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Foreword

I have much pleasure in writing this forward. It is my first official task since becoming president following the retirement of Dr Tim Paine who did so much work for the National Association for Patient Participation (N.A.P.P.) I would also like to take the opportunity of saying how good it is to work with all those volunteers who are helping N.A.P.P. grow from strength to strength.

Since the 1960's lay people have worked to influence changes in the way that health care is delivered. Think of organisations such as the National Association for Women and Children in Hospital whose members campaigned so successfully to ensure that parents could be with their child in hospital, something we take for granted nowadays. Or The National Childbirth Trust (NCT) that argued for good preparation for childbirth for parents and the involvement of the mother in her pregnancy and planning for the birth. Forty years on these achievements are accepted as the norm.

The NCT example of encouraging pregnant women to be involved in the planning of their pregnancy and birth is similar to the Government's more recent Expert Patient Programme devised to help people with chronic health problems such as asthma or arthritis, to be more in control of their health and their lives. With the publication of two recent documents, A Stronger Local Voice (Department of Health, 2006) and Our Health, Our Care Our Say (Department of Health, 2006) the Government has now strongly emphasised the importance of patient and public involvement in health. These documents extend the meaning of involvement to mean not only the active involvement of the patient in their own health but the wider strategic involvement of patients and the public in planning and decision making.

N.A.P.P. was arguably ahead of its time in encouraging the formation of Patient Participation Groups to, amongst other things, link with their local communities and to have, as tax payers, a say in how services were run. And this publication demonstrates, as Danny Daniels says in his introduction, how in 2006, patient groups working in partnership with their individual practices are achieving a range of diverse objectives designed to enhance the care and welfare of patients.

Patient participation and patient involvement are concepts encouraged by government and to an increasing extent supported by the medical profession. Where there is doubt it is often because doctors and indeed organisations really do not know how to involve patients. N.A.P.P. can continue to help in the establishment of more groups founded with clear objectives to help improve services for the community they serve.

There are, however, more and exciting challenges for N.A.P.P.. The introduction of practice based commissioning will involve practices in a geographical area making decisions that will affect the way that health care is delivered to patients. Patient Participation Groups know their own area and can help alert their practice to specific problems. Working with their practice they can be involved in setting priorities and can help ensure that commissioning decisions are made known to the wider patient population.

Groups may also like to consider what patient issues could be surveyed by the practice. All practices are now required to carry out patient surveys and the General Medical Council is likely to require that all doctors seeking revalidation to remain on the medical register will have carried out patient surveys. Practices often use a very general questionnaire that does not necessarily capture unique aspects of the practice that affect patients. Patient Participation Groups should be involved in setting some of the questions in the survey to ensure that the findings reflect the patient perception of the practice.

Patient involvement is here to stay. This document shows N.A.P.P.'s great experience and understanding of how patients, doctors and other health care professionals can work together for the benefit of the patients that they serve. It is hoped that patient participation groups will, with the help of N.A.P.P., have the confidence to take the new challenges and lead the way in patient involvement.

Patricia Wilkie
President N.A.P.P.

Introduction

This publication is the result of detailed research and collaboration with primarily Patient Participation Groups and is intended as a resource for health professionals and lay volunteers interested in patient and public involvement. The work forms part of the 'Best Practice Project' (commissioned and funded by the Department of Health) undertaken by the National Association for Patient Participation (N.A.P.P.) and due for completion in mid 2007.

Because of the size of the catalogue of case studies contained within our files we have concentrated on recent examples. If your group is not featured we apologise in advance and we are sure you will understand.

Within the publication there are many vivid examples of how patient groups, working in partnership with their individual practices are achieving a range of diverse objectives designed to enhance the care and welfare of patients.

It is recognised, in this document, that each Patient Participation Groups is unique and that what is needed or required by one practice may differ completely from another.

However the case studies are a valuable source of reference, particularly if a group is considering embarking upon an initiative that has already been implemented elsewhere.

One of the key aims of N.A.P.P. is to encourage the sharing of best practice and we continually strive to ensure that case studies are publicised through the medium of our quarterly newsletter. A campaign was recently launched to facilitate lines of communication between PPGs affiliated to N.A.P.P. and we have recently recruited 26 of our affiliated groups to act as pilot sites.

Finally, a note of thanks to our past President Dr Tim Paine for his contribution concerning the history of N.A.P.P. This account is featured within the appendix and it brings to mind the adage concerning acorns and oaks. It is hoped that the reader will find the publication both interesting and a worthwhile resource feature.

Danny Daniels

Chairman N.A.P.P.

The work of Patient Participation Groups

It is only worth having a Patient Participation Group (PPG) if it can be of help, to the practice, to its patients or (most commonly) to both. As the needs of practices vary enormously, so too do the activities of PPGs. In this chapter, we hope to convey that diversity, highlighting the many ways in which PPGs work to improve the health and well-being of their local communities. But first, a little background.

In 2005/6, N.A.P.P. carried out two major surveys. First, we wrote to 1800 practices in England, six in each Primary Care Trust (PCT). This generated 500 responses. One in four practices reported having a patient participation group (though they often went under other names) and described the work of that group. 44% believed that the patient group was either quite or very influential in the life of the practice.

Nearly 70% of practices without a PPG had considered establishing one. Their decision not to proceed was most commonly explained by a lack of time. Other reasons included a feeling that the practice was already close to its patients, a perceived lack of interest among patients, fear that the wrong patients would be interested, opposition from one or more GPs and the difficulties of working with a diverse patient population.

The second survey involved writing to the public involvement leads in every English PCT. Over 80 responses were received and this indicated that one in five practices now has a PPG. Fourteen of these PCTs had created a network for their PPGs and 48 reported that their PCT was quite or very active in promoting patient participation groups.

During these surveys, we also invited responses on the work of PPGs across the country. This has been combined with our own knowledge of the work of the PPGs that are affiliated to N.A.P.P. to produce the commentary that follows. We have organised the activities under the following headings:

- Health promotion and information provision
- Influencing and communicating
- Service delivery

We regret that we are only able to include below examples of the work of a small number of PPGs. We hope that this will not cause offence to the hundreds of excellent PPGs that we have not been able to accommodate.

Health promotion and information provision

The rhythm of health promotion events varies by PPG. Some run six or more a year while others focus on a major annual event. The list of topics covered is impressive and includes:

HRT, heart disease, first aid, infant and baby courses, diabetes, cataracts, men's health, teenage health, women's health, mental health, services for older people, sickle cell disease, community safety (in partnership with the police), Alzheimers, osteoporosis, babysitting courses, menopause, blood and sugar testing, strokes, breast cancer, walking groups etc.

In practices such as the **Cookham Medical Centre** or the **Lea Valley** Medical Group, the PPG does most of the leg work to organise the health promotion evenings but the practice sends letters of invitation to those with a relevant diagnosis. Guest speakers are invited from local services, as well as from the practice, and may include patients describing their experience of living with a particular condition. These events are often opened out to other practices in the area. **The Lambsgate Surgery PPG**, for example, joined forces with a neighbouring practice to run How to Live in Today's World and there was standing room only.

The Wilson Practice PPG was national winners of the Royal College of General Practitioners award for PPGs in 2005. This acknowledged their success in setting up a Men's Weight Loss and Fitness group. The same PPG organised the 2006 health fayre in Alton. This was an opportunity for all age groups in the community to find out about a wide range of health issues that may affect them and their families. Invitations to support the event were accepted by over 25 expert groups, and health professionals volunteered their time to give information on a wide range of subjects. Care and support groups were on hand to answer questions as well as local complementary therapists. Throughout the day, both blood pressure and cholesterol tests were also available to most age groups.

Two Sussex PPGs focussed on men's health in a particularly effective fashion. The Hassocks PPG arranged their men's health evening in the function room in a pub, next to the railway station to attract commuters. The PPG had sponsorship to pay for publicity and the room hire. More than 60 men attended and many queued for up to half an hour for their "Men's Health MOT" tests, comprising BMI readings and blood pressure plus cholesterol and diabetes checks offered by the local Moss Pharmacy. Fitness instructors from the local gym were present along with smoking cessation advisors from the PCT and practice nurses giving advice on weight reduction and other concerns.

Nearby, Hurstpierpoint PPG organised an informal drop-in evening session in a local High Street pub, attracted no doubt by an offer of a free pint of beer for the first 30 men through the door. They nevertheless waited for quite a time to have blood pressures taken and carbon monoxide levels monitored, with health promotion specialists on hand with advice on stopping smoking. Lloyds Pharmacy agreed to offer screening for blood pressure and diabetes and BMI readings. The Hurstpierpoint health centre nurses were present to offer advice on healthy diets and weight problems with the support of fitness trainers from a local gym. Running throughout the evening was a video all about testicular cancer. Feedback from some of the 50 or so men present was very positive.



PPGs also run information resource centres and other forms of patient library. One of the most sophisticated can be found at the **Friends of Testvale Surgery PPG** which is located in a dedicated room within the practice and staffed 23 hours per week by the PPG. Practice staff are able to refer patients into the resource centre to find out more about their conditions, including techniques for self-care, using validated information such as Patientwise and drawing upon other materials such as booklets and videos. The Testvale Surgery PPG also offers travel advice, based on Traveller software, that saves the practice nursing team considerable time.

A similar model has been developed by the **Friends of Hadleigh Practice PPG**. This can be used independently by patients but is also staffed by volunteers for two sessions per week. It offers on the spot blood pressure checks and supplies some extremely popular booklets, notably *Is Life Getting you Down?* and *Keeping Well in Later Life*. This information provision is complemented by two health promotion events each year, where attendance typically exceeds one hundred.

Spotlight on Davenport House PPG

The PPG has been in existence for more than a decade and operates on a membership basis, costing £5 annually. Roughly 20% of the patient list of 5,000 are members and they receive highly informative quarterly newsletters (hand delivered) together with invitations to the other events that are run by the PPG. This arrangement relieves the PPG from any need to fundraise so that it can concentrate on its core activities.

Four times a year, including the AGM, they hold events at an impressive local lecture theatre, with attendances reaching as high as 200. One of these sessions is offered to the PCT to describe key local issues (the provision of emergency care, for example) and the other two are dedicated to health promotion activities, typically with 2-3 speakers at each event. In practice, the meetings are open to everyone although they are more actively promoted to members. The programme is publicised a year in advance.

The PPG also coordinates small group discussions that are run by the practice doctors, with nursing input where appropriate. Members are able to express an interest and receive personal invitations. It is an opportunity for patients to learn more about their situation (eg the menopause) and for the practice and patients to meet in a different setting.

Finally, the PPG is active in responding to the findings of the patient survey and interviews the senior partner and practice manager before agreeing priorities that are discussed at the full PPG and then reported in the newsletter. This year, they are undertaking a myth-busting exercise, calling the practice at different times throughout a four-week period to assess the ease of telephone access. The findings will be reported back to the practice and may lead to changes, including advice to patients on how to make best use of the system.

Influencing & communicating

The new General Medical Services contract for GPs provides a financial incentive for practices to share the findings from their patient survey with a patient group. Some PPGs have adopted the critical friends model developed by Client-Focused Evaluations Programmes (CFEP). A first meeting identifies the three key issues to be addressed, and then quarterly meetings are scheduled to work through each of these in turn and develop an action plan.

Other practices take different approaches. **The Sheepmarket Surgery** shares the findings of its survey with the PPG and asks for suggested improvements in any areas where the practice is rated less than excellent. **The Bridge Road Surgery PPG** has a retired businessman with an interest in statistics who took a keen interest in the data and how it might best be interpreted. Working with the practice, the PPG fed back to the patients using a poster with headings of This is what you said and This is what we did. Changes have included a complete redesign of the waiting room, removal of the TV, provision of an extended library and a more subtle way of calling patients for appointments.

But strategic input is not limited to the findings of the patient survey. **The Hadfield Medical Centre** has been pioneering the development of on-line patient access to records. The PPG has been actively involved in this process and has played an important role in addressing the serious issues that are involved. The practice also provides patients with their records on disk to take on holiday with them.

Near Bournemouth, the **Highcliffe Medical Centre** has encouraged significant input from its PPG in practice decision-making for over a decade. The PPG has around ten members, broadly reflecting the demographic make-up of the local community. The PPG is described by the practice as operating similarly to a Board of Governors within a school. Over time, the patients have become extremely knowledgeable about local NHS and health issues.

The PPG membership was initially chosen by the practice but now they undertake their own recruitment. Its members have a close working relationship with the practice and attend practice away days. Their names are also included in the practice newsletter so that patients are able to direct their ideas and concerns to PPG members. Dr Stephen Collins described one of its most important functions in the following terms:

“The PPG are a good litmus test of how it is going to go down with the local population. And that is terribly important – we don’t want to go around upsetting people.”

Spotlight on Medcats

“Medcats” is the PPG of the Taynuilt Medical Practice in Argyll which has three surgeries serving 4650 patients in an area of approximately 700 square miles of mountains and lochs in the Scottish West Highlands. Medcats was set up in 2002 and has a management committee of 13 patients, one surgery staff and one GP member (by rotation of the partners).

There is no town within the practice area and therefore no central meeting place. In order to cover 11 villages/localities, meetings are held in different village halls, particularly as travel distances are considerable for many patients. The committee meets 6-7 times a year and holds 3-4 public events. These typically have attendances of 20 to 40 (but occasionally many more) and can include talks about specific conditions or have a more general medical theme.

Medcats has been well served by two principles:

1. The PPG is a two-way conduit for information, not a “moaning shop”
2. Activities are grown slowly to avoid “running out of steam”.

The philosophy that it is better to produce ideas carefully and correctly for future benefit has helped build the reputation among fellow patients and professionals. Committee members have diverse areas of healthcare and education interests which are encouraged by Medcats so that meetings often include reports of project developments from members.

Medcats’ first major project was the production of a new practice Information Book for patients (which included a competition for schoolchildren to design the cover artwork). Recently, the PPG has provided the impetus and initial facilities to help set up a local Diabetes UK support group while in 2005 it became involved with the extension of a pilot scheme providing volunteer drivers for people with transport difficulties. There is also an ongoing project to renew the Patient Library and extend it to all three surgeries. The Library project included a survey to assess patients’ areas of interest which had the extra benefit of generating ideas for topics for public meetings.

Liaison with the practice is excellent, with a GP present at committee meetings and MedCats has provided a representative to sit on the interview panels for recent GP appointments. The PPG has been regularly involved in both the evaluation of patient questionnaires and sometimes in the formulation and pre-testing of such surveys.

On a wider front Medcats was invited to give evidence to the Scottish Executive’s Remote and Rural Healthcare Competencies project, were observers to the setting up of the Gold Standard Scheme of home care for cancer patients, and following reorganisation of the local health board boundaries in 2006 is actively involved in maintaining influence for patient representation developments.

It is important that patients are able to influence the work of their practice and how it provides its services. But PPGs can also speak powerfully for patients in the wider health context. The **Sheepmarket Surgery PPG** mentioned earlier has recently protested – unsuccessfully - against ward closures but successfully against the introduction of car parking charges at Stamford Hospital. The practice is adjacent to this hospital and a likely consequence of parking fees was that Hospital patients would choose to park in the practice car park.

In Stockton-on-Tees, the **Riverside Medical Practice PPG** has proved an important help to the practice in three major areas. Internally, they have educated patients to make more appropriate use of out of hours services, running a campaign to discourage their peers from calling GPs out of hours to address minor ailments. Externally, they lobbied the local council to retain their car parking spaces next to the practice and they proved influential in securing new premises, as Dr Ramaswamy explained:

“The PPG has been a great help for us in moving to new premises – they have represented the practice to the PCT Board and have even attended meetings on our behalf.”

PPGs provide a vehicle for communication between patients and the practice. This can be a highly effective method to keep the practice aware of the feelings of their patients. Equally, it allows the practice to share important messages with the wider community. The techniques are often simple, such as compliments and complaints boxes, newsletters, websites and the active recruitment of PPG members who already have strong links into the local community.

The **Twyford Practice PPG** (just south of Winchester) meets informally on a quarterly basis, often with a glass of wine. The PPG emphasises the value of working in an informal, supportive and constructive way, nipping problems in the bud before they have become significant. The PPG Secretary, Angela Forder-Stent, has free access to the staff and tends to pop in once a week. She very much feels part of the team and has become the face of the PPG on the shop floor. She describes the PPG's more structured work as follows:

“The steering group has representatives from all the villages but any patient can attend these meetings at any time. Together with the practice manager, and following each steering group meeting, we produce a news sheet reporting on the issues raised in the meeting. This sheet is available on the reception desks and is printed in the village magazines. Our meetings are always attended by one of the partners; each partner takes a turn on the rota so this allows us to form a relationship with each of them.”

Service delivery

Volunteer transport is one of the most important and developed services offered by PPGs. The **Kennedy Way PPG** in Yate, Bristol has been running a transport scheme for 14 years to meet the needs of elderly patients without family support and to help patients without access to private transport. The scheme is staffed by a controller and seven drivers who perform an average of five journeys per month to local hospitals. Public transport to these sites is either non-existent or very poor.

The patient requests transport via the reception staff who phone or email the controller with the necessary information. The driver is then responsible for phoning the patient and arranging a time of collection. Drivers are expected to see the patient booked in, and will wait for the patient and take them home. Drivers are interviewed prior to taking on the role and are paid 40p per mile (the limit to avoid taxation as a benefit in kind). Each driver has an identity badge and a car sticker stating that it is a Surgery Hospital Car.

Patients are charged 40p per mile from their home to hospital and back, while the PPG subsidises the journey to and from the patients' homes, parking fees and public liability insurance (which costs roughly £250). The PPG advises that as more treatments are carried out as day cases in hospital, the drivers may face ever longer waits. This may be a reason to switch to single journeys. Equally, it is important that the service is not seen as a substitute for ambulance or hospital transport.

As with so many areas of PPG activity, there are spin offs from the initial idea. The transport work of the **Compass House Friends Support Group**, for example, has grown so that three annual coach trips now take place (14 on the last trip were aged 90 or more). The organisers love the excited buzz of conversation on these trips, which are paid for out of PPG fund-raising events, such as the annual garden party, ploughmans, cheese and wine and Christmas coffee morning.

Patients are often acutely aware of the real needs of other patients. They are also well placed to help meet those needs. PPGs have been particularly innovative in this area, and have achieved outcomes that benefit the patients and practice alike.

The **Woodcote Group Practice Patients Group** has a brilliantly simple support service. Patients with a particular condition express a willingness to share their experiences with others in a similar position. Patients are then referred to these volunteers by their GP (or can self-refer) to find out more about what to expect from somebody who has experience of a particular intervention or of living with a certain illness. The support is initially by telephone but sometimes develops beyond that.

Spotlight on Elliott Hall Medical Centre PPG

The PPG, located in Pinner, was formed in 1993. One of its earliest activities recognised that the needs of carers often went unmet, even unconsidered. With the support of a social worker and the local branch of Crossroads (the carer support organisation) the PPG initiated monthly coffee mornings for carers, accepting referrals from GPs, self-referrals and referrals from family members.

Although the PPG believes that the wider support for carers has improved over the last decade, the carers group has continued to grow. Its current membership stands at around 25. Bereaved carers are encouraged to attend if they wish, allowing them both the opportunity to share their insights into caring and to enjoy companionship. Lunches and theatre visits are also arranged through the year.

The value of the initiative was recognised when it won the 2005 HSA Gold Carer Aware Award, worth £2500. The judges were impressed by the Carers Protocol within the practice and the fact that support for carers was surgery wide, not resting with just one or two people. They were also impressed by the support of the PPG in driving carers to the meetings, providing a respite carer if needed. Carers who choose not to attend the meeting can also receive support in their own homes, arranged through the PPG.

As well as the carer support activities, the PPG runs a transport service, a shopping service, monthly tea parties for lonely and isolated patients, a home visiting service including bereavement visiting, a support group for parents of children with special needs, Babble and Chat (a group for mothers and toddlers), a twice yearly newsletter that is hand delivered by volunteers and social events such as the annual quiz supper. Two PPG members also look after the practice library and website.

The **Milton Abbas Surgery** serves a number of villages in rural Dorset across a radius of 6 miles. The PPG therefore takes problems associated with isolation very seriously. They invite parents with young children to a tea party at the Surgery each month, they phone carers regularly and they hand deliver the newsletter to all but the most distant addresses. The PPG also offers practical support, such as supplying special mattresses to patients on a short-term basis until the permanent one that they need is delivered.

A splendid example of innovation in primary care comes from the **Patient Support Service at the Medical Centre Frances Street Doncaster**. This recognises the fact that patients with psychosocial problems contribute significantly to the workload of primary care. Instead of relying exclusively on the practice counsellor, the Patient Support Service is a team of trained volunteers who see patients with non-medical problems in a 45 minute consultation.

The patient's problems are explored, prioritised and agreement is reached on a course of action. Referrals are organised to a wide range of support agencies to help with, say, relationship or bereavement difficulties and some are helped into employment or further learning opportunities. Patients are also referred to a local firm of solicitors who can help with debt and employment issues. Strategic Manager, Chris Simmonds, explains:

"The more you talk to patients, the more you realise that there are gaps in services. I was aware from the PPG that there was a gap in service in helping people who kept coming back to us all the time and we were putting sticking plasters on the situation."

The Patient Support Service is able to refer to the in-house counsellor if more in-depth counselling is required. It has been evaluated by Sheffield University who confirmed how highly the patients value the service, while the practice's own rolling audit shows a 25% reduction in medical interactions for patients who use the service.

The **Lansdowne Patient Group** has introduced a similar scheme that is running well. They also run a weekly programme of health walks that have proved very popular with patients. The PPG mans the waiting room on set days to seek views and provide information, and produces a quarterly newsletter.

Our final illustration comes from the **North Brink Practice PPG** which has established a bereavement befriending service. This helps the recently bereaved to come to terms with their loss and assists them through the grieving process. Volunteers undergo extensive training from a Cruse trainer so that they can offer help, support and a listening ear to the bereaved.

The process begins with Doctors at the practice referring patients who need support after bereavement. The befrienders then make contact and arrange a mutually convenient time for the first visit. Their duties include helping the bereaved talk about the events surrounding their loss, offering reassurance and explaining the grieving process, and helping the bereaved to explore ways of coping with their feelings.

The Organisation of Patient Participation Groups

There is no single model for the organisation of Patient Participation Groups (PPGs). They are recruited in many different ways, their level of formality differs markedly and they vary considerably in the range of activities that they undertake. Here we give some pointers based on our experience of working with PPGs but we emphasise that there is no single blueprint.

Engagement with the practice

The strongest PPGs tend to have excellent links with the practice. This does not mean that someone from the practice needs to attend every meeting, though this is often the case. It does mean that the PPG is an integral part of the practice, rather than sitting on the periphery.

Leadership within the practice is crucial. This can be provided by a GP, different GPs attending in rotation, by a practice manager, by a receptionist, or some other member of the practice staff. But the PPG needs to feel that it is influential and that its messages are being taken on board by whatever decision-making structures are in place. Practices can also turn to the PPG when they need support with respect to other organisations within, or outside, the NHS.

Social events can also strengthen bonds between the PPG, practice and the wider practice population. They serve a further important purpose in allowing the PPG and practice insights into what patients think, as well as overcoming some of the barriers that can exist between patients and professionals.

This is exemplified by the **Friends of Hadleigh Practice PPG** who are currently gathering information to mark the practice centenary. Celebrations will include a strawberry tea for the over 75s and a cheese and wine reminiscences event. At the time of writing, there is still the possibility that a centenarian, born under the care of the practice, will attend. Equally, the **Friends of New Court Surgery** organised a highly successful fashion show where practice staff modelled the clothing (and raised £700 in the process).

Recruitment and representation

A PPG is only as good as the people in it. In particular, that means the committee members who run it. So it is important to think carefully about how to recruit to the Group. Keep in mind that the abilities necessary to get the PPG off the ground may be different from those needed to run an established Group.

Recruitment to a PPG can take several forms. The “safest” method is probably for the practice to invite patients to form a “think tank” or a steering group to get the PPG up and running. In most cases, this will progress to recruitment from the wider patient body and a number of techniques can be adopted:

- Advertise for volunteers using notice boards, newsletters etc
- Select individuals to reflect the practice list or to cover major disease areas
- Invite prominent local organisations to send a representative to sit on the PPG
- Establish an election process so that patients can be voted on to the committee
- Develop job descriptions with a formal application procedure

Not surprisingly, there are advantages and disadvantages with any approach to recruitment. Although selecting patients to be on the PPG initially may not seem very democratic, it can be defended on grounds of pragmatism. You have to start somewhere and it is not unreasonable for the practice to want to minimise the risk of attracting individuals who may destabilise the Group. Nonetheless, over time, it is good practice for the PPG to look to become as inclusive as possible. This will require a special effort to recruit younger patients (the under 45 age group) and certain minorities.

Committee work is not equally attractive to, or possible for, all sections of society. So PPGs should also consider outreach work whereby they learn the views of under-represented patients by attending their own gatherings. PPG members can also speak to patients in the waiting area to learn their views, or set up email or telephone networks that make it easier for patients to offer their views.

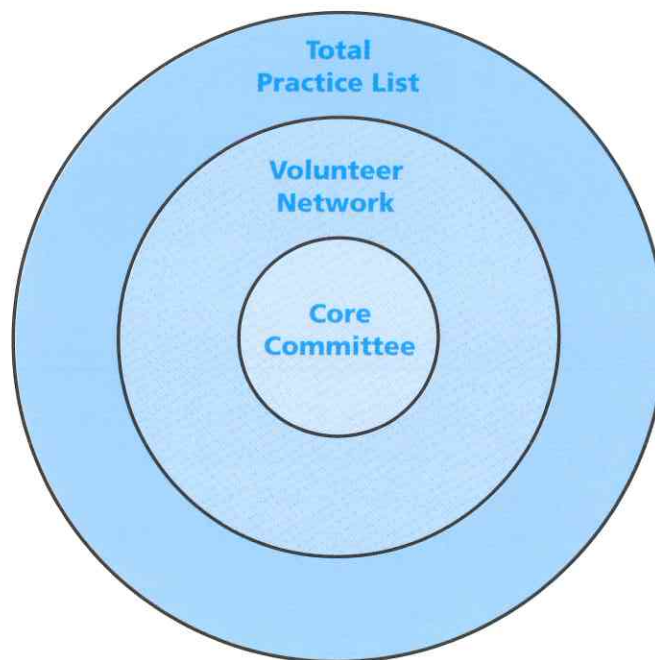
Every community is different but the approach of inviting representatives onto the committee from local organisations can be highly effective. Not only do those organisations then have the responsibility for replacing committee members who leave, but this model strengthens the relationship between the practice and the wider community, enhancing communication. A hybrid method of recruitment may also be adopted, with a mix of invited and elected members. This can combine the virtues of ensuring that the committee has appropriate skills with offering everyone the opportunity to participate.

PPGs often draw strength from their links with other community organisations. Some PPG committees include representatives of key local groups. So the chairman of **Church End Medical Centre PPG**, for example, is also vice-chairman of Fortunegate Community Housing. Other links might be to local day centres, schools, carers’ organisations, parent and toddler groups, local or parish councillors, PPI Forums and so on. These connections bolster the representativeness of the PPG and are highly valuable in improving communication between the practice and the local community.

Committee structures

Most PPGs rely upon a core committee and some are also able to call upon a wider network of volunteers to support the work of the PPG. The **Elliott Hall Medical Centre PPG**, mentioned in the previous section, numbers some 120 volunteers (from a list size of 7000) who support carers, provide volunteer transport, hand-deliver twice yearly newsletters and so on. Their scale is such that they organise an annual tea party to thank their volunteers.

The relationship between the committee, volunteers and the wider practice list is indicated below. Depending on the range of activities provided, some PPGs have worked hard to increase the size of the middle circle, effectively raising awareness of the work of the PPG and maximising its impact on the well-being of the local community. The core committee should always remain relatively small so that it can provide effective leadership and decision-making.



Setting objectives

Practices thinking of starting a PPG need to be clear about what they would like from the patient group. But they must also leave space for the PPG itself to determine its priorities. This requires some discussion and negotiation of objectives, and these should be reviewed annually. PPGs that affiliate to N.A.P.P. receive advice in this area within the Handbook that is provided to members.

Links to the Primary Care Trust (PCT)

Members of established PPGs can play an important role in the wider health community, sitting on PCT committees, taking part in consultations and contributing to discussions around practice-based commissioning, for example. They tend to offer a valuable generalist perspective and, where most practices within the PCT have a PPG, they also offer a broad geographical base.

Fundraising

PPGs are normally not expensive to run. Those that focus purely on strategic input may require no funds at all, other than to pay expenses. At the other extreme, some PPGs choose to raise extensive sums of money, often meeting a need that would not otherwise be met locally.

An example of the latter is provided by the **Friends of New Court Surgery** who (in addition to the fashion show mentioned above) run a monthly draw that effectively pays for the services of a podiatrist (roughly £3000 annually). Patients pay £12 per year to take part (often by standing order) and 50% of the proceeds go to the PPG. The same PPG also runs an annual concert.

The **North Baddesley PPG** is highly active, running the Michael Witt information room within the surgery which is staffed by volunteers every morning of the week. This entails expenditure on books and videos, and they also fund urgent counselling as well as meeting some of the equipment needs of the practice.

This is paid for by hugely popular quiz evenings that are run three times per year, attended by 140 people, and raising £750 each evening. The £5 attendance charge includes a hot meal, usually a jacket potato with various toppings. Every few years, the PPG also arranges a charity golf day, the last of which raised £7,500 as they took over the entire golf course for the day.

Patient Participation Groups and the changing NHS

Patient Participation Groups are not driven by a central agenda. Instead they evolve to meet local needs. This is a great strength and perhaps one reason why the model has endured throughout four decades of continuing organisational change within the NHS. Nonetheless, PPGs do need to be aware of the wider policy agenda and this section highlights some of the main reforms currently being implemented, together with some thoughts about their potential impact on PPGs.

We start this review with new General Medical Services (GMS) contract that was introduced in April 2004. The majority of general practices are covered by these arrangements. Within the quality framework, it rewards practices financially if they discuss their action plan (based on the results of the patient experience survey) with a patient group.

There is some evidence that this is leading to the formation of more patient participation groups. N.A.P.P.'s November 2005 survey of 1800 English practices secured over 500 responses with 135 reporting having a PPG. 38% of these had been formed in the previous two years ie since the introduction of the new contract. If this is the main driver for PPGs to be set up, it seems likely that the function of these PPGs will be more strategic than service- or support-driven. This may change over time, however, as the groups become more aware of the wider possibilities.

A second major reform currently affecting primary care in England is the introduction of practice based commissioning. Its objective is to secure greater engagement of primary care clinicians in the decisions on which care is needed for their local communities. Practices, or groups of practices, are asked to identify how services can be provided in a different, and more cost-effective, way. Although voluntary, the Department of Health has set itself a target of universal coverage across England by the end of 2006. There is also a financial incentive for practices to take part in this process.

National guidance requires PCTs and practices to engage with patients in these commissioning decisions. In particular, patients can:

- help practices to determine which areas should be prioritised
- provide feedback on whether changes are working
- advise on how any savings should be reinvested

Some patient participation groups are well-placed to work with their practices in this endeavour and can provide a valuable generalist perspective. But current levels of interest among PPGs in practice based commissioning are not high (as indicated by our survey of affiliates in Spring 2006). Because practices are tending to form locality groups to carry out this work, there may be greater interest in PPGs working together to provide the necessary patient perspective.

The next two major policy areas link to the information provision and health promotion roles of PPGs. From 1 January 2006, patients being referred by their GP to see a specialist should be offered a choice of locations for that care to be provided. This is part of the government's commitment to providing more choice within the healthcare system. Patients are also able to choose the day and time of their appointment from a menu of available slots.

As this is a new system, some patients are not sure how to use it. Others are keen to understand more about how to exercise their choice and require signposting to sources of information about the possible venues that they might choose. A third group of patients would like to exercise choice but are not sure how they can travel to their preferred location. Patient participation groups may wish to discuss with their practices whether they can help to meet patients' needs in any or all of these scenarios.

Spotlight on Easington

In the District of Easington, PPGs have strong links with the local PCT. PPGs are seen very much as part of Patient and Public Involvement across the District and aims and objectives for PPGs are included in the PPI strategy. The PPI team offer support to all GP Practices that wish to establish PPGs. This is done by working closely with Practice Managers to recruit patient volunteers initially, facilitate meetings and offer administrative support for as long as necessary.

The PPI team is committed to supporting and developing PPGs and will offer training and development opportunities for their members. To date there are seven PPGs in the District all working closely with Practice staff and the PCT. They are also engaging with the local community due to the fact that many members are involved in other community organisations such as the Disabled Club and local Health Forums. Many members are active in the wider PPI network locally which has aided them in expanding their knowledge of the NHS and contributing to the development of their PPG.

The PPI team is also working closely with Health Promotion staff and a group of volunteers to design a newsletter template for each Practice Forum to add their own information to distribute locally. The newsletter will include information on local services and health promotion initiatives.

PPGs are encouraged and supported to write yearly Action Plans for activities, which to date have included fundraising events, a drug awareness information evening, working with other community groups and the PCT to provide exercise classes for people with disabilities and raising awareness about Men's Health issues.

Turning to health promotion, the Wanless report commissioned by the Treasury in 2002 argued that an annual saving of £30billion could be achieved by 2022 if we could move to a scenario in which patients are “fully engaged”. This will require that individuals engage in their health in a far more meaningful way than is currently true, with more self-care, better health promotion and major improvements in the availability of health information.

Primary Care Trusts are increasingly recognising the contribution that PPGs can make in securing the objectives identified by Wanless. Many of them have encouraged and supported their practices to develop PPGs and then created a network of the resulting groups. It is important that this approach is not lost with the reconfiguration of PCTs in October 2006 that halves their number and greatly increases the size of some.

These innovations, together with ongoing concerns such as the reduction of health inequalities, may influence the future role of PPGs. There is not space here to cover each of them in detail and, in any case, the list is far from exhaustive. Other changes that may be relevant to the work of PPGs are:

- The growing numbers of Foundation Trusts developing a new kind of relationship with their local communities
- Greater diversity of organisations providing care, notably the private sector, which will inevitably lead to services being marketed and advertised in a way that we have not seen before in the NHS
- The use of payment by results, whereby providers are paid according to the number of patients that they treat (rather than on a “block contract”) so that there will inevitably be greater financial volatility which may affect your local Trust
- The January 2006 White Paper which promoted a shift in services away from hospitals and towards primary and community care, with implications for where patients receive care, and the care that is available

In summary a great deal is changing within the NHS with the new GP contract, greater clinical engagement with commissioning, more competition among providers, a stronger emphasis on choice for patients, a drive to secure financial balance and a stated commitment to reducing health inequalities. It is vital that the patient voice and contribution is not lost in the pressure to deliver this change.

Useful contacts

The National Association for Patient Participation

The National Association for Patient Participation, a registered charity, is the umbrella organisation for Patient Participation Groups within primary care. PPGs can affiliate to N.A.P.P. for an annual fee of £25. They will receive a Handbook of Patient Participation, regular newsletters, telephone and other support, and reduced conference fees. Primary Care Trusts can also affiliate to N.A.P.P. for a fee that varies according to the size of the organisation. For more information, please contact our Membership Secretary Audrey Hoggard.

Audrey Hoggard
Audrey.hoggard@napp.org.uk
0114 287 4035

Individual Patient Participation Groups

The following PPGs that are mentioned in this booklet have agreed to have their contact details included below.

Bridge Road Surgery Patients Group

Jan Dickinson
18 Romany Road, Oulton Broad, Lowestoft NR32 3PJ
Telephone: 01502 513554

Cookham Medical Centre PPG

Roger Battye
Email: roger.battye@btinternet.com
Telephone: 01628 523890

Davenport House PPG

Roger Gedye
Email: rogergedye@dial.pipex.com
Telephone: 01582 832374

Doncare Medical Centre Patient Support Service

Chris Simmonds
Email: Practice.manager@gp-c86025.nhs.uk
Telephone: 01302 811199

Elliott Hall Medical Centre PPG

Lesley Walmsley

Email: lesleywalmsley@fairelmscottages.eclipse.co.uk

Telephone: 020 8428 7954

Friends of Testvale Surgery PPG

Ken Fielder

02380 292151

Hadfield Medical Centre PPG

Shirley Wallwork, c/o Hadfield Medical Centre,
82 Brosscroft, Hadfield, Glossop, SK13 1DS

Highcliffe Medical Practice PPG

Mr Alan Brown

Tel: 01425 272673

Email: alnbrown@lineone.net

North Baddesley PPG

Barrie Williams, 17 Hollywood Close,
North Baddesley, Southampton
SO52 9HA

Telephone: 02380 411288

Riverside Medical Practice PPG

Ms Lisa Elliott

Tel: 01642 604117

Email: lisa.elliott@nhs.net

Sheepmarket Patients' Group

Stamford

Jim Medcalf

Email twojs@beeb.net

Telephone 01780 482583

Taynuilt Medical Centre Medcats

Steve Eccles

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Telephone: 01631 720 438

Twyford Practice

Angela Forder-Stent

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Appendix: The Early Years

We are extremely grateful to Dr Tim Paine, who retired as President of N.A.P.P. in January 2006, for drafting this chapter. It describes the origins of Patient Participation Groups and the early years of the National Association for Patient Participation.

Background

The very first practice-based patient group was established by Dr Peter Pritchard in his Berinsfield practice, south of Oxford, in 1972. He believed that he could improve the quality of service provided by inviting some patients, who were also involved in local community groups (such as the Red Cross), to offer their ideas and suggestions.

Meanwhile, in Aberdare, in the valleys of South Wales, Dr Alistair Wilson had become committed to setting up a group in his practice. Alistair was a very political figure – with a capital ‘P’. He stood (unsuccessfully, it has to be said) as the local Communist Party candidate in a number of general elections. He felt very strongly that there should be more democracy at the ground roots of the NHS – at practice level. The patients of his practice, he argued, had a right to a say in the way their GP’s practice was run. He also thought that they should be given the opportunity to meet, and talk and listen to, local health experts. After it got going in 1973, the Aberdare Patients’ Association organised regular health education meetings at the surgery, which were very well attended, and reported in the local press.

Neither Peter Pritchard nor Alistair Wilson had any idea that the other had established a patients’ group. Nor did Tim Paine, when in early 1974 patients of his Bristol practice formed The Practice Association. He had become interested in the way well-run organisations depended on regular feed-back from their clients, and realised this was highly applicable to general practice. Not only that, but how much sense it made to tap the experience, skills and goodwill of patients. ‘His’ patient group was self-selected and had four main aims – to give patients a say in the way the practice was run; to provide voluntary help – mainly transport - for fellow patients; to organise regular health education meetings; and to operate an informal complaints service.

A decade before these three groups were formed the Patients’ Association had been founded, to represent the concerns of those NHS patients UK-wide who felt badly about the way they had been treated in hospitals. This was really the start of consumerism in the NHS, which tended to operate in a confrontational way – at least that is how it was felt by the medical profession: so-called ‘patient-power’. Practice-based patient participation, in contrast, was, from the start, a far more co-operative endeavour, based on friendly relationships and mutual trust.

NAPP is born

By 1976 a few other groups had started – Glyncorrwg, Taunton, Newport (IOW), Limes Grove, West Kirby - and had begun to communicate with each other. An informal network developed. The following year a meeting of 8 groups – now christened patient participation groups (PPGs) – was held in Bristol. The idea of a national body for PPGs was discussed and adopted. In February 1978 the inaugural meeting of the new National Association for Patient Participation in General Practice (NAPPGP) was held at Green College, Oxford. Sir George Godber, recently retired Chief Medical Officer, was the Association's first President. Dr Alistair Wilson of Aberdare, and Alec Dakin, Chair of the Practice Association in Bristol, were joint Chairmen.

The Oxford meeting was exciting. There was a very good attendance of PPG representatives, interested patients and GPs from other practices, members of community and consumer organisations, and the Press. The aims and roles of the new Association were presented and discussed – to link and support existing PPGs; to provide practical help and encouragement to other practices interested in starting a PPG; and to promote patient participation to the public, GPs and Government. Joan Mant, who ran the Central Information Service at the Royal College of General Practitioners, volunteered to act as the link-person for NAPPGP. She went on to become the Association's Chair, from 1981-5 (succeeded by Keith Smith), and did an enormous amount to keep it going in the early years. She also started the Newsletter.

Membership & Organisation

Every PPG could affiliate to NAPPGP for a small annual subscription, which entitled it to vote at the Association's AGM, and to receive support and information about the practical aspects of patient participation. NAPPGP's aim from the start was to encourage experimentation and the sharing of new ideas and experiences. There was no 'official line', or 'correct' way for a PPG to operate. When it came to problems, groups were encouraged to tell the Association about these and say if, and how, they had got round them.

For the first few years NAPPGP was run by a Steering Committee made up of several PPG representatives plus three GPs. Once charitable status was achieved (see below), steering committee officers and members became trustees of the renamed Executive Committee.

NAPPGP – shortened to N.A.P.P. after a few years – soon began making a difference. Its help was valued by existing and aspiring PPGs; and its membership started to rise healthily. In 1979 there were 19 N.A.P.P. - affiliated groups; in 1980, 27; in 1982, 50; in 1985, 70; and by N.A.P.P.'s 10th birthday in 1988 the numbers approached 90 [editor's note: affiliation in 2006 stood at 270]. Not all new PPGs chose to affiliate, however, preferring to 'do their own thing'. Keeping score of all existing PPGs became quite difficult.

During 1980/1 a network of Regional Organisers (ROs) was set up. The RO's job was to act as N.A.P.P.'s PPG-facilitator in his or her region, and to organise local conferences. Over the three years 1981-3, for example, these were held in Bath, Bristol, London, Sheffield, Manchester, Basingstoke, Todmorden, Isle of Wight, Aberdare, Abertillery and Livingstone. They proved very popular. Talks given on different aspects of patient participation and PPG logistics stimulated much lively discussion; and PPG members were able to share experiences and new ideas, and discuss problems and solutions together. A commonly aired difficulty was the period of doubt and indecision that PPGs often go through after the first two or three years' 'honeymoon': "Where do we go from here?" Coming to N.A.P.P. conferences helped to give such groups fresh ideas and renewed confidence – often very necessary when trying to persuade hesitant GPs to grasp the nettle!

N.A.P.P. and the Profession

In spite of all this activity and enthusiasm, however, getting GPs to embrace patient participation proved harder than had been hoped. The author of this article rather naively expected PPGs to become the norm in practices within a few years of N.A.P.P.'s birth. After all, the enterprise seemed so obviously sensible and worthwhile! He hadn't reckoned with three facts of life: a deeply engrained suspicion among his GP colleagues about 'patient power'; scepticism that patients could contribute something positive to a practice other than a source of income; and the time it takes for professional attitudes and habits to change. "PPGs, by definition, are likely to attract the more volatile and extrovert...complainers and neurotics" – *World Medicine* 1981. "To many practitioners, few innovations [PPGs] can ever have seemed so threatening." – *Lancet* editorial 1981. "In most parts of the country the relationship between practitioner and patient is extremely good. In these cases there is little or nothing that this type of activity can add" – *BMA*, 1983.

Fortunately, N.A.P.P. did have some powerful allies. Our President, Sir George Godber, helped greatly to oil wheels for us. And in January 1980, the Royal College of General Practitioners (RCGP) hosted a national conference on patient participation. 68 GPs were among those who attended; and 50 were turned away! 19 new PPGs were established largely as a result of this conference; and following it the College published an 'Occasional Paper' entitled "Patient Participation in General Practice", edited by Peter Pritchard, which explained and promoted patient participation and the work of N.A.P.P.

In 1983 the Presidency of the Association passed from Sir George Godber to Dr John Horder, President at the time of the RCGP. Dr Horder, together with Dr (now Prof Sir) Denis Pereira Gray – N.A.P.P.'s current Patron – and Dr Pritchard, helped to establish a PPG within the College – the Patients Liaison Group. Tim Paine, representing N.A.P.P., served on the PLG for the first 3 years. The PLG – since renamed the Patient Partnership Group – was made up of 4 lay and 4 professional members, and was chaired at the start by a member of Council of the RCGP. (A manifestation of the prevalent professional resistance to patient participation was the refusal by the RCGP Council to allow a lay PLG representative to attend its meetings. It was "iN.A.P.P.ropriate". Fortunately, this situation was remedied after a few years.)

Charitable status

The Association first applied for charitable status in 1980, but due to the fact that its rather sketchily written Constitution contained some aims and objectives that were viewed as 'political', the request was turned down. There was a strong feeling at the time, mainly emanating from PPGs in South Wales, that the new Association should lobby against prescription charges. Surely this was a legitimate and important task for any organisation pretending to represent the interests of less-well-off patients in the NHS, they argued. It was such attempts to 'change the system' that the Charity Commission bridled at. The issue of 'activism' also led to something of a split in the Association between those holding opposing political views. It became clear to all concerned after a year or more that the only way forward if N.A.P.P. was to survive, was for it to abandon any pretence of being a political ginger-group. The Constitution was rewritten, and N.A.P.P. finally achieved charitable status in 1985.

National involvement

Because patient participation was something new and newsworthy, during its early life N.A.P.P. received considerable attention from the media – radio, TV and the Press. Numerous invitations were received to meetings and conferences organised by organisations such as the King's Fund, the National Consumer Council and the National Council for Voluntary Organisations. There was an increasing demand for speakers and many articles were written, for lay and professional journals, by N.A.P.P. members. In 1978/9 N.A.P.P. was consulted by the Royal Commission on the NHS, chaired by Sir Alec Merrison, about the contribution that PPGs could make to the quality of primary care. This led to the first 'official' and published acknowledgment of the value of patient participation. The Royal Commission's report stated that 'positive steps' should be taken to encourage the establishment of PPGs, and that funding should be made available for this. Sadly, Government did not rise to this challenge.

In 1979 the thorny issue of publicising PPG activities hit the headlines. One group had left leaflets detailing its work and programme in a local pharmacy. The GPs in a neighbouring practice complained about this to the British Medical Association, claiming that it was, in effect, advertising the practice, thus contravening the rules of professional conduct. The BMA supported this claim, and its Ethical Committee published a strong statement which declared that PPGs should not be allowed to publicise their activities in this way. N.A.P.P. reacted vigorously to this, and a meeting was held at the BMA to agree a more sensible approach. Clarification followed: the publicising and reporting of health education activities by PPGs was to be allowed, but not those matters domestic to the practice concerned, such as transport and other PPG-run facilities available to patients. Several years later the General Medical Council considerably relaxed the restrictions on general practice advertising; the need to provide the public with information and choice overrode concerns that GPs might gain, or lose, by such publicity.

Then and Now (2006)

The world of general practice at the time of N.A.P.P.'s birth was a very different one to that of today. In the 1970s the notion that patients might have a positive contribution to make to the way a practice was organised was considered a bit odd, even by patients, let alone GPs. As for having a right to participate, that was considered unacceptable by the vast majority of doctors (and still is by many); and Government was not the slightest bit interested. Nowadays, public involvement in the NHS at primary care trust (PCT) level and above is statutory, although still not so at practice level. It was declared a signal victory by one PPG in 1976 to have persuaded their GPs to appoint a woman partner! Now general practice is fast becoming a predominantly female profession.

The end of N.A.P.P.'s first decade coincided with the introduction of Thatcherite 'reforms' in the NHS. In some ways the attempts by Government to gain more control of what went on in primary care married well with the aims of PPGs – to improve the overall quality of service provided. The past 15 years, however, have seen a reverse trend, a steady erosion of two aspects of good general practice that N.A.P.P. has always extolled – personal care and continuity of care. Governments wedded to (blind) consumerism – a 'deformity' of true patient participation - have sacrificed these two precious standards on the altars of 'choice' and 'access'. This has given rise to a feeling of powerlessness among those PPGs that have tried unsuccessfully to argue for the retention of these traditional aspects of family doctoring, the way things were during N.A.P.P.'s early years.

Dr Tim Paine

Co-founder and former President of The National Association for Patient Participation