



Registered Charity No. 292157

**South West Regional Conference
Held at Taunton School, Somerset
February 2010**

CONFERENCE REPORT





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The National Association for Patient Participation

The National Association for Patient Participation is unique. It is the umbrella organisation for patient-led groups within general practices. Set up in 1978, it speaks for patients in general without being limited to any specific disease or condition. N.A.P.P. is a registered charity and, as such, is independent.

Our Board

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Our Patron is Professor Sir Denis Pereira Gray OBE

Affiliation

Patient Participation Groups (PPGs) can affiliate to N.A.P.P. for a small annual fee. Members benefit from our resources and from networking opportunities. With more than 450 groups now affiliated, we are increasingly able to speak with confidence and authority on issues that matter most to patients. Membership packages are also available for Primary Care Organisations. For more information, please call 0114 2874035 or email admin@napp.org.uk

Growing Patient Participation: Report on the South West Regional Conference for Patient Participation Groups

Introduction

The Conference was held in early February 2010 with 110 delegates. The day was organised in three workstreams:

- Practices and individuals interested in establishing a Patient Participation Group (PPG) in a GP surgery
- Patient Participation Groups seeking to network with other groups and pick up some fresh ideas
- Individuals with a personal or professional interest in promoting patient participation

This report summarises the key messages from each of those workstreams. It also describes the plenary sessions that began and ended the day.

The National Association for Patient Participation (NAPP) would like to thank the delegates, speakers and exhibitors (<http://www.sixpartswater.org>). We are also extremely grateful to the Department of Health Access and Responsiveness Programme and NHS South West for funding the Conference. Equally, we are indebted to NHS Somerset and the steering group members (Bob Bryant, Clive Oakley and Barbara Tilbury) for all of their help in planning and delivering the day.

Keynote presentation

The opening presentation was delivered by Dr Michael Dixon, chairman of the NHS Alliance and Cullompton GP. Dr Dixon spoke with passion and wit about the crucial relationship between patients and their practices in primary care. He expressed his frustration at the excessive influence wielded by hospitals within the NHS and the continuing centralisation of decision-making. Coupled with this, he lamented recent reforms to the formal structures of patient and public involvement that had failed to deliver a stronger lay influence over local decisions.



Dr Dixon's tone brightened, however, as he described the journey that his own practice had undertaken in developing its relationship with its patient group. Initial reluctance, even resistance, had been replaced by a deep admiration for the contribution that the practice's patients were able to make to the life of the practice (from herb garden to information centre to analysing the patient survey to fundraising).

Dr Dixon saw this engagement as a model that could work in any setting with patients and their practices working together to improve outcomes (collective co-production of health). Crucially, this partnership should then inform local commissioning decisions so that services are designed around the needs of particular localities.

SixPartsWater

Chris Cromey-Hawke, CEO of sixpartswater.org, gave a brief introductory presentation on how Patient Groups can use online social networking to help increase membership and encourage patient participation.

www.sixpartswater.org is a new online patient support charity providing independent, authoritative health information and a range of resources for patients. These include a patient-dedicated social-networking platform, with a model designed specifically for Patient Participation Groups.

Helped by College Surgery Practice Patients' Group in Cullompton, they are developing a live pilot PPG programme, which was outlined at the Conference. During this brief demonstration, they showed how the model can help patient groups to grow, operate more efficiently and communicate with a wider audience.

Sixpartswater had an overwhelmingly positive response, with many patient group members and Practice Managers asking for more information about participating in their pilot programme. Anyone interested in learning more can contact chrisch@sixpartswater.org (07785 238 589) oonahawley@sixpartswater.org (07792 297 294).

Workstream A:

For practices and individuals looking to establish a PPG

The morning session of this workstream was designed to share information from different perspectives and to enable interested parties to reflect about the purpose of their PPG and how to get it started.

Clive Oakley shared his experiences as a lay person active in promoting PPGs across Somerset. He described the twin purposes of a Patient Group as (i) a communications hub between the practice and its patient population and (ii) a support group assisting the Practice in the delivery of good patient care throughout the Practice area. Clive Oakley believed that a Patient Group needed no more than three "good patients and true" to get started and that this nucleus was best selected by hand by the Practice having particular regard to identifying a possible Chair to guide the embryo Group through the initial set-up stages. An early remit of the Group would then be to grow itself to ensure good geographic and demographic representation.

He emphasised that the Patient Group must reflect the views of the patients as a whole and not just their own opinions, valuable as they may be. This led to a discussion on how best to promote both the existence of the Group and its purposes to the patient body including articles in parish magazines, using the Web, talking to patients in the surgery waiting room and even considering a blog or two.

Bob Bryant (a Devon practice manager) then explained that there is no single right approach to setting up a Patient Participation Group. He considered that there are three phases to the growth of a PPG.

Phase 1: Led by the Practice to identify a small group of people who could work with the Partners and Practice Manager to identify what the PPG could achieve and how it would function. This phase would end with a draft constitution or terms of reference detailing how the group would function.

Phase 2: Informing all the patients of the existence of the group and its objectives. Hold an open meeting to find out who is interested in getting involved and appoint officers (Chair, Secretary Treasurer) and lead patients for different projects. Bob's PPG had found a volunteer car service and fundraising to be two easy starters. Although some PPG's do not wish to raise funds, Bob's PPG finds fund raising activities helps bind the group together and gives them something to be proud of. This growth phase took approximately 18 months.

Phase 3: The PPG is now up and running with lots of projects and active patient involvement. Some of the projects at Imperial Surgery, Exmouth are Volunteer Car Driving, Weight Loss Club, Fundraising activities, Gardening (we won the Exmouth in Bloom competition), Educational evenings, flowers in the Practice Reception area; Swimmathon; Self Help Training programme for patients (this helped regular attendees to reduce visits to the Surgery); Beetle Drive for the house bound etc etc.

The third perspective came from the National Association for Patient Participation Chief Executive, Graham Box. Graham encouraged those present to focus on the purpose of their potential PPG and delegates reflected on how they would "sell" the idea of a PPG within their practice or to a member of the public.

The afternoon discussions looked in more detail at how the PPG could take its first steps, including selecting priorities from the document *21 ways to help your practice thrive* which can be found at www.growingppgs.com. Participants were encouraged to reflect on the main challenges faced by their individual practices (eg support for carers, obesity, poor communication, loneliness, access to local services, men's health) and to consider how the PPG might make a difference.

Other issues covered included how to avoid acquiring or how to get rid of "problem" members of a Patient Group and debated the difficulties faced by a Bristol-based Practice whose patients embraced fifteen different languages with English poorly spoken and rarely read. Margaret Grizzell, NHS Somerset Patient and Public Involvement Lead, who had formerly worked in the Bristol area was able to give good advice on how to establish communication, particularly through local community workers.

Workstream B:

For existing PPGs

This workstream covered four broad areas, described below:

Obstacles to growing PPGs and possible solutions

Delegates identified a range of issues, including the time involved, resistance from some GPs, lack of awareness and interest among patients, lack of clarity about the purpose of PPGs. These are major challenges that have been tackled by the Growing Patient Participation campaign that has seen major national organisations making the case for PPGs and developing resources to simplify the formation of new groups and support existing groups. For more information see www.growingppgs.com and www.napp.org.uk

The role of PPGs in promoting good health

PPGs are able to make a real contribution to improving the health of the practice population. This can take place through health promotion events, self-care courses, signposting patients to local support, running support groups, sharing information and running support groups of various kinds.

The role of PPGs in influencing commissioning decisions

Delegates explored how PPGs can influence local commissioning decisions, identifying opportunities such as:

- Sharing the insights of PPG members
- Sharing information with the wider public
- Gaining a better understanding of local funding issues
- Getting involved at Board meetings
- Communicating with MPs and other elected officials
- Identifying opportunities to receive high quality training
- Making contact with the Local Involvement Network (LINK)

A diabetes case study

The afternoon session looked at a diabetes case study and was kicked off by Dr Phil Evans, a GP in Exeter with a special interest in this area. The topic was chosen because there is currently an epidemic (or even a pandemic) of type 2 diabetes. Over 90% of patients diagnosed with diabetes now have type 2 diabetes. Ways of addressing this include targeting those at higher risk via general practices and a population approach via the promotion of exercise and healthy eating.

The former high risk approach is to be promoted via the NHS Health Check programme. As part of this, patients who are at high risk will be screened for type 2 diabetes or pre-diabetes (a raised blood sugar but not high enough to be diabetes).

The good news is that there is now clear research evidence that patients with pre-diabetes can be prevented or delayed from progressing to type 2 diabetes by losing

weight and exercising more and these lifestyle interventions are more effective than drug interventions.

There are several methods of identifying patients who are at high risk, including the use of GP databases such as in St Leonard's Practice in Exeter (Evans et al., 2008). Other techniques include the use of questionnaires, such as the Findrisc questionnaire or the recently developed DUK-sponsored questionnaire from our colleagues in the University of Leicester. Patients scoring above a threshold then proceed to have blood tests taken (for a high blood sugar) to see if they have diabetes. All of these programmes should impact on this increasing national problem.

David Jones from Diabetes UK then outlined a small Department of Health funded project that they are developing with NAPP. The project will aim to support PPGs to influence their practice to provide good diabetes care and to help them to deliver health information events on diabetes. A small pilot scheme is under consideration that would see PPGs play a role in encouraging people at higher risk of diabetes to get to their GP. David explained that he wanted to use the workshop to get feedback on the project from the PPGs and a number of concerns were raised from some of the delegates:

- That it involved PPGs going beyond their remit
- That it could endanger patient confidentiality
- That it wasn't right to expect patients, in their role as PPG members, to ask questions of other patients in the practice
- That it is likely to meet resistance from practice staff

Other delegates pointed out that some PPGs do this kind of activity already and that volunteers can act professionally. It would be crucial to get support from the whole practice team and to ensure that good training is in place. David agreed to look at the project again and ensure that concerns are addressed before work begins. It will, of course, be voluntary and the aim is to provide valuable support to PPGs who want to be active in this area.

Workstream C:

For individuals with an interest in promoting patient participation

This session began with a case study describing the systematic work that has been undertaken by NHS Somerset to promote more, and better, PPGs. This was complemented by case studies from other PCTs in England that have been part of NAPP's national project called *Making the Most of Patient Participation*.

The learning from the work in NHS Somerset highlighted the value of:

- Knowing the situation in each practice/PPG
- Making resources available for new groups
- Providing practical support for emerging groups
- Creating self supporting networks for established groups

Areas of Good Practice included:

- Active PCT involvement with senior level leadership
- Financial incentives for PPGs through the commissioning framework
- Engagement with Local Involvement Networks
- Support from other health communities as practice based commissioning groups and the Local Medical Committee

The Somerset strategy also identified the value of having mentors not only to aid the initiation process but also to help sustain PPGs. NHS Somerset is working towards establishing a network of PPG Chairs covering the whole of their area to meet occasionally to consider common issues with regard to primary health care.

In the afternoon, participants considered how champions for PPGs might be identified and trained. It is clear that local support is critical to help new PPGs to get started and to support existing PPGs, especially through difficult periods. The discussions concentrated on the contents and organisation of a Train the Facilitator course for which NAPP is currently seeking national funding. Brainstorming suggestions with respect to the contents were:

Background to patient and public involvement – Understanding the relevant structures – Understanding primary care and its drivers – Purpose of PPGs – Practice based commissioning – Influencing and communication skills – Guidance on committee development – Recruitment models – Roles, responsibilities and relationships – Sources of support – Marketing and funding – Legal issues including confidentiality, equality, safeguarding – Overcoming pitfalls – Selling PPGs -

With respect to delivery, there was a consensus that those trained should be required to commit to being active and should undergo a selection process. The face to face training should take place over two days (20 per course) with an overnight session and should be backed up by electronic resources, mentoring and a review meeting after 6 months.

Question and Answer session

The afternoon plenary session began with a panel of Sir Denis Pereira Gray (NAPP Patron), Dr Phil Evans (GP, St Leonards Surgery, Exeter) and Margaret Grizzell (head of patient and public involvement, NHS Somerset) answering questions from delegates. Their responses are summarised in the Appendix, together with some thoughts on questions that could not be answered due to time pressures.

Closing address

Sir Denis Pereira Gray gave the closing lecture at the end of the day. His subject was “The NHS in the next ten years—challenges, resources, opportunities, and predictions.”

He started by summarising the reasons why the NHS was facing cuts in its budget of at least £20 billion pounds. He described multiple failures by five sets of people.

He then went on to consider the challenges facing the Health Service, many of them international, and emphasised how an ageing society will certainly mean many more age-related illnesses.

Several resources were listed to address the challenges, some already available, some still to come. Sir Denis saw patients themselves as a huge resource.

As an aside, he set out some policies that the Health Service should eschew in order to avoid losing money in the long term. He judged that the financial squeeze will affect hospitals particularly and notably so in big cities where several hospitals exist. The new punitive tariffs may lead to hospital closures.

Finally, he ventured some predictions including one that by 2018, the proportion of funds spent on health in the UK will be at least 12.5% of GDP.

NAPP has invited Sir Denis to deliver a similar lecture at its Annual Conference in Sheffield in June 2010.

Appendix: Questions and Answers

How can PPGs become more influential with PCTs?

PCTs are required to engage with patients and the public as part of the World Class Commissioning programme that is heavily performance managed. So PCTs should be actively seeking out PPGs to work with them. Equally, the public health and communication challenges faced by PCTs are great and they need to recognise that PPGs can help in both these areas.

Where are PPGs headed within the NHS? How can professionals be better educated about PPGs?

PPGs have varied in importance since the first Groups were founded in the early 1970s. At times, they have been disregarded by GPs who felt that they had little to offer. Good progress has been made in recent years with major national bodies (such as the British Medical Association, NHS Alliance and the Royal College of GPs) supporting PPGs. It is also vital that patient participation is part of the training of primary care professionals.

Will we only see larger practices in future?

This is clearly the trend although some communities will not easily support larger practices. The Panel expressed concern at the possible loss of continuity care as practices grow in size but, equally, there are some interesting models emerging where practices share certain functions so that they can operate more efficiently.

Should practice boundaries be abolished?

Panel members expressed serious concerns about the wisdom of complete removal of practice boundaries (this is currently under discussion nationally). It was felt that existing mechanisms are, in most cases, sufficiently flexible to allow patients to access primary care near to their place of work, for example.

Are PPGs independent of practices or partners with the practice?

The PPG model is one of partnership but, at times, the role of the PPG should be to challenge and advocate on behalf of patients. This is a difficult balance that requires maturity from all parties.

How can PPGs recruit people who don't see them as relevant? How big should a PPG be?

Only a limited number of people will want to join a PPG committee (the typical size of which is 6-12) but PPGs across the country have had good success in growing their own memberships or in raising awareness of the PPG among those who rarely access their GP surgery. Health promotion events, suitably marketed, also reach out to large numbers of people.

The following questions were not fully discussed by the Panel but the suggested responses come instead from the National Association for Patient Participation.

How do PCTs incentivise PPGs?

Many PCTs now have an incentive scheme that encourages practices to have a PPG. The sum involved varies between £500 and £3000 and the requirements also differ. Some PCTs also make money available to the PPGs so that they have some resources to implement their own ambitions.

What is NAPP doing to promote PPGs in the media?

NAPP is a partner in the national *Growing Patient Participation* campaign. This has the support of a communications agency that has secured good coverage in the trade press and over 40 articles in regional media over the past couple of months. Woman magazine also carried a full page article on PPGs in their edition in the last week of January. The campaign has also produced a communications toolkit for PPGs that can be found at www.growingppgs.com.

Does NAPP have a strategy for working with Local Involvement Networks?

NAPP encourages PPGs to make contact with their Local Involvement Networks (and vice versa) and we actively support LINKs who wish to work closely with their PPGs.

What advice could be given concerning setting up a PPG in urban or rural settings?

Hard to address this briefly but the three key issues in setting up a PPG in any setting are practice commitment, purpose and recruitment. The last of these may require a different mix of face to face meetings and “virtual” engagement in urban and rural settings, and communication methods are likely to be different as well. Perhaps the best advice is to link up with a practice in a similar setting that has already established their PPG.

How, and why, do PPGs succeed?

The three critical success factors for PPGs are leadership from the practice, leadership from the PPG and good understanding from the PPG of how the practice operates. There are many examples of successful PPGs at the NAPP website www.napp.org.uk and the Making a Difference fund award winners will provide three dozen more examples (see www.growingppgs.com).

The National Association for Patient Participation

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