

## Research Papers

# “No point having a voice if no-one’s listening” – The views of members on the current and future challenges for Patient Participation Groups

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### ABSTRACT

**Background:** Patient and public involvement in the development of health services is central to current government policy. In 2011 new financial incentives were introduced to promote the establishment of Patient participation groups (PPGs) which led to an increase in the number of PPG groups in England. PPGs are now well established in many practices.

**Objectives:** The aim of this study was to explore PPG members’ views of the current and future challenges for Patient Participation Groups.

**Methods:** Six focus groups were conducted with members of PPGs (n=31). They were audio recorded and transcribed verbatim. Qualitative analysis followed established principles with data coded and recoded into categories and themes.

**Results:** Beyond acting as a conduit for patient feedback and as advisors to their practices, there was variation and some confusion about the roles of PPGs. All groups struggled to

engage the interest of the patients they purport to represent. Their ability to improve quality of care was limited by several factors including the information available to them, their ability to interpret it, their perceived remit, and their relationship with the practice team. Many participants foresaw a future expanded role in relation to commissioning but this had yet to be defined in practice.

**Conclusions** PPG members are willing and eager to contribute to service development at practice level. However, their roles were confined by the boundaries within which they were able to operate. Government policy literature and funding, through the Direct Enhanced Service payment, advocates input from patients into primary care. Yet this research demonstrates limitations in the support PPGs are able to provide to surgeries.

**Keywords:** Patient participation, primary care, patient involvement, patient participation groups, focus groups, qualitative.

### Box - How this fits in with quality in primary care

#### *What do we know?*

Government policy and funding, through the Direct Enhanced Service, advocates patient involvement in primary care.

#### *What does this paper add?*

Despite Government rhetoric and funding there are limitations in the support PPGs are able to provide practices due to the shortage of information available to them, the confines of their remit, their relationships with practices and a lack of training and support. Without an improved support structure it is difficult to see how PPGs can efficiently contribute to a future commissioning function or more widely to service development.

### Introduction

The opinions of service users of the National Health Service have long been promoted as a means of driving quality of care and improving patient experience. The White Paper of 2010 emphasized the importance of patient and public involvement as being central to government health policy.<sup>1</sup>

Patient participation groups (PPGs) emerged over thirty

years ago and are well established in many practices in the UK with roles which include helping patients take responsibility for their health, contributing to continuous improvement of services and quality of care, improving communication between the practice and patients and providing practical advice for the practice.<sup>2,3</sup> A postal survey carried out by the National Association of Patient Participation (NAPP) between 2005-09 (n=500) revealed significant regional variations. PPGs were

more likely to be found in rural communities than urban ones.<sup>4</sup> The survey found that 41% of GP practices had been reported as having a PPG. Seventy seven percent of practices without a PPG had thought of starting one.

Currently, there is no national requirement for practices to have PPGs although they are viewed as 'good practice' for the purposes of practice accreditation and professional revalidation. In 2011, an optional clause in the GP contract (a Direct Enhanced Service or DES) gave financial incentives for GP practices to set up patient reference groups.<sup>5</sup> This was designed to enable GP practices to gain feedback from their practice population, collate patient views by means of surveys, agree action plans and publicize any resulting actions and achievements.<sup>5</sup>

It is now thought that two thirds of all practices in England have a PPG.<sup>6</sup> The new DES roughly trebled membership of the National Association for Patient Participation (NAPP) to over a thousand groups. The policy was introduced rapidly and many practices were ill-prepared for it.<sup>7</sup>

More recently, the Keogh report stressed the importance of involving patients and public as partners in the development of local services.<sup>8</sup> This year, the Care Quality Commission, which regulates general practices and other primary care service providers, has highlighted the importance of PPGs in providing feedback to practices and ensuring that services are responsive to patients' needs.<sup>9</sup>

While their roles are alluded to in guidance, such as agreeing topics to be included in a practice survey, remarkably little previous research has examined the activities of PPGs.<sup>5,10</sup> Despite more funding for patient participation there remains uncertainty about what PPGs are doing. This study was conducted to explore PPG members' views of their current roles and activities and future challenges.

## Methods

General practice surgeries in the Eastern region of England (across 5 counties) were identified. From all practices a sample was selected to include those from a range of areas (urban and rural) and in areas with varied levels of deprivation. Attempts were made to identify if practices (n=20) had a PPG group, through contacting the practice manager or viewing the practice website. It was difficult to locate the contact details of PPG members and Practice Managers often did not respond to requests for this information. Where groups were identified the Chairman was written to (n=8) and the PPG group invited to participate in a focus group.

Considerable difficulty was experienced identifying contacts for PPG groups, but where successful contact was made with a named individual six of eight PPG groups agreed to participate in the research. Reasons for declining to participate were lack of interest amongst members (n=1) and the group no longer being active (n=1).

After ethical approval had been obtained (from the Devon and Torbay research ethics committee -reference 09/H0202/65) focus groups were conducted with six PPG groups. A topic guide was developed, informed by the literature and was piloted with the first group, no changes were necessary. Open questions were used and topics covered included membership

of the group, participants' perceptions of the role of PPGs, relationships with the practice and patients and future roles for PPGs. Two members of the research team attended each focus group, one led the group (JN or SG) and one took notes.

Focus groups were audio recorded and transcribed verbatim. Analysis was informed by the approach of Lofland and Lofland in which data are coded and categorized into themes. Two researchers (JN and SG) independently coded all transcripts and met regularly to develop, amend and refine the coding structure throughout the analysis process. Where new codes were identified all transcripts were re-read and the codes applied systematically to all data. The computer programme NVivo® 8.0 was used to assist data management.<sup>11</sup>

## Results

### Sample

Six focus groups were conducted with PPG groups (n=31 PPG members) from a range of urban (n=2) and rural (n=4) practices. The practices also represented a range of social environments; with deprivation scores (based on the Index of Multiple Deprivation 2007) ranging from 7.6 to 28.9 the UK national range of deprivation scores is 2.6–68.4.<sup>12</sup> Groups varied in the amount of time they had been established from several years to six months. The numbers of participants in each group ranged from 3-8 people, the length of focus groups ranged from approximately one to one and a half hours.

### Roles of the group

All groups acknowledged their importance as advisors to the practice:

*Well you're supposed to be a go-between between the doctors and the patients aren't you really, and then the sounding board for anybody that wants to say something to you. (PPG 03)*

However, this did not extend to dealing with individual patient complaints:

*And it was emphasised at the beginning... that individual problems will be dealt with by the surgery. We are looking at things that affect more of the patients than just one incident of something which must be taken up directly. (PPG 04)*

Beyond that, PPG members varied widely in their professed purposes both across groups but also within groups. Table 1 reports role and responsibilities of the groups, as outlined by PPG members. Some roles were noted by all groups, such as feedback to the practice team, whilst others were only reported by some, such as fund-raising.

Whilst many were able to articulate roles and responsibilities for the PPG some members exuded a sense of aimlessness or lack of self-confidence about their purpose:

*It's unclear the role of the PPG. (PPG 04)*

Many respondents commented that the practice team had determined the roles their PPG was able to undertake. They felt they were confined by the extent to which the surgery team would listen to them:

*I think, and I think it'll happen more, but I think that the practice likes answers to the questions it wants to ask. (PPG 05)*

Table 1: Patient participation groups – roles and responsibilities:

Advice/feedback to practice team, particularly on how things could be improved  
 Seeking patients' views  
 Health promotion, e.g. organizing educational events, arranging speakers  
 Fund-raising  
 Commenting/collecting patient survey and other data  
 Support for commissioning activities  
 Guidance for practice manager  
 Advocate for patients/answering patients questions  
 To help implement NHS reforms  
 To aid communication as a conduit from doctors to patients and patients to doctors  
 Helping in the surgery (e.g. 'flu clinic or showing patients how to use self-check in system)  
 Representing the PPG at community events (e.g. carnival/church fete etc.)  
 Producing newsletters for patients  
 Holding regular meetings as a PPG group  
 Running 'healthy walks' session for patients  
 Support group for patients (carers support group)

### Challenges to PPG groups

All six groups spoke of the challenge of finding enough people to come forward to be members:

*I think it is so sad that we are in a situation where there's six of us, you know in a practice of 20,000 and we cannot get any new faces. (PPG 02)*

In particular, groups spoke of the difficulty of getting a PPG membership that was representative of the patients who attend the surgery. Several groups described ways they had tried to recruit new members such as notices in waiting rooms, articles in surgery newsletters, talking to patients in the waiting room or holding open meetings. Participants often noted that they struggled to recruit people who worked or were of a younger age, and were concerned that PPG members were often elderly and had health problems:

*We're not representative of the patients, we're not expressing the patients' views. We're, you know, we're just people who are willing to give up the time to come along, partly out of interest and partly for what we might contribute, to talk about things. (PPG 05)*

Some groups expressed limitations in their role as they were unable to contact patients directly, due to confidentiality policies:

*Patient confidentiality is a big issue. Patients are not talking to the PPG, how do we talk to patients and contact them if the practice won't give us contact numbers? This is a big issue ...*

*(PPG 01)*

Lack of engagement with the practice population sometimes led to feelings of lack of appreciation for their efforts:

*We are not valued by patients at all; we give out all this info and get no feedback at all. (PPG 03)*

Views varied in relation to how people felt able to contribute to the group. Some participants felt membership was about giving their own views:

*I don't think I was ever told what my role was expected to be,*

*so it was up to me to see what it was. I saw my role as coming to meetings and contributing to any discussions, giving my views. (PPG 05)*

Some PPG members spoke about how some form of training would be beneficial, particularly if the remit of the PPG was to be expanded:

*I think if the government are really serious about wanting patient participation the one thing I feel is lacking is, for the want of a better word, training for people like us because I couldn't tell you how the NHS works. (PPG 04)*

Some participants related the role to their previous experience as school governors, for which training and ongoing support was provided.

### Quality of Care

Groups were asked about their role in ensuring quality of care for patients in the surgery. Most groups appeared to have rather limited notions of what 'quality' might mean or how to assess it. Their main concerns were with respect for patients and access:

*I have noticed that our surgery isn't open for all of the core time, which is 8.30 till 6.30, well they close at 6.00...that's an issue for working people. (PPG 03)*

Respondents preferred to judge quality in terms of subjective perceptions than numerical data. Indeed, it was not clear that groups saw improving quality as within their remit. Members were asked if they saw or discussed data from the national patient survey or from surveys conducted by the surgery:

*I think it's extremely useful because it's the patients that can give vent, if you like, to their feelings in the survey. When we get the results of those surveys, we will go through them with the practice and say "well, okay, what can we do to improve this, what can we do, how can we help? (PPG 02)*

### Relationship with surgery

PPG groups described varied relationships with practices, although on the whole relationships were constructive. Some groups were well integrated into the practice, for example with

the practice manager as a member of the group or with GPs attending most meetings. Several of the groups had been started by one of the GPs. Examples were given of how PPG members had worked with GPs, for example on joint presentations or judging a carnival.

Some groups had started within the practice but had begun to pursue their own direction and activities as time had passed. People spoke about how membership of the group meant a different relationship with members of staff such as receptionists or GPs:

*I suppose we're still here because we feel loyal to Sally\* (Practice Manager) and to the doctors don't we? [Some agree] Because it is nice to know that we've got contacts in the surgery if we've got any problems ourselves and I'm not saying that we pull rank or anything else but it is nice that when you go to see a doctor, he knows you... (PPG 02)*

There were sometimes tensions in the relationship. For example, one group had volunteered to help with the 'flu clinic but surgery staff had made tea for themselves but not PPG members:

*No thank you, won't do that again. Did not feel valued therefore we are not participating again this year- Dr Smith\* is not happy about that, but it's important to feel valued and accepted. (PPG 01)*

The relationship with the surgery was sometimes discussed in terms of whether or not the recommendations of the PPG were implemented:

*We're used as a sounding board to an extent, but I don't know, you know, what happens with the things that we say. (PPG 05)*

*...no point having a voice if no-one's listening. (PPG 03)*

One group reported a planned frank conversation with a GP about his poor communication style with elderly patients. Otherwise there was little evidence of PPGs providing critical feedback.

### Future roles and wider links

Given the scale of changes taking place within the health service at the current time, groups were relatively modest about their future roles other than as a continuation of their current remit. Some participants did feel patients' views would become increasingly important:

*I think the role of the PPG is probably changing or is trying to sort of slowly change, in that I think in the past ... it's been quite practice-centric, if you see what I mean... it's tended to be more the practice giving information which is absorbed, and I think it's moving ... with the GP commissioning coming in. There's becoming more of an interest in trying to elicit the opinions of practice members. (PPG 05)*

Changes within primary care had led a number of groups to meet with members of other PPG groups, sometimes at CCG level. This had led to wider discussions about delivery of care and resources across areas.

Other participants did not feel it would equate to a change in the position of PPGs:

*If we are lucky our voice would carry more weight and go straight to policy makers. In practice it won't work out. (PPG 01)*

### Strengths and limitations of the study

The key strength of this study is the exploration of a topic which is under-researched, PPG members were able to talk at length about their experiences and views. The sample size is a limitation of this study and those PPG groups which did agree to participate may not be representative of all PPG groups.

### Discussion

In this study PPG members appeared willing and eager to contribute to service development at practice level. However, their impact was reduced for many reasons: recruitment difficulties, ill defined responsibilities, lack of training in quality improvement and lack of support for a more clearly defined role. The principal activity described as being undertaken by PPGs was giving advice and feedback on services provided by the practice, although they often felt their voices were not heard.

Previous studies have identified practical challenges in establishing and sustaining groups.<sup>13</sup> Our study highlights the difficulty of recruitment to PPGs and that memberships are seldom representative of the patient population. The CQC places increasing importance on the feedback given by PPGs about practices during their inspections<sup>(9)</sup> but this may not be truly reflective of the practice population's views, nor will it be entirely objective. There is an inevitable tension for PPG members between retaining their status as 'representative' patients and becoming 'preferential' patients.

The potential role for patients in relation to quality of care, as advocated through Government policy remains under-developed.<sup>15</sup> Challenges in providing feedback to improve quality of care include the preservation of confidentiality, not having access to key data sources, such as patient records, financial statements and details of complaints. The measurement of patient experience is complex and data collection is only the first step.<sup>14-16</sup> Engagement of patients in quality improvement is a challenge, with patient involvement often liable to be dismissed as tokenistic or a 'tick box exercise'.

The roles of PPGs were confined by the boundaries within which they were able to operate. Government policy literature and funding, through the DES payment, advocates input from patients into primary care. However, our research demonstrates limitations in the support PPGs are able to provide to surgeries. To enable a fuller role PPGs need clearer goals, resources, training and support.

The patient participation DES has led to an increase in the number of PPGs being established. However, the level of their involvement in decisions about services provided at their practice is mixed. Pollard et al found that the financial incentive alone had not secured greater influence and power as social factors such as inter-personal relationships were a more important determinant of involvement in decision-making.<sup>17</sup>

In conclusion, PPG members are willing and eager to contribute to service development at practice level but groups need further support to be an effective mechanism for ensuring quality patient care in the NHS.



## **ETHICAL APPROVALS**

Ethical approval for this study was obtained from the Devon and Torbay research ethics committee (reference 09/H0202/65).

## **ACKNOWLEDGEMENTS**

The authors wish to thank Dr Emily Taylor for conducting focus groups and Prof. Martin Roland for his comments on an earlier draft of this paper.

## **PATIENT CONSENT**

Patient consent was obtained from all study participants prior to the focus groups and all reasonable steps have been taken to maintain patient confidentiality.

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