

# More to Offer

A celebration of Patient Participation Groups  
and the 30<sup>th</sup> birthday of the  
National Association for Patient Participation

October 2008





Registered Charity No. 292157

## 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

President	Dr Patricia Wilkie
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Treasurer	Edith Todd
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Trustee	Sandy Gower
Trustee	Dr John Dracass
Trustee	Royce Franklin
Chief Executive	Dr Graham Box

Our Patron is 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 350 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

### Acknowledgements

N.A.P.P. would like to acknowledge all of the PPGs and all of the volunteers whose work is referred to in this booklet, often without explicit recognition. Special thanks go to everyone who has commented on earlier drafts and to the incomparable Audrey Hoggard for her time and skills.

# More to Offer

## 1. About N.A.P.P.

### 1.1 Introduction

The National Association for Patient Participation was formed in 1978. It is a UK-wide independent charity and the umbrella organisation for patient groups based in primary care: it is not limited to any specific disease or condition. Throughout its history, N.A.P.P. has been run by lay people in the interests of patients but has also enjoyed the support of professionals who have pioneered patient participation within their own organisations.

This document celebrates the achievements of N.A.P.P. and PPGs over the past thirty years. It acknowledges the enthusiasm, resilience, compassion and wisdom of the many thousands of people, nearly all volunteers, who have worked so hard to foster patient participation. As a result of their collective efforts, it is clear that PPGs are here to stay.

### 1.2 Activities

Over the years, N.A.P.P. has developed extensive know how and resources to promote patient participation in primary care. These include a Handbook of Patient Participation for affiliated Patient Participation Groups and a Toolkit of Patient Participation for affiliated Primary Care Organisations. In addition, N.A.P.P. distributes a quarterly printed newsletter and a monthly ebulletin. In 2004, we produced a case-study DVD describing the work and organisation of seven Patient Participation Groups.

Additional resources can be found on the N.A.P.P. website at [www.napp.org.uk](http://www.napp.org.uk). This includes project reports, such as our recent three-year (Department of Health funded) study of best practice in patient participation, and occasional publications. The website also contains details of our national annual conference which is chaired by our Patron, Sir Denis Pereira Gray OBE, a former Chairman and President of the Royal College of General Practitioners). The

Conference always offers extremely high quality speakers and is an important networking opportunity for our members. It moves around the UK and will be held in the Coventry area in June 2009.

### 1.3 Influencing

In recent years, N.A.P.P. representatives have published articles and contributed to national policy-making in several different areas, including:

- ❖ patient safety
- ❖ support for carers
- ❖ practice based commissioning
- ❖ self care
- ❖ the Quality Outcomes Framework of the GP contract
- ❖ medical education
- ❖ access to services
- ❖ patient and public involvement structures

We also organise occasional workshops on issues of particular interest which, in recent years, have included:

- ❖ Improving urgent care for over 75s and their carers
- ❖ Choose and book
- ❖ Patient access to their electronic health care records

### 1.4 Future Plans

Following our Board Away Day in April 2008 and our Annual Conference in June 2008, N.A.P.P. is committed to the following priorities:

- ❖ Strengthening N.A.P.P. by continuing to grow our membership base (well beyond the current 350), building up a network of local ambassadors and developing new income streams
- ❖ Spreading patient participation by supporting new groups, continuing to share good practice and working effectively with national partners
- ❖ Undertaking, and learning from, research about what matters most to patients so that we can speak with confidence at national level and support our members to do the same at local level

## 2. Early days

***“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”***

(Margaret Mead, American anthropologist)

In 1978, the National Association for Patient Participation (N.A.P.P.) held its inaugural meeting in Oxford. Then, as now, Patient Participation Groups (PPGs) had to find a way to speak up for patients while maintaining a relationship with their practices. Then, as now, N.A.P.P. had to win official support and encouragement from policy makers and professional bodies. Then, as now, patients had to be encouraged and supported to participate effectively and constructively.

Dr Tim Paine, a long-serving former N.A.P.P. President, reported on this first meeting of N.A.P.P. in the Journal of the Royal College of General Practitioners.<sup>1</sup> Around 90 people attended, including representatives from twelve PPGs.

They agreed clearly defined roles for the Association which remain true today:

- To act as a link between existing PPGs.
- To be a source of useful information for those thinking of starting a group.
- To promote the principles and benefits of patient participation.
- To win official support and encouragement.

There was great optimism and excitement about the possibilities of greater patient participation in Primary Care. The Rev. Stephen Barnes from Glyncoirwg expressed the view that patient participation should provide a consumer voice promoting improvements in the health service and break down the barriers between medical teams and the people that they served.

Dr Alistair Wilson from Aberdare felt that the strengths of PPGs were that the patients who were involved with such groups were able to

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<sup>1</sup> Paine T, (1978) Journal of the Royal College of General Practitioners (28) 377-382

represent their fellow patients, to be accountable to them and to use their experience to participate with the doctors and other members of the staff to provide better primary health care services. He also saw the role that the patients could play in promoting health.

The representativeness of PPGs was a widely shared concern and it was recognised that it was a reason for scepticism in some practices that didn't have a group. But one member of the audience explained that no representative group was ever representative. Innovative means of engagement are required. A GP from a tower block practice in Birmingham had found a lack of interest in lectures and talks but he'd increased involvement in his patients enormously by introducing activities such as jogging.

The meeting also included a fascinating discussion about the purpose of PPGs. Ms Beryl Steel, a patient from the Limesgrove Patients' Collective, explained:

*“If you see patient groups simply as a support for the doctor or a way of making the doctor understand what the average patient might want, then with the better education of doctors and perhaps more sensitive doctors you might not need these groups.*

*But if you see patient groups as people wanting to take back into their own hands control of their own health and if we are to say what health is to us, rather than allow doctors to tell us, then it is going to need more than a sensitive doctor.”*

In short, many of the themes that were discussed remain relevant today, including challenges around the representativeness of groups, the importance of promoting the concept in high places, the scope for patients to be truly influential within their practices and even their potential to contribute effectively to programmes of self-care.

## 3. Patient Participation Today

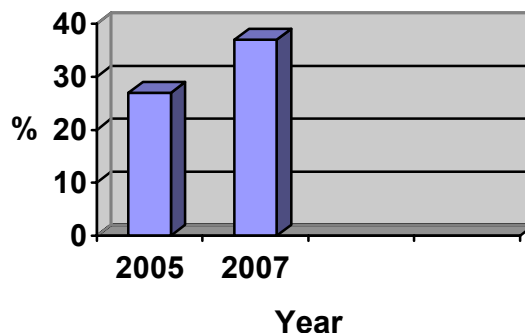
**“The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”** (World Health Organisation, Alma Ata Declaration, 1978)

In 2005 and 2007, N.A.P.P. carried out the most extensive study ever of patient participation in primary care in England. This involved a survey of 3600 practices, half in 2005 and half in 2007. Over one thousand replies were received, representing a response rate of nearly 30%.

### 3.1 Numbers of Groups

In 2005, one in four practices (25%) reported having a PPG. By 2007, this figure had risen to 37%. Note, however, that this is likely to overstate the total number of groups since practices with a Group are more likely to take part in such a survey than practices without a PPG.

**Percentage of practices reporting having a PPG**



In 2007, nearly 77% of practices without a PPG had considered establishing one. Their decision not to proceed was most commonly explained by a lack of time. Other explanations included:

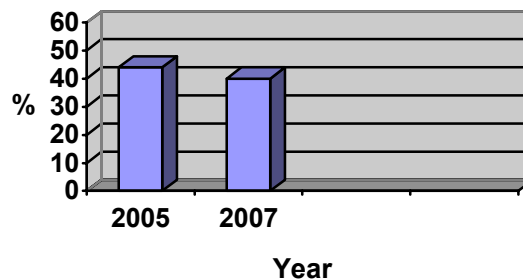
- a feeling that the practice was already close to its patients
- perceived lack of interest among patients
- fear that the “wrong” patients will be interested
- the difficulties of working with a diverse patient population
- a previous failed attempt at establishing a group

The new GP contract seems to have been a significant driver in the formation of new Groups. In the 2007 survey, 58% of the PPGs had been formed since the contract came into force in 2004. At the same time, a significant number of PPGs had been in existence for a decade or more meaning that the average age of the PPGs was five years old.

### 3.2 Influence of Groups

There was a slight reduction in the perceived influence of the PPGs from 2005 to 2007. This is probably explained by the increased numbers of PPGs since it normally takes time for a PPG to start to make a difference.

**Percentage of practices rating their PPG as quite or very influential**



The four most important factors explaining the influence of the PPG at practice level were:

- PPG understands the constraints on the practice
- Attitude of the practice manager to the PPG
- Attitude of GPs
- Good leadership within the PPG

Examples of PPG influence and interaction with their practice included appointment and telephone systems, waiting area, access to the surgery, plans for redevelopment, communication, repeat prescriptions, patient information, health promotion activities, opening hours, follow up to the patient survey and medicines management.

Where PPGs reported problems, it was most likely to reside in the fact that there are not enough people willing to participate and that the same people sometimes end up doing all of the work. Tensions between the PPG and practice or uncertainties about the PPG's role were relatively minor concerns by comparison.

### 3.3 Discussion

Previous published research into the nature of PPGs, and their effectiveness, established that PPGs have endured as a model for public engagement through decades in which public policy has shifted considerably.<sup>2</sup> Throughout this time, PPGs have tended to be viewed favourably by practices that have them, but with some reserve or even scepticism by those that don't.<sup>3</sup>

The findings from these surveys are consistent with those broad messages. But it is clear from recent trends that this form of patient participation is becoming a more mainstream feature of general practice. This is not a purely rural or semi-rural phenomenon although inner-city practices are less likely to have PPGs than those in other geographical settings.

These research findings set a clear agenda for N.A.P.P. and others who would like to see more, and better, PPGs operating in general practice. This includes:

- Promoting the excellent work undertaken by the best PPGs, including the important contribution that they can make to the smooth running of the practice and the health of the local community
- Challenging some of the fears felt by practices without a PPG, including the concern that PPGs are a forum for moaners and too easily abused by those with their own personal agendas
- Advising on recruitment techniques and working practices that can begin to overcome some of the legitimate concerns that are raised about the lack of representativeness of PPG members
- Developing training for practice staff and PPG members so that their relationship is constructive and valued on **all** sides

N.A.P.P. would like to thank those practices that took the time to participate in this survey. We were delighted with the response rate and feel that the findings have provided us with a deeper understanding of the current position with respect to PPGs.

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<sup>2</sup> Pritchard, P. (1993) *Partnership with patients: a practical guide to starting a patient participation group*. London: Royal College of General Practitioners

<sup>3</sup> Brown, I (1999) Patient participation groups in general practice in the National Health Service *Health Expectations* 2 (3) , 169–178

## 4. Offering More

This section describes some of the other activities of PPGs. Each PPG is unique and evolves to meet local need. This diversity is a great strength.

### 4.1 Health Promotion

*“The patients went away very happy. Nobody had ever explained their condition to them before.”* (Brent Practice Manager)

Health Promotion activities are seen by many as the jewel in the crown of PPGs. They make a real and lasting difference to the health of the people who benefit from the activities that are arranged. The health promotion events take many different forms, from large village hall events to cosy discussions in practice waiting rooms. They respond to patients’ deep interest in their health and recognise the limits on information transfer within the conventional GP or nurse appointment.

### 4.2 Running and supporting campaigns

The impact of PPGs, including health promotion activities, can be greater if they are coordinated in a concerted manner. PPGs have campaigned in areas such as falls prevention, appropriate use of out of hours care, redesign of local services and reducing the number of non-attendances for appointments. PPGs can also promote the use of schemes such as Message in a Bottle (with key personal information kept in a bottle in the fridge) or the ICE number (In Case of Emergency) that allows emergency contacts to be immediately identified from someone’s mobile phone.

### 4.3 Critical friends

The GP contract that was introduced in 2004 encouraged practices to work with their PPG to discuss the findings of the annual patient survey. This kind of strategic input isn’t, however, a new phenomenon and there are several well established groups who were set up to inform the practice of the views of the wider community and to support the practice in developing its services in the ways that patients and the wider community most want. The critical friend model sees PPG and practice working constructively and honestly to improve services

provided by, or (particularly important nowadays) commissioned by the practice.

#### 4.4 Patient information

*“Mum had been to see her GP and I could tell that she was upset but she just couldn’t remember what the GP had told her.”* (Hampshire practice manager)

The practice manager quoted above responded by working with her PPG to set up a patient library that is currently staffed more than twenty hours per week by volunteers. Quite rightly, she recognised that patients need information available to them at the time of their visit to the practice. This reduces anxiety and increases our own understanding of our health. The library also represents an opportunity for the PPG to pick up informal messages from patients which can be usefully fed back to the practice.

#### 4.5 Survey delivery

Most PPGs recognise the difficulties involved in claiming to speak for the wider practice population. They have responded in various ways:

- by designing bespoke surveys in partnership with the practice to address key issues
- acting as “mystery shoppers”, for example, phoning the practice in order to evaluate ease of telephone access
- sitting in the waiting room and chatting to patients informally as they wait to be seen

In these, and many other ways, PPGs can inform themselves of the wider experiences and views of those who use the practice.

#### 4.6 Sharing experiences

Some very simple schemes can be highly effective. PPGs have developed an arrangement whereby patients who have been through a particular illness, course of treatment or operation volunteer to go on a register held by the practice or the PPG. They thereby agree to be contacted by other patients who find themselves in a similar situation and who would like to learn from someone else’s personal experiences. That support can be a vital aid to support patients to make the best choices for themselves and to aid recovery.

## 4.7 Volunteer services

Some PPGs provide services on behalf of the practice or its patients. These can be essential in filling gaps in local provision following a traditional voluntary sector model. So, for example, in a rural setting volunteer transport can make a huge difference to patients who would otherwise be faced with two or three bus journeys to get to the clinic or the hospital to which they had been referred. In more deprived urban or suburban settings, volunteer transport (possibly in partnership with the local voluntary sector) may be a far preferable way for some patients to get to their GP surgery.

Other voluntary activities led by PPGs include setting up support groups, bereavement counselling and attending flu clinics to provide support and information to fellow patients.

## 4.8 Patient Support Service

*“The more you speak to patients, the more you realise that there are gaps in the services that are provided.”* (Chris Simmonds, Doncare Medical Centre)

The Doncare Medical Centre recognised that patients with non-medical problems contribute significantly to the workload of primary care. They set up a scheme whereby lay volunteers are trained to see such patients, if they so wish, in a 45 minute consultation. The patients' problems are explored and prioritised with the trained volunteers and agreement is reached on a course of action. Referrals can be organized to a wide range of support agencies to help with, say, relationship, debt or bereavement difficulties and some patients have been helped into employment or further learning opportunities. Contacts and links can also be made to local solicitors or Citizen Advice Bureaux to help with debt and employment issues.

Other PPGs may feel that the best way that they can contribute is simply to create a register or directory of existing local support, including self care groups. Rather than provide additional services themselves, their role is to make sure that patients in the practice are aware of the services that already exist.

## 4.9 Self Care

In the last 12 months, a number of PPGs have taken part in a pilot organized by N.A.P.P. and the (now disbanded) Working in Partnership Programme to deliver self-care courses. These provide an opportunity for patients to reflect upon their lifestyle and how they can improve it. The course covers areas such as the process of change, promoting self esteem and confidence, dealing with stress, changing lifestyle, living more healthily, eating better and taking more exercise. Akadine Research has evaluated the pilot.

## 4.10 Introducing new technologies

PPGs are working with their practices to promote patients' access to their electronic health care records. This brings significant health benefits but it is not straightforward and strong patient involvement in the design and development of systems is hugely beneficial. PPGs have also worked with their practices, sometimes "leading" them, to introduce online booking systems, email consultations and touch screen reception devices.

## 4.11 Communication

It is vital that patients understand how to access services and how best to manage their own health. PPGs can support this process through the production and distribution of newsletters, and through other approaches such as reviewing literature that has been written for patients and helping to design websites. Forward thinking practices are now involving their PPGs in their social marketing and branding activities, helping to ensure that messages are appropriate and well-targeted.

## 4.12 Support to carers

It is vital that carers are provided with the support and information that they need, when they need it. PPGs that run support groups can help to address an area which is, rightly, being given greater prominence within general practice. Equally, they can promote Carers Week and support the "nothing registered, nothing gained" campaign to ensure that carers are registered with their local practices.

**N.A.P.P. would like to congratulate all of those volunteers who have made such a difference within their respective PPGs.**

## 5. More to Offer

***“Patients have more to offer doctors than their illnesses”***

(Joan Mant, former chairman and vice-president, N.A.P.P.)

Over the past thirty years (and more) effective PPGs have made a significant difference to the lives of their practices and the well-being of their communities. Based on goodwill and trust, they have always been ahead of the game, promoting patient and public involvement long before it became “trendy” and empowering patients to move beyond deference a long time before cultural change delivered the same outcome.

Yet, frustrations remain. Too many PPGs have been set up without adequate knowledge and support. Their shortcomings have sometimes given PPGs an unwarranted reputation as “doctors’ fan clubs” or “forums for moaners”. Equally, policy makers and professionals have proved slow to accept our call for a PPG in every practice. As a result, N.A.P.P. continues to devote energy to promoting the model itself, rather than supporting its successful implementation.

Nonetheless, it is right to celebrate. To celebrate the selfless energy of the hundreds, and now thousands, of PPGs that have come together since the first groups were formed in 1972. To celebrate the many Trustees and other volunteers who have worked so hard on N.A.P.P.’s behalf, often against a strong headwind. To celebrate the excellent primary care staff who have looked after us and our families throughout that time.

PPGs have more to offer.

First, as Wanless noted in his 2002 report to Gordon Brown, demographic and other cost pressures mean that there is a great deal that can be gained if patients are more engaged in their own health and health care.<sup>4</sup> PPGs can help to lead the process within primary care towards this “fully engaged” scenario.

Second, the ambitions of World Class Commissioning invite patients to be more involved and more influential in local service provision. PPGs can offer a vital, general perspective at practice and cluster level.

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<sup>4</sup> See Wanless D (2001) *Securing our Future Health: Taking a Long-Term View* (London, HM Treasury)

Third, the modernisation agenda within the NHS has produced a sense of constant, sometimes demoralising change. PPGs have a key role to play in local implementation of reforms (including new accreditation regimes) arguing **forcefully** for those that serve patients' best interests but resisting those that do not suit local needs.

N.A.P.P. looks forward to working with our members to meet these challenges and will also develop further our partnerships with major national players such as the NHS Alliance, the Royal College of General Practitioners (especially their own Patient Partnership Group), the Improvement Foundation and the Department of Health.

We will continue to argue the case for high quality primary care and for the importance of patients and professionals working constructively together to deliver this. With our generalist perspective and our large and growing membership base, it is clear that N.A.P.P. has a great deal more to offer.

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## The National Association for Patient Participation

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