



Growing Patient Participation

**A report of the East of England regional conference
held on 24th June 2010 in Cambridge**

Acknowledgements

The National Association for Patient Participation would like to thank everyone who attended this regional conference. We are grateful to NHS East of England and the Department of Health for supporting the event financially.

Special thanks are also due to those who presented, facilitated or organised during the day:

- Professor Simon Gregory (GP and Dean of Postgraduate Medical and Dental Training, NHS East of England)
- Rebecca Champion (Engagement Manager, NHS Norfolk)
- Candida Hepworth (Management Assistant, Bennetts End Surgery)
- David Levitt (NHS Bedfordshire), Jennie Fisher (NHS Suffolk) and Susan Last (NHS Cambridgeshire)
- Caroline Humphreys (Commissioning Manager, Primary Care and Practice based commissioning, NHS East of England)
- Wendy Bath (NHS East of England)
- Sandra Ferrelly (Charles Hicks and Roman Gate PPG)
- Mike Wilcox (Lansdowne Patient Group)
- Roger Gedye (Davenport House Patient Group)
- Edith Todd (National Association for Patient Participation)

Introduction

The third regional conference of the National Association for Patient Participation took place on 24th June 2010 in Cambridge. The keynote address was delivered by Professor Simon Gregory, a practising GP and Dean of Postgraduate Medical and Dental Training in the East of England. The afternoon session featured three PPG chairmen who described their activity and the day closed with a presentation from Caroline Humphreys (NHS East of England) followed by a question and answer session.

The three workstreams were aimed at:

- practices that are looking to get started with a PPG
- existing PPGs wishing to share ideas and learn from each other
- current and future champions of PPGs across the region

The audience was attended by 120 delegates from a wide range of backgrounds such as GPs, practice managers, other practice staff, Patient Participation Groups members, Primary Care Trust staff and other voluntary organisations.

Keynote address: Professor Simon Gregory

Professor Gregory, himself a practising GP, delivered an entertaining, insightful and inspiring keynote address that made important references to his own concerns and experiences as a patient. This immediately reminded delegates of the emotional realities of receiving (and providing) care that should not be forgotten.

The presentation opened with a slide listing the eleven pledges that underpin the work of NHS East of England. Professor Gregory highlighted the two that state “*We will deliver year on year improvements in patient experience*” and “*We will ensure that GP practices improve access and become more responsive to the needs of all patients.*” He further emphasised the importance of the NHS Constitution and encouraged all delegates to read a copy and take note of the rights and responsibilities that it contains.

Professor Gregory then offered an honest account of the work of the PPG at his practice in Northampton. This has secured national recognition for its work and is seen as vital and integral to the life of the practice - indeed, it has supported the practice through some difficult periods of transition.

The PPG has been extremely active in health promotion areas such as weight loss (their *waist management* group) and falls prevention and they help the practice to improve the quality of its services. The PPG is not reflective of the practice population but Professor Gregory thought that it was almost inevitable that older people would be most strongly represented in such a Group.

Professor Gregory reminded the audience of the motto of the Royal College of GPs (*scientia cum caritas* or *scientific knowledge applied with compassion*) and explained what this means to him. It calls for a family physician who is a generalist and who sees patients as partners. The goal is to look after people - not diseases - and to recognise the inherent complexities and uncertainties, alongside an understanding of the patient’s own context.

The education of GPs, and others who work in primary care, is a critical element in improving the quality of care and this is reflected in the training of the Royal College of GPs. It needs to be person-centred but it also needs to be holistic and with a strong community orientation. Here the PPG has a key role to play in strengthening the bonds between practices and the communities that they serve.

Finally, Professor Gregory flagged up the many opportunities for lay people to influence the work of the NHS, including his own work in the Deanery. Anyone who would like to discuss this further can email Professor Gregory via his personal assistant, sarah.bishop@eoe.nhs.uk.

Workstream A: Getting started with a PPG

Workstream A was led by Rebecca Champion, Engagement Manager at NHS Norfolk, with Jennie Fisher from NHS Suffolk as “scribe”. The aim of the morning session was to give the patients and practice managers present practical ideas and resources for establishing a PPG at their practices. Following a power point presentation, and discussion with the participants, the main learning points were:

- Each group is individual to the practice
- Avoid raising expectations among the patients as to what the practice can change in the delivery of services – if something cannot be done, then be clear about why.
- PPGs can be a good forum for communication with patients - the PPG can often serve as an advocate for the practice
- Be clear from the start that the group is not the place for single issue complaints or patients who are not interested in representing the whole practice population.
- PPG members may not represent the practice population themselves but they can still take active steps to make sure the views of others are sought actively.
- If a lot of people are interested in joining the PPG, it may be best to have an executive committee, which changes regularly, linking closely to the other interested volunteers.
- The ideal mix is to involve as many practice staff and GPs on the group as possible.
- It is important to have a good Chair, a clear constitution and a work-plan with short, medium and long term objectives to maintain focus and motivation.
- If you use a process of ‘selection’ in recruiting members, be aware of issues around discrimination.

The afternoon session was an action planning activity, where delegates worked together to plan the first year for a PPG. Many used their local knowledge and experiences to design groups for their own practices. Roger Gedye was available for help and advice as an experienced PPG member. The groups were encouraged to think about the following:

- Why are you doing this and why now?
- Do you need to sell the idea to others in the practice?
- Recruitment – open or invited? How?
- Organise your first and second meetings
- How are you going to communicate, be representative, and report back?
- How are you going to keep up the momentum?

Following the planning exercise and discussion, the participants identified the following issues:

1. There are pros and cons between open versus invited recruitment, and some saw the merits of having an application and selection process.
2. PCTs can do a lot to promote PPGs and foster networking and support.
3. A list on the NAPP website of potential good quality speakers for health promotion events would be useful.
4. Explore the connections that PPG members may have as these can be very useful.
5. PPGs with paying membership - If you pay for something, you value it more! However, this can exclude people in less affluent areas.

Workstream B: Sharing learning among existing PPGs

Workstream B was led by Candida Hepworth with Sue Last from NHS Cambridgeshire as “scribe”. The aim of the morning and afternoon session was for the group to look at the obstacles to PPG development and then to consider the support they might need, with a view to considering possible solutions and how they could be delivered.

In the morning, delegates identified a range of obstacles that they felt were hindering the growth of their PPGs, notably:

- Growing age of PPG members
- Lack of clarity about the remit of PPGs, with debate about the concepts of participation, engagement, involvement, support and partnerships
- Lack of clear objectives for PPGs (some focus exclusively on fund raising)
- Meeting times and places often limit the age range of participants
- Lack of diversity within PPGs – not representative of practice area
- Communications challenges (including issues of Data Protection)
- Influence of PPGs – are they equal to the practice, followers/supporters
- Expectations of GPs and members
- Control of PPGs
- Difficulties of a partnership with a partnership
- Lack of GP interest
- Absence of financial support from practices
- Not taken seriously (seen as a tick box exercise)

The morning exercise clearly demonstrated that there is a huge diversity in terms of what a PPG can look and feel like. What works for one does not necessarily work for another.

During the afternoon the group debated the solutions to the obstacles that were raised in the morning:

- Clear terms of reference for PPGs
- PPG newsletter
- Recruiting by personal invitation
- Having a physical presence at meetings and virtual models
- Forming Groups i.e. Walking groups to get patients involved
- Appoint champions to talk to patients about PPGs (face to face)
- Use waiting areas for surveys
- Use prescriptions as a vehicle to send communications
- Invite clinical staff to give presentations
- Visit other groups (eg mums and tots) and not expect everyone to come to you.
- Start a facebook, twitter page and other media communications
- Dedicated email address for PPGs

The afternoon session clearly demonstrated solutions to obstacles are easier to identify if you have a clear idea of what it is that you want to achieve.

Workshop C: Developing PPG champions

This workshop was facilitated by Graham Box from the National Association for Patient Participation, with David Levitt of NHS Bedfordshire as scribe. It allowed a broad discussion among the various experts in the room.

Patient participation has many different elements (Improving the patient experience, providing different perspectives, improving two-way communication, patient education, monitoring the practice and the services, giving patients a voice in what happens, ensuring services are built around the patient) and each PPG is different. They are also different structurally but a basic framework (with some flexibility) is generally advisable at start-up, especially with respect to ground rules and the importance of clear objectives (though these can take time to develop).

Delegates discussed what success looks like for PPGs and this included a high profile for the PPG among patients (and the practice staff), reaching out to different people, improving the quality of the practice and the care that it provides, addressing both “internal” (to the practice) and “external” issues (ie the work of the wider NHS that has an important impact on patients and on general practice). Support needs to be available to PPGs so that they can play these diverse roles effectively.

Outreaching to the wider community requires ongoing promotion of the PPG, in practice literature and websites etc. PPGs are also encouraged to think about how they can communicate with the housebound, how they can link to existing community groups, how they can be relevant to audiences of different ages, how they can tailor health promotion work to local health needs and how that work can influence local commissioning decisions.

Delegates looked at the NAPP document that is entitled *21 ways to help your practice thrive* and considered how this might be used to help PPGs to prioritise and evaluate their work each year. It can be found on the NAPP website at www.growingppgs.com. It is also important to celebrate achievement and review any failures to help to maintain momentum.

Successful championing of PPGs also requires an understanding of the obstacles to their development. Some of the key solutions were thought to be:

- Developing a concise and clear case for PPGs that positions PPGs as a solution to problems, not as another problem
- Identifying champions who are influential locally and making support available to help practices and PPGs, whatever stage they have reached
- Reminding practices that PPGs were initiated by GPs who recognised that patients have great skills to offer, that patients have a right to influence the care that is available and that practices can only succeed if they understand those who use their services
- Raise awareness of the legal requirements around consultation, especially in the context of practice based commissioning decisions

As closing thoughts, delegates suggested that PPGs need to prioritise carefully, network with other PPGs, make use of new technologies (especially email) and, once established, PPGs might consider having sub-groups for particular sections of the population.

Showcase 1: Charles Hicks and Roman Gate PPG

Sandra Ferrelly described the early development of this PPG which has only been running for a year or so. Initially, they spent some time discussing their purpose and their focus has been on acting as a critical friend of the practice and serving as an interface with the wider community.

In the latter role, they chose to focus on carers with a core insight being that general practice is an ideal setting to identify and support carers. At the start of their project, only 0.1% of the practice list had been identified and placed on the register of carers. Their aim is to grow this number and to provide confidential support to carers, signposting them to support services, including financial help, and maximising the peer support that is available to them.

Sandra also described the work of the PPG within the Huntingdonshire Patients Congress that influences commissioning decisions. She has, for example, been part of a working group that was established to review dermatology services. The resulting discussion document has been shared with other PPGs in the area so that they can comment upon some of the key areas as part of the ongoing consultation.

Showcase 2: Lansdowne Patient Group

The Lansdowne Patient Group was established in 2004 with the core purpose of improving communication. The PPG has developed its newsletter over time, including local advertisements to cover costs, and PPG members periodically attend the surgery waiting area to gather views and raise awareness of their work.

For the past five years, the PPG has run a “Walking for Health” scheme with over 70 walkers joining the walks on a regular basis, with two levels of difficulty. This has further raised the profile and value of the Group. Through donations, book sales, raffles etc, the PPG has developed a steady source of income to cover its running costs and also occasionally provides equipment for the surgery that will benefit patients and practice alike.

Showcase 3: Davenport House Patients Group

Established in 1993, the Davenport House Patients Group is based upon a membership model that sees 20% of families in the practice subscribe, each household paying £10 per year. This funds the quarterly newsletter, a regular programme of health education meetings (a recent event on carers had generated a checklist of suggested improvements that are now being addressed) and it allows the PPG to make contributions to the surgery.

The Patients Group is run by an elected committee of 8 patients together with the practice manager and the senior partner. The current focus is on making the Group more attractive to younger patients and this includes developing a better balance of articles in the newsletter and changing the profile of the education programme. They also make contact with young families through their annual health fayres, by supporting the Harpenden Teddy Bears’ Picnic and by providing folders for the ante-natal paperwork for parents-to-be.

Listening to the Voice of Patients: Caroline Humphreys

Caroline Humphreys, from NHS East of England, began her session with a slide that stated the ambition of the Strategic Health Authority to “provide the best health service in England.” This is to be delivered by actions under three headings; “a better patient experience”, “improving people’s health” and “reducing unfairness in health”. Good progress has been made across the region with 76% of practices opening for longer hours, 14 GP-led health centres established and two additional practices opened in Luton.

With respect to primary care, one of the key challenges is to reduce the variability between practices, including those within the same Primary Care Trust area. The Strategic Health Authority is therefore particularly concerned to improve access and responsiveness of the poorest performing 10% of practices, using the General Practice patient survey as the key measure. Telephone access and the availability of advance booking are particular areas of concern.

Caroline saw a role for PPGs as agents for change in this, and wider, policy areas. She encouraged Primary Care Trusts to involve PPGs in their commissioning roles, called for practices to discuss their survey results with PPGs, encouraged PPGs to get involved with broader healthcare issues (such as raising awareness of the role of community pharmacies) and further argued that PPGs can help in some of the key public health areas such as smoking cessation.

Evaluation

Overall, the Conference was well-received by delegates. On a scale of 1 to 5 (where 1 is poor and 5 is excellent) the conference scored 4.2 for providing delegates with what they wanted from the day (there were 91 responses) and at least 4.0 in all of the areas that were evaluated. The keynote presentation was particularly well-received and there were many positive comments about the PPG showcase slots. The practical arrangements were generally highly rated although a hearing loop and more use of the roving microphones during the workshops would have been beneficial to some delegates.

We were delighted by the interest in the Conference that led to it being fully booked several weeks in advance. Reservations were allocated on a first come first served basis and a waiting list was held so that places could be offered to fill any late cancellations. Given the level of interest and subject to funding arrangements, we are exploring whether it will be possible to organise another event in the region.

For more information about the National Association for Patient Participation, please visit our website at www.napp.org.uk or email admin@napp.org.uk.