A 'Third Way' for lay involvement: what evidence so far?

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Abstract

Aims and objectives This article considers evidence regarding lay involvement in the NHS, following the White Paper's commitment to rebuild public confidence in an NHS 'accountable to patients and open to the public and shaped by their views'. It looks at two aspects of lay involvement: the lay board member's involvement in primary care group (PCG) decision-making and the engagement of the PCG with the wider public.

Methods The paper analyses data from the first sweep of the annual Tracker Survey of a sample of PCGs in England, led by the National Primary Care Research and Development Centre in collaboration with the King's Fund between September and December 1999. It draws specifically from the postal questionnaires sent to lay members. Firstly, however, it contextualizes this data by reviewing the history of lay involvement before 1997 in the NHS and particularly in primary care.

Conclusions The paper concludes that, during the first 6 months of their operation, the lay voice was faintly heard in PCGs. The lay member's role in decision-making at board-level was peripheral. The majority rated their involvement in key aspects of decision-making as low and their influence on decision-making below that of other board members including the Chief Officer, the chair and the GP board members. Beyond the arena of the board, what little contact there was with the lay voice has taken the shape of informing rather than consulting. Mitigating factors include the early stage at which the survey was completed and the lack of precedents for lay involvement in primary care in a broad sense on which PCGs can draw.

Introduction

English Primary Care Groups (PCGs) were established following the new government's health White Paper (1997) which announced a radical departure from general practitioner (GP) fundholding and the internal market. They were constructed to reflect a range of local interests including GPs, nurses, lay people and representatives from social services and health authorities, all of which are represented at board level. On 1st April 1999, 481 English PCGs assumed wide ranging responsibilities for the provision of health-care, health improvement and management of unified budgets for health-care. In April 2000, the first 17 of these PCGs became Primary

Care Trusts (PCTs). This restructure constitutes a radical departure from what has gone before, namely GP fundholding and the internal market and ushers in a new cultural and organizational environment driven by primary care professionals and underpinned by an emphasis on partnership working, on efficiency and quality; and on being 'accountable to patients and open to the public and shaped by their views'.

This paper presents data from the first sweep of the annual National Tracker Survey of a sample of PCGs in England, carried out by the National Primary Care Research & Development Centre (NPCRDC) at the University of Manchester in conjunction with the King's Fund.[1] It draws specifically on data from postal questionnaires sent to the lay member of each PCG board in August–September 1999 and, from their responses to the structured and semistructured questions, explores the extent to which lay voices were involved in PCG decision-making within the first 6 months of their establishment.

Background: lay involvement in the NHS before 1997

From its very inception, a tension has existed at the heart of the NHS between professionals, managers and patients or the public. In 1952 Richard Crossman suggested that no effort had been made to 'encourage popular participation in the Welfare State'. He believed that the answer was to increase 'even at the cost of efficiency' the citizens' right to participate in the control, not only of government and industry, but of the party for which he votes and of the trade union whose card he carries'.[2]

At a national level, very few initiatives were taken before 1997 to involve users in health policy making, with exceptions in the fields of mental health and carers' issues.[3] However, there has been considerably more activity at the local level, since the 1974 reforms and in particular since 1991.

Approaches towards lay involvement have been grouped theoretically into either a consumerist or a citizenship framework. The consumerist framework relates to the market

relationships found within the private sector. Its emphasis is on the rights of consumers to access, choice, information and complaint in relation to a specific service or product, and its focus is on the individual as a member of a service group, patient or carer.[4,5] Approaches that can be located within this framework include the Patient's Charter; Complaints procedures; Consumer Audit and Patients' Participation Groups (PPGs) centred around general practices (which are about participation in a very limited sense, as we see below). By contrast, the citizenship, or democratic approach relates to people primarily in their capacities as citizens and taxpayers with rights to use public services and duties to contribute or participate with others collectively in the society in which they live. It emphasises the importance of equity and empowerment, with 'participation' being seen as a key concept, and 'shared decision-making' in which citizens are 'formally engaged with the processes whereby decisions are made'.[6] Mechanisms that can be placed within this framework included Local Voices;[7] Citizens' juries; Health panels; and Community Health Councils (CHCs). However, all have been subject to criticism on issues related to accountability and representativeness: CHCs in particular have been criticised with regard to the unrepresentativeness of their membership.[8] In addition, while superficially, consumerism can be equated with quasi-market approaches and citizenship with more traditional public administration/management of services, the contrast can be overdrawn and oversimplistic and certainly some mechanisms fit within both concepts.

With the exception of PPGs these mechanisms were located largely within the context of the Health Authority or Trust; very little lay involvement occurred in the context of primary care and within primary health-care PPGs were both exceptional and disappointing in character, as we see below.

Lay involvement in primary care

Historically, primary care has had little interest in lay involvement for a variety of reasons,

including the status of the GP as an independent contractor and the absence of obvious community identity amongst those on a practice list.[9–11] Although there has been little empirical research into the relationship between primary care and public involvement, the evidence we have suggests a strong reliance on traditional methods of general practice participation, including PPGs and also feedback from individual patients,[12–14] rather than a focus on the local population. Those practices that have involved users in planning or decision-making[15,16] appear, by contrast, exceptional. In its study of fundholding, the Audit Commission (1996)[17] found a poor record of involving the public, even among the 'first-wave' fundholders, despite the onus, in the Accountability Framework for GP Fundholding[18] on being accountable to patients and the wider public.

The main instrument of user involvement in primary care has been the patient participation group movement which started in 1972 with the establishment of the first two practices. Despite the initial surge of optimism that surrounded this, 'the movement… failed to live up to its initial promise',[19] and progress was slow, with only 3% of all practices establishing such groups by the mid 1990s.[3,19] It has been noted that there is little consistency or uniformity among PPGs, which exhibit a wide variety of purposes.[19,20] At the same time they have been subject to considerable criticism: for example, there have been doubts about the degree to which group members are representative firstly of patients as a whole and secondly of those groups whose health needs are greatest.[19] This is particularly significant in the light of suggestions that 'reaching isolated and marginalized people is the major challenge for those attempting to involve consumers and the public and it is on this that their efforts should be judged'.[21]

A new approach to lay voices in a new NHS?

Post-1997, developments in the NHS are taking place within a new political and philosophical environment which has become known as the 'third way'. It has been suggested that within this framework 'community' and 'partnership' are the new buzz words replacing 'markets' and 'contracts'[22] and in this context *partnership* means not only interagency co-operation but also partnership with lay people in decision-making. Lay involvement in primary care will take place in a new environment which rejects competition and market values, synonymous with consumerism, and locates itself within a commitment to democratic renewal which runs throughout the government's reforms. The stated aims of these reforms include:

> 'to make Britain's democracy work better: to bring politics closer to the people, to strengthen the rights of every citizen, and to make government more open, responsive and accountable'.[23]

Mechanisms for lay involvement in the New NHS

Health Improvement Programmes and Health Action Zones both involve users as participants in decision-making. At the same time, NHS Direct, the National Electronic Library for Health and National Patient Surveys (of which General Practice Survey was the first) are intended to provide information and advice to patients. The active involvement of carers, both in the provision of care to the person they are looking after and in the planning of services, is another explicit aim of government policy[24] and National Service Frameworks were developed with input from users and carers who sat on the External Reference Group.

The NHS Plan,[25] published after the period in which the data for this paper was collected, significantly underlines the commitment to lay involvement in the NHS declaring as a key principle:

> 'The NHS will shape its services around the needs and preferences of individual patients, their families and their carers'.[25]

It puts in place several new mechanisms through which lay people can be more involved in the NHS including: all party scrutiny committees and independent local advisory fora in each Health Authority area chosen from residents of the area.

In addition, the Plan has instituted major increases in the citizen and lay membership of all the professional regulatory bodies and declared that one third of the members of the NHS Modernization board will be citizen and patient representatives; that citizens and patient representatives will make up one-third of the new Independent Reconfiguration Panel and that citizens and users will be more represented on the Commission for Health Improvement (CHI) review and inspection teams and will advise the National Institute for Clinical Excellence (NICE) on its clinical assessments.

However, by far the most significant development in the new NHS is the establishment of PCGs/Ts with the onus on them to 'involve' the public and patients. Previous attempts to involve users and local communities have focused largely on secondary and community health services. The establishment of PCG/Ts represents the first attempt to involve people directly in making decisions about primary care provision, that is beyond practice-level. Government guidance so far indicates that PCGs should involve users in the following ways:[24]

- by means of strategic plans for involving and communicating with patients and the public.
- being able to demonstrate that they have done this and to provide feedback on the outcome of involvement.
- seek to develop good working relationships with their local CHCs.
- provide sufficient resources and support to lay members who lead on patient and public involvement work.

Before looking at the data on lay involvement in PCGs, we should say a little more first about the role of the lay member on the PCG/T board.

The role of the lay member on the PCG/T board

PCG boards have been constructed to represent a wide range of interests, including the lay voice in the form of the lay board member, as well as a representative, of Social Services and the Health Authority in the area. However, who it is exactly that the lay member represents – whether the public in general, local users of health services, users of particular services or simply themselves – and how and if they are accountable to those whom they represent lacks clarification and is down to individual PCG/Ts and lay members to determine. It has been suggested that the interests of the user cannot be adequately represented through such a structure, where there is but one lay voice among several professionals, and that there is a need to widen the base of government structures.[26]

However, since all PCGs are obliged to become PCTs by 2004 it is the latter's governance structures and processes which will be crucial for lay involvement in the future. Each PCT comprises a board and an executive committee. The board comprises more lay than professional members (five lay members and a lay chair with only three professional members). The Executive Committee, by contrast, has a majority of professional members (up to 10, including up to seven GPs) and a chair chosen by these professional members. The role of the PCT board is to provide strategic oversight, but the executive committee will be responsible for the daily management of the PCT, including developing and initiating service policies, investment plans, priorities and projects to be delivered by the PCT. Only time will tell whether in practice these arrangements confirm professional dominance, although it is a promising sign that the White Paper explicitly states that 'Patient and public involvement is the responsibility of the whole PCG and not just the lay member's job'.[24]

When examining evidence of lay involvement over the first 6 months of PCGs' establishment we recognized that we were likely to witness considerable diversity across PCGs in terms of both the mechanisms used and the degree to which lay people were involved, given the different histories of lay involvement in the locality, the different stages at which PCGs were located in terms of progression towards Trust status and the lack of specific guidance on lay involvement in the White Paper.

Methodology: the annual Tracker survey

The data for this paper was taken from the first round of the National Tracker Survey commissioned by the Department of Health and carried out by National Primary Care Research and Development Centre and the King's Fund between September and December 1999, six months after PCGs had gone 'live'. The purpose of the Tracker Survey is to provide a longitudinal study of PCG/Ts, monitoring their progress and achievements over the first three years of their existence, with the aim of informing future development and implementation guidance and developing models of good practice.

The sample consisted of a random sample of 72 (15%) of all PCGs in England, stratified by region. Following piloting in five PCGs, data was collected through three primary channels: interviews, postal questionnaires and key documents.

Structured interviews were held with Chief Officers, Chairs and a designated Health Authority representative. In addition, postal questionnaires were sent to the Chief Officer, two GP board members, two nurse board members, the lay member, the social services representative and the PCG leads for clinical governance, prescribing and Information Management and Technology.

The data presented here draws from the questionnaires sent to the lay members. The response rate for lay members was high, at 78%, which meant that 56 questionnaires were available for analysis (response rates for other questionnaires used in the survey ranged from 53% to 100%). The lay members' questionnaire explored several areas including:

- Circumstances of the lay member's appointment,
- the involvement of the lay member in aspects of decision-making at board level including:

(i) clinical governance
(ii) commissioning hospital services
(iii) commissioning community services
(iv) developing primary care
(v) prescribing policy

- perceived influence of board members on decision-making.
- PCG's relationship with the wider public.

The structured elements of the questionnaire comprised Yes/No responses (for example, Do you have a role in representing the views of local people? Would you like more involvement in developing primary care?) or the selection of a number from 1 to 5 (e.g. *Rate the Influence of the GP board members* on a scale of 1–5 where 1 = no influence and 5 = great influence; How would you rate the effectiveness of the PCG in informing the public?). Approximately 22% (37 questions out of 167) were open-ended, requiring text responses in the form of a brief description (e.g. Which groups do you represent? What do you consider to be the priorities for developing general practice?)

Findings

The lay element of the Tracker survey examined two facets of lay involvement which we present and analyse below. The first section focused on board level processes, particularly the role of the lay member in PCG decision-making; the second focused on the nature of engagement between the PCG and the wider public.

However, before discussing the findings we need to emphasise the relatively early stage in PCG/T formation which these questions capture, with boards newly established and some members only recently in position. These findings, then, depict a 'snapshot' of the situation as it existed during the first 6 months of PCG operation which almost certainly will have significantly changed when we come to carry out the next survey. We should also underline the fact that, since the first PCTs were formally established in April 2000, the findings reported here relate exclusively to PCGs.

Lay member and representation of lay interests at board level

The role of the lay member was ill-defined and as a result was subject to a wide degree of variation: the lay member's position on the board

was marginal and in the majority of cases their involvement in key aspects of decision-making was very low. However, this seems to be related directly to the newness both of their position and of the PCG organization itself.

In terms of the circumstances of their appointment, most lay members (49%) first found out about the post through an advertisement in the press and applied for the post in competition with others (93%). Only 2% were elected to the post. The remainder were not obliged to go through a competitive process and, in 2 cases, were not even formally interviewed for the position. 18% applied by personal invitation.

In terms of lay involvement at board level, there was some ambiguity around who the lay members believed themselves to be representing and their role remained unclear. Most lay members (77%) felt that their role was to keep local people informed, and in addition they saw their role as representing the *views* of local people (86%) as well as representing local *users of health services* (79%) although some were keen to make a distinction between the latter, suggesting that there were boundaries around their remit. As one lay member put it: 'I represent the *views* of the community but cannot act as *advocate* or *representative*.' Several lay members (five) felt that their key role was to remind the board of their existence and purpose and to ensure the interests of the public/users are considered in all aspects of the working of the board.

A minority (although a fairly large one, at 33%) also considered themselves to have a role in representing particular groups. These included carers organizations; voluntary organizations; those who weren't registered with a GP (e.g. homeless people); 'marginalized and historically excluded groups' and non-users of health services. While they saw themselves as representing these groups, it is not clear how their role *vis-à-vis* these groups were reconciled with their role *vis-à-vis* the wider public, nor how a two-way process of communication was effected (with the lay member both representing and feeding back to these constituencies).

Lay members were not involved in a wide range of decision-making, however, at board level. On a scale of 1–5, with 5 as the maximum, the majority rated their involvement in clinical governance as a 2; felt they had no involvement in commissioning hospital services; rated their involvement in commissioning community health services as a 2; and rated their involvement in developing primary care as 3. By contrast, a high level of involvement was reported by 15% in clinical governance, 5% in commissioning hospital services, 9% in commissioning community services, 29% in developing primary care and 8% in prescribing policy.

However, the majority were satisfied with a low rate of involvement (approximately two-thirds claimed that they did not want more involvement in various aspects of decision-making: this rose to 87% for prescribing). It is difficult to know why this was so and more detailed qualitative research will be needed to tease out the issues. Several explanations may be suggested at this stage. For example, it may be that they saw lay interests as something separate from mainstream business; or because they saw lay interests as being the responsibility of the entire board (and professionals such as GPS may see themselves as qualified to represent patient interests in key areas.) Indeed, while 73% of lay members did believe that it is the lay member who is responsible for representing the views and interests of the public, 54% also said that it was the responsibility of the *whole* board.

There were also particular factors which certain lay members described as hampering their role, several of which were not necessarily inherent in their role but were rather connected to the relative newness of their position and of the establishment of the board itself.

'Initially I felt totally ineffective due to a lack of medical and health authority knowledge. However I realise now that it is the lack of this knowledge which helps me to bring a different perspective.' 'It takes months before one is able to grasp the enormity of the tasks and therefore it has been a frustrating time in that I cannot believe that I have made as significant a

contribution as I thought I would have done 12 months ago.' They also suggested further specific explanations for their role being hampered in some cases. One of these was the training and other support currently offered by PCGs. Indeed, training was sporadic and varied considerably over the range of PCGs. It ranged from a one day seminar and a basic induction to regular meetings for lay members at the Health Authority, College of Health training, meetings and training over both general and specific aspects of their role within the PCGs themselves. Some PCGs offered training in specific areas of PCG business such as finance, legal matters, prescribing, management techniques and clinical governance. Other lay members had received specific training in aspects of public participation such as focus group training and questionnaire design. For those who have not received such training, as one member described, they received much training during seven years experience with a CHC: 'Could not have been an effective lay member without CHC experience'. Most (nearly three-quarters) felt that they had sufficient information to make a full contribution to the board. Those who did not cited several reasons for this. One of the most prominent reasons was the huge amount of information that was required and which had been hard to assimilate in a short period of time. As one lay member explained what was needed was 'time to absorb information and build up a greater knowledge', and as another pointed out, 'Too much [is] happening too quickly. We're still working on our internal communication methods' an issue which was linked again to the novelty of the role and of the board itself. Again, in this situation it was easier for the professions to stick together. As one lay member put it, 'medical board members meet together... there is a tendency for each discipline to do this' which indicates either that the boards may not yet have achieved sufficient cohesiveness in terms of team-working or that lay members are simply excluded from professional cabals.

Similarly, they rated their influence on decision-making as moderate, ranking it a 3. By contrast, the majority rated the influence of the Chief Officer as a 5 (great influence); the influence of the chair similarly as a 5; the influence of GP board members as a 4 and of nurse board members as a 3. In terms of representing the views of the wider public, the CHC was deemed to have the highest influence, with a 3; patients and carers, the general public and voluntary organizations all got 2. It is possible, however, that the prior experience of many of the lay members in CHCs coloured their perception of the CHC's influence: almost a quarter (24%) cited experience in CHCs, although this is perhaps offset by the fact that for lay members the most common background experience was in voluntary organizations (49%).

Their involvement, in whatever form it took, with *local* people was significant. Over three-quarters of lay members lived in the PCG area and several said that, among board members, this was exceptional. As one lay member put it: 'I am one of the very few members of the board who actually lives in the area'.

Engagement with the wider public
Engagement with the wider public relied very much on the mechanisms and organizations that were already in existence prior to the formation of PCGs. Despite the White Paper's intention of exploring new forms of public involvement this in fact was not occurring yet but relied instead on the 'usual suspects': CHCs and voluntary groups. Engagement with the wider public also largely took the form of information-giving rather than consulting.

Most said that the PCG had consulted the CHC (84%) but very few other user groups had been either consulted or informed. Indeed, for several PCGs, most communication was done via regular, pre-existing channels, such as CHCs, the Council for Voluntary Services (CVS), PPGs and voluntary groups. The range of activities in which PCGs were involved consisted largely of giving information, rather than consulting lay voices or enabling them to participate or share in decision-making (with the exception of the CHC). PCGs had been active in distributing information through newsletters to organizations and groups (55%) or to households and

patients (41%); through articles and features, for example in local newspapers (50%); or through public meetings (53%). By contrast, 66% of PCGs had not consulted local patient groups; 82% of PCGs had not produced patient questionnaires and comment forms; 70% of PCGs had not organized focus group or user fora and 64% of PCGs had held no public meetings to consult lay people. Most surprisingly, there were very few plans to do any of the above. Nearly 70% had no plans to consult local patient groups; less than one-third planned to organize focus groups or user fora. While several lay members considered involvement with the public to be the key task for the PCG, there were very few indications that these were taking place.

Amongst those PCGs who had consulted the public, several interesting approaches were indicated. One PCG discussed establishing a Public Participation Group which would initially provide information and then tackle consultation with patients (and groups). Another explained how it had researched methods of consultation; had produced a report which was accepted by the PCG; had set up a PCG Public Forum on a continuing basis and had been experimenting with several other methods, e.g. community lunch to obtain reactions from the informed public. However, whether these were regular or one-off events is unclear and certainly not revealed through our data. Also uncertain at present was the degree to which these mechanisms feed back directly into decision-making processes.

Meanwhile, most lay members rated the effectiveness of PCGs consulting the public as low. 40% say that no significant attempts had been made yet; slightly less rated the attempts that have been made as moderately effective (36%). In other words, over half of lay members believed that attempts to consult the public had either not occurred or had been ineffective. Only about one-third of lay members considered such attempts to have been moderately effective.

While it may be tempting to see this as evidence of tokenism, it is also important to bear in mind that 45% of lay members rated the PCG's commitment to consulting the public as very high, giving them a 4 rating on a scale of 5. This may partly reflect a somewhat narrow vision of lay involvement on the part of lay members, perhaps based on their own experience and background. On the other hand, given primary care's lack of prior experience in lay involvement, we may rate their efforts so far more highly than if we had been judging the activity of health authorities with their extensive prior experience of such activity. We may also have to consider the reluctance of the public to be involved where they do not have an obvious personal interest[3] and this will continue to present a real challenge to PCGs' attempt to involve the public.

Discussion

For the first 6 months of PCGs' existence, the lay voice was faintly heard in PCGs. While this may appear disappointing in the context of the government's avowed intention to encourage the winds of democracy to blow through public services, including the NHS, it is perhaps less so when we relate it to the weak foundations for user involvement previously laid in primary care, and reflect that some slight progress has been made in bringing the lay voice in where previously it had barely existed. Again, it is important to emphasise the extreme newness of PCGs' establishment and of the lay member's position within it at the time the research was carried out.

At the time this survey was carried out, the lay member's role in decision-making at board level was peripheral. The majority rated their involvement in key aspects of decision-making as low and their influence on decision-making below that of other board members, including the Chief Officer, the chair and the GP board member. Beyond the board, lay members judged the effectiveness of PCGs' attempts to consult users as poor or insignificant. Certainly, what little contact there was took the shape of informing rather than consulting. The CHC had the most dominant voice by far in terms of user involvement, as did other pre-established channels, like the CVS and, at practice-level, PPGs.

Certain PCGs, however, seemed to be working towards developing potentially innovative alternative mechanisms for involving the public, including subgroups, fora and committees dedicated to lay involvement issues.

In terms of our two frameworks of consumerism and citizenship, while most lay members considered themselves to be representing the views of local people, they also saw themselves as representing local users of health services. A small minority considered themselves to be representing in addition particular sectional groups, so that they saw themselves as representing both *citizens* and *patients* or *consumers*. What we may be witnessing here in its early stages is the search for a Third Way – characterized by an approach of 'building on what has worked, but discarding what has failed',[23] a framework that is neither purely one of consumerism nor of citizenship but that combines both and applies it, for the first time, to a primary care setting. There are merits in both consumerism and citizenship approaches: while the focus on the consumer has led to increased responsiveness, particularly patient information, quality monitoring, standards and individual rights, focus on the citizen has led to concerns about accountability and legitimacy and the collective involvement of local communities in making choices that potentially impact on every citizen. The combination of both approaches may offer the best way of establishing an effective 'partnership' approach and it is this dual approach that we see reflected in the NHS Plan[25] which both emphasises the shaping of services around the needs and preferences of individual consumers as well as strengthens the active role of citizens within the NHS through local and national bodies, including professional bodies.

We have been concerned to emphasise the relative newness of the PCG and the fact that lay members had only recently been in post when this survey was carried out. However, if progress is to be seen to be made in the future, PCG/Ts will need to demonstrate the fact that lay interests are represented in all aspects of decision-making at board level and that they provide sufficient support to enable them to do so. While the data indicates that involvement of users beyond board-level was restricted during the first 6 months of PCGs' operation to information-giving, this needs to progress towards consultation and mechanisms need to be developed that allow for the involvement of lay stakeholders in ways that move beyond reliance on the pre-1997 channels of CHCs (which have been abolished by the NHS Plan) and voluntary organizations. Most importantly, we will require evidence that involvement of the lay voice makes a real difference to decisions made and we will be searching for evidence of this in subsequent sweeps of our data collection.

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