

Growing patient participation

– promoting quality and responsiveness in general practice

“The British Medical Association’s (BMA’s) General Practitioners Committee encourages all practices to consider developing a Patient Participation Group to help improve their services. One of the greatest strengths of UK general practice is its ability to respond to local circumstances, and a huge variety of practices deliver high-quality care precisely because they cater to local patient need. We, along with the BMA’s Patient Liaison Group, believe that listening and responding to the views of patients using a PPG is the best way not only to develop the practice for the benefit of patients, but also for the surgery itself.”

**Dr Laurence Buckman, Chairman, General Practitioners Committee,
British Medical Association**

“Throughout its history, spanning more than 30 years, the National Association for Patient Participation has argued that the best healthcare results from a partnership between practices and their patients. Patient Participation Groups, invented by GPs in the early 1970s, help practices to understand more about what matters most to patients. They also improve communication and encourage patients to take more responsibility for their health.”

Danny Daniels, Chairman, National Association for Patient Participation

“Patient Participation Groups represent a new paradigm for general practice and primary care, putting patients at the heart of each general practice. PPGs provide practices with expert help so that they can better suit the needs of patients. They also signal a new era of co-production, where patients and professionals stand side by side in improving self help, personal and community health and in making better use of NHS money. Nothing speaks quite like experience and my own practice’s PPG has revolutionised the way we work and the care that we give. It is not only a partner and a critical friend, although it fulfils both these roles. It is now an intrinsic part of what we are and what we do as a practice.”

Dr Michael Dixon, Chairman, NHS Alliance

“The Royal College of General Practitioners is committed to improving partnerships between patients and GPs. The experiences and input of patients are invaluable in improving the way that services are provided through practices and offer real added value. Patient Participation Groups (PPGs) are good practical vehicles for achieving greater patient involvement that can bring benefits for patients, GP practices and community healthcare.”

Professor Steve Field, Chairman, Royal College of General Practitioners

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Foreword from the Editor

It is my pleasure to write the foreword for this collection of essays that celebrate the importance of Patient Participation Groups (PPGs) in general practice. This comes at a time of debate about the different ways in which patients can access GP services, as well as about the different services that can be offered.

It is also a time when the importance of patients' involvement in all aspects of healthcare is being emphasised – from the planning of services at national and local level to participation in the consultation between an individual patient and their clinician. It is, therefore, particularly gratifying that the Department of Health, the Royal College of General Practitioners (RCGP), the NHS Alliance, the British Medical Association (BMA) and the National Association for Patient Participation (NAPP) have all collaborated to enable the production of this booklet.

There are four sections, written from the perspectives of patients, practice managers, GPs and primary care trusts (PCTs). All of the authors are experts in their fields.

Richard MacRae and Clive Oakley are experienced patient members of PPGs. Although living in geographically diverse parts of the country, they both emphasise the importance of working in partnership with the practice for the benefit of the patients and to maintain an independent voice. Amanda Sayer and Sandy Gower are managing partners of their respective practices. They describe the importance of PPGs, their relevance to practice management and suggest ways to establish a PPG and allow it to flourish.

In the section by GPs, Dr Brian Fisher and Dr Has Joshi emphasise the importance of GPs listening to patients. They further discuss the ways in which PPGs can work together and how they can improve health. The final section by Dr Graham Box, Chief Executive of NAPP, explains why PCTs have an interest in promoting and supporting PPGs in GP surgeries. He argues that effective PPGs will contribute to World Class Commissioning and allow patients to be put at the heart of the work of PCTs.

The enthusiasm and commitment of all the authors – all of whom are from different backgrounds – to the work, achievements and potential of PPGs, is inspirational. I recommend this publication to you and hope that it will encourage, enthuse and inspire you to achieve the aims of the authors to ensure that there is a good PPG in every practice.

Dr Patricia Wilkie, MA, PhD, FRCR (Hon), FRCGP (Hon), President of NAPP

Editor



1. The Patient Perspective: From deprived inner city to windswept moorland: a tale of two contrasting PPGs

Richard MacRae (Chairman, Eric Moore Partnership PPG, Warrington)

Clive Oakley (Chairman, Exmoor Medical Centre PPG)

- **PPGs are collaborations between patients and their practices designed to improve understanding**
- **It is essential to add humanity to the targets and to place patients at the centre of planning**
- **PPGs can help a practice to deliver the highest possible quality of service to its patients**
- **By contacting hard-to-reach patients, PPGs are able to present the wider patient perspective**
- **Effective communication has many benefits, from reducing complaints to helping patients to manage their own health**
- **PPGs can help in many ways but practices and the wider NHS have to be willing to listen**

Introduction

The authors of this section, Richard MacRae and Clive Oakley, are both experienced lay members of PPGs. The focus of the section describes how these two PPGs work with their practices. There are many similarities. There are also differences that may reflect the individual circumstances of the practices, the areas in which the practices are based as well as the interests of the members. The work of both PPGs emphasises the importance of working in partnership with the practice, of supporting the practice for the benefit of

patients and of maintaining an independent voice.

Background

The NHS wants patients to have the opportunity to help shape the health service of the future while drawing attention to some of its failings. This is an admirable aspiration. A patient group is the chosen communications system for general practice and it is possibly the only system which can hope to fulfil that aspiration. Thus every practice should have one! But the conception of a PPG is often anything but immaculate.

In effect, a PPG is a joint venture between a general practice and its patient population. Joint ventures almost always suffer from excessive teething troubles in their early stages, whether these ventures are between two multinational aircraft manufacturers or a couple of greengrocers in a small town seeking to maximise their potential. At least in the commercial world, partners to a joint venture generally have a good understanding of each other's business. But unlike the commercial world, doctors and patients do not always understand each other's business well. This is where a PPG can help.

Doctors and patients bring to this scenario a unique existing relationship that is based very much on trust. The old-fashioned saying "Doctor knows best" still holds good today for many patients. A PPG turns this

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relationship on its head, bringing together doctors and patients on equal terms. It is fair to say that many in the medical profession and other healthcare professionals can find this adjustment difficult, and this can bring tensions to the development of PPGs.

What patients want from general practice

For a potential user of healthcare services, it is comforting to know that the service is there and that, should it be necessary, the patient will get to see a doctor quickly, their symptoms will be examined and an accurate diagnosis will be made. The patient will receive good medical treatment, the course of which they will get through with the minimum of hassle and in the shortest possible time. From start to finish they will be treated with compassion, dignity and respect, and return to getting on with their life with no bad memories of their experience. Should a long-term disease or condition have been diagnosed, they will be made to feel comfortable, helped to gain an understanding of their illness, and will be kept up-to-date on new treatments.

Those of us who are, or have recently been, patients know that this is a vision of the NHS that everyone shares and which we must strive for. We have a clearer insight into this journey through our own individual and varying experiences and are aware of the good bits and the bad bits, of the constraints and the pitfalls. We know what it is like to be a patient. Real healthcare is about having good doctors who build a relationship with patients and their families, and who show an awareness of the social context in which their patients live. Its effectiveness is measured not just by the targets reached in the treatment of patients, but by how those targets are achieved and by how patients feel about the treatment they receive. It is about putting humanity into the targets and placing patients at the centre of any healthcare plans.

In this section, the work of two PPGs from very different parts of the country is described. It can be seen that although the PPGs have been set up differently and operate in contrasting parts of the country, both have successfully tackled similar topics and worked constructively with their practices.

The first example: an inner city PPG

The practice that serves our community is located in one of the most significantly deprived areas in Cheshire. This practice is forward-thinking in every sense, and patient involvement is taken seriously. The formation of a PPG, therefore, was regarded almost as a natural development. Patient participation and involvement is about all stakeholders (lay and professional) using and sharing their skills and expertise where appropriate.

Working in partnership with the practice

Working in partnership with the practice, a PPG can help to make services more user-friendly and improve patient experience. By identifying issues that are important to patients and by responding to any new initiatives, it can improve and influence the way in which services are planned and delivered, and increase patients' confidence in the healthcare provided. A PPG can support the practice when it is faced with impositions from outside sources which may not have a beneficial impact on the practice or its patients.

When the primary care trust (PCT) recently proposed a radical change to local health services, the voices and opinions of patients and the public were heard over and above those of the policy makers. The PCT was open to suggestions and flexible enough to do a U-turn and re-think its strategy. Our PPG contributed by expressing our views in consultations, at public meetings, in written correspondence to the PCT (which was copied to the strategic health authority (SHA)

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and local MPs) and by organising a petition at our health centre. It was as a result of patient and public pressure in support of our local practices that the proposals were rescinded.

Quality assurance

There is a role for the PPG in quality assurance. Information offered as feedback can be used by the practice as a basis for self-evaluation of its services. It can assist a practice in meeting the needs of its local community by gaining a better understanding of its patients' concerns, and of what really matters to them. Results and analyses from surveys, questionnaires and reports on patients' experiences and views of new initiatives can be very useful tools on which a practice can base its assessments. A PPG can also assist the practice management by reporting general issues of concern, eg parking problems, condition of toilets and wheelchair access.

Good practice: always consulting the PPG

Consulting and involving the PPG at every stage in the development of services can give the practice an insight into how an action may be received by its patient population. Ours is a practice that can already demonstrate a trend of upward improvement and it is one of the best-performing practices in the locality in terms of 'quality points'. It is recognised and commended by the PCT as being cost effective and a practice where patient views are acted upon, and where there is good teamwork among staff and all stakeholders.

The practice fully supports patient involvement and the role of its PPG. Recently the practice has purchased the health centre building and has some exciting plans for its development. The PPG has been involved since the start of negotiations and has been invited to take a leading role in the re-design of the waiting area and its facilities.

Representativeness of PPG membership

A PPG must endeavour to represent the views of as many patients as possible, though sometimes just seeing things from a different perspective to that of the medical professionals can help. To ensure that membership is representative of the community, the practice must encourage the inclusion of all patients in the PPG, and aim to involve all those relevant when seeking the views of patients and when researching their needs and experiences. This being the case, the size of the group is not of paramount importance. Our PPG has just a dozen or so active members but they are all enthusiastic, work very well together and bring a wide variety of different skills.

The PPG represents a diverse profile of medical and social needs and can provide a forum for sub-groups, for example people with a disability, new and expectant mums or carers whose views are important but who have least time to contribute. This similarly applies to those registered patients that rarely visit the surgery. Though the contribution of the retired and elderly cannot be underestimated, encouraging and enabling younger patients and those who work full-time to take an active part in the PPG remains problematic and a challenge.

Meetings

We hold meetings twice a year at the health centre with the practice staff, including GPs, the practice manager, the assistant practice manager, the reception manager and a practice nurse. Meetings last approximately two hours. The agenda is set by the PPG and always includes an update from the practice on developments and proposed new initiatives, etc. In addition to these meetings, the chair of the PPG is in regular contact with the practice's executive partner by phone, email or occasionally at the surgery, and PPG members get together as and when necessary. Whichever way is chosen to

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establish the membership, the practice will play an important part in helping to identify the suitability of representatives of the local community.

PPGs provide an independent voice

If people are willing to give their commitment and time freely, they must be assured that their efforts will be taken seriously as part of the process of change and development. They need to feel that their contributions are valued and respected. Having a PPG should make the patient experience both different and better. The quality of the practice can also be assessed by questioning individual patients who are new to the practice and asking them to compare their previous experience to their present experience.

The PPG works in partnership with the practice but if it is to offer new ideas and present accurate feedback based on patients' honest feelings and points of view, it is important that there is some level of independence. Patient involvement should not always be guided by the interests of the practice staff. There must be systems in place that allow initiatives to be led by the PPG from its own experiences. In order for the group to be effective and improve services, it has to be able to challenge the status quo.

Communication

As a PPG devotes a great deal of time to gathering and disseminating information and providing feedback to patients and practice staff, it is essential to develop good methods of communication as soon as possible. PPGs can engage with patients to promote and raise awareness of the group and its activities in many different ways. These can include having a noticeboard in the practice on which can be displayed such items as:

- the role of the PPG;
- the PPG membership;

- the minutes of full PPG meetings;
- the database of evidence;
- a newsletter;
- results of surveys;
- information on practice-based initiatives;
- feedback; and
- information updates.

This information is kept up to date and therefore changes over time. The PPG also engages directly with patients by talking to them at flu clinics, through organising surveys, by having informal chats in the waiting room, by networking with specific groups such as new patients, by discussions at PPG meetings and at talks given by the doctors.

The PPG has developed a webpage linked to the practice site. We also produce fliers about specific subjects and a newsletter. As well as displaying these on the noticeboard, they are handed out at appointments or to patients collecting prescriptions. All actions undertaken by the PPG are recorded on a simple database, showing evidence of the impact on patients and on the practice. This helps to support the evaluation of the effectiveness of the PPG and it can also help the practice to demonstrate accountability.

Responsiveness of practice

For participation and involvement to be effective and for the PPG to have any impact on services, a practice must ensure patient-centredness by making certain that any reform or changes support the needs of its patients. It must engage with them in the earliest stages of a planning process and be prepared for, and open to, changing direction after consultation if there is substantial disagreement over plans.

Our own practice can be described as being proactively responsive. Some examples which show that this practice takes patient

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participation and involvement seriously are as follows:

- The PPG was established at the request of the practice.
- Secretarial facilities are provided for the PPG by the practice and are available throughout the year.
- Members are provided with a room for informal meetings and refreshments are always on hand.
- Each year, the General Practice Assessment Questionnaire (GPAQ) report is presented to the PPG by the practice manager for comment and action plans are then shared with the group for discussion.
- There is early consultation with the PPG on all new initiatives and their development.
- GPs give talks on topics of interest to PPG members.
- A branch surgery was re-opened in an area with a greater concentration of elderly, disabled and more disadvantaged patients, in order to improve accessibility.

As a final illustration of our work, the PPG chose to conduct its first piece of patient research – which concerned the provision and location of services – by surveying patients face-to-face. The group felt that this method could achieve a wider representation of patients' views than those resulting from the distribution of a questionnaire. It would also give members the opportunity to promote the PPG and make patients aware of its existence; as a direct result, a new member was enlisted.

We decided to spend a full week in the surgery talking to patients in the waiting area before their appointments to see a GP or nurse. Despite the focus of the questions being very explicit, members were also given unsolicited feedback on other issues by patients. These were reported to the executive partner who requested that

the PPG chair presented them, including actual quotes from patients, to the senior management team at the practice.

The PPG could see the benefits in this and, having been assured it would not compromise his relationship with practice staff, the chair duly delivered his PowerPoint presentation, which included the results of the original survey. The concerns were collated into six topics: appointments; reception; GPs; the waiting area; car parking and other areas. The issues raised were addressed by the practice and updates on the progress of actions taken have been given at subsequent PPG meetings.

The second example: a rural PPG

The second example of a PPG at work comes from a very different setting, in rural Somerset.

Getting started

Don't do what we did and spend endless meetings in the early days discussing mission statements. The mission will evolve; all practices are different and so are all PPGs. To the Government of the day: please note that one size rarely fits any, let alone all. The mission cannot be pre-determined. Many evolving PPGs must reach an early stage when they meet and sit and think, at first to themselves and then out loud, "What on earth are we doing here?" but the true purpose of the group will emerge and develop in time.

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Prioritising

PPGs must learn to distinguish between issues that should be resolved and issues that can and should be defused. For example, the old surgery in Dulverton, which we may have left by the time that this article is published, is accessed from a narrow pavement and through a narrow alleyway between terraced properties. Wednesday mornings were designated for rubbish collection and, like all good citizens, the surgery staff for many years carried all their black sacks out to the curtilage of their property, ie the pavement end of the alley. Practice staff were blissfully unaware of the extremely hazardous problem this posed for people using walking aids (especially frames) and those who are visually impaired. As for ourselves, my wife is permanently in a wheelchair and we simply did not make appointments for that day until after the collection had been made! It took some time for the PPG to get the practice manager and the local authority to resolve this issue.

Perseverance

On the other hand, we do not learn even now when to give up. Recent PPG meetings have been dogged by discussion on the packaging of some disposable aspirins, which are difficult to open and tend to “self-disperse” in the process. We even contacted the manufacturer, Bristol-Myers Squibb, a pharmaceutical company of some standing, which kindly advised us that its packaging met all appropriate EU legislation but that the patient “could always ask for the drug to be dispensed in a bottle”. Try telling this to a hard-pressed dispensary if you want to be really appreciated. This, however, is an example of an issue where it is advisable to attempt to placate members and move on to numerous other pressing matters.

The bigger picture

There are much weightier matters in which to be involved. Much of our work has concerned the following:

- out-of-hours services
- ambulance response times
- generic prescribing
- patient transport
- the Choose and Book service.

Choose and Book, disastrous when launched, chose to ignore that our practice area borders and encroaches into Devon, where there is a good district hospital within easy reach of a proportion of our patients. Out-of-hours services likewise will now call on the Devon service when it is more appropriate and the dispatcher remembers. Both the PCT and the South West Ambulance Service have provided us with speakers for open meetings, which have been both illuminating and helpful. I believe it is incumbent upon PPGs to include improving patients’ understanding of the services they receive under “public involvement”. People complain less when they understand more.

Meetings

PPGs bring a variety of skills to the table – the skills will be different for every group, as will be the needs of every practice. Our PPG has drifted into an area of conference management: organising meetings about the new building, the recent ‘dispensing doctors’ crisis and general health prevention and healthcare. These all portray the practice in a positive light and the PPG relieves hard-pressed and limited numbers of surgery staff from the chore of setting up and running such events themselves. These open meetings, usually held in the evening, generate an attendance of between 100 and 150 patients, where the GPs have an opportunity to meet them in a non-consulting-room environment. The doctors

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have the chance to talk at some length on specific subjects and to hear the responses from patients at first hand. A great deal of mutual understanding can result from these meetings, provided that GPs can learn to speak more slowly and provide some literature to take away to ensure that messages are not all too quickly forgotten.

Feedback to practice

Sometimes feedback relates to minor irritations and, to some extent, this is what the practice fears most – being required to debate matters that they think they have fixed, have no intention of fixing or hope will go away if they ignore them for long enough. I am talking about waiting times, telephone response times (the PPG has often heard “It’s all very well being told to ring in the morning for an urgent appointment that day but I can never get through”), opening hours, and even whether they play music in the waiting room and, if so, what type of music. This is something like conducting a running audit of the annual patient survey (though with additional, unexpected responses) and enlightened practices should realise that when these queries start to diminish they are beginning to get it right.

Other work

Our PPG is involved in the running of flu clinics, with which many other PPGs seem to get involved these days. We run two whole-day events in the town hall and three separate afternoon events in remote villages on the moor – all excellent opportunities to meet with other patients and stakeholders. This year, we are thinking of combining the town hall flu events with displays and advice on all aspects of care for the elderly.

Currently we are maintaining a very close watch on patient transport, where responsibility is being transferred from the Ambulance Service to the county council without, we hope, a reduction in the service

or entitlement. Our next project is seeing if we can set up a Weight Watchers-type activity at the new surgery and combine it with the growing interest in “healthy walking”. This fits in with a lot of national directives on the subject of body mass ratios, as the nearest commercial outlets catering to the wish to slim require on average a return journey of around 30 miles for most of our patients.

Working in partnership with the practice

The PPG’s most recent project saw us running a successful campaign to save the practice dispensary, in close collaboration with the GPs. This was a major exercise involving all the patients, the county, town, district and parish councils, the Dartmoor National Park Authority, a miscellany of figures prominent in the NHS, the press and every MP or member of the House of Lords who was foolish enough to put their head above the parapet. The message to two standing-room-only meetings in the town hall, that the dispensary must be saved, was reinforced at the flu clinics, which were running in parallel.

Conclusion: the future

After outlining the current situation with regard to PPGs, and describing how two diverse PPGs work in partnership with their practices for the benefit of patients, it is important to look at the long term and envisage the future. Support from the medical profession for PPGs continues to increase and consequently there are a growing number of practices that have PPGs. The next stage is to create local area cluster groups of PPGs, which will have a greater role to play in Practice Based Commissioning.

Through PPGs’ face-to-face engagement with the end users of healthcare services, patients are likely to reap dividends in services that are well matched to the needs of each local community.

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The NHS is now committed to encouraging the growth of PPGs and overcoming any resistance to such ventures. PPGs merit a much higher profile, as well as closer liaison with – and greater support from – the PCTs. Patients should be closer to the centre of the NHS and their contributions could be extremely valuable, but much work on the mechanisms is still necessary to achieve this aspiration. We have shown in the examples of our two PPGs that when there is a problem to be solved or a need to be fulfilled, we can work alongside the practice and reach satisfactory conclusions.

Nevertheless, one is still conscious that there can sometimes be a desire on the part of the practice for extended periods of hibernation from the PPG. Much imaginative and lateral thinking is needed before public involvement in the NHS becomes a permanent, effective fixture. Yet the NHS is for all of us, used by all of us and paid for by all of us. We should all participate and be involved in its future developments.



2. The Practice Manager Perspective: An asset that every practice should have on its books

Amanda Sayer (Managing Partner, Lighthouse Medical Practice, Eastbourne, and Patient and Public Involvement Lead for the NHS Alliance National Steering Group for Practice Managers)

Sandra Gower FRCGP (Hon) (Managing Partner, Bennetts End Surgery, and NAPP Trustee)

- **PPGs can make a major difference to practices and help to deliver much-needed cultural change**
- **PPGs can also help with revalidation and practice accreditation requirements**
- **Practice managers are critical partners if PPGs are to succeed**
- **Practices' earnings can be maximised by working with PPGs in order to meet national access targets**
- **Practice managers' fears need to be addressed and they need support and information in order to establish good PPGs**
- **Practices can work more effectively with the local community by working in partnership with a PPG**

Introduction

This section offers ideas, information and insight into PPGs and looks at the benefits for practices of working with patients and the public in this way. Written by two very experienced practice managers, Amanda Sayer and Sandra Gower, it includes an overview of national policy documents recommending the involvement of patients and the public in healthcare at national and local level. It also considers the challenges relating to establishing a PPG in every practice, together with examples from the

authors' own practices of how PPGs have helped them to become more responsive.

Why practice managers should encourage PPGs

In order to provide the high-quality responsive service that is so important for both managers and patients, it is essential to have the right balance of key ingredients that combine to produce a professional and innovative practice. These key elements are:

- clinical safety and quality;
- public acceptability and patient experience; and
- financial affordability and sustainability.

In each of these areas, patients have much to offer. As users of the practices, patients' views on safety and quality should be taken very seriously. Equally, their assessments of the acceptability of the services offered and the ways in which public money is spent should be influential. In short, sound and informed decisions cannot be effectively made and implemented without the support of patients. High-quality services are best delivered when patients and professionals work constructively together.

In 2008, the National Association for Patient Participation (NAPP) celebrated its

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thirtieth anniversary and the achievements of PPGs over those decades.¹ NAPP argued that PPGs have even more to offer their practices but it also challenged professional practice managers to support their successful implementation. It is clear from NAPP's research that practice managers are now critically important to the success of PPGs. Today, we would go one step further by recommending that in order to support and sustain successful patient participation, there needs to be an effective PPG in every practice.

Why is there not a PPG in every practice?

While innovation and dedication to patient participation does exist in practices around the country, it is not as widespread as it should be. We should be asking why front-line surgery staff (GPs, nurses, managers and receptionists) are so frightened of engaging in meaningful dialogue with patients. What are the barriers?

One possible explanation is that a culture of criticism and blame has developed in the NHS that makes staff feel vulnerable. However, if that is the case, there is a paradox as many national polls show how much the public value their GPs and the services offered in the practices. Another possible explanation is that organisations sometimes struggle with the concept of involving users, in this case the patients. Practice managers, or their employers, may not see helping to establish and sustain a PPG as a priority in the target-driven everyday business of managing a practice. Where this is the case, cultural change and the acquisition of new skills will be required in order to see the advantages of having a PPG – advantages that may not be immediate or even obvious.

A further barrier to the successful introduction of PPGs is that practice staff do not always perceive patients as potential colleagues (and, indeed, vice versa). Some practice managers can only think of the "heart sink" patients, patients perceived as "trouble makers" and those with very focused single issues. Fear of awkward or unrepresentative patients is a commonly stated barrier to initiating a PPG.

Given these potential barriers, it is understandable that some practice managers may simply be overwhelmed and not know where to start. However, these managers need to begin to change and to understand the added value that working with a PPG can bring to the practice. They need to appreciate that patients within their practice will have skills and knowledge that can be used constructively for the benefit of the practice and its patient population.

Reasons for a PPG in every practice

Responsiveness and improved communication are essential concepts for both a successful practice and a successful PPG. The PPG needs to be responsive to the views of the wider practice population and the practice should be responsive to the PPG. This means that the practice will listen to the views of patients, as captured by the PPG, and address them. Moreover, a successful PPG will involve regular communication between practice staff and patients, providing an opportunity for staff to explain to patients the reasons why services have been set up in a particular way and why certain procedures are carried out. Once all views are heard and understood, then a mature discussion can take place with the opportunity to change procedures or routines. A responsive PPG in a responsive practice may look at a number of issues, including:

1 *More to Offer* (2008) National Association for Patient Participation

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- appointments systems and consultation times;
- the provision of practice information;
- first-aid training for volunteers;
- health promotion events and healthy social activities;
- voluntary transport;
- establishing a carers group;
- lobbying on behalf of the practice and its patients;
- possible fundraising activities, for items like a refreshment machine;
- contributing to, or producing, the practice bulletin or newsletter; and
- commissioning decisions.

The practice can help the PPG to become more widely representative by helping with recruitment through advertising in newsletters, use of posters and other practice literature, as well as through personal invitation. It is helpful to have members from a diverse number of groups, including:

- high-volume users of the system;
- expert patients;
- a mix of age, gender, ethnicity;
- people living with a disability;
- people involved in community groups;
- those with an awareness of wider health issues; and
- those with personal experiences.

A responsive practice should gradually support the PPG to develop. The ultimate aim is for the PPG to lead, not the practice. This requires careful planning to ensure that while letting go of the reins, the practice still maintains an active interest, with practice staff attending PPG meetings and remaining an active partner. For this to happen there needs to be mutual trust and respect.

Just as with the previous section, we now look at two contrasting PPGs, but this time from the practice manager perspective.

The first example: a south coast PPG

In Eastbourne, the formation of a PPG at the Lighthouse Medical Practice has brought about a huge cultural shift – from an “us and them” scenario to a united team of patients and practice staff working towards a single vision. The PPG has developed from a group of people meeting to discuss the patient survey into a living and breathing part of what makes the practice work. The PPG and the practice are there to help and support one another. The Lighthouse Medical Practice PPG has:

- taken control of the surgery environment, reorganising the waiting room and noticeboards, updating posters and producing clearly themed areas;
- served to meet and greet patients on busy days (including flu clinics), helping with queues, teaching other patients to use the touch screen check-in systems and gathering comments, criticisms and compliments. They chat to other patients and obtain real and meaningful feedback;
- organised an Intercare project collecting, sorting and sending medicines to developing countries;²
- created and administered patient surveys in order to get detailed feedback on specific issues, such as telephone access to the surgery;
- co-ordinated and produced joint practice/patient newsletters;
- planned and delivered awareness days, such as a Diabetic Day and a Falls Awareness Day;

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- worked on commissioning ideas, plans and projects, coming up with proposals for service improvement and feeding into practice plans;
- participated in local PCT committees and focus groups, influencing the health issues and priorities of the local area;
- begun work on producing patient-specific leaflets for areas that it feels are not adequately covered currently, such as bereavement;
- supported other local PPGs and worked jointly on linked projects; and
- influenced practice decision making on issues such as the purchasing of equipment and the spending of monies from commissioning savings (following the redesign of wound care, the PPG has been given £30,000 to spend on improving care for patients within the commissioning group).

The PPG is financed by the surgery but the total cost has been no more than around £200 over the past three years, which has been spent on things like hire of halls and printing of leaflets. However, the PPG is now looking at fundraising as a way to have more money available in the future.

The PPG is a precious resource for the whole practice team. It relieves hard-pressed staff of some everyday tasks and has also helped the practice to understand the gap between its own perceptions of patient need and the patients' own views.

In the words of Mahatma Gandhi, speaking in South Africa in 1890:

“A customer is the most important visitor on our premises. He is not dependent on us. We are dependent on him. He is not an interruption of our work. He is the purpose of

it. He is not an outsider of our business. He is part of it. We are not doing him a favour by serving him. He is doing us a favour by giving him the opportunity to do so.”

The second example: a large Hemel Hempstead practice

In Hemel Hempstead, the benefits of a PPG have been demonstrated for the last 22 years by the Friends of Bennetts End Surgery. Effective partnership has led to new and improved services to meet identified patient needs, such as the introduction of a Citizens Advice Bureau clinic in the practice.³ In addition, the PPG:

- has worked with the practice team to pilot and introduce the first confidential touch screen automatic check-in system for patients – a system rolled out nationally in 2008;
- manages a minibus transport service for patients to reach the practice;
- provides a warm and friendly welcome, by serving refreshments from a special kitchen area in reception;
- addresses priorities jointly with the practice team, for example by promoting the annual Carers Week and by supporting the national ‘Nothing registered, nothing gained’ campaign as well as self-care;
- has attended the training for lay assessors at the Royal College of General Practitioners (RCGP), facilitated by the RCGP and the Institute of Healthcare Management, and has contributed to the assessment of quality initiatives; and
- acts as a resource for other patients and managers, helping to set up PPGs in other practices and sharing its experience and good practice, including a clip about its work on YouTube, filmed by the National Association for Patient Participation.⁴

3 Gower, S, A Beacon of Cooperation, *Health Management*, 23 October 1999

4 www.youtube.com/watch?v=jxNcJ7Z4Nlw

The Practice Manager Perspective

The legal and policy framework

Many practice managers have committed themselves to ensuring that patients are at the heart of professional primary care management.⁵ This commitment is sustained throughout their career development and was a central theme in the first vocational training scheme for general practice managers.⁶ Its importance was captured by the NHS Director General of Workforce Planning in her assertion that “once you recognise it starts with the patient and high quality care for all, you are less likely to take a functional, siloed view of things”.⁷

This partnership model has been supported and encouraged by various legal and policy developments in the past few years. In 2004, the Quality Outcomes Framework (QOF) formally introduced patient surveys into primary care and incentivised practices to discuss the findings with their PPG. The 2009/10 removal of the practice-based survey from the QOF is a real opportunity for practices to work with their PPGs to undertake local surveys in areas that are of most importance to them.

At the same time, the revisions to the QOF in 2009 mean that practices will have a strong financial interest in working with their PPG to ensure that their 48-hour and advanced booking arrangements are the best possible. Of course, practice-specific surveys (as contrasted with the national Ipsos MORI survey) are the only way for individual clinicians to get detailed feedback on how they are seen by patients. These will be particularly valuable with the revalidation of all doctors on the near horizon. PPGs can help practices in the design and the

administration of the surveys, helping and encouraging patients to complete the forms, especially those who would not normally bother to do so. Such feedback will be of great assistance to the practice manager who wants to deliver the best possible services.

The broader policy context is that, since the 2000 NHS Plan, the Government has been committed to a health service that is designed around the patient.⁸ Subsequent publications have consistently stressed the themes of patient-centred services and patient-led reforms. Among other things, this means giving people access to more information, more support, greater choice and a stronger voice in the ways that services are provided. The thrust of government policy is about creating a profound shift in culture and attitude, regarding patients as genuinely equal partners in all healthcare encounters.

The aspiration to listen more to the views of patients and the public was given legal force in Section 11 of the Health and Social Care Act 2001. This has now been amended by Section 242 of the consolidated National Health Service Act 2006, which places a duty on NHS trusts, primary care trusts (PCTs) and strategic health authorities (SHAs) to make arrangements to involve patients and the public in service planning and operation, and in the development of proposals for changes. Subsequent guidance from the Department of Health has emphasized the role that PPGs can play in meeting this duty, as well as the contribution that they can make to improving commissioning.⁹

The 2009 NHS Constitution reaffirms that patients have a right to be involved in

5 Gower, S (1997) AMGP Code of Principles, *The Primary Health Care Management Handbook*, Kogan Page, pp89–97

6 Foster, R and Gower, S, The Quiet Revolution, presentation to the Institute of Healthcare Management Annual Conference in 2006, www.ihm.org.uk/_files/documents/147/SandyGower&RoseyFoster.ppt

7 Pickard, J, A Healthy Constitution, *People Management Magazine*, 29 January 2009, pp20–3

8 *The NHS Plan: a plan for investment, a plan for reform* (2000) Department of Health

9 *Real Involvement: working with people to improve services* (2008) Department of Health

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planning and developing services provided by the NHS.¹⁰ In addition, there are new opportunities for the use of real-time patient feedback (using hand-held devices, for example) and the new NHS and social care complaints system came into effect from 1 April 2009. Putting all of this together, there is no doubt that the time is right for practice managers and patients to work more closely together.

The wider context

The retail and other commercial sectors spend millions of pounds every year to find out about customers' wants, needs and aspirations in order to retain a loyal customer base and thus achieve increased turnover and profit. This is done through market research, customer focus groups and talking directly to customers/service users. In the words of Stephen Ballmer (Microsoft chief executive officer), "We can believe that we know where the world should go. But unless we're in touch with our customers, our model of the world can diverge from reality. There's no substitute for innovation, of course, but innovation is no substitute for being in touch, either."

The endeavour to meet wants, needs and aspirations is made more complicated by the fact that they are constantly changing and practices tend to lag behind them.

As noted in the British Journal of General Practice in January 2009; "Society is changing; we now live in a post-modern, consumerist world. Patient consumerism is endorsed by current political attitudes, which support immediate access to healthcare."¹¹

Making it happen

So, the work is important and the legal framework is fairly developed, but managers in primary care need supporting in the area of patient and public involvement. They need practical guidance, training and development in how to work with patients. Shared learning with patients, too, would be beneficial for both the professional manager and the patient representative.

The NAPP website (www.napp.org.uk) hosts a range of resources that should be helpful to practice managers who wish to set up and develop PPGs. In addition, resources have been prepared as part of a national campaign to promote PPGs that brings together the British Medical Association (BMA), the Department of Health, NAPP, the NHS Alliance and the RCGP.

Conclusion: future challenges for practice managers

We hope that future governments don't just tick the boxes with patient surveys on pieces of paper. We hope that they will make PPGs mandatory in every GP practice in the country, by creating a directed enhanced service or a local enhanced service with funding to support the setting up and running of PPGs. Not only will this kick-start some surgeries into action, but it will give much-needed recognition to the patients and practices who are already working together to create a better service for everyone. There are very many reasons why creating and working with PPGs in general practice is hugely beneficial; there are only excuses when it comes to not creating meaningful engagement.

¹⁰ www.dh.gov.uk/en/Healthcare/NHSConstitution/DH_093184

¹¹ Moore J, A consideration of the qualities of a "good" doctor with some help from the humanities, *British Journal of General Practice*, January 2009

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The role of the practice manager is becoming increasingly challenging as a result of national policies to promote choice and competition within primary care. In many areas of the country there are demographic changes – increasing numbers of older people; patients living with complex long-term conditions; and greater ethnic and linguistic diversity. There are also major public health challenges, such as obesity and drug and alcohol misuse.

Effective practice management now needs to be able to see the bigger picture. From 2011, practices will have to meet 16 essential standards of quality, safety and registration with the Care Quality Commission under the Accreditation for Practices. How can a practice manager successfully achieve accreditation without the support of a PPG? We strongly recommend that practice managers start talking to, and working with, their PPG about accreditation.

The benefits of a PPG include those relating to learning, with an improved understanding for practice managers of what service users and carers think about the quality of the services they receive. However, shared learning also means giving patients the opportunity to learn about the work of the practice manager as well as about what can be achieved by working together. Such shared learning contributes to the development of trust and confidence between patients and the primary care team.

Practice managers are carrying out excellent work in forging strong links between practices, patients and even the wider community. But now is the time to spread this to every surgery in every setting. The benefits of PPGs will take time to filter through to every surgery and to the wider patient population. However, with the foundations in place, practice managers, their surgeries and patients will see significant change and improvement.

A PPG can become the eyes and ears of the practice and a base for tackling future improvements. With the encouragement of practice managers, PPGs can help to forge links with the wider community, to promote healthier living and greater health awareness, to recognise the needs of carers and to manage change in a way that generates confidence among both staff and patients. Services may come and go, change and adapt but practices will always have patients. It is time to invest in the future of primary care and in a patient-led NHS.

In the words of Winston Churchill, when receiving his honorary degree at Harvard in 1943:

“If we are together nothing is impossible. If we are divided all will fail.”



3. The GP Perspective: Experts meeting together on a new level

Dr Has Joshi, Vice Chair, Royal College of General Practitioners (RCGP)

Dr Brian Fisher, MBE, GP and Patient and Public Involvement Lead for the NHS Alliance

- **Well-established PPGs demonstrate just how much can be achieved by integrating patients in the life of the practice**
- **PPGs can help GPs to communicate accurately and honestly about key health matters**
- **PPGs support the changing relationships between patients and their doctors**
- **Constructive patient feedback, pulled together by the PPG, will help practices to be more responsive to patients' needs**
- **Wider models of patient participation should be considered, reaching out beyond the PPG committee**
- **Doctors need to support and value PPGs so that they can both reach their full potential**

Introduction

There are currently several words for patients used by civil servants, politicians and the media, including 'customer', 'client', 'consumer' and 'stakeholder'. The same group of people use the terms 'empowerment', 'engagement', 'choice', 'involvement' and 'patient centredness' to describe what the NHS should be aiming to achieve in its relationship with patients. However buzzwords may change to reflect new trends, the importance of the doctor–patient relationship remains.

Nowhere in the NHS is this relationship more crucial than in general practice, where patients have long valued the relationship with a GP and the continuity of care that has been offered.

In this section two well-known GPs, Dr Brian Fisher and Dr Has Joshi, describe the importance of PPGs to GPs as well as to the practice, and the ways in which PPGs can help the practice to be more responsive. They suggest different ways that PPGs can work, as well as how the practice and primary care trusts (PCTs) can support PPGs. The activities of some recent winners of the Royal College of General Practitioners (RCGP) Patient Participation Award are given as an Appendix on pages 36–37.

Changing relationships

There is no denying that the GP–patient relationship has changed dramatically compared from even a decade ago. While the provision of high-quality care remains the foundation of that relationship, today's patients want much more say in their own healthcare and the decisions affecting them – and rightly so. Gone are the days when the patient sat passively while the GP worked out what was wrong.

Developments in primary care – coupled with what's happening in the wider world, such as the growth of internet use – mean that

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people are taking much more of an active interest in their own healthcare needs and they are much better informed when they visit their local GP. Patients don't want to be viewed as a condition or ailment; they want to be treated as people – as a whole person – and as equal partners with members of the GP team who provide their care.

Despite (or perhaps because of) the ticking time bomb of obesity and its knock-on effects, we are all becoming more aware of disease prevention and the need to protect ourselves from getting ill in the first place. We're now just as likely to attend the GP surgery for preventive care, such as blood pressure and cholesterol checks, as we are to be "patched up" when we're sick.

Today's relationship between GP and patient is much more equitable, with both parties aiming for a mutual agreement on diagnosis, options for treatment and the choice of how that treatment is implemented. With 90% of NHS patient contact provided in primary care – over 1 million consultations and 1.5 million prescriptions issued per day – GPs, their teams and their patients are in the best position to be leading the developments in this crucial relationship.

GPs listening to patients

GPs recognised a long time ago that we and the whole NHS can gain a great deal from using the experience of patients to improve the way we run our current services and how we shape the delivery of services in the future. We appreciate that patients have very different and varied lives and many skills – skills that can be used to help practices run more effectively and provide services that local people need and want. It's also worth remembering that underneath it all, doctors are patients too – albeit some of the worst kind! – and that our approach to the care and treatment of our patients should be of

the same high quality and respect we would expect for ourselves and our families.

PPGs and the RCGP

The objective of the RCGP is "to encourage, foster and maintain the highest possible standards in general medical practice", an objective shared equally by patients. The RCGP was the first medical royal college to set up a patient liaison group, a form of PPG, in 1983. The lay chairman of the group sits on the RCGP Council, and lay members of the group are represented on most RCGP committees. The views of the group (which is composed of both lay and GP members) are sought on many topics, influence consultation responses and are included in press releases.

For some years, the RCGP has also been running a Patient Participation Award aimed at encouraging the development of patient participation in general practice within the UK. The RCGP is grateful to the late Nancy Dennis, a former RCGP patient liaison group chairman, who donated the fund to establish the award used to benefit the patients of a practice or to further patient participation. The award is presented every year and comes with a financial incentive. More information about the award can be found at www.rcgp.org.uk

Award-winning PPGs have developed projects that reflected the needs of their patient population and, sometimes, the wider community. These projects, some of which are described in more detail in the Appendix, include:

- running health promotion activities;
- assisting with lifestyle changes;
- running exercise classes;
- supporting carers;
- organising transport;
- working with teenagers;

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- producing a newsletter for patients; and
- working with the ethnic community.

The importance of PPGs to GPs

GPs and patients share the same objectives. Patients want accessible care, high clinical standards and safety. They wish for time for communication and to share decisions, and they would like their care to be given in a supportive environment.¹² The clinical relationship between the GP and individual patients in the consultation does not necessarily provide the appropriate opportunity to discuss the wider issues often raised by PPGs.

For GPs, the PPG can provide a different and more efficient way of linking with the whole patient population, making it easier for both GPs and patients to raise issues that may be seen as uncomfortable to the practice or to the individual GP.

The importance of PPGs to practices

PPGs can bring significant benefits to the practices which have them: reducing costs, improving services, allowing resources to be used more efficiently and, most importantly, developing mutually supportive networks outside the GP or nurse appointment. They help the practice by enabling GP teams to be proactive in providing services that truly reflect what patients want and need. Some PPGs aim to benefit wider patient care within a practice, for example by arranging transport for older or disabled patients or by running self-help groups, such as weight management sessions. Others embark on fundraising drives to buy useful medical equipment or improve local amenities.

PPGs can also play a helpful role in separating the “wheat from the chaff” in the deluge

of information about health issues. Some use their regular newsletters to fulfil this important function.

One thing that all good PPGs have in common is that they develop and strengthen the patient–doctor relationship to make it a more effective partnership. It is important, therefore, that they exist and that all practices have them.

PPGs aiding responsiveness

It can be seen from the examples of the most successful PPGs in the RCGP awards that the majority of them focus on supporting the healthcare functions of their practices. They organise screening events and teaching events, they fundraise for the practice. They become advocates for the practice and the services provided. These are valuable and needed facilities.

However, one aspect that we highlighted earlier in the section – aiding feedback and responsiveness of the practice as a whole – can be less evident. This function is no more complex than running health promotion events or improving communication, but it seems to happen less frequently. There are other examples, of course – PPGs help to select staff members of their surgeries, they organise feedback sessions, comment on the patient survey results and have made significant changes to the priorities and direction of surgeries.

Some PPGs have influenced decisions that staff members have found too hard: one practice was not sure how to deal with patients who are not entitled to NHS care – the PPG was able to make an informed and thoughtful decision that the practice was able to implement. In addition, there are PPGs that have been involved in helping the practice to commission services, as part of

12 Roland, M (1999) James Mackenzie lecture 1998: quality and efficiency: enemies or partners?, *British Journal of General Practice*, 49(439): 140–3

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the practice's Practice Based Commissioning role. This is sophisticated work that involves understanding of finances and alternative pathways of care and trade-offs between different options. But this aspect of their work is less common and less rigorous in many cases. Being a critical friend can be hard and is not always appreciated by the practice.

PPGs can have different structures

Many PPGs begin with regular meetings attended by members of the practice. Often the practice starts the group by selecting members who they think can help from among the patient population. The PPG slowly gets things done, and can become stronger and less dependent on the practice.

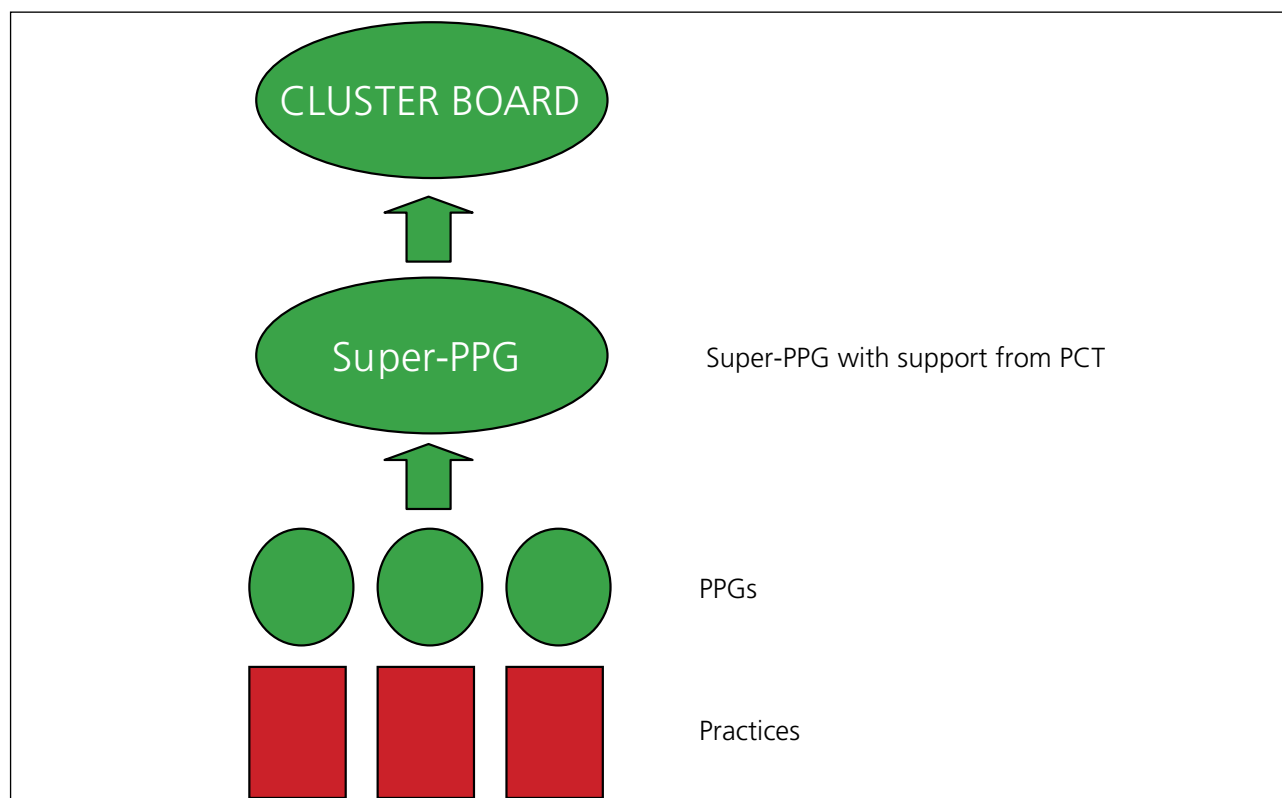
There are disadvantages to this design, too. The group can become less representative of the local population and can drift towards semi-retired people who have more time to spare. Sometimes PPGs can become

somewhat institutionalised, supporting the practice and becoming progressively less critical.

One alternative is to design a group on a slightly different basis: a panel. The practice contacts a random, representative sample of its patients and requests that they consider themselves a virtual group. Their main job is to respond to questions posed by the practice, essentially acting as an advisory group. In addition, they are also asked to meet, but less often than a traditional PPG. They are encouraged to develop their own agendas at these meetings and to offer criticism, in order to enable the practice to improve.

The advantages of this approach is that a wider group becomes available; less of a commitment is required, so more people tend to get involved and they are more likely to be representative of the practice population. The disadvantages are that: the panel can be led by the practice, which asks the questions;

Figure 1. A Practice Based Commissioning model



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and people do not know each other so well, so do not feel involved and eventually drift away. A mix of PPG and panel may combine the strengths of each approach.

PPGs working together

While PPGs are primarily concerned about what is happening in their own surgeries, it can be valuable for them to link to other PPGs in the local area to pool resources and expertise, perhaps to organise wider public meetings on issues of local concern or to discuss the local slant on national issues, such as planning for pandemic flu or NHS reform. There are a growing number of examples of this around the country. We hope that this will become a more common approach, particularly as practices are beginning to work more closely together on Practice Based Commissioning. Figure 1 shows one model that is promoted by the NHS Alliance/Humana Practice Based Commissioning Academy.

Using this model, PPGs can help practices by advising the Practice Based Commissioning board on key aspects of the commissioning agenda, for instance on:

- the priorities of the board;
- the difficulties that current pathways pose to local patients;
- new approaches that might work better;
- the acceptability and maybe the effectiveness of the changes; and
- how to spend any savings that may have been generated.

There is another key relationship that may be important in the future – that with local involvement networks (LINKs). These umbrella bodies are likely to have increasing influence over patient involvement in every locality in England. PPGs and LINKs need to get together and use their mutual interests to support practices and commissioning groups

to engage with their local communities on sharing decision making.

How the practice can help the PPG

The dynamic that sees GPs and patients interact is an evolutionary one, and the involvement of patients and increased patient satisfaction levels are huge motivators in delivering wider improvements in healthcare. PPGs are important if GP practices are to run successfully, maintain high standards of patient care and keep up their energy. But even where there are established groups, practices must never become complacent.

Practices can always do more to ensure that all patients have a forum that makes them feel comfortable about coming forward and that PPGs are representing the views of the majority of patients. Wherever possible, we also need to ensure that membership reflects the age, gender and diversity of the local population. It is hard to accommodate everyone, but we need to be aware of factors such as making sure that transport is arranged or meeting times are flexible. Older people might be reluctant to attend evening meetings as they are worried about being out in the dark, while busy working parents are unlikely to have the time or inclination to participate if meetings are always held in the afternoon.

Teenagers are notoriously hard to engage with, as when you're young, fit and able-bodied, you hardly ever have to visit your GP. So we need to reach out and communicate with these young people in language that they understand – after all, they are our drivers of healthcare services in the future.

Practices must make sure that they publicise what they are doing and what they have achieved. If you have arranged a baby massage clinic every Tuesday, make sure this information is widely available in the waiting room, so that other patients can see what

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you are doing – and it might encourage them to suggest other ideas or even join up.

PPGs are growing more ambitious about what they want to achieve, and wider engagement with local organisations can bring many benefits. Local charities are always keen to send their representatives to speak about their work – and might be happy to promote the existence of your PPG in return. While PPGs should remain non-political and non-partisan, local MPs are usually more than happy to talk to “real people” about health – especially coming up to an election – as patients and doctors are big target audiences for winning votes!

PPGs and resource implications

PPG members should not be out of pocket in carrying out their PPG work. It takes some person-hours to set up the group or panel in the first place and then to keep it going. It involves a small amount of finance as well. It is only right that expenses are paid, but speakers or food may also be required. The more a group takes on a life of its own, the better it will be for both the group and the practice. PPG members are a resource for the practice and their work should be valued.

How the PCT or Practice Based Commissioning groups can support PPGs

It can be hard for practices to start PPGs: they may be concerned at the extra workload or they may be scared that the patients will demand things that the practice cannot or will not provide. The practice may feel that involving patients is just not a priority.

Practices may be running a PPG very successfully, but it might be more productive if the PPG ran itself; if the PPG became more independent and proactive. There are a range of situations where a shift needs to be made. It is in the interests of practices, commissioning groups and PCTs that there are as many effectively functioning PPGs as possible. There is some evidence that more and more effective PPGs spring up when a PCT takes an interest in supporting the process.

Conclusion

Being a family doctor and being a part of so many people’s lives is an extraordinarily privileged role in society – but the best measure of success for the practice comes from the views of the people who use it. Patients have the most personal interest in healthcare, and GP practices need to have an approach to care that takes in the needs of the community and responds accordingly. It is also worth remembering that without patients, there would be no GPs, so it is in all our interests to work in partnership to develop this most special of relationships – and to get it right.



4. The Primary Care Trust Perspective: Building the foundations of patient and public involvement

Dr Graham Box MA DPhil (Oxon), Chief Executive, National Association for Patient Participation (NAPP)

- **Primary care trusts (PCTs) are required to work in new and different ways in order to be seen as World Class Commissioners**
- **PCTs should promote and support PPGs since they are a sensible, locally driven model to help deliver on these strategic requirements**
- **PPGs will help PCTs by improving communication, promoting the work of the PCT, organising health promotion activities, contributing to community development work and building social capital, and advising on service developments**
- **It is time for PCTs to work in a different way, engaging with communities at a far earlier stage in service planning and recognising that patients and the public are essential partners in “adding years to life and life to years”**

Introduction

This section draws together arguments from other parts of the document, together with some new ones, to explain why PCTs have an interest in promoting and supporting PPGs in GP surgeries. It is written by the Chief Executive of NAPP, Dr Graham Box, himself a former senior manager in a PCT. He argues that PCTs are being challenged to work in

new ways and he is convinced that PPGs should be part of that changing practice.

Background

Despite considerable legislative and policy activity over the past 10 years, referred to elsewhere in the document, patient and public involvement has remained a somewhat marginal activity. Although often led by managers with great skills and passion, the value of the activity has not always been recognised by PCTs confronted with reorganisations and financial pressures. This situation looks set to change with the World Class Commissioning framework that now requires a real commitment to engagement work as well as the broader policy thrust in favour of improving the patient experience and the quality of care (as determined, in part, by the patient).

World Class Commissioning

World Class Commissioning seeks to add years to life and life to years. It is structured in line with 11 competencies that PCTs will have to develop and demonstrate.¹³ These include:

- leading the NHS locally;
- working with community partners;
- engaging with public and patients; and
- prioritising investment to meet local needs.

¹³ www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/DH_083204

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PPGs have an important contribution to make in each of these areas. Telephone research carried out by NAPP (not yet published) indicates that patients and the public receive relatively little information about local health services at present. Communication often takes place through local media and can be biased towards negative/controversial stories. As a result, there is often a lack of understanding of the role of PCTs and their objectives.

It is difficult, in such a climate, for PCTs to be seen as leading the NHS, and new forms of communication are required. The more forward-thinking practices are already working with their PPGs to address this issue through production of regular newsletters that reach an impressively large proportion of the practice population. This allows information to be provided from a trusted source (the practice/GP), with editing and production by PPG members who thereby increase the likelihood that the material will be written in a way that interests and informs members of the public.

There is, of course, a cost involved in producing and distributing newsletters. PCTs need to see the value of this communication model and to be prepared to subsidise the work of the PPG in this area in return. Yet, the costs could be substantially reduced if practices were encouraged to collect email addresses for their patients on a consistent basis. The evidence from NAPP workshops with practice managers suggests that this is still not normal practice. It is a real missed opportunity. Subject to suitable consent being in place, PCTs could use this email network to send occasional messages direct to very large numbers of people.

World Class Commissioning, quite rightly, stresses the importance of PCTs working with community partners. Given that around 40% of English practices now have a PPG, this must include working with PPGs. Indeed,

if every practice had a PPG, the PCT would have access to a geographically broad base of community members, all with a general interest in health, and especially in primary care.

Not only that, many PPGs have very good networks into their wider communities. They can help to place articles into local publications (such as village, town or parish council magazines), they can suggest the best meetings for PCTs to attend if they want to consult, and they can signpost to the key community organisations and opinion leaders. Through these mechanisms, PCTs can develop relationships with organisations that are already doing a great deal to promote health. Working in this way will also increase the chances of learning from, and supporting, the carers who make such a contribution to the work of the NHS.

Engaging with patients and the public is not straightforward. The sheer diversity of the audience is problematic, as is the lack of interest among those who rarely access services and are not receptive to preventive health messages. More pernicious is the weary cynicism that NAPP sometimes encounters from highly committed people who believe that consultations are designed to rubber-stamp decisions already made. So, there are some significant obstacles to be overcome before success can be achieved.

PPGs are not a universal panacea, and they certainly cannot shift the culture of PCTs, but they can act as intermediaries in the engagement process. For example, PPGs run health promotion events that convey valuable health messages to rather large numbers of people. By supporting this type of activity, PCTs will find that some of their engagement work is done for them at fairly low cost.

Equally, PPGs can be asked for their views in advance of decisions being taken. Early engagement of this type is critical to address

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the perception of formal engagement exercises as “done deals”. We need to move away from the situation whereby engagement takes place on the solutions to problems, both of which are defined by the professionals. Instead, we need a model whereby communities are full partners in identifying and understanding the problems themselves, before working in partnership with commissioners and providers to come up with solutions.

This way of working could make a real difference to the commissioning activities of PCTs and, especially, the work of practice based commissioners. Several PCTs and Practice Based Commissioning groups are already working actively with their practices to ensure that all, or nearly all, have PPGs. This then offers an essential foundation for engagement in commissioning, allowing patients and the public to say what matters most to them.

A network of PPGs can also help with difficult decisions about priority setting. First, PPGs are likely to have insights into making existing resources stretch as far as possible, cutting out waste and encouraging patients to access care appropriately. Second, they can help commissioners to think through the relative merits of different courses of action. Third, PPGs can help to communicate the complexity of some of the challenges facing the NHS, helping to increase trust in the system as a whole. Finally, by encouraging healthier communities, the activities of PPGs can reduce demand on the system as a whole.

Legal obligations: Section 242 of the consolidated National Health Service Act 2006

World Class Commissioning is not, of course, the only driver for PCT activity in this area. There is a legal duty (under Section 242 of the consolidated National Health Service Act 2006) on NHS trusts, PCTs and strategic health authorities (SHAs) to make arrangements to involve patients and the public in an ongoing manner in service planning and operation, and in the development of proposals for changes. As acknowledged in the national guidance, a comprehensive network of PPGs would help to meet this duty, as well as providing valuable insights, especially where the operation of primary care is concerned.¹⁴

NHS Operating Framework

PCTs are also required to implement the annual national operating framework, which in 2009/10 is called *High Quality Care for All*.¹⁵ PPGs have an important contribution to make across three of the five national priorities, namely:

- improving access through achievement of the 18-week referral to treatment pledge, and improving access (including at evenings and weekends) to GP services;
- keeping adults and children well, improving their health and reducing inequalities; and
- improving patient experience, staff satisfaction and engagement.

Best practice in each of these areas has seen PPGs:

- working with their practices to identify which additional hours would prove most valuable to those patients currently having difficulties accessing primary care;

14 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089787

15 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445

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- organising health promotion events in partnership with their practices (and other voluntary organisations, in many cases) and taking health messages out to where people meet (sports grounds, pubs and cafes, faith-based organisations, etc); and
- helping providers of care to understand what services look like from the patient perspective and how experiences can be improved.

Closing thoughts

As stated in the introductory paragraphs, PCTs are now required to work in a new way, developing skills and approaches that will forge a new relationship between the NHS and those who use (or may use) its services. The old culture of “Doctor (or manager) knows best” is no longer appropriate. Instead, progress requires partnership at each level: the individual consultation, the practice and the wider commissioning arenas. Optimal performance requires a major shift in joint working and the sharing of information and objectives.

The scale of the challenge is illustrated by NAPP’s 2009 Members’ Survey (not yet published), which showed that only a quarter (of the 135 PPGs that have replied to date) have received any help from their PCT. This help took the form of annual grants, organising PPG networking events, attending meetings and providing speakers for health promotion events, and responding to queries.

However, we are confident that, in future, PCTs will work more effectively with their PPGs as a result of World Class Commissioning, legal duties, the challenges facing the NHS and recognition of the immense goodwill and good sense of the PPGs themselves.

The NAPP message for PCTs is almost the same as our messages to practices, namely:

- put patients and PPGs at the heart of what you do and not the periphery;
- value and acknowledge the work of PPGs;
- recognise that patients will have skills and experiences that you do not have;
- work in partnership with patients and PPGs to improve health;
- use PPGs as a source of information and intelligence; and
- work with PPGs to improve communication with the wider practice population.

A PPG in every practice, producing information for patients, promoting health, advising on the patient perspective and influencing services represents a sound, sensible and effective method of achieving a National Health Service that is truly patient-led.

Essential References

**[www.dh.gov.uk/en/
Publicationsandstatistics/Publications/
PublicationsPolicyAndGuidance/
DH_089787](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089787)**

Department of Health guidance on the duty to involve and good involvement practice

www.napp.org.uk

The website of the National Association for Patient Participation

**[www.bma.org.uk/patients_public/
ppgintro.jsp](http://www.bma.org.uk/patients_public/ppgintro.jsp)**

The British Medical Association's web resource on PPGs in primary care

**[www.rcgp.org.uk/patient_information/
patient_partnership_group.aspx](http://www.rcgp.org.uk/patient_information/patient_partnership_group.aspx)**

The website of the PPG of the RCGP

**[www.rcgp.org.uk/councils_faculties/
rcgp_scotland/patients_p3/pg_tips.aspx](http://www.rcgp.org.uk/councils_faculties/rcgp_scotland/patients_p3/pg_tips.aspx)**

Web resource on PPGs developed by the P3 Group of the RCGP Scotland

**[www.nhsalliance.org/eventsAcorn.
asp?year=2008#](http://www.nhsalliance.org/eventsAcorn.asp?year=2008#)**

The website for the 2008 NHS Alliance Acorn Award winners for patient and public involvement

Appendix: Recent past winners of the Royal College of General Practitioners Patient Participation Award

Moss Grove Surgery, Kingswinford, West Midlands, 2008

The Moss Grove Surgery has had an active patient panel for 8 years. As well as over 50 patient panel members, it also has a satellite panel of 35 consultation members. It has organised a wide range of activities since its inception, including implementation and development of a patient library, quarterly patient newsletters, development of a home visiting, policy, and planning and implementation of twice-yearly health awareness events.

The patient panel has focused on the dissemination of information on health awareness to teenagers. It hosted a successful teen health awareness event, with information on healthy eating, health promotion, sexual health, drug awareness, dealing with stress and bullying, and smoking. The Patient Participation Award was used to develop the surgery's links with its teenagers. Following feedback from the event, the practice was also keen to develop a confidential teenage electronic health card system.

The practice also wanted to develop a visual display board to assist those patients with a hearing impairment and complement the loop system. This suggestion came from several patients and was an outcome of a patient survey.

The Mansfield Medical Centre, Coventry, 2007

The Mansfield Medical Centre Patient Panel had been running for 10 years when it received the RCGP award. It has 12 members on its panel (10 of whom are patients) and meets monthly to discuss ways of maintaining and improving services and information for patients. As a result of a survey carried out by the group, they worked with the practice to deliver a series of improvements suggested by users of the surgery.

The panel has developed a project to run "Self Care for You" courses to at least 48 people over an 18-month period, by training two people to run four courses lasting six weeks. These will be offered at different times of the day to suit participants' needs. They will enhance information already available at the surgery for patients by making use of resources. The aim will be to evaluate the effect of training on the participants' health and well-being.

The King Edward Road Surgery, Northampton, 2006

The King Edward Road Surgery PPG was formed in 1991. Its role has changed over the years from simply being a support group to being an active group seeking to contribute to the life of the surgery and to enhance the patient experience and patients' lives. In its application for the RCGP award, it proposed a "Waist Management Programme" that included:

- sending letters to every household with an adult registered with the practice, including a 1-inch-wide strip of paper with a mark for males at 94cm and for females at 80cm. Patients were encouraged to use this to measure their waist and if they exceeded the "health risk line" to contact the practice/PPG to participate in a "waist management day";
- "waist management days" promoting healthy eating and drinking, including cooking demonstrations and stands for local groups including the Bangladeshi Association, Afro-Caribbean Elders Society, Food for Thought and the Healthy Communities collaborative; and
- exercise demonstrations.

The Wilson Practice, Alton, Hampshire, 2005

The Wilson Practice PPG was established in May 2002. The practice serves approximately 15,000 patients in a small market town and surrounding rural villages. The Wilson Practice PPG is committed to supporting the practice to meet patient needs. The aims and objectives of the group are:

- to provide a means of communication between the patients, doctors and staff of the Wilson Practice;
- to provide a means for patients to make positive suggestions about the practice and their own healthcare;
- to encourage health education activities within the practice;
- to develop self-help projects to meet the needs of fellow patients; and
- to act as representatives to attempt to influence the local provision of health and social care.



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