

# **A guide for Patient Participation Groups**

## **Step 1 Introduction to PPGs**

## Contents

Introduction .....	3
The PPG model.....	3
What is a Patient Participation Group? .....	4
PPGs and PRGs: What's the difference? .....	4
Patient participation is.....	6
Patient participation is not .....	6
What are the benefits of a Patient Participation Group? PPGs are .....	7
The bigger picture - patient participation.....	8
Care Quality Commission (CQC) .....	8
Supporting Patient Online- online GP services .....	9
Local Healthwatch.....	9
Patient Participation Groups locally and nationally .....	9
Appendix 1: What can Patient Participation Groups do? .....	11
Appendix 2: PPG Flyer.....	12

## Introduction

Welcome to our [step-by-step guide to setting up a Patient Participation Group \(PPG\)](#). It offers practical guidance and support to general practices and to patients who are interested in getting actively involved with local healthcare in Patient Participation Groups.

This guide sets patient participation in the new NHS landscape where every GP practice **in England** is required to have a PPG. It builds on N.A.P.P.'s specialist knowledge and expertise developed from over forty years' experience in the formation and development of hundreds of PPGs. Further supporting materials are available on the N.A.P.P. community platform.

Each group will reflect the unique aspects of the practice and its population. This guide will help you to get started and provides advice on maintaining a sustainable group.

*'As a GP in a practice which has had a PPG for over twenty years, I know at first hand the value of patient participation'* [Professor Mayur Lakhani FRCGP, Practising GP and Past Chair of the Royal College of GPs](#)

*'I don't know how I could manage or be without our PPG. They are my eyes and ears and tell me exactly how patients view the practice. They keep me on my toes, which is what I want them to do'* [Practice Manager, Luton](#)

## The PPG model

A PPG is a tried and tested model built on mutual trust and respect between GPs, practice teams and their patients. The first PPGs were set up by GPs in 1972. All GP practices in England should have established a PPG and groups are now being formed by dental practices and pharmacies.

There is long standing evidence and recognition of the success of the PPG model as one that empowers patients, supports practices and leads to high quality responsive services. Effective PPGs and excellent practices go hand in hand!

Prior to 2011, many GPs had recognised the intrinsic value to their business of having a closer relationship with patients and had formed PPGs without any financial incentive. Between 2011 and 2014, Patient Reference Groups (PRGs) were formed, based on targets defined in an **optional** Patient Participation (Directed Enhanced Service) clause in the General Medical Services (GMS) contract, with emphasis on implementing action plans based on feedback from patient surveys. Provided that these targets were met, the practice received a financial incentive of £1.10 per registered patient.

From April 2014, the Friends and Family Test (FFT) replaced the survey, with emphasis on participation rather than feedback. The per capita payment was reduced to 33 pence per patient.

The 2015-2016 GMS contract specified that all GP practices in England should have a PPG by March 2015. The 2016-17 GMS contract includes the following statements

- The patient participation enhanced service ceased 31 March 2015 with the associated funding reinvested in core funding.
- It remains a contractual requirement for practices to have a PPG and to make reasonable efforts for this to be representative of the practice population.
- It is an expectation for CQC assessments that practices have a PPG.
- The practice PPG should be open to the involvement of carers of registered patients but who themselves are not registered patients.
- Practice engagement with the PPG will need to include obtaining patient feedback and, where the practice and PPG agree, acting on suggestions for improvement.
- Practices must confirm by e-declaration that they have fulfilled the requirements.

## What is a Patient Participation Group?

Every PPG is unique, based on the relationship with practice staff and evolving to meet local needs. Their members work in partnership with their practices to offer the patient perspective on the services that are provided. PPGs also work to improve communication, encourage patients to take more responsibility for their health and provide practical support.

N.A.P.P. is unique as the umbrella organisation for patient-led groups within general practices. Formed in 1978, it

- helps GP practices to establish new groups
- helps develop and sustain existing groups
- enables PPG networking
- shares good practice
- promotes and secures patient participation in national policy development and research.

N.A.P.P. also supports Clinical Commissioning Groups which are actively encouraging their member practices to have strong and effective PPGs and ensuring their effective engagement.

Between April 2011 and March 2014, the optional patient participation clauses in the General Medical Services Contract in England emphasised feedback from patient surveys and implementing action plans

Since 2014, the emphasis has been on

- promoting innovative forms of patient participation
- ensuring participation is representative of the widest cross section of the population particularly hard to reach groups and those with mental health issues and
- improving the focus on outcomes of patient participation

From April 2015, PPGs have become compulsory, as stated in the GMS contract as follows

### **“Patient participation**

It remains a contractual requirement for practices to have a PPG and to make reasonable efforts for this to be representative of the practice population. It is an expectation for CQC assessments that practices have a PPG.

The practice PPG should be open to the involvement of carers of registered patients who themselves are not registered patients. Practice engagement with the PPG will need to include obtaining patient feedback and, where the practice and PPG agree, acting on suggestions for improvement.

There are no prescriptive requirements on how to run a patient participation group, and all reporting requirements have been removed. Practices will only be required to confirm through the e-declaration that they have fulfilled the requirements.”

Further details of the GMS Contract 2016-2017 are available at <http://bma.org.uk/practical-support-at-work/contracts/gp-contracts-and-funding/generalpractice-funding/gp-contract-2015-2016-england>

## PPGs and PRGs: What’s the difference?

The term Patient Reference Group (PRG) was introduced in the 2011 Patient Participation Directed Enhanced Service (DES), and the guidance used the terms interchangeably.

The Enhanced Service Specification (ESS) which replaced it reverted to blanket use of the term PPG - the term PRG had disappeared, but there are practices that still use the ‘PRG’ model. It is important

to understand the distinction between the **true PPG model** and PRGs created by the DES even though this model is not advocated by the ESS. The main differences are

- PPGs have always been grass roots organisations initiated by mutual agreement between patients with an active interest in their health and their local practice. They are groups which respond to the needs of their own patients and practice community. They contribute to continuous long term improvement in quality of patient care. *PRGs had targets imposed (top down) which were the same for every practice with a narrow focus based on a survey and action plan.*
- PPGs have a much wider remit than PRGs did, and are usually able to follow the patients' agenda, not one defined by an external body.
- PPGs can negotiate with the practice their own aims, terms of reference and activities, e.g. health promotion, newsletters, surveys, patient transport. *For PRGs, practices were responsible for meeting, within a set period, the stated objectives.*
- PPGs can have autonomy and be pro-active. *PRGs were reactive i.e. acting as a sounding board to meet specific externally driven objectives, for which the practice received a financial reward. This model no longer applies.*
- PPGs are formed for the long term, based on mutual agreement working with the practice. *PRGs had a lifespan initially dictated by the DES, but the label is still in use. Many practices have now discovered some of the benefits of patient engagement and have begun to work with their patient group in a more flexible way i.e. as a PPG.*
- PPGs have traditionally been “real” i.e. they meet regularly face to face with practice staff. *PRGs have often been entirely “virtual”, simply a list of email addresses of patient who are willing to participate in online surveys or short questions, without any opportunity to discuss issues with each other.*

## To recap:

PPGs can

- act as critical friends of the practice.
- offer feedback on the patient perspective;
- assist 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 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.
- make a positive difference to both patients and the practice

### 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.

### A 'talking shop'

Groups whose sole purpose is confined to meeting, receiving information from the practice and discussing items of interest are unlikely to thrive or grow. It becomes difficult to maintain interest and there is the significant risk that discussion becomes negative and is at risk of being monopolised by one or more strong individuals with strong views on particular issues. Without clear evidence of some activity or results showing benefit to the patient community or to the practice, patients will not sustain interest and will drift away. New members will see no point in being involved

## What are the benefits of a Patient Participation Group? PPGs are

### Good for patients because:

- Patients will be more responsible for and take an active interest in their own health.
- Patients will have a better understanding and knowledge of the practice and its staff and how it must operate within the structure of the NHS.
- All sections of the community will be enabled to get involved through virtual PPGs which use email networks and online surveys
- Patients will be actively involved in developing arrangements for their primary healthcare before decisions are made.
- Patients benefit from improved communication and relationships with staff.
- Patients will have a forum for positive ideas and voicing concerns.
- PPGs can offer some peer support to patients in managing their conditions, making healthy choices and accessing information

### Good for GPs and practice staff because

- PPGs assist GPs and the practice team to develop an equal partnership with patients and an increased understanding of patients' priorities, needs, wishes and perspectives.
- PPGs help GPs and their staff to communicate accurately and honestly with their patient population, ensuring there is regular two-way dialogue and feedback between them.
- Through virtual PPGs, GP's and staff can connect with a wide diversity of their patients, particularly from minority communities and those whose voices are seldom 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 and target resources more effectively
- PPGs can take pressure off practices by helping patients with non-medical and social care issues.
- The practice will be able to get help from patients in meeting national targets and objectives such as the CQC Essential Standards, patient involvement in Revalidation of doctors and the implementation of national programmes such as Patient Online.
- The practice will have a forum to voice concerns, ideas and suggestions to patients.
- PPGs help ensure shared decision-making with patients and with the wider community about key health matters, reflecting patient needs locally.
- Practices 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 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 two-way 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 opportunities to become involved in other community initiatives focused on local health care provision e.g. PCN's and Local Healthwatch

## The bigger picture - patient participation

PPG members play a vitally important role in reaching out to their wider patient population actively 'championing' health and wellbeing in their local communities. PPGs seek to connect with those who may have difficulty accessing services and whose voices are less often heard. PPGs empower and motivate people to get involved in activities, help others to enjoy healthier lives by removing barriers in the system, raising awareness of health, wellbeing and lifestyle choices and offering supportive environments for others to gain information and assistance.

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.

## Care Quality Commission (CQC)

From April 2013, GP practices and other primary medical services have been regulated by the Care Quality Commission (CQC). The CQC checks services to ensure that national standards of quality and safety are met. A central part of this involves listening to the views and experiences of people who use a service to help the CQC make judgements about that service.

With their focus on quality and responsiveness of care, PPGs are a valuable source of information about patients' views and experiences.

CQC inspectors will expect every practice in England to have a PPG in place. It is essential that the CQC is able to work in partnership with them when they inspect GP practices. Either before or during the inspection, an inspector will usually contact some PPG members. The CQC has worked together with representatives from PPGs and N.A.P.P. to produce guidance to help people who are involved in a PPG, so that they can work with the CQC. The guide can be found on the N.A.P.P. community platform, available to members.

The importance and potential of PPGs as a mechanism to gain insight from and to engage patients in decisions about their local health services has been reflected in the authorisation criteria for Clinical Commissioning Groups introduced by the Health and Social Care Act 2012. To become fully authorised and to meet ongoing assurance requirements, CCGs had to demonstrate that the voice of each practice population is sought and acted upon. CCGs also have a legal duty to engage with their local populations and PPGs are uniquely placed to support CCGs in meeting this legal requirement.

NHS England guidance expects that CCGs will strengthen the use of the everyday contact member practices have with patients as an invaluable source of insight about the quality of local services for all their local communities. CCGs are expected, in turn, to develop effective mechanisms to capture this insight so that it underpins and informs CCG decision-making processes, and so that it drives tangible improvements to local services.

N.A.P.P. is the national patient's champion for the Self Care Forum [www.selfcareforum.org](http://www.selfcareforum.org); many PPGs already promote good health to their local communities. Supporting self care provides a further opportunity for PPG members to have an active role in their GP practice, ensure that local people understand and get the best out of their NHS services; and that GPs, nurses and practice staff are able to focus on providing treatment and support for those with long-term and complicated



health problems. N.A.P.P. worked with PPGs to develop a Guide to Self Care for PPGs to assist them in supporting their practices to convey self care messages to patients.

## Supporting Patient Online- online GP services

PPGs are important sources of support for their practices in implementing the Patient Online programme helping patients increase the range of transactions they can deal with online, including appointment booking and cancellation, ordering repeat prescriptions and access to their medical records.

## Local Healthwatch

Healthwatch England is the national consumer champion in health and care with significant statutory powers to ensure the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services.

Each local Healthwatch, based on the area covered by the local authority, has a similar remit at local level, is part of its local community and works in partnership with other local organisations, including PPGs. Local Healthwatch across England provides insight into people's experiences of health and social care issues, acting as "the eyes and ears on the ground" highlighting what matters to their local communities.

Information and contact details for the nearest local Healthwatch can be found on the Healthwatch website <http://www.healthwatch.co.uk/find-local-healthwatch> using the map, by entering your town, city or postcode, or clicking the A-Z list. You can also download an Excel copy of the information.

## 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. The N.A.P.P member community now represents over 17.5 million patients.

Many real PPGs based physically within practices are extending their reach by adding Virtual members for those who either prefer not to attend meetings or are unable to do so because of ill health, disability or lack of time. Such email communication also enables PPGs to improve representation of the demographic composition of the whole patient community. In some cases, forums or networks are developing using social media.

By communicating through email and using online survey tools, practices can receive feedback from a wider diversity of interests and backgrounds across the practice population particularly those people who are harder to reach.

Many networks of PPGs are formed across localities to co-ordinate with other PPGs taking a wider perspective in shaping and improving services and are linked to their Clinical Commissioning Group (CCG) ensuring the patients perspective informs commissioning decision making. Case studies of PPG practice-based activities, involvement in commissioning and the annual PPG of the Year Corkill Award are available on the Community platform, available for members.

## Nationally

The GPs who formed the first groups in the 1970s were motivated in several different ways. 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. They are a proven model demonstrating true partnership, involvement and responsiveness where patients' views actively influence improvement in services.

Research carried out by N.A.P.P between 2003 and 2009 (covering over 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 how the practice operates.

PPGs, positioned within general practice, are the lay bodies closest to the GP- led commissioning structure of the NHS landscape created by the Health and Social Care Act 2012. Their role, value and potential have become strategically significant as a mechanism for the health system to deliver many of the key policy requirements brought in by the Act.

PPGs facilitate access to the voice of every practice population, the existence of PPGs in all member practices is essential for CCGs to meet their legal duty to make arrangements to involve patients and the public at various specified stages, of the commissioning process.

PPGs collect patient and carer feedback from the respective patient populations of member practices and are an invaluable source of insight about the quality of local services to inform locality commissioning decisions.

*"Creating vibrant, successful and sustainable PPGs is vital to the ambitions of Leicester City Clinical Commissioning Group. By affiliating and working closely with N.A.P.P. we are benefiting from its years of expertise, evidence and best practice, which is helping to turn our ambitions in to a reality and build genuine two-way dialogue and collaboration between patients, their practices and the CCG."*

[Richard Morris, Chief Corporate Affairs Officer, Leicester City CCG](#)

N.A.P.P. offers resources to support PPGs and CCGs to work effectively together. More information is available for members on the N.A.P.P. community platform.

**Uniquely placed at the heart of GP practices, PPGs have an essential role in** empowering individuals to access and understand appropriate information that supports shared and informed decision-making about treatment, self-care, self-management (or self-care including self-management) and lifestyle choices.

PPGs through their contact with patients in the practice population can:

- convey and share self-care messages through their health awareness activities, events and patients' surveys
- signpost patients to other means of support such as support groups, health related activity, self-management courses

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.

**For further information, please see [Starting, Growing and Sustaining successful PPGs, parts 2-4, available to members.](#)**

## Appendix 1: What can Patient Participation Groups 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. practice flu clinics, ensuring that patients are comfortable.
- Improving practice facilities, e.g. toys for waiting room, maintaining plants or gardens.
- Helping to obtain the patient view, e.g. for planning permission for a new-build project
- Exploring the changing needs of patients.

### Offering support to other patients

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

### Providing information

- Organising a health fair and/or health awareness displays, possibly health information 'shops'.
- 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-care
- 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 representatives that influence the local provision of health and social care.

## Appendix 2: PPG 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 the 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