Patient participation groups in general practice in the National Health Service

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Abstract

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General practice remains the organizational hub of first level health services in the United Kingdom. Patient participation groups are probably the most well known model for public participation in this setting and, although still not widespread, they have been a slowly expanding area of development for almost three decades. This paper sets out to critically assess patient participation groups in general practice by considering the context of their development and reviewing the research literature about groups. Critical issues needing more study and key methodological challenges are then discussed.

Patient participation groups have been a somewhat shifting and contested phenomenon, embracing trends and changing as policy priorities have changed over the years. There is some evidence to think that they might have potential as a local element within a public participation strategy in the National Health Service. However, the field studies are very limited and more research of a better quality is needed. The state of knowledge is not adequate to be able to say with any confidence if or how such groups should be developed. A better understanding is needed of the public's perspectives on this and other models of participation. There are many other questions to do with patient participation groups' purpose, equitable access, and effectiveness that need to be addressed. The methodological challenges include issues of how to involve all stakeholders in the research process; and how to study less tangible aspects of general practice organization, such as culture and power, that effect the public's participation.

Introduction

Over the last decade, spanning changes of government, an increasing emphasis has been given to the idea of involving the public in the United Kingdom (UK) National Health Service (NHS). During the same period primary care has moved centre stage in NHS policy and development.¹ Whilst providers and users of

primary care services might be in favour of the broad idea of participation it is not at all clear what it entails in practice. Efforts to involve the public in primary care must relate to general practice as the organizational hub of first level health services in the UK. This paper reviews and critically assesses one relatively high profile development of the last few decades in this setting: patient participation groups (PPGs).

Although not widespread, these groups, usually made up of a small number of users of services, are probably the most well known model for public participation in general practice.

It should be emphasized that there are other – probably better resourced and more effective – developments in primary care to do with public participation.^{2–4} Many of these are projects initiated by health authorities and community trusts rather than individual general practices; some of them organized in partnership with other public services and local authorities. It is beyond the scope of this paper to review the breadth of activity in primary care in a rapidly evolving field. However, it is worth focusing specifically on PPGs for several reasons. They continue to be an influential model for practitioners and managers in primary care, and have been a slowly expanding area of development in the UK. Furthermore, because the model of a PPG has been around for almost three decades, there has at least been some research about functioning groups. It is important to learn from this research as the idea of public participation gathers momentum. Finally, whatever labels are used, the idea of a participation group at the level at which most people use services appears (at least in theory) to be a fundamentally sensible one.

The paper is divided into four sections. Firstly, the development of PPGs is introduced chronologically and in the context of other key trends and policy initiatives. Secondly, the field research about groups is reviewed to establish what is known about these groups in practice. The third section highlights critical issues requiring further study. The fourth section focuses on three key challenges in considering the research methodologies needed to inform further development.

Changing contexts for patient participation groups

From the outset of the NHS general practice was largely outside either democratic or management accountability as Collings observed.⁵ It appeared to be untouched by the upsurge of interest in ‘participation’ that characterized the

1960s. However, there was an awakening of interest in consumer perspectives.⁶ In the 1970s a very few general practices developed participation groups which were the focus of debate and some research in the following decade.⁷ The earliest groups actually developed independently in different parts of the country.^{8,9} In the late 1970s a National Association for Patient Participation was founded and this was still functioning two decades later.^{10,11}

At the outset of the 1980s the Royal College of General Practitioners (RCGP) took up the idea of PPGs and consumer responsiveness as part of its quality initiative.¹² Much of the government policy initiatives of the late 1980s and early 1990s were also oriented to improving information, choice and responsiveness to consumers.^{13,14} In fact the 1986 green paper on primary care appeared to give some encouragement to PPGs whilst dismissing an alternative neighbourhood model proposed in the review of nursing services.¹⁵ Later policy again backed the broad idea of PPGs (usually as part of quality development) without specifying detailed models or the resources needed to achieve meaningful outcomes.^{16–18} Despite all of this considerable approval only a very few groups developed over the decade: by 1980 there were only 30 known groups and in a national survey undertaken in 1986 only 63 groups were confirmed to be functioning.¹⁹ Pritchard estimated there were about 300 groups by the early 1990s,²⁰ and they continued to be widely advocated as a mechanism for involving users and communities.^{21,22}

The 1980s also saw the emergence of various community health projects in the UK and increasingly the influence of more community oriented approaches to health promotion and needs assessment, particularly among nurses.^{23,24} Although largely outside general practice the influence from the international health development literature of the idea of ‘community participation’ became more apparent from this time in the rationale for groups.²⁰ A greater emphasis was given to their potential as vehicles for health promotion and community development.

More recently the great expansion of the responsibilities of general practice in the NHS

has given rise to a renewed concern with accountability and the democratic voice in local services.²⁵ PPGs have not really engaged with this debate but in a rather nebulous way they have been put forward in policy as a model for improving accountability to the public at the primary care level.^{26,27} The latest white paper, *The New NHS*, whilst putting great store by the principle of public involvement, has not given any real detail of how this is to be achieved.²⁸ Specifically it is not clear how initiatives at the practice level such as PPGs should relate to the new primary care groups. It is likely that a number of models will be required as part of a strategic approach across different levels of the NHS.^{29,30} Patient participation groups at the individual practice level are potentially one element that practitioners and managers are likely to turn to. The analysis so far of the context of their development suggests they are not likely to be a simple single phenomenon. Rather they have arisen from and embraced a complex mix of influences and policy trends over the years. But what is known about PPGs from research?

The research about patient participation groups

Essentially two search methods were used for the literature review below: firstly, a search of both paper and electronic databases using key words; secondly, a snowball or chain method in which citations in a book or paper indicated literature to be studied. The focus was restricted to developments within the NHS from the first reports of PPGs in the early 1970s and up to 1998. Descriptive field accounts, where they were of adequate critical quality, were included as well as the more conventional research studies. Medline, CINAHL and the Social Sciences Index were searched as well as the University of Sheffield's library databases.

The field research about these groups is not extensive. Early descriptions of groups and other discussion papers were collected together into an RCGP occasional paper edited by Pritchard 1981.⁷ This included two more critical descriptive studies, based on interviews of practice staff and patients, undertaken by researchers who

were not part of a group.^{31,32} These earliest studies of the handful of functioning PPGs drew attention to their varied activities, their unrepresentative membership – in comparison to the practice or locality population as a whole – and their ambiguous relationship with the newly established Community Health Councils.

Wood & Metcalfe conducted a small qualitative study in 1980 of general practitioners' (GPs) attitudes to PPGs.³³ They interviewed 25 GPs – 10 with personal experience of a PPG, the remainder without. Not surprisingly those with experience were favourable, whereas those without were likely to have mistaken ideas about the purpose and functioning of PPGs and were much more sceptical about their value. Apart from Wood & Metcalfe's small exploratory study there has been a dearth of research about professional attitudes to PPGs – especially of people not involved in groups. Another qualitative study was conducted in 1994 by Brown.^{34,35} Twenty-three GPs and 38 community nurses from neighbouring general practices in an inner-city district in the north of England were interviewed about a number of aspects of public participation. The study showed that a PPG was a familiar model for most of these health professionals, although hardly any had direct experience of one. Attitudes varied: a majority were positive about the broad idea of a PPG but doubtful about its practicality in an inner-city area without additional resources; only a small minority were openly as negative or misinformed about PPGs as Wood & Metcalfe found in their study.

A census of the 37 known groups in the UK was undertaken by Paine in 1981.³⁶ A postal questionnaire for self completion by PPG members was used to collect information about the background, activities, problems and achievements of groups. Only a brief mention will be given to this first national survey of groups because the findings were updated by a larger study (reviewed below) just a few years later. Paine found that the groups were very varied in their activities and difficult to categorize. Amongst the problems were those of attracting participants beyond a few (unrepresentative)

activists. Improving 'rapport' between staff and patients was felt to be the essence and key achievement of these groups.

The largest and most rigorous study into the origins, purpose and workings of PPGs was that undertaken by Richardson & Bray in 1985 for the Policy Studies Institute.¹⁹ This combined a national survey with six case studies of different groups around the country. For the postal survey a questionnaire was sent to all 86 known groups (after an extensive search). Eighty (93%) responded and some key findings are summarized here:

- only a minority had been going for more than five years;
- they were unevenly distributed around the country with the majority in rural or small town practices. Seventy-one per cent were in this category of area, whilst less than 10% were in inner city areas;
- they were associated with larger group practices. Over 50% were with practices with more than five partners. Only about 16% were associated with small practices (1–2 doctors). The association with a larger list size reflected this finding as well – 65% were associated with practices with a list size of over 6000 patients;
- in 78% of cases the group was initiated by the doctor; in less than 10% was it formed by patients on their own;
- the vast majority of groups were open to patients of the practice or users of a health centre. Only three per cent were explicitly open to all residents of an area. (However, advertising of group activities beyond the surgery was a problem at this time³⁶).
- typically between 11 and 50 people had attended the last Annual General Meeting where one was held.

Richardson and Bray concluded there are three types of activity that PPGs engage in. These categories are very similar to those proposed by the 1991 World Health Organization (WHO) study group examining the concept of involvement in health.²³

1 *Voluntary services to patients.* For example, transport and prescription collection schemes, visiting and befriending schemes, running a crèche at the practice. Fundraising and organizing of social events could also be included here.

2 *Feedback about the practice organization.* This includes the use of suggestion boxes, surveys and interviews with patients, open meetings and mechanisms for dealing with complaints.

3 *Health education.* Richardson & Bray use the term 'health education' but the description of activities is considerably broader and can perhaps be better categorized as including health promotion or community health development as defined by WHO.³⁷ (Certainly the term health education has a narrower connotation now – in the late 1990s – than the range of activities encountered in Richardson & Bray's study). Examples of activities include organizing of lectures, discussion groups, encouraging the formation of self help groups and campaigning on local health issues.

Richardson & Bray also undertook six case studies in which they interviewed group participants from amongst staff and patients. This gives a more qualitative picture of how groups came to be founded and the processes and problems in organizing activities. The motivation and perspective of the doctors initiating groups appears to have been fairly diverse. Extending the means of helping patients through voluntary schemes and establishing feedback mechanisms were stated to be the key reasons for founding groups. The idea for a group seems to have originated from other doctors – for example, reading in a medical journal about an established group.

Overall, Richardson & Bray were quite enthusiastic about the achievements and effects of PPGs and pointed to the visible achievements in changing services, fundraising, and development and voluntary work. It also reported on participants' impressions of less tangible changes in the relationships and atmosphere in a practice and the benefits and enjoyment people have felt in taking part. A major problem raised by

participants was the difficulties of widening participation beyond the few 'same old faces'. In attempting to estimate the level of involvement the authors conclude that most patients are probably unaware of the existence of their group. Further problems related to the relationship with doctors and considerable vagueness about the purpose and motivation for a group. There was some tension over what level of decision making and influence group participants expected.

In a different study Mann interviewed the GPs concerned with 17 groups that had stopped functioning in the early 1980s³⁸ In a majority of cases (14) lack of interest by patients was thought to be the cause of the failure to establish a group.

At a practice with an established PPG Hutton & Robbins used a structured questionnaire to collect information from 154 patients in the waiting room with a view to ascertaining knowledge of and interest in the group.³⁹ As the authors emphasize the sample was unrepresentative of the practice population in being heavily weighted to high attenders at the surgery. Just over half of those responding were unaware of the group's existence; very few (only nine) had ever attended a group meeting and only a small proportion (22 people) thought they would do so in the future. Even so, large majorities appeared to be favourable to the broad idea and potential activities of a group.

A small but important study focusing on the representativeness of PPGs was undertaken by Agass *et al.*⁴⁰ A response rate of 73% was obtained for a postal survey of 4066 patients (aged between 16 and 64 years) at a practice with a long established PPG. Only 45% of respondents were aware of the group's existence and only 7% had attended a meeting. Awareness and use of the group was significantly less for men, younger people under 30 years, single people, smokers, those in lower social classes (as indicated by occupational class and education), and those who attended the surgery less frequently.

Although supposedly on the increase there are very few accounts of PPGs from the 1990s.

Thomas has described the development of a thriving PPG in a rural area,⁴¹ in which a part time facilitator was paid for by the Family Health Service Authority. This paper is of note because it gives some indication of the resources and skills that may be necessary to sustain a PPG over a longer period. A more critical account of a PPG, reflecting on changes over a period of years, is given by Pietroni & Chase.⁴² A users' group was founded at their group practice in London with aims and activities broadly in line with those described in Richardson & Bray's study. It initially met every 8 weeks. The volunteer scheme was the most successful and a number of initiatives were established and continued to thrive independently of the main group. The user group itself underwent several metamorphoses and changes of name as enthusiasm dwindled and priorities changed. It was eventually dissolved and replaced by twice yearly open meetings with a more informal style. Pietroni & Chase, who are doctors, felt in an ambivalent position in relation to the PPG but argue that the participants wanted and expected them to remain directly involved. They argue that it is important for volunteers to have a member of staff to relate to directly. Issues of accountability, confidentiality and the extent of influence a group can have on decision making and policy surfaced frequently.

In summary, then, although there has been some research about PPGs it is of limited quantity and quality. The state of knowledge is dated and rather patchy: holding out some tantalising evidence of benefits but perhaps greater evidence of a need for caution. On the one hand those with direct experience are enthusiastic about the benefits including those of cultural change and improved relationships. The activities undertaken by PPGs include those that are broadly congruent with policy expectations and with widely accepted typologies about participation in public services.^{43,44} (The extent to which voluntary activity counts in this respect is debatable, but that is not to say that it is not of great value to the NHS and wider communities). On the other hand there is certainly evidence that PPGs 'success' is strongly related to

types of general practice in terms of values, size and environment. Professional attitudes are a key factor in establishing a PPG and the (limited) evidence is that attitudes vary, with a proportion of professionals probably sceptical about the value of a group.

Critical issues for further research and development

Five interrelated sets of issues needing further research and development will be highlighted here. Firstly, it seems that the label PPG does indeed cover a range of activities with quite divergent purposes in relation to involving the public. With such a potential breadth of activity it is not surprising that there are tensions over the purpose and expectations of PPGs, and fundamentally what and who they are for: just users of the practice or the wider locality for example. It is not at all clear how PPGs relate to other mechanisms and institutions for public participation organized across a district or primary care group. A central issue for policy and research, then, is in clarifying the purpose and scope of PPGs and how they best fit in a variety of levels for public involvement – including concepts of democracy.⁴⁵ (Occasionally proponents of PPGs have put them forward as part of the democratic fabric,^{20,46} but research has not examined this aspect at all).

A second set of issues relates to the uneven distribution of PPGs by type of area and general practice. The evidence suggests they are not readily established in areas where health needs are greatest; in other words precisely those areas where public participation should be more of a priority for providers of services.⁴⁷ Patient participation groups are also not readily established in smaller general practices. Further research is needed to examine how efforts to establish a PPG relate to the environment and the practice organization; and how any obstacles related to these variables might be overcome.

A third set of issues concerns the unrepresentative use of PPGs by the public where groups are established. Only a very small proportion of people become involved and this

is skewed to certain sections of the population (older, non-smoking, educated, married women if the study by Agass *et al.* is accurate!). This is a critical issue for any efforts to involve the public,^{45,46,48,49} and in fact we do not really know if PPGs are any less representative than other participation initiatives in public services. Again it is an area that requires systematic study to inform policy rather than one or two small reports or anecdotal accounts. For example, the use of PPGs by minority ethnic groups should be studied. It seems likely that PPGs are a model that suit some people in the community and not others. This leads on to the next issue.

Fourthly, the difficulties in sustaining groups may point to a lukewarm reception by the public (clearly other issues are relevant as well). It is really not clear whether the public at large favour this way of getting involved. It seems to be the case (from the limited evidence available) that the development of PPGs has been driven by professionals rather than any ground swell of public opinion. A critical issue here, discussed further in the next section, concerns the lack of any research about the public's perspective on this subject. This gap needs to be filled swiftly to understand better the various perceptions and preferences there are in the community for participation in primary health care.

A fifth, and final set of issues, concerns the costs, benefits and the effectiveness of PPGs. Their track record in terms of taking of instrumental decisions and influencing NHS policy directly appears to have been only very superficially effective; especially when set against some established 'ladders' of participation.⁵⁰ However, this might be to miss their purpose and more substantial outcomes in terms of being a catalyst for cultural change, better relationships and communication.⁵¹ The costs of groups, though, have been largely invisible. It is impossible to judge how much staff time, levels of expertise and experience and so on have been employed in attempts to set up groups. Reports of training and preparation of staff for these initiatives are notable by their absence. Research is needed to examine the costs and benefits of groups in different settings and in comparison to

other means of public participation. However, this is likely to be methodologically complex and would have to take account of the less tangible benefits mentioned such as changes in culture and relationships. In other words the usual 'hard evidence' of some mainstream research methodologies may miss the point and give a distorted picture of the benefits to the NHS and to local communities.

Methodological issues

It is very apparent that research is needed that is more up to date and also more rigorous.^{2,3} Amongst the priorities is the need for a survey of functioning groups to give more accurate information of their distribution and activities. Case studies of groups in different settings are also needed – with a more systematic assessment of their outcomes. Evaluation studies comparing the effectiveness (and cost effectiveness) of different models and methods would also be useful. However, this should not be taken as merely advocating more of the narrow methodological approaches that have dominated health services research previously.⁵² Researchers studying public participation in general practice face several additional methodological challenges aside from those conventional matters of rigorous design, valid data collection tools and so on. Three critical issues are highlighted below in identifying some of the limitations of previous field studies.

Firstly, although the voices of some members of the public have been heard much of the research is dominated by the provider's perspective. In addition the use of a fairly narrow quantitative methodology has meant that the parameters of study, the meanings of key concepts and variables and so on, have been decided at the outset by the researchers.^{52,53} It is interesting to compare the research about PPGs with other developments that have more of a 'bottom up' or social movement element. In the latter case great emphasis is given to issues of whose voice is heard in research and to participation within the research process itself.^{54,55} The research on PPGs is somewhat remarkable in

not appearing to engage with this area of methodological debate. This is not to suggest there is a simple answer: research must be about answering questions in a way that provides useful answers. There is no *a priori* quota. It is a matter of practical judgement about how all stakeholders can be involved *and* also gain useful new knowledge.^{56,57} Nevertheless, this is a critical issue for research on this subject; and one that rarely surfaces in the mainstream of health services research.

A second issue, to some extent complicating the first, relates to the sampling strategies (such as they have been) in research about PPGs. The focus has been largely restricted to exceptional general practices and, within these untypical settings, those who are most active and favourable towards a patients' group. The field studies are weighted to enthusiasts and activists in other words – as is the case in the wider literature about participation. A broadening of the research focus is needed to give a better understanding of PPGs. Why, for example, do many practices not succeed in establishing a group? Why do people not attend established groups even when they know about and approve of them?

Thirdly, the emphasis in previous studies has been on only the most tangible structures such as practice size and very broad categories of the environment. There is very little consideration about how PPGs are affected by the organizational context and processes.⁵⁸ Indeed, a major methodological limitation of previous studies is the lack of theoretical depth or perspective on the context of initiatives. These studies give the impression that the organizational setting is not relevant. Clearly, though, given the uneven progress of participation initiatives in general practice, the organizational context is all important. Culture, attitudes and power within the general practice organization are probably key variables in developing PPGs,^{33,34} and, as noted earlier, changes in these may be the most substantial benefits.⁵⁹ Such variables are difficult to measure of course.^{60,61} They are unlikely to be illuminated by the research approaches that have dominated this area so far; but will need to

draw more widely from social and political theory.

To a large extent these limitations are those of purely descriptive studies – no real attempt has been made to explore key dimensions and critical issues. They are limitations also of a narrow quantitative methodology and the unreflective stance of much mainstream research in health services during the 1970s and 1980s. These limitations can be overcome, as has been implied, by a continuing exploratory orientation that: one, adopts a more qualitative strategy incorporating more perspectives – especially those of service users and the wider public; two, selects cases for study by criteria other than that they are high profile enthusiasts; and three, makes use of a theoretical framework for considering general practice as an organization in which the social complexities (of attitudes, cultures, power, relationships and so on) are adequately addressed.

Conclusions

patient participation groups are one model for involving the public that has emerged in the last decades of the 20th century. They are a somewhat shifting and contested phenomenon, embracing trends and changing as policy rhetoric and priorities have changed over the years. There are now several decades of experience of these groups in the NHS and some research about their distribution and types of activity. There is sufficient evidence to think that they might have potential as a local element within a public participation strategy. However, the field studies of such groups are very limited and much more research of a better quality is needed. The state of knowledge at this point is not adequate to be able to say with any confidence if or how such groups should be developed across the NHS. Virtually nothing is known of the wider public's perspectives on this and other models for public participation. There are many other questions to do with PPGs' purpose, equitable access, costs, benefits and effectiveness that need to be addressed. There is certainly evidence, though, that without a robust

development strategy they will not be an equitable or effective model for public participation. Previous research has been methodologically limited. A broader research strategy is needed incorporating a greater theoretical depth, balancing the appropriate involvement of all stakeholders, and balancing sampling strategies to include all environments and types of general practice organization.

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