in the context of the development of public involvement in decision-making in the NHS. The national survey revealed a high level of commitment to public involvement, and significant efforts to involve the public were being made but there was little evidence of clear strategic policy. The case studies identified considerable activity related to public involvement in both PCOs, and again little evidence of written strategies or policy to direct the activity. Findings indicated that success in engaging the public was greater where attempts were made to work in partnership and build longer-term relationships. Despite this, PCOs were undertaking a substantial amount of public meetings and events to inform the public. There appeared to be a lack of a strategic approach to public involvement, which could undermine the evident enthusiasm of PCOs and the public.

Keywords: patient participation, user involvement, primary care, public participation

Background

Debates about the need to involve patients and the public in decision-making in the health services are not new. The growth of the patient and user movement from the mid 1980s and concern about the perceived democratic deficit in the NHS post the 1990 reforms have gradually strengthened interest in the issue. As Beresford and Croft (1993) eloquently stated:

> *A powerful idea is gaining ground. People have a right to a say and involvement in the services they use, in the neighbourhood where they live and in the institutions that affect them*
>
> (1993)

The rise of pressure for individual patients and groups of patients to have some level of influence on the delivery of health services has been supported by a series of directives from the Department of Health (DoH) starting with the 'Griffiths Report' (DHSS, 1983) which argued that the NHS had to recognise and respond to the needs of its 'customers'. How patients and the public should be involved has been a matter for debate. Rhodes and Nocon (1998) propose two possible models; an 'advocacy' model where the public have the opportunity to become actively involved in decision making contrasted with a 'consumerist' model which emphasises rights to redress and choice in the services an individual uses. Different approaches to the 'advocacy model' are discussed by Barnes and Evans (1998) including direct

participation of users in service developments and more effective systems for ensuring public scrutiny and accountability. The introduction of market principles through the White Paper 'Working for Patients' (DoH, 1989), cast recipients of health care as consumers in an economic sense. This concept of health service users as consumers was reinforced by 'The Patient's Charter' (DoH, 1991), and the policy document 'Local Voices' (DoH, 1992), emphasised the need for health authorities to make services more responsive to patients through consultation processes.

The discussion document 'Involving Patients and the Public in Healthcare' (DoH, 2001), further reinforces the role of public involvement in decision making in the NHS. It describes a vision of '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 (1997) guidance and onwards has explicitly required PCOs to have clear arrangements for public involvement and made open Primary Care Group and Trust board meetings mandatory. In many ways it could be argued that the whole concept of PCOs is to facilitate the development of local health services with the maximum input and support of the local community, staff and, perhaps most importantly, service users. So how and what are they doing?

Anderson and colleagues (2002), in their report on similar work in London, emphasise how public involvement is value driven; people and organisations do it because they believe in the process. They state that partnership approaches to public involvement have many benefits as

expertise, knowledge and resources can be shared. They make the point that sustained initiatives need corporate commitment. Milewa and Harrison (2001) provided evidence that a high proportion of Primary Care Organisations could demonstrate some sustained consideration of public and patient involvement in their work. The question is how effective are PCOs in involving the public in their decision-making processes and how clear are they about what they require from the public?

This paper reports on an 18 month case study of a rural and an urban PCO undertaken by the University of Sheffield in conjunction with North Derbyshire Health Authority into the nature of public involvement undertaken by PCO and considers how these organisations can best employ their resources in this area. To place the findings in a national context the study was supported by a postal survey of all PCOs in England.

Definitions: Level of Involvement

The requirement to 'involve the public' can be interpreted very widely. Drawing on the concept of a ladder of increasing power proposed by Arnstein (1969) public involvement in health services can be considered as a continuum (see box 1) from information provision through consultation

Box 1: Continuum of involvement	
Manipulation Therapy	Non-participation: e.g. people on 'rubber stamp' committees for the purpose of educating them or demonstrating their support for decisions that they can't influence
Informing Consultation Placation	Informing the public of their rights, and options, and seeking their opinions and inviting individuals onto the boards of public bodies can be the first step to legitimate participation. However these are not true participation as views are sought which may or may not be taken into account in the final decision.
Partnership Delegated power Citizen / patient control	Degrees of citizen power: power delegation in which part or all of the decision making is devolved to local people

and partnership to degrees of delegated power. Arnstein developed the hierarchy to describe the degrees of citizen participation in Community Action Programmes in the late 1960s in the U.S.A and argued that there is a critical difference between going through the empty ritual of participation and having the real power to affect the outcome of the process.

Definitions: Success of Involvement

The research literature emphases the importance of good preparation including consideration of the aims, methods, resources and required outputs before launching into attempts to involve the public (Chan, 2000; Barker et al, 1997). Three criteria were therefore taken into consideration in assessing the case studies: was there evidence of a planned strategic approach to attempts to involve the public, what level of involvement was achieved and was there evidence that this had any impact on PCO policy or practice?

Local Case Studies

Methods
We studied two PCOs in the former Trent Region for an 18 month period from the summer of 1999 focussing on initiatives, lead by the PCOs, which had the aim of involving the public. One PCO covered a large predominantly rural area, the other a deprived inner city area.

Case studies offer a holistic research strategy for investigating phenomena within their real life context (Robson, 1993; Yin, 1994; Stake, 1995). Within each case study multiple methods, sources of data and levels of analysis are required to strengthen reliability, validity and the possibility of generalising from the findings (Barlow and Herson, 1984; Sandelowski, 1996). Thus in this study qualitative and quantitative data were collected in different ways from a range of sources:

(a) Semi-structured interviews were held with PCO staff; and with a range of stakeholders related to specific initiatives identified for each PCO

(b) PCO meetings and public meetings were observed and documents of meetings were examined

(c) For one of the case study initiatives a postal questionnaire survey of the community involved was undertaken.

Semi-structured interviews were held with PCO staff to explore attitudes to public involvement, to gain an understanding of the range of initiatives undertaken and to identify any impact on PCO practice or policy. Semi-structured interviews, and in one case a questionnaire, were employed with other stakeholders involved in identified initiatives (e.g. PCO subgroups, community groups and residents of an estate). These were intended to clarify the scope of the initiative, and to identify their perceptions of the issues raised and the extent to which these had been addressed by the PCO. The questions for the interviews and questionnaire were derived in discussion with the study advisory group. The advisory group comprised a sociologist with experience of researching the area of public involvement, two members of a PCO, two members of local Community Health Councils and a former Health Authority Manager. The interviews with PCO members were held at two points in time with one year in between. The issues covered in the two interviews with PCO staff included the following in relation to public involvement in their organisation: - existence and development of a formal policy; aims and expectations for the coming year (1st interview) and then progress against these expectations (2nd interview); importance of involving the public; issues which they perceived as being important to involve the public with and ones which were considered to be inappropriate; specific activities and initiatives planned or in progress; lessons learnt; resources available staff skill; barriers to implementation; impact on the organisation; the roles of lay members and other PCO members and implications for new PCOs. Eight board members from each PCO were interviewed. The interviews lasted between 30 minutes and one hour and were tape recorded and transcribed. A thematic analysis was employed paying attention to the main themes as identified by: regularity with which they came up, paying attention to disconfirming cases (where individuals didn't confer on an issue); importance that individuals ascribe to them and, in the case of the interviews with PCO board members, disconfirmation between first and second interviews for the same individuals. Thematic

analysis is a well established method (Leninger, 1985; Talor and Bogdan, 1984). We used a simplified approach to a pragmatic method described previously (Aronson, 1994), identifying themes from direct quotes or paraphrasing from the interview transcripts. Related issues were combined into sub-themes and our interpretation was fed back to the interviewees for validation.

PCO meetings were observed and documents related to these meetings were scrutinised to elicit: level of interest/importance apparently attached to discussion of items related to public involvement; how often such issues were raised and by whom; whether the discussion was noted in records and whether the issues were followed up. Meetings arranged by the PCO for the public and records of these meetings were scrutinised to elicit, for example: numbers of attendees and whether these were members of the public or representatives of organisations; nature of meeting (e.g. one off open public meetings or meetings with specific groups as part of on-going exchange); response to and follow up of issues raised.

Results
Both PCOs had undertaken a number of initiatives to involve the public in the first year of their establishment although neither had produced a comprehensive written strategy. Interestingly, all the board members interviewed had taken part in some of the public involvement work, and the responsibility did not rest solely with the lay member. Apart from issues affecting individual patients and staff, board members saw few issues that should not be in the public domain. Both PCOs had held public meetings as part of their consultation on the proposed move to a PCT. The Health Authority had led the process for the city PCO. PCO board members voiced concerns about the level of public consultation achieved. For the rural PCO, the PCO took the lead in collaboration with the Health Authority and the local Trust. One meeting had been attended by about 50 people, which included service users as well as representatives of groups.

Board members in both PCOs identified barriers to involving the public. One was the limited time and skills available to carry out the work. Engaging the public's interest unless it was a topic of direct

concern to them was perceived to be another important obstacle.

The City PCO

There was consistency between interviewed members of the city PCO that public involvement was a key priority for the organisation. No dedicated resources were made available to the issue of public involvement at the start of the work. However, at a later stage, staff with experience in this field were transferred from the local district health authority to the PCO. Work was delegated to a public and community participation subgroup of the board. The area already had a well-established network of community and voluntary organisations, and the PCO had participated in some activities involving the public that were led by members of this network. The PCO itself had:

- Held three public events to raise awareness about coronary heart disease and consult on related services;
- Produced an annual report available in Braille and in ethnic minority languages;
- Produced a newsletter
- Established a community health advisory group with patient representatives from local practices and community groups

Most of the activities that had been initiated by the PCO were at the level of information provision to the public or information exchange between members of the public and the PCO. These would in the main therefore be classified according to Arnstein's as non-participation. However the liaison with the community health advisory group on issues of concern to both the PCO and its members would be classified as 'consultation'. At the time of the case study it was too early to say where this activity had influenced PCO practice or policy.

Although the principles of public involvement had been agreed at a board level, there was no written plan for how that may be implemented or what the intended outcome was. In the interviews with PCO members coronary heart disease was identified as a priority for the PCO and the public events organised had addressed this area. However, there were difficulties in venue, timing and publicity.

Issues raised by attendees at these meetings were given respectful consideration and were documented. However, although there was some follow up of issues raised at these public events there were no discernable changes in practice or policy apart from those related to the process of involving the public in the future. This was generally attributed by PCO members to lack of resources and more pressing priorities, such as establishing the PCO structure and dealing with issues like prescribing overspends. This again would be classified therefore as consultation and not true participation.

The Rural PCO

The rural PCO had taken a number of initiatives to involving the public including information provision, developing formal and informal communication networks, holding public forums and focusing on community participation. In particular it had:

- Made efforts to increase awareness of the PCO through production of a newsletter and worked at the community level, developing joint partnerships and links with community organisations.
- Undertaken a consultation process in partnership with a local community, for residents of a housing estate in a deprived area to identify and address the community's concerns. This had developed into a longer-term collaboration with members of the community through creation of a multi-agency working group involving residents.
- Developed formal links with local community groups: - members of a local planning group were attending board meetings on a rota basis. A link had been developed with the local maternity services lay committee that included recent users of maternity services, as part of a review of local maternity services.
- Worked proactively at establishing more systematic links with local communities. For example, attempts were made to facilitate patient participation groups at some local practices. Two were already in existence. The PCO was also assisting the development of a local Council for Voluntary Service.

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The majority of the work undertaken by the rural PCO was targeted at the level of what might be considered as working in partnership in that members of the public or specific community groups were involved in groups and meetings with PCO members on an on-going basis. Relationships between these groups were developing. However, this is not partnership as envisaged in Arnstein's model but a form of consultation as there is no delegation of power and all decision-making remained with the PCO. In the words of one resident 'In the past people used to come into the area and told you what was needed. Now they come in and ask what is needed.' Even at this level it was obviously a challenging experience for members of the PCO. One member commented on the process that '…you've really got to take on board what people are saying and it's part of the decision making process and you can't ignore this… it's a bit of a shock to actually take this on board.'

There was some evidence of public involvement activity influencing PCO policy and practice. The consultation exercise with residents, resulted in support in principle by three local GP practices for the residents' main request, primary care facilities located on the estate. Options for resourcing this were being explored and proposals were being developed for a public health nurse to be based on the estate. These developments took place through the on-going multi-agency partnership and in interview one of the PCO members remarked that that without the ongoing commitment the PCO would lose its credibility. This was the clearest example of an attempt to involve the public resulting in a change in PCO policy with a likely future impact on service delivery and would have met Arnstein's classification of participation.

Discussion
Both PCOs had devoted appreciable time and effort to involving the public in some of the key decisions they had to make. There were no attempts in either organisation to devolve power to groups of users or the public and control of decisions was maintained firmly with the PCOs. The majority of the activity was at the level of 'informing' or 'consultation' with no clear evidence of influence on PCO policy apart from on policy related to how the process of involving the public may be carried out in the

future. However, there was at least one example where an attempt to seek the views of a specific subgroup of the public (residents of an estate) had influenced PCO policy and practice. This outcome had been realised, after several months through an on-going relationship with the representatives of the community within a multi-agency partnership group. There was also an attempt in the other PCO to establish an ongoing dialogue with patient representatives from each practice and local voluntary organisations about health policy issues. However it was too early to judge the success of this initiative on influencing policy.

Although both PCOs had formulated some policy on public involvement issues neither had formulated policy relating to the level of public involvement that was intended or to the outcome expected from public involvement work. Neither had a clear implementation plan or strategy that addressed issues of capacity, skills or resources. This was despite these issues being identified as possible barriers to involvement and in hindsight being considered by members of the PCOs to have hindered the ability to effect change.

Success of involvement was measured in terms of the level of engagement of the public and evidence of influence on PCO policy or practice. Success in both respects was greatest where the PCOs had been able to create on-going involvement with communities or groups. The community consultation exercise and on-going partnership resulted in a policy of trying to deliver primary care services closer to the community and some steps had been taken to address this aim.

National Perspective

Method
To obtain a wider perspective on public involvement we carried out a postal survey of all PCOs in England (486) in the summer of 1999. The questions were derived in consultation with the advisory group and addressed similar themes to those included in the semi-structured interviews carried out with PCO members. We had a 45 per cent (n=218) response rate. Data were analysed using SPSS software to identify statistically significant differences between the sub groups.

Results

Virtually all respondents (96.8%) identified at least one issue that they thought it would be important to consult the public on in the coming year. The issues raised most frequently are given in Table 1.

Table 1. Key issues considered important for public consultation (n=218)

Issue	Number of PCOs (%)
Change from PGC to PCT status	76 (34.9)
Health Improvement Plans	67 (30.7)
Acute services – current services & service development	45 (20.6)
Service development –mental health	24 (11.0)
Primary care investment plan	21 (9.6)
Primary care development – general	20 (9.2)
Rationing / Prioritising	18 (8.3)
Health Living Centres /Sure Start	16 (7.3)
Service development: Community services	12 (5.5)

In answer to the question of whether there were any topics on which it would not be appropriate to consult the public 49 (22.5%) replied that there were none. A further 12 (5.5%) replied that none had been identified 'as yet'. Other frequent responses are given in Table 2.

Table 2. Key issues identified as being inappropriate to consult the public on (n=218)

Issue	Number of PCOs (%)
None	49 (22.5)
Matters confidential to practices or the board	16 (7.3)
Performance management	14 (6.4)
None as yet	12 (5.5)
Any issue where change is not possible or where the decision is imposed on the PCO	13 (6.0)
Payment of staff	11 (5.0)

The range of methods employed by PCOs to obtain the views and interests of the public included almost the whole range of approaches available for obtaining public opinion from surveys, focus groups, roadshows and public meetings to recruitment of dedicated staff and development of multi-agency initiatives. The most frequent responses are given in Table 3a.

Table 3a. Main methods used to identify the views and interests of the public

	Number of PCOs (%) employing this method
Open Board meetings	211 (96.8)
Formal links with user groups	152 (69.7)
Written information	145 (66.5)
Occasional meetings	137 (62.8)
User representation on the Board	116 (53.2)
Regular meetings	111 (50.9)
Surveys	87 (39.9)
Open public meetings	83 (38.1)

Table 3b Other methods identified by respondents

Method	Number of PCOs
Multi-agency initiative	21
Newsletter	10
Website forum	9
Roadshow	9
Locality based meetings	8
Links with Community Health Council	7
Employed project worker /staff	7
Stakeholder conference	6
Public participation working group	6
Health panel	6
Press release	5
Health forum /participation group	5
Others	24

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Only 32 per cent of PCOs had a written policy for public involvement in place though, for a further 40 per cent a written policy was in preparation.

The questionnaire also asked for any general comments on involving the public in decision-making. Ninety respondents took this opportunity to give their views. The most frequent comment was that it was 'difficult'. Other frequent responses are given in Table 4.

Table 4: Most frequent issues raised in open question: 'Any comments on involving the public in decision-making'

General theme	Frequency of response
It is difficult	22
A priority for the PCO	8
Lack of resources	8
A clear purpose is needed	7
Public need to be supported to achieve this	7
Multi-agency approach recommended	7
The lack of public interest is a problem	6
It is time consuming	6
PCO have a role in education of the public	5
Desire to do it properly	4
Query about the right way to go about it	4
It is stimulating	4

The considerable amount of activity in this area within the first year of creation of PCOs, despite the effort required simply to establish the organisations, and the relatively good response rate to our questionnaire are indications of the importance PCOs placed on public involvement. However, the findings show that activity is preceding development of clear strategic policy.

Conclusions

At the time the research was carried out it was very clear that public and user involvement was a major theme underpinning health policy in the UK. It was also clear that many PCOs were working hard to develop public involvement initiatives and indeed were proving to be imaginative in their approaches. Few PCOs appeared to have a documented strategic approach. It appears from evidence from two case studies that arrangements where the public are involved as partners in initiatives sustained over time are more likely to impact on PCO policy and practice. The success may have been due in part to the involvement of a number of other local organisations and their involvement may also have provided resources and skills additional to those held within the PCO.

The authors therefore recommend that PCOs need to develop a more strategic approach to involving the public to avoid undermining the enthusiasm of both the health care professionals and the public for these types of initiative. Without a more focussed approach there is a danger that public involvement initiatives will both disillusion the participants and divert resources from patient services without any discernable benefit.

For PCOs intending to undertake this type of work it is suggested that they consider the following issues:

- What questions do we wish to answer and which elements of the public are best placed to answer them?
- What will we do with the information we receive from the public? How will information be fed into the decision making process?
- How will the impact be demonstrated or measured?
- What level, for example on Arnstein's ladder, of involvement is intended?
- How can initiatives be sustained and developed as part of a continuing dialogue?
- Can lessons be learnt from experience elsewhere? There is a substantial body of valuable literature available that should be utilised (CHEPAS, 2000; Wensing and Elwyn, 2003).
- Have the questions already been asked by other organisations?
- What skills and resources are required and how will these be found?

- Can the two prior questions be addressed through working with other agencies?
- What level of priority does this activity really have in relation to other PCO responsibilities?

Note on Terminology

At the time this research was carried out both case study organisations were Primary Care Groups. PCOs surveyed were in transition from Primary Care Groups to Primary Care Trusts. This research has implications for PCOs today. Therefore, for simplicity, we have used the term PCOs throughout.

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