

Chapter 2. Getting started

GP practices now have to consult their patients about the services they provide. It is usually more effective to do that through an organised patient participation group (PPG) that can act as a bridge between the practice and its patients and represent the 'patient voice'. Some practices have e-mail 'patient reference groups' through which they communicate with patients and which perform some of the functions of a PPG but often a PPG with an elected chair and other officers and regular meetings works better.

Practices can take the first steps to set up a PPG and that is often the best way to start. Sometimes GPs or practice managers know individual patients who are likely to want to get involved and can ask those patients to help. Notices in surgeries or on community notice boards, items in practice newsletters and local blogs, e-mails and text messages can all be used to find out which patients are interested.

After setting a date for the first conversation, the next step is to ensure publicity about the meeting reaches as many patients as possible and not just those who regularly attend the practice. Chapter 3 contains many other practical tips on communicating with registered patients from your practice. It is not always easy to ensure that those patients who express an interest are representative of a practice's patient population but once a small group of patients has been formed, it is usually possible to find others prepared to join.

If practices do not take the first steps, they will often respond if approached by patients, or groups of patients, who want to set up a PPG. Since practices control access to their patients, it is important that those groups of patients and the practice work together from the start so that each knows what the other is doing. Particularly in the early stages, practices can provide the necessary administrative support for

PPGs, including contacting patients and helping to arrange meetings and meeting rooms.

It is better for PPGs not to be too ambitious, particularly when they are first set up. Setting up a PPG requires plenty of patience and perseverance because you might find only a few people turn up to the first couple of meetings. What follows in this chapter is intended to guide people wanting to set up a PPG for the first time, but you do not have to do it all at once.

The templates for this chapter are only suggestions and you do not have to use every template. You might find that the Terms of Reference and the Code of Conduct may appear overly formal for your PPG. This is not a problem - you do not need to use them (or you can modify them to suit the needs of your PPG). The templates are intended to provide you with a starting point for setting up your PPG and to give you pointers on what to consider.

A great deal depends on which patients are willing to be involved and how much time they have. It is more effective to do a few things well than to try to spread yourselves too thinly and end by doing nothing properly.

The most important part of getting started are the conversations - between the PPG, the practice and the patients registered at that practice. Setting and clarifying expectations early on is crucial to the success of your PPG, as is regularly checking back on these expectations and agreements with all members involved.

Checklist: Getting Started

This checklist covers the initial processes you can use to get started with a PPG, including running your first meeting and running an election for PPG Steering Group members.

Getting started	Done	Help
Agree the PPG model with your practice		2.1
Tailor the Terms of Reference		Template 4
Tailor the PPG Code of Conduct		Template 5
Print 'PPG membership expressions of interest' form and distribute at your practice		Template 2
Print 'Becoming a PPG Member' form		Template 3
Agree the first meeting date		
Agree what communications will be distributed prior to the meeting		Chapter 4

At the first meeting	Done	Help
Give new PPG members the Introduction Letter		Template 1
Give new PPG members the 'Becoming a PPG Member' form		Template 3
Give new PPG members the Code of Conduct (to be signed and returned)		Template 5
After the meeting <ul style="list-style-type: none"> • Refer to Chapter 4's Checklist: Running effective meetings, for post meeting follow ups • New PPG members' details added to the contact database and scanned / stored electronically • Review the skills audit result for the PPG 		Chapter 4 Template 9 2.6 and 2.7

Running an election	Done	Help
Decide which roles are needed in your PPG		2.2
Circulate the 'PPG Steering Group Election Notice'		Template 6
Circulate the 'PPG Steering Group Election Nomination Paper'		Template 7
Arrange the election		2.5

2.1 Different models for running a PPG

There is no one way to run a PPG. In setting up a PPG, you will need to consider the number of people who are involved at the start, what availability they have to attend meetings and the level of involvement you are likely to receive from patients registered at the practice. Some points to consider are listed below.

1. Open membership

Open membership for PPGs is where all registered patients at the practice are invited to attend PPG meetings. Meetings will require plenty of notice and are usually held in an open forum, such as the practice's surgery. Section 3.1 provides suggestions and communication tools to reach as many registered patients as possible.

2. Invited membership

The reality is that only a small number of patients registered at a practice will actively seek to become involved in the PPG. Some practices assume that all registered patients are automatically members of the PPG. At others, registered patient will specifically have to enrol to become members; a list of those who have enrolled is usually kept by the practice, (please read 2.7 on data protection). The PPG can be led:

- By a small fixed number group, usually a Steering Group or Core Group (see section 2.2 for an overview of roles people can take in a PPG).
- By a chairperson and other officers and not to have a "closed" core group as above. This is to encourage more new PPG members to attend meetings.

Steering Group members will represent the patients registered at the practice and can be self-appointed to start with or elected, if there is a large enough pool of interested patients. Chapter 3 provides a range of suggested activities to receive input from patients to use a representative voice.

Whatever structures the PPG chooses, it will need to ensure it works inclusively and its activities and meetings are accessible to all registered patients at the practice.

3. Virtual membership/online forum

Some PPGs may choose to have a virtual group, likely to be an email distribution group or an online forum. Members of a virtual PPG group can provide feedback on consultation papers and respond to surveys and questions as they arise. Virtual membership will require the maintenance of an email distribution list and forum (section 2.7 covers points to consider on data protection).

Equality, diversity and representation of all registered patients

Each PPG should work towards being representative of the registered patient population of their practice. All practices will have a diverse patient population and some will also have a specific concentration of different groups, for example, a higher proportion of older people or a particular ethnic group. To effectively represent the views of all registered patients at a practice, it is important that you understand the demographic makeup of your practice's patient population.

Your practice can run a report to help you understand the makeup of the registered patient population at your practice. Each practice records and holds certain information about their registered patients. This usually involves information about patients' age, gender, ethnicity, disability and maybe certain health conditions that the practice is required to keep lists of. There are still gaps in the information that the practices collect, for example, there might be very little information on sexuality. Any report a practice would produce would be completely anonymous, in that it would exclude personal identifiable data such as patient names and addresses, or other information that could be attributed to an individual.

In addition, you may also find it helpful to refer to data from the Lambeth DataNet programme. The DataNet programme collates anonymised information from all Lambeth GP practices to explore health inequalities across Lambeth. Recent projects have included an exploration of health inequalities in blood pressure control, diabetes control and the use of anti-thrombolytic therapy in atrial fibrillation. Data from this programme can be used to run analysis such as providing maps of different spoken languages across Lambeth. Practices can also request analysis reports on data from their own practice.

When a PPG is starting out, it is common that the composition of the PPG Steering Group may not reflect the diversity of the practice's registered patient population. However, as the group develops, effort should be made to reach out to patients from different groups at the practice. Chapter 3 provides some suggestions on how to do this. You might also want to link up with community groups in either your area or in Lambeth for information or joint working with a particular group or issue.

Finally, when collecting patient feedback, planning activities and events, you should ensure that all of your plans do not only focus on one group of patients. Consideration should be given on how to include different groups of patients across the practice. Chapters 3 and 4 provide further guidance on this, including considerations on the times and days that events will be held and how the event will be publicised to increase the impact on who will be reached.

2.2 What roles can people take in a PPG?

There are a number of roles that exist to support the running of an effective PPG, including the chair, vice-chair and secretary.

Role of the chair

- Ensure PPG meetings are planned in advance
- Oversee the smooth running of the meeting by starting the meeting on time, welcoming people and outlining the meeting purpose and agenda purpose
- Keep the meeting moving along on time according to the agenda
- Introduce speakers when required
- Ensure everyone has the chance to contribute
- Summarise decisions at the end of each agenda item
- Ask clarifying questions and challenge disruptive behaviour
- Thank everyone for their time and input
- Ensure the PPG functions in accordance with its Terms of Reference and Code of Conduct
- Represent the PPG as appropriate
- Ensure there is successful dialogue between the PPG and its GP practice

Qualities of an effective chair

- Willingness to lead
- Conducts themselves with tact and diplomacy
- Able to listen impartially to many opinions
- Works inclusively and openly

Role of vice-chair

- Stand in for the chair when they are away
- Assist the chair with matters between meetings

Role of secretary

- Deals with communications and correspondence
- Sends out meeting invitations and circulates agenda and any other relevant documents before the meeting
- Sends minutes of meeting and decisions taken to chair for approval
- Sources necessary equipment/materials
- Circulates finalised minutes

Qualities of an effective secretary

- Good communications skills
- Attention to details
- Good organisational skills

Further details on the roles and activities each PPG member has in running effective meetings can be found in Chapter 4.

2.3 What effective relationships and communications look like

Excellent GP practices and effective PPGs usually go hand-in-hand. For PPGs, it is important to foster a positive, interactive relationship with the representative(s) from your GP practice, as both parties are working toward the common goal of improved services and patient health and wellbeing.

PPGs can usually expect to primarily interact with the practice manager. However, it is always useful to build good working relationships with as many of the practice staff and GPs as possible. Some guidance on practical ways of building productive working relationships are below.

Set goals

- Take the time to jointly establish the PPG's short and long term goals and objectives with your practice manager. These should be documented in the PPG's Terms of Reference (refer to the Terms of Reference template at the start of this chapter).
- The PPG's goals and objectives should complement the practice's wider goals.

Plan PPG meetings

- All meetings should be coordinated with support from the GP practice. Meeting dates and times should be set in partnership with the practice, and the practice should contribute to agenda items
- At least one GP and the practice manager (or their delegated representative) should attend the meeting
- Ensure questions/concerns/suggestions that have been raised by PPG members are fed back to the practice representative(s) and discussed. Some PPGs are tabling questions before the meeting, so that practice staff have the opportunity to pull together the required information before the meeting.

Regularly meet with your GP practice

- It may be useful to schedule additional meetings between the practice manager and the PPG chair (or their representatives) to further discuss current activities, new ideas, issues, and support that either group may need from the other
- The representatives should also jointly review current membership and ensure it reflects the practice's registered patients. Suggestions to increase the diversity of PPG membership are included in Chapter 3.

Communicate with patients

- PPG and practice representatives should have regular conversations about engagement and communication with patients, and how communication opportunities can be mutually shared and maximised
- A specific PPG notice board that is eye catching and can be used regularly for patients to build a habit of reading and getting information from

- PPG members can regularly organise sessions in the practice talking to patients. This will increase the visibility and credibility of the PPG
- Develop a joint plan on how new patients will be contacted and invited to join the PPG. A suggested approach for this, along with templates (*Template 2: PPG Membership Expression of Interest; Template 3: Becoming a PPG Member*) to capture contact information and a skills audit, are provided in the Templates section.
- Any correspondence that is to be sent to the wider patient database, such as the PPG newsletter or surveys, should be approved by the practice manager before it is distributed.

In-practice activities and promotions

- Make sure any promotions planned for inside the practice waiting room itself have either been planned in partnership or approved by the practice manager in advance
- Agree on clear guidelines on what space the PPG can use so practice staff are aware of what to expect
- Chapter 3 provides a range of suggested activities to increase PPG membership.

Overall, it is important to remember that all staff in your GP practice are valuable partners and the relationship should be kept open and positive at all times. Try to ensure the PPG doesn't do anything that 'surprises' the practice – keep the practice manager abreast of all important decisions and upcoming activities, seeking their input, ideas and approval where appropriate.

2.4 GP practice: responsibility and support

PPGs need support from the GP practice in order to be effective. While the relationship between each PPG and its practice is unique, PPGs can expect certain support from its practice. Expectations and an agreed way of working should be openly discussed, negotiated and reviewed to make sure both parties are satisfied and happy with how the relationship and the PPG is progressing.

Timely feedback

- PPGs can expect to receive timely feedback and/or approval from the practice manager on draft event plans, communications and engagement activities.

Contact with patients

- The PPG can expect the practice to support them in either making contact with patients, or passing on relevant communication to the patients on behalf of the PPG. Contact with patients must be relevant and justified though – practices will not want to bombard patients with letters or emails. This chapter includes practical guidance on the implications of data protection when it comes to contacting registered patients at the practice.
- Procedures for contacting patients (who aren't PPG members) will be different for each practice. The communication plans for patient surveys, event promotions, encouraging PPG memberships should be jointly planned
- PPGs should be able to manage direct communication with registered PPG members, although some communication may need to be approved by the practice manager before distribution, e.g. newsletters, brochures.

Active engagement

- PPGs can expect their practice to actively engage with the PPG, by attending meetings, responding to questions and providing feedback on ideas and issues that have been raised.

Financial support

- Each GP practice is able to decide the level of financial support, if any, it will provide to its PPG. This matter should be openly discussed and reviewed.

Administration support

- At times PPGs will need administrative support from the practice staff. While PPGs should aim to be as self-sufficient as possible, it is reasonable to request some administrative support for particular projects, such as mailing out letters or sending survey request emails because the practice holds the contact details of registered patients.
- Requests should be discussed with the practice manager, giving them as much advance notice as possible before your deadline.

2.5 Running elections for a PPG Steering Group

While a PPG may start with volunteers, after a year of getting established, it will be appropriate to formalise the process, which will involve running an election for a PPG Steering Group.

Patient-led PPGs should have an elected Steering Group, which oversees the general course of the PPG's activities and decisions.

Notice should be given in advance to PPG members that an election for Steering Group members will be taking place. Refer to the *Template 6: PPG Steering Group Election* for a template to use for your election notice. This should be published widely, such as through the practice's notice board, website, newsletter, and emails.

People wishing to put themselves forward for nomination should do so in writing using a nomination form. Refer to the *Template 7: PPG Steering Group Election Nomination Form* for a template to use.

A vote should be held to elect members if the number of applications received exceeds the number of positions available. Votes should be confidential and use a voting form. Refer to the *Template 8: PPG Steering Group Election Voting Form* for a template to use. This will need to be modified according to the roles available for election and the number of names seeking election under each role.

All PPG members are eligible to vote, although it should not be compulsory to do so. Elections should take place at a set meeting, and those who are unable to attend should be able to either send in their voting form beforehand to the returning officer, or vote by proxy (the returning officer should be notified in writing before election who they have nominated to vote on their behalf).

Each person has one vote for each place available. If there is a tie for a particular position, consideration will be given to a joint role (eg. co-Chairs), otherwise an election by lot should take place at the meeting between the names that have tied. Some PPGs may wish to seek nominations for a joint role to share the workload (e.g. co-Chairs, co-Vice Chairs).

The PPG should nominate a returning officer before the voting commences who is responsible for collecting, counting and announcing the votes, or electing by lot if necessary. Their decision will be final.

2.6 Conducting a skills audit

Everyone who becomes part of your PPG has their own unique set of skills and interests. People are more likely to stay involved with the PPG if they are able to contribute in ways that play to their strengths and skills – so it is important for PPGs to find out what each member not only can do, but would like to do.

The best way to discover people's skills and interests is by conducting a skills audit. This should generally be done when a new person joins the PPG by asking them to complete a *Becoming a PPG Member* form (refer to the Template 3). For existing members, you can modify the language on the form and circulate it to current members.

Make a note of people's individual skills and interests in your membership database (refer to Template 9: *Contact database fields*) and take the time to consider people's preferences when asking for help on specific tasks.

NOTE: Once information from the *Becoming a PPG Member* form (Template 3) has been entered into the secure PPG membership database, the form should be destroyed to protect the individual's privacy.

2.7 Data protection

Every organisation must handle people's data with care and according to the law. The UK's [Data Protection Act](#) controls how someone's personal information is used by organisations. Take the time to familiarise yourself with the data protection principles.

Below are a few tips to get you started.

DO

- Collect people's information. You are allowed to build a database of members' contact details with their explicit consent and knowledge of what it will be used for (i.e. you will use their information to contact them about PPG meetings and latest news)
- Keep personal information secure. You need to ensure there is limited and controlled access to people's information. Your database should be stored in a controlled shared access location that is password protected (e.g. in an Excel spreadsheet that is saved on [Dropbox](#) which only a small selected group of people have access to). If information is stored on a laptop or desktop computer, it must be password protected and the device kept in a safe location
- Regularly check the security surrounding the data to ensure it has not been compromised
- Ensure those who have access to people's information are aware that data protection rules apply and personal information must be handled with respect and privacy
- Allow people to check their personal information you have on file if they request access to it
- Keep any sensitive information that you collect on a person's sexuality, religion, politics, health or ethnicity separate from their general information and highly secure. There are stricter laws surrounding such sensitive information and these details should only be gathered if absolutely necessary (note: PPGs should rarely need to collect such information)
- Conduct periodic checks to ensure your data security measures remain appropriate and up to date

DON'T

- Disclose someone's identifiable information to another organisation without their consent
- Collect unnecessary personal information (eg. family details, religion, political views)
- Keep someone's information for longer than necessary. Your PPG should regularly review information and securely delete records that no longer need to be kept