



National Association for Patient Participation

Getting Started

**A step by step guide to setting up
Patient Participation Groups
(PPGs)**

Patron:- Professor Sir Denis Pereira Gray OBE
President:-Dr Patricia Wilkie, PhD, FRCR (Hon), FRCGP (Hon)
Registered Charity No. 292157

Contents

	Page
Foreword	
Welcome and introduction	1
What is a Patient Participation Group?	2
What are the benefits of a Patient Participation Group?	3
GMS Contract Agreement	5
Patient Participation Groups locally and nationally	6
A step-by-step guide to setting up a Patient Participation Group:	
Step 1: Getting started	7
Step 2: Recruiting your group	7
Step 3: The first meeting	10
Step 4: The second meeting and ongoing issues	12
Step 5: Communication and reporting back	15
Appendices:	
Appendix 1: What can a Patient Participation Group do?	17
Appendix 2: Patient flyer	19
Appendix 3: First meeting agenda	20
Appendix 4: Second meeting agenda	21
Appendix 5: Sample terms of reference	22
Appendix 6: Troubleshooting	23

Welcome and introduction

Welcome to the second edition of step-by-step guide to setting up a Patient Participation Group (PPG). The aim of this guide is to offer support and practical guidance to general practices and patients who are interested in getting more involved with their local healthcare by setting up Patient Participation Groups.

Each group will be individual and will reflect the unique aspects of the practice and its population. This guide will help you to get started.

The first edition of this resource built upon the work of NHS Norfolk, Liverpool PCT and NHS Milton Keynes / Quality:MK) was produced as part of a national campaign between June 2009 and March 2010 to promote PPGs in primary care.

This new edition includes guidance for GP practices on meeting their new Patient Participation Directed Enhanced Services (DES) requirements under the terms of the 2011-2012 GMS Contract.

Supporting materials can be found on the NAPP website a www.napp.org.uk

What is a Patient Participation Group?

Every PPG is unique, evolving to meet local needs. Most commonly, they work with their practices to offer the patient perspective on the services that are provided. PPGs also help to improve communication, to encourage patients to take more responsibility for their health and to provide practical support.

NAPP is unique as the umbrella organisation for patient-led groups within general practices. Formed in 1978 it helps new groups to get started and existing groups to network with each other. It also supports PCTs that are actively promoting PPGs.

PPGs assist GP practices to meet their new Patient Participation Directed Enhanced Scheme (DES) requirements under the recent changes to the 2011-2012 GMS Contract to promote the proactive engagement of patients and obtain feedback from the practice population.

Patient participation is:

Patients working with a practice to:

- contribute to the continuous improvement of services ensuring practices are more responsive to the needs and wishes of patients;
- foster improved communication between the practice and its patients;
- help patients to take more responsibility for their health; and
- provide practical support and help to implement change.

Varied to suit local needs:

- Each group determines its own activities according to the needs of the community and the practice itself.

Based on co-operation:

- PPGs work by building a relationship between the practice and its patients that breaks down barriers and shares information.
- PPGs can develop to influence the wider NHS, most notably the decisions that are made on behalf of patients about the services that are to be available to them.

Patient participation is not:

A forum for complaints

- Clear ground rules are needed to ensure that PPG members do not use the PPG as a vehicle to resolve their own personal issues (however, PPGs often lead to a reduction in the number of complaints overall).

A doctors' fan club

- In order to be valuable, PPGs must have the confidence to challenge the practice in line with the critical friend model.

A time-consuming activity for practice staff

- Some effort is required to get PPGs going but thereafter they should be self-organising and patient led and will often undertake activities that save the practice time.

What are the benefits of a Patient Participation Group?

PPGs are:

Good for patients because:

- Patients will be more responsible for their own health.
- Patients will have a better understanding and knowledge of the practice and its staff.
- All sections of the community will be enabled to get involved through virtual PPGs which use email networks and online surveys
- Patients will be consulted about arrangements for their primary healthcare before decisions are made.
- Patients will benefit from improved communications with staff.
- Patients will have a forum to suggest positive ideas and voice concerns.
- PPGs can offer some peer support to patients in managing their conditions, making healthy choices and accessing information

Good for practice staff because:

- They assist GPs to develop an equal partnership with their patients and an increased understanding of patients priorities, needs, wishes and perspectives
- They help GPs and their staff to communicate accurately and honestly with individual patients ensuring there is regular two way dialogue and feedback between the practice and its patients
- Through virtual PPGs, GP's and staff can connect with the wide diversity of the practice population particularly those from minority communities and people who seldom have their voices heard
- PPGs are an additional resource for the practice raising awareness of and signposting wider services, promoting health and well being choices, providing practical help in administering specific campaigns
- PPGs can encourage more self care for minor ailments empowering patients and the public to use services more effectively and appropriately
- GPs and their staff will be able to plan services jointly with patients in order to increase their effectiveness.
- They will be able to help patients with non-medical and social care issues.

- They will be able to get help from patients in meeting targets and objectives.
- They will have a forum to voice concerns, ideas and suggestions to patients.
- They help ensure shared decision making with patients and with the wider community about key health matters reflecting patient need within a locality.
- They will get closer to the community for whom they care.

Good for the community because:

- Patients will have an organisation through which they can identify their own needs and priorities.
- Patients will be able to get an idea of what is needed to improve healthcare, and make sure that the patient view is always represented.
- Patients will maintain an open dialogue with GPs and other healthcare professionals.
- Patients will be able to have a say in shaping local services through local PPG networks feeding into commissioning arrangements
- Patients will have an opportunity to become involved in other community initiatives such as their Local Involvement Network (LINK)/Local Healthwatch and their GP commissioning Consortia.

The bigger picture – patient participation:

The NHS Plan in 2000 emphasised the importance of patient and public involvement so that the NHS can better shape services around the needs of patients, their families and their carers. This principle was given legal force as Section 242 of the consolidated NHS Act 2006 and the Local Government and Public Involvement in Health Act 2007 placed a duty on PCTs to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes. This is a statutory duty, which means consulting and involving patients:

- not just when a major change is proposed, but in ongoing service planning;
- not just in the consideration of a proposal, but in the development of that proposal; and
- in decisions about general service delivery, not just major changes.

The Health Bill currently going through parliament, which may be subject to change, emphasises the principle ‘no decision about me without me’ and outlines a similar statutory duty on GP Commissioning Consortia and the NHS Commissioning Board to secure that individuals to whom the services are being or may be provided are involved (whether by being consulted or provided with information or in other ways):

- in the planning of the commissioning arrangements by the consortium,
- in the development and consideration of proposals by the consortium for changes in the commissioning arrangements where the implementation of the proposals would have a significant impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and

- in decisions of the consortium affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact.

PPGs are one significant way to involve people in local healthcare decision-making.

PPGs are uniquely placed to represent a collective unbiased view of patients' and the wider community's needs and priorities. PPGs collect feedback on patients' experiences at the patient/practice interface and through analysis and evaluation of patient insight data including annual GP Patient Surveys. PPGs provide valuable intelligence that helps GP practices become more responsive to the needs and wishes of patients.

2011- 2012 GMS contract agreement – Patient Participation DES

The 2011-2 012 GMS contract agreement sets out a new national Directed Enhanced Service (DES) to improve Patient Participation from April 2011 for two years requiring GP practices to promote the proactive engagement of their patients through 'Patient Reference Groups' and to undertake local surveys.

Key requirements of the Patient Participation DES are that GP practices:

- develop a structure that gains the views of patients and enables the practice to obtain feedback from the practice population, e.g. a patient reference group
- agree areas of priority with their patient reference group
- collate patient views through a patient survey
- agree an action plan with their patient reference group
- publicise the results of the patient survey
- publicise the actions taken and what is achieved as a result.

Around £60m of released investment will be available to practices, provided that they successfully meet these requirements, which is equivalent in total to £1.10 per registered patient.

To recap:

PPGs can:

- offer feedback on the patient perspective;
- help practices to make the most effective use of their resources;
- improve communication;
- help to promote good health;
- influence decisions about which services are provided; and
- offer practical support to the practice.

Patient Participation Groups locally and nationally

Locally

Each PPG is unique to its practice and local community. Members of N.A.P.P can access the contact details of all affiliated PPGs in the Members area of the N.A.P.P website to network, share good practice, learning and experiences.

Virtual PPGs based on email networks are now developing alongside 'real' PPGs based physically within practices. By using online survey tools practices can communicate with and receive feedback from all diverse interests and backgrounds across the practice population particularly those people who are 'harder to reach'.

Networks of PPGs are now forming across localities to co-ordinate with other PPGs taking a wider perspective in shaping and improving services and ensuring the patients perspective informs commissioning decision making. Case studies of PPG practice based activities and involvement in GP led commissioning arrangements are available at www.napp.org.uk

Nationally

Over 50% of general practices in England now have a PPG. PPGs are also now developing in dental practices. The first groups were established in 1972 by GP surgeries with very different motivations. These included giving patients a greater say, tapping into the goodwill of patients and gaining a deeper understanding of the needs of service users and carers. PPGs are not a political fad.

Research carried out by N.A.P.P in 2005 and 2007 (covering 3,600 practices) revealed that the critical success factors for PPGs are leadership from within the PPG, commitment from the practice, and the PPG understanding the ways in which the practice operates.

With growing interest in PPGs and a new national incentive, N.A.P.P is keen that groups are allowed to develop in a sensible and measured way, with realistic objectives and good support from both practices and PCTs.

Appendix 1 contains a list of some activities in which PPGs are currently engaged in practices across the country. This is not exhaustive but gives an idea of the types of contribution an effective PPG might make.

Step 1: Getting started

The idea to start a group can come from:

- a practice manager;
- a GP or other member of practice staff; or
- a patient or group of patients.

A staff member at a surgery can:

- talk to the communications and engagement manager at their PCT for advice;
- become a champion for patient involvement at the practice;
- canvass the level of interest among patients or approach selected individuals;
- approach surgery user groups (e.g. parent and toddler groups, screening clinics for elderly people and well women/men clinics);
- contact NAPP for advice;
- read the literature already available about PPGs; and
- talk to other practices with a PPG.

A patient can:

- approach the practice manager or the practice patient and public involvement champion;
- contact NAPP for advice;
- read the literature already available about PPGs;
- talk to other practices with a PPG; and
- canvass the level of interest among other patients.

Step 2: Recruiting your group

There are three main ways of recruiting members for your group:

- open groups;
- invited groups and
- email contact for virtual groups

Open groups

Open groups are formed from open meetings, which any patient may attend. You will need to advertise widely, giving plenty of notice. (Appendix 2 has a suggested patient flyer.) It may also help to offer an incentive to come along, such as free refreshments, a talk on first aid or a tour of the surgery. Make the invitation positive and upbeat and don't forget to target the fit and healthy and those who have not visited the surgery for some time. Here are some ideas for circulating your invitation as widely as possible:

- posters/flyers in the waiting room and around the local area;
- details on the electronic message board if the practice has one;
- notes at the bottom of prescription slips or sent out with prescriptions;
- articles in the practice newsletter and on the website;
- send an email or text to patients who have agreed to be contacted electronically;
- an article in town and parish magazines and in free sheets; and
- ask staff and patients to spread the word.

Invited groups

Invited groups are formed by contacting individuals directly who are known to the practice and its staff and who are patients at the practice. These patients may also be known in the community because they are local parish, town, district or county councillors. They may include the parish vicar or a local journalist. Some members of staff, especially in general practice, such as district nurses or physiotherapists, see the same patients regularly, or have appointments that last longer than regular GP consultations, and so have the opportunity to have a more general chat with the patients while they are treating them. They may identify patients who might be interested in joining a PPG.

It is also possible to have a group which is a mix of open and invited representatives. Use the invited method to get things going and then do some open recruiting as well.

Here are some other ideas for contacting invited group members:

- Ask staff to nominate patients they have cared for who they think might be interested.
- Ask staff to hand out flyers to patients during a consultation if they think they might be interested.
- Ask staff to hand out flyers during clinics and groups, such as parent and toddler groups, well women/men clinics or carers' groups.
- Approach other local community groups to share information.

Remember that, whether you are recruiting through the open or invited method, always ask people to contact you if they want to attend, so that you can have an idea of how many people are going to be at your first meeting. If no one turns up you have wasted time and

resources organising the meeting and it can leave you dispirited. If too many people turn up you may not have enough room or refreshments and it can be difficult to get through the agenda. You should find out in advance if anyone has special requirements such as a hearing loop or wheelchair access.

Virtual groups

To establish a virtual PPG it will be necessary to create an email list of patients willing to help practices by giving their views electronically. The practice may already have email addresses from individual patients who have given permission to be contacted in this way.

A report of a pilot project undertaken by the Department of Health with four practices, 'Community Voices – Developing Virtual Patient Participation', can be accessed on the N.A.P.P website. This report describes the processes involved for setting up and recruiting members to virtual groups. In the pilot project, the vast majority of people invited to join the groups who had an email address responded positively.

Recruitment across all time periods, e.g. across a whole day and a whole week, can support the achievement of a more representative sample of patients. Asking all new patients who register if they would like to join is an ideal way to achieve a greater representative cross section of interests and backgrounds within the group over time.

Your practice may or may not already have in place a 'real' PPG which meets face to face. If it does, it may be simplest to use the 'real' PPG as the main point of email contact. If you do not already have a 'real' PPG, creating an email contact list is a good starting point.

Being representative

A common criticism of PPGs is that they are not representative of the practice population. It is always going to be difficult to get a group that exactly reflects the demographics of the local population, and volunteer roles tend to attract those that have a certain level of confidence and free time, and have flexibility about working and earning money. However, a PPG is there to make sure that the patient voice is listened to and not necessarily always to be the voice itself. The issue can be addressed by:

- being proactive about getting out into the community to canvass opinions;
- targeting certain groups of people not represented on the group to find out what they think;
- approaching certain representatives to join the group for a short time or for a specific purpose;
- setting up a virtual group to operate alongside the 'real' PPG and running online surveys with virtual members and
- making sure that you try to contact a diverse range of people, so that you get the views of people from other ethnic communities, the travelling community, those with disabilities, gay people and those whose first language is not English.

It takes time to develop this wider outreach and PPGs will naturally grow and become better known over time. Making use of virtual PPGs allows practices to gain a more representative view from the practice population but does not replace the role of a 'real' PPG group which meets face to face and works closely with the GPs and staff within the practice.

Step 3: The first meeting

Many people who express an interest in joining the group use the first meeting to decide whether it is something to which they want to commit time and energy. This applies to staff from the practice as well and so it is important that the first meeting is as positive and productive as possible. Having practice staff, especially medical staff, at least at the first few meetings shows the volunteers present that their time and commitment are valued.

Keep the first meeting fairly short – about an hour is enough – and try to leave with some consensus of what everyone wants to get from the PPG. It is a good opportunity for everyone, both patients and the practice, to discuss ideas and point out the skills and networks that they can bring to the group.

Appendix 3 has a suggested template for a first meeting agenda. This can be adapted to suit different groups. Someone will need to volunteer to take some brief notes/action points from the meeting.

Use the item 'What don't we want from a PPG?' to reinforce the point that a PPG is not a forum for individual complaints or for single issue campaigns. The correct mechanism for dealing with these is one of the following:

- the practice complaints system;
- the PCT complaints manager;
- the PCT Patient Advice and Liaison Service (PALS);
- the Independent Complaints Advocacy Service or the Local Healthwatch organisation once established; or
- writing to the chief executive of the PCT.

Use the item 'Being representative!' to assess the membership of the group, and discuss ideas for how the views of other patients not represented can still be canvassed. It will be useful to discuss how your 'real' group might relate to and communicate with a virtual group at this point if you have one, or discuss the idea of forming a virtual group in the future. Look at reviewing membership annually.

Use the item 'Next steps' to make sure that everyone is still happy with being a member of the group and to address any final concerns.

Agree a date, time and venue for the second meeting, and don't leave it more than 4–6 weeks, as any enthusiasm may fade.

Ground rules

These are important as a point of reference when the group meets and should be agreed at the beginning of the first meeting. They should include a statement emphasising that the PPG is not a forum for pursuing individual personal complaints. A reminder could initially be included in each agenda to reinforce these ground rules. See Appendix 3 again for an example.

Communicating with your Virtual PPG

Email is a fast and effective way to carry out simple surveys to get feedback from patients. There are a number of online survey tools available which are simple to use and have clear instructions on how to set up a survey. Once you have finalised your survey questions it takes just minutes to set up the survey online. Links to some free survey tools are set out below:

- www.surveymonkey.com/
- www.kwiksurveys.com/
- www.esurveyspro.com/
- www.smart-survey.co.uk/

More tips and basic principles on developing online surveys can be found in the Department of Health 'Community Voices – Developing Virtual Patient Participation' pilot project report at www.napp.org.uk

Your 'real' PPG will have an important role in the formation and choice of virtual PPG survey questions by ensuring that surveys reflect patients' priorities. It is also important that the questionnaire allows respondents to raise issues which are important to them in the form of open questions in addition to requesting feedback on the questions put by the practice. The 'real' group will play a role in discussing what changes the practice makes in response to the feedback it receives.

It is essential to communicate with survey respondents to provide feedback on the changes and outcomes realised by the practice based on survey responses. Many practices and PPGs have adopted the approach of a response that says 'You suggested..... We did.....' to ensure people know their voice has been heard.

Practices may find that some of the patients who are on the virtual PPG are willing to join the 'real' group. Inviting members of the virtual group to get more involved can be a good way of expanding and refreshing membership of the 'real' group.

Step 4: The second meeting and ongoing issues

The second meeting

It is important in the second meeting to address some of the administrative and organisational issues surrounding the new PPG. Appendix 4 has a template for a suggested second meeting agenda that can be adapted to reflect the individual PPG. Here are some of the issues that you will need to address:

- **Chairperson** – manages the meetings. They should be a lay member rather than a member of the practice staff.
- **Secretary** – responsible for taking minutes and general administration. This role may be undertaken by a member of staff from the practice. Discussions, decisions, attendees and any apologies for absence should be recorded in formal but brief minutes.
- Decide if your group is going to do any fundraising. If so, a **treasurer** will be needed to take care of funds and finances.
- Agree a first draft of a constitution or **terms of reference**. Appendix 5 has some template examples. This can be developed over the first few meetings.
- Review the ideas about the role of your PPG from the first meeting and try to prioritise them into a work plan, sorting them into **short, medium and long-term objectives**.
- Make sure that you set some good short-term objectives in your work plan so that your group gets some **'quick wins'** to boost confidence. Appendix 1 has a list of some examples of roles and projects adopted by PPGs.
- Decide on the **frequency, timing and venue of meetings**.
- Decide how the 'real' PPG will relate to and communicate with a virtual group if one exists
- Decide on the **quorum** – the minimum number of members of a PPG who must be present for the PPG to conduct business.
- Decide on how big a PPG you need. Some groups have a large membership with a small executive committee that does most the work while others are co-opted for specific projects or will turn out to support events, for example. Remember that there are no set rules, but a group of fewer than six members risks becoming a clique, while one bigger than 15 would be cumbersome to manage as an executive committee.
- Make plans to **review** these arrangements and the PPG objectives annually to make sure that everything is working properly.

Ongoing development

Your PCT can help you to establish a new group but it can also help your PPG at various stages of its development. If at any stage your group feels it could do with some new ideas or a review to help it keep going, contact your PCT for help.

PPGs can also affiliate to NAPP at a cost of just £30 annually and receive a range of resources, support and information on an ongoing basis. For more information on how to join N.A.P.P please contact admin@napp.org.uk or telephone 01932 242350.

Support from N.A.P.P includes:

- Practical tested, evidence based resources and toolkits on starting and growing PPGs
- Resources on starting and growing Virtual PPGs using email networks and on-line tools to reach all sections of the practice population
- A monthly e-bulletin and five printed copies of N.A.P.P's quarterly Newsletter 'Patient Matters'
- Ongoing telephone advice, information and guidance on the formation and development of groups
- Access to UK wide contacts for PPGs and networks to share good practice and learning
- Support in the formation of local PPG networks
- Bespoke support and input for individual groups, practices and networks
- A representative to speak at meetings on an expenses only basis where possible
- Substantial discounts to N.A.P.P national and regional Conferences
- Guidance on legal matters from N.A.P.P's pro bono solicitors
- Access to the N.A.P.P website's membership section, including a full range of useful resources and online discussion forum
- Opportunities to promote the PPG and patient voice at a national level, shaping and developing health policy and responding to national consultations
- Involvement in and access to patient participation research studies

It might also be a good idea in the early stages at least to find a 'buddy' group. There are likely to be other PPGs in your area that would be happy to help you through the early stages or any difficult times (see Appendix 6 for examples of potential problems). For further details contact your PCT communications and engagement manager or N.A.P.P admin@napp.org.uk

Other sources of support may be available locally for established PPGs. These may include the local Council for Voluntary Services (CVS), which can advise on funding and other issues, the LINK soon to become Local Healthwatch, which may have training or other support in place, and any local network of PPGs that has been set up.

Sharing the work

In order for a group to be successful, at least a couple of members need to be very committed. However, it is important that all the work is not left to one person. In such cases, the PPG is likely to run into difficulties if this key player leaves. So, consider:

- establishing roles and responsibilities and review these regularly;
- supporting members so that they can develop their skills and play a more active role; and
- using a rota system, e.g. for taking minutes.

Funding issues

It is inevitable that the group will incur some costs. These may be minimal running costs for administration etc which the practice may absorb, or the greater costs of funding some of the more ambitious objectives, e.g. a wheelchair for the practice. Some PPGs do not want to engage in fundraising activities but it is worth keeping the possible funding opportunities in mind:

- a small membership fee for patients to join the PPG;
- fundraising at community events, possibly in partnership with other organisations such as the local hospice;
- coffee mornings, quiz nights, golf days, etc;
- jumble sales, raffles, auctions;
- applications for small grants; and
- any local incentive schemes or awards relating to PPGs.

Around £60m of released investment will be available to practices that successfully meet the DES requirements for Patient Participation contained within the new GMS Contract; this is equivalent in total to £1.10 per registered patient.

The main reasons groups fail

If PPGs fail, it is usually due to one or more of the following reasons:

- a lack of focus and commitment;
- poor planning;
- poor communication to and from the group;
- hostility between group and practice or vice versa;

- relying too heavily on one or two people; or
- poor ground rules.

A strong, well-balanced group will have a mix of the following people:

- active volunteers – people who have the time and commitment required to action decisions;
- interested professionals – the GPs and administrative staff who work within and know the system; and
- key supporters – people with influence within your locality, e.g. local councillors or business people who help to raise the profile of the group and improve the chances of your group finding financial or other forms of support.

Step 5: Communication and reporting back

Communication within the group

PPGs tend to operate most effectively if representatives from the practice, as well as patients, are present on a regular basis. This ideally means clinical as well as management staff. As a result, up-to date information can be given to patients alongside greater clarity about what can be influenced and what cannot.

This mix of disciplines allows the practice staff to gain a deeper understanding of the patient perspective. Between PPG meetings, it can be useful for the PPG chair to have one-to-ones with the practice manager on a regular basis and/or to attend the practice management meetings. This greatly adds to the insight of the PPG – a key factor if the PPG is to be really effective.

Reporting back

PPG activities should be regularly fed back to all practice staff and patients. This will allow everyone to be aware of the activities of the group and may increase involvement and interest. Feedback from online surveys and communication with the virtual PPG if one exists will also need to be included. You will need to consider:

- How will the work and the issues discussed at the meeting be disseminated to the wider practice population? Options include email, websites, newsletters and notice boards.
- Are there any parish magazines or free sheets produced locally that would include regular updates on your PPG's activities?
- Would it be possible to have regular 'surgeries' where a PPG member(s) spends time sitting in reception to make themselves available to patients for questions and

feedback? You might want to have badges made for group members so that they can be easily identified by patients.

- Feedback to the virtual group through your email networks

Support for your practice and your group

Example Posters/Flyers, Sample Terms of Reference and Agenda's along with trouble shooting tips can be found along with other resources, further support and advice at: **National Association for Patient Participation: www.napp.org.uk or telephone 01932 242350.**

For more information about N.A.P.P and the support available to your practice and PPG ('real' and virtual) please contact admin@napp.org.uk or the Chief Executive: Stephanie Varah, email: stephanie@varah.plus.com or telephone 01909 540678.

Appendix 1: What can a Patient Participation Group do?

PPGs are voluntary organisations. They should not be exploited, nor should they be overstretched. The list below summarises some of the activities in which PPGs are currently engaged. Groups are certainly not expected to do all, or even most, of these. Instead, they are invited to choose areas where they are most likely to succeed and which would be of most benefit to their own communities, patients and practices.

Helping the practice to improve services

- Providing feedback from patients, e.g. on appointment systems, consultation times and repeat prescription systems.
- Monitoring the accessibility of practice communications, e.g. developing the practice booklet and leaflets and designing the website.
- Carrying out surveys into a whole variety of subjects, e.g. measuring patient satisfaction, health needs, awareness and expectations.
- Offering practical help, e.g. flu clinics in practices – making sure that the patients are comfortable.
- Improving practice facilities, e.g. new toys for the waiting room, or maintaining plants and gardens.
- Helping to obtain the patient view, e.g. for planning permission for a new-build project for practice premises.
- Designing new services and initiatives, e.g. extended opening hours for practices.
- Exploring the changing needs of patients.

Offering support to other patients

- Bereavement support.
- Carers' group.
- Hospital visiting.
- Befriending housebound patients.
- Volunteer transport scheme for medical appointments.
- Providing health-based social activities, e.g. 'walking for health' group, exercise classes, creating babysitting circles or trips out for older people.

Providing information

- Organising a health fair.

- Offering handouts and support on special days, e.g. National No Smoking Day.
- Individual patients as 'teachers' and expert patients with long-term conditions who could help those who are newly diagnosed, e.g. diabetics.
- Producing patient newsletters for the practice.
- Ensuring that patient information and advice is as user friendly as possible.
- Representing the practice locally and nationally when patient voices are needed, e.g. collating responses to government healthcare consultations.

Arranging special health events

- Encouraging health education activities within the practice.
- Training in basic first aid for patients.
- Training new parents to distinguish when to call for medical assistance and when to self-treat.
- Increasing awareness of particular illnesses, e.g. breast cancer.
- Increasing awareness among particular cultural groups of issues that relate to them, e.g. the higher risk of coronary heart disease in people from the Indian subcontinent.

Representation

- Acting as a representative group that can be called on to influence the local provision of health and social care.

Appendix 2: Patient flyer

XXXXX Health Centre Patient Participation Group

Are you interested in finding out more about XXXXX Health Centre?

Would you like to influence the development of local health services?

The Health Centre is keen to set up a Patient Participation Group, so why not come along to discuss your ideas and hear about planned changes.

The meeting will take place at: XXXXXXXX

A time and date will be arranged once a number of people have expressed an interest.

If you would like to come along to the meeting, or if you have any queries about the Patient Participation Group, then please contact

XXXXX (Practice Manager) on XXXXXXXX
For suggested discussion topics see the list below.

Refreshments and travel expenses will be provided.

Discussion topics at the first meeting could include:

- an update on planned changes at the Health Centre;
- ideas for the development of the group – what would you like to see your Patient Participation Group doing?
- how your PPG might work alongside a virtual group
- planning a community event at the Health Centre in the future; and
- any other ideas you want to bring along about how you'd like to see the service develop and how you think patients might be involved.

Appendix 3: First meeting agenda

Name of group
Patient Participation Group (PPG) introductory meeting
Date
Agenda

Ground rules

- This meeting is not a forum for individual complaints and single issues.
- We advocate open and honest communication and challenge between individuals.
- We will be flexible, listen, ask for help and support each other.
- We will demonstrate a commitment to delivering results, as a group.
- Silence indicates agreement – speak up, but always go through the chair.
- All views are valid and will be listened to.
- No phones or other disruptions.
- We will start and finish on time and stick to the agenda.

1. Aims and objectives

2. Welcome and introductions

3. What do we want from this meeting?

4. What do we want from a PPG?

5. What don't we want from a PPG?

6. Being representative! Starting and working with a virtual group

7. Next steps

Appendix 4: Second meeting agenda

Name of group Date Agenda

Ground rules

- This meeting is not a forum for individual complaints and single issues.
- We advocate open and honest communication and challenge between individuals.
- We will be flexible, listen, ask for help and support each other.
- We will demonstrate a commitment to delivering results, as a group.
- Silence indicates agreement – speak up, but always go through the chair.
- All views are valid and will be listened to.
- No phones or other disruptions.
- We will start and finish on time and stick to the agenda.

1. Welcome and introductions

2. Group business

- Election of chair, secretary and treasurer
- Terms of reference
- Frequency of meetings
- Working arrangements between 'real' and virtual groups
- Quorum
- Annual review arrangements

3. Work plan

- Review ideas from first meeting
- Prioritise into short, medium and long-term objectives
- Communications and reporting back

4. News from the practice

- Feedback on current issues from the practice

5. Any other business

Appendix 5: Sample terms of reference

This PPG will:

- 1 contribute to practice decision-making and will consult on service development and provision;
- 2 provide feedback on patients' needs, concerns and interests and challenge the practice constructively whenever necessary;
- 3 serve as a 'safety valve' for dealing with grumbles and complaints about the practice – representing patients but also helping them to understand the practice's viewpoint;
- 4 assist the practice and its patients by arranging voluntary groups/support within the community;
- 5 communicate information about the community which may affect healthcare;
- 6 give patients a voice in the organisation of their care;
- 7 promote good health and higher levels of health literacy by encouraging and supporting activities within the practice and promoting preventive medicine;
- 8 influence the provision of secondary healthcare and social care locally;
- 9 monitor services, e.g. hospital discharge and support when back in the community;
- 10 give feedback to NHS trusts on consultations;
- 11 fundraise for medical equipment or other facilities to improve the practice and/or fund the activities of the PPG; and
- 12 liaise with other PPGs in the area.

Appendix 6: Troubleshooting

Potential problems and challenges

These problems and challenges can all be overcome if they are handled in the right way. It is important that the practice takes advantage of the help that is offered to it when setting up a group.

1. Practices may fear that the group will become exclusive and that it will not be representative of the general make-up of the patient population.
2. Patients may think that by joining such a group they will experience better service from GPs, nurses and the practice generally.
3. Practices may fear that patients will see the PPG as a forum for airing any complaints they have.
4. GPs may fear that they will spend a lot of time answering personal queries or complaints rather than achieving anything positive for the practice.
5. User involvement in the decision-making process calls for cultural and organisational change on behalf of healthcare professionals.
6. It may take time for patient and practice representatives to develop a sense of group identification, possibly leading to an initial sense of lacking confidence or competence.
7. A PPG takes time to plan, organise and support on an ongoing basis. Do not expect a successful group to arrive on your doorstep.

Overcoming difficulties

1. Beware of dominance by a group or individual. Have clear ground rules.
2. Try to make sure that healthcare professionals do not outnumber patients and that voluntary groups are not consulted at the expense of the patients themselves.
3. Try not to take anyone for granted. Use every talent.
4. Try not to take anything for granted, e.g. set up a formal system for communicating.
5. Ensure that patients in the group have sufficient information that they can understand so that they can make informed decisions. Their perception is important because if they are poorly informed this illustrates a need for clearer information.

6. Recognise that there will be differences in the perceptions of managers, professionals and lay representatives. Put in place mechanisms to balance these views.
7. If you want to avoid the problem of members who do not attend meetings, you should have a minimum attendance requirement built into your constitution, e.g. non-attendance at three consecutive meetings.
8. Patients should serve on the group for a fixed term. Patients who become long-term members of the panel may lose sight of the patient agenda and become too focused on the practice's priorities and problems.
9. Remember that for some people, meetings can be daunting. The purpose of meetings should be clearly defined:
 - Always have an agenda.
 - Avoid excessive discussion about unimportant details.
 - Avoid the meeting dragging on.
 - Make meetings accessible, e.g. for people who work, have young children or do not have transport.
 - Ensure that decisions are made openly and, after discussion, decide not just what will be done but who will do it, how and to what timescale.
 - Agree on dates for progress, and reports for long-term projects.
 - Remember to set the date for the next meeting.
10. Committees:
 - Try not to push people into jobs they do not really want.
 - Do encourage people to take on roles, but recognise when they are sincerely saying no.
 - Avoid re-electing someone who has not been doing the job well.

Officers should not carry on for too long. Your constitution should define the length of the maximum term of each office, and also how long a committee m

National Association for Patient Participation

19 Harvey Road

Walton on Thames

Surrey, KT12 2PZ

www.napp.org.uk

© copyright NAPP 2012