


Patient Participation Groups (PPGs)

A step by step guide to setting up Patient Participation Groups (PPGs) for General Practice and Patients



Reader Information Box

Title	A Guide to Setting up PPGs for General Practice and Patients
Description	This aim of this guide is to offer some support and practical guidance to General Practice and Patients, who are interested in setting up Patient Participation Groups.
Audience	Patients, Practice Managers, General Practice
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1. Welcome

Welcome to the NHS Norfolk & Waveney ICB Step By Step Guide to Setting Up a Patient Participation Group (PPG). The aim of this guide is to offer some 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 pack should help you get started.

Integrated Care Boards (ICBs) are responsible for planning and paying for healthcare services. They do not provide healthcare like a GP Practice or hospital. Their role is to make sure the appropriate NHS care is in place for the people of Norfolk and Waveney, within the budget they have.

We value the hard work of our PPGs. We also recognise the valuable knowledge they have about the various groups and networks that exist within their communities. PPGs are seen as a significant way of involving people in local healthcare decision-making, and this document gives practical ideas to support the development of new PPGs. It is intended as a guide **only** and should be adapted to suit the needs and ideas of local groups.



Members from Sheringham Medical Practice PPG receiving their Dementia Friendly Certificate from Norfolk and Waveney Dementia Lead Dr Liz Waddy, watched by representatives from the practice, South Norfolk CCG (now NHS Norfolk and Waveney ICB) and Norfolk Healthwatch.

2. What is a Patient Participation Group?

Patient Participation Groups (PPGs) are sometimes also referred to as Patient Reference Groups (PRGs) or Patient Liaison Groups (PLGs).

The National Association for Patient Participation (NAPP) is a unique umbrella organisation for patient-led groups within general practices. Set up in 1978 as an independent charity, it describes a PPG as a group of people who work in partnership with their practices to:

- ✓ **help patients to take more responsibility for their health.**
- ✓ **contribute to the continuous improvement of services and quality of care**
- ✓ **foster improved communication between the practice and its patient**
- ✓ **provide practical support for the practice and help to implement change**

What is the purpose of a Patient Participation Group?

- To give practice staff and patients the opportunity to discuss topics of mutual interest in their Practice.
- To provide means for patients to make positive suggestions about the practice and specific medical conditions as an 'expert' or experienced patient.
- To encourage and support health education and promotion activities within the practice.
- To work with the practice to develop self-help projects to meet the needs of fellow patients, such as carers support.
- To act as a representative group that can be called upon to influence the local provision of health and social care
- To involve further patients from the wider population

A more detailed list of the types of activities that could be undertaken by a PPG is available in Appendix 1.

More information on the National Association of Patient Participation is available at: www.napp.org.uk

3. Benefits of a Patient Participation Group

Good for the patient because:

- Patients will be more responsible for their own health
- Patients will have a better understanding and knowledge of the practice and its staff
- Patients will be consulted about arrangements for their primary health care before decisions are made
- Patients will benefit from improved communications between patients and staff
- Patients will have a forum to suggest positive ideas and voice concerns.

Good for practice staff because:

- Doctors 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 issues such as loneliness.
- 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 will get closer to the community for whom they care.

Good for the community because:

- Patients will have an organisation through which they can help other people in need.
- Patients will be able to get an idea of what is needed to improve health care, and make sure the patient view is always represented.
- Patients will increase the accountability of the staff by maintaining an open dialogue with doctors and other health professionals.
- Patients will have an opportunity to become involved in other community initiatives eg Dementia Friendly Communities.

4. A Step by Step Guide to Setting up a PPG

Step 1 – Getting Started

Who can suggest starting a Patient Participation Group?

The idea to start a group can come from:

- A practice manager
- A doctor or other member of practice staff
- A patient or group of patients

A staff member at the surgery can:

1. Talk to the NHS Norfolk and Waveney ICB Communications and Engagement team or visit the relevant sections at: <https://improvinglivesnw.org.uk/>
2. Become a champion for patient engagement at the practice.
3. Call an open meeting of patients or approach selected individuals.
4. Approach surgery user groups (e.g. Mums and Toddlers, Older People's Clinics, Screening Clinics).
5. Contact the National Association for Patient Participation (NAPP).
6. Read the literature already available about PPGs.
7. Talk to other practices with a PPG.

A patient can:

1. Approach the practice manager or practice patient engagement champion.
2. Follow the steps 1, 5, 6, and 7 above.
3. Canvass the level of interest among other patients.
- ✓ Don't forget to ask for extra advice and support if needed from the ICB.

Step 2 – Recruiting Your Group

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

1 Open

2 Invited

1 Open groups are formed from open meetings, which any patient may attend. You will need to advertise widely and give plenty of notice. 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/fliers in the waiting room, and a few around the local area
- Put details on the electronic message board if you have one in your waiting room
- Put fliers in prescription bags for about 2 weeks and leave some on reception
- Put an article in the practice newsletter and on the website and on social media
- Put an article in local town and parish magazines and free sheets
- Ask staff and patients to spread the word

2 Invited groups are formed by contacting individual patients directly who are known to the practice and its staff, and who are patients at the practice. These may also be known in the community because they are a local parish, town, district or county councillor. Or they may be 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 whilst they are treating them. They may identify patients who might be interested in joining a PPG.

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 fliers to patients during a consultation if they think they might be interested.
- Ask staff to hand out fliers during clinics and groups, such as Parent and Child, Well Woman/Man clinics, or Carer's groups.

- Approach other local community groups and ask them to tell their members, such as the Women's Institute (WI).

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.

Remember! 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 if there is a large crowd to deal with. You can also find out in advance if anyone has special requirements such as a hearing loop or wheelchair access?

Being representative!

A common criticism of many 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 not necessarily always to be the voice itself. This can be redressed 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.
- Recruiting certain representatives to join the group for a short time or for a specific purpose.
- Hold meetings at different times of the day, including evenings, to enable people who have family, caring or work commitments to attend.
- Consider starting a 'virtual' or online group to run alongside your other group. This might be more attractive to people who may not want/be able to attend regular meetings in person but who might be interested in coming to special events or volunteering on a more ad hoc basis.
- Remember to make sure that you try and contact a diverse range of people, so that you get the views of people for example, from other ethnic communities, the travelling community, those with disabilities, Lesbian, Gay, Bisexual and Transgender (LGBT) people and those whose first language is not English.

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 they want to commit time and energy to long-term. 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 is valued.

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

Appendix 2 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
- NHS England, **Tel:** 0300 311 22 33; **Email:** england.contactus@nhs.net;
Address: NHS England, PO Box 16738, Redditch, B97 9PT

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. Look at reviewing membership annually.

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

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

Ground rules

These are important as a point of reference for behaviour for 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 box could be included as part of each agenda to reinforce these rules. For more detail please see Appendix 2.

Step 4 – The Second Meeting

It is important in the second meeting to address some of the administrative and organisational issues surrounding the new PPG. Appendix 3 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:

1. Elect a **Chairperson** – who manages the meetings, and is usually a lay member rather than a member of the practice staff.
2. Elect a **Secretary** – responsible for taking minutes and general admin. This role may be under taken by a member of staff from the practice. Discussions, decisions, attendees and any apologies for absence should be recorded in formal but brief minutes.
3. Decide if your group is going to do any fundraising. If so, a **Treasurer** will be needed to take care of funds and finances
4. Agree a first draft of a constitution or **terms of reference**. Appendix 4 has some template examples. This can be developed over the first few meetings.
5. Review the ideas for the role of your PPG from the first meeting and try to prioritise them into a workplan, sorting them into **short, medium and long term objectives**.
6. Make sure 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.
7. Decide on the **frequency, timing and venue of meetings**.
8. Decide on the **Quorum** - the minimum number of members of a patient participation group who must be present for the PPG to conduct business.
9. Decide on how big a **committee** you need. Some groups have a large membership with a small executive committee who does most the work, and others who are co-opted for specific projects, or who will turn out to support events for example. Remember that there are no set rules, but a group of 6 risks becoming a clique, while one bigger than 15 would be cumbersome to manage as an executive committee.
10. Make plans to **review** these arrangements and the groups work plan annually to make sure everything is working properly.
11. **Remember** – make sure the practice gets a chance to feedback on any issues important to them.

Don't forget to make arrangements to tell your practice population about the new group, what they plan to do, how to contact them and how others can get involved. See step 6 below – communications and reporting back - for some ideas.

Step 5 – Keeping your group going

On-going development

The ICB can help with establishing a new group, but it can also help PPGs at various stages of their development. If at any stage a group feels it could do with some new ideas or a review to help it keep going, contact us for help.

The ICB are also producing resources and organising events which aim to keep groups in touch with each other, keep them updated and let them know about new ideas and opportunities. Keep in touch via the ICB website.

It might also be a good idea in the early stages at least to find a 'buddy' group. There are many other PPGs in Norfolk and Waveney who would probably be happy to help you through the early stages or any difficult times. Find your nearest group by contacting the ICB Communications and Engagement team.

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 does not fall on the hands of one person. In such cases, the group is likely to run into difficulties if this key player leaves. So consider:

- Establishing roles and responsibilities and review these regularly
- Looking into training for members so that they can develop their skills and play a more active role e.g. chairing meetings, fundraising.
- Using a rota system e.g. for taking minutes.

Funding Issues

It is inevitable that the group will incur some costs. These may either be minimal running costs for admin 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 this sort of activity, however some funding ideas are listed below for those that do:

- Membership fee
- Fundraising at community events
- Coffee mornings and quiz nights
- Raffles in the reception area
- Applying for small grants

The Main Reason Groups fail

- Lack of focus
- Poor planning
- Poor communication to and from the group
- Poor relationship between the group and practice
- Relying too heavily on one or two people
- Poor ground rules

A strong well-balanced group should try to have a mix of the following people:

- **Active volunteers** – people with time and commitments to action decisions.
- **Interested professionals** – the doctors and administrative staff who work within and know the system.
- **Key supporters** – people with influence within your locality, e.g. local councillors or business people who help raise the profile of the group, and improve the chances of your group finding financial or other forms of support.

Step 6 – Communications and reporting back

Communication within the group

Patient participation groups tend to operate most effectively if representatives from the practice as well as patients are present. This ideally means clinical as well as management staff.

This allows up to date information to be given to patients and will inform what decisions can be influenced and what cannot. It will also allow the practice staff to gain an understanding from the patient's perspective. It may also be useful for the chair to have meetings with the Practice Manager on a regular basis or attend management meetings of the practice. This ensures that two way communication is achieved.

Reporting back

Group activities should be regularly fed back to all practice staff and to the rest of the patient population. This is not an easy task, but will ensure that everyone is aware of the activities of the group and may increase involvement and interest. You will need to consider:

- How will the work and the issues discussed at the meeting be disseminated to the wider practice population?
- Is it possible to have a PPG newsletter or display in reception?
- Does the practice have a website on which you could have your own page?
- Does the practice have an electronic noticeboard in the waiting area?
- Are there any parish magazines or freesheets produced locally that would be glad to 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.

5. And finally some useful links....

Further support and advice on PPGs and on public and patient involvement generally, can be found at the following links:

National Association of Patient Partnership:

www.napp.org.uk

The Patients Association:

www.patients-association.org.uk/patient-participation-toolkit



South Norfolk PPG Event 2017

Appendix 1

What can a patient participation group do?

Helping the practice to improve services

- Providing feedback from the practice population e.g. appointment systems, support for carers etc
- Monitor the accessibility of practice communications e.g. develop the practice booklet and leaflets, design of the website
- Carrying out surveys into a variety of subjects or supporting the implementation of the Friends and Family test (FFT) e.g. Measure patient satisfaction
- Practical help e.g. helping out at flu clinics in GP practices or showing patients how to use automatic check-in machines in reception
- Improving practice facilities e.g. new toys for the waiting room, maintaining plants and gardens
- Helping obtain the patient view for e.g. planning permissions with a new build project for practice premises.
- Designing new services and initiatives e.g. GP online services
- To explore the changing needs of patients

Offering support to other patients, including:

- Bereavement support
- Carers group
- Hospital visiting
- Befriending for housebound patients
- Volunteer transport scheme for medical appointments
- Providing health based social activities e.g. walking for health group, exercise classes, creating babysitting circles, 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 illnesses to newly diagnosed e.g. Diabetics etc
- Producing patient newsletters for the practice
- Ensuring that patient information and advice is as user friendly as possible
- Representing your practice locally and nationally when patient voices are needed

Arranging special health events

- Encouraging health education activities within the practice, such as:
 - Training in basic first aid for patients
 - Training new parents to distinguish when to call for medical assistance and when to self-treat
 - Awareness around particular illnesses e.g. breast cancer
 - Awareness for particular cultural groups around issues that relate to them

Representation

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

Appendix 2

First meeting agenda

Name of Group

Patient Participation Group Introductory Meeting

Date

Agenda

Ground Rules

1. This meeting is not a forum for individual complaints and single issues	5. Silence indicates agreement –speak up but always go through the Chair!
2. Open & honest communication - & challenge between individuals	6. All views are valid and will be listened to
3. Be flexible, listen, ask for help & support each other	7. No phones or other disruptions
4. Demonstrate a commitment to delivering results, as a group	8. Start & finish on time, stick to the agenda.

- 1. Welcome and Introductions**
- 2. What do we want from this meeting?**
- 3. What do we want from a PPG?**
- 4. What don't we want from a PPG?**
- 5. Being representative!**
- 6. Next steps.**

Appendix 3

Second meeting agenda

Name of Group

Date

Agenda

Ground Rules

1. This meeting is not a forum for individual complaints and single issues	5. Silence indicates agreement –speak up but always go through the Chair!
2. Open & honest communication - & challenge between individuals	6. All views are valid and will be listened to
3. Be flexible, listen, ask for help & support each other	7. No phones or other disruptions
4. Demonstrate a commitment to delivering results, as a group	8. Start & finish on time, stick to the agenda.

1. Welcome and Introductions

2. Group Business

- Election of Chair, Secretary and Treasurer
- Terms of Reference
- Frequency of Meetings
- 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 4

Sample Terms of Reference

This PPG will:

1. Act as a planning tool - can be consulted on service development and provision.
2. Provide feedback on patients' needs, concerns and interests.
3. 'Safety valve' for dealing with grumbles and complaints about the practice – help give the practice's viewpoint.
4. Assist practice by arranging voluntary groups/support within the community.
5. Feedback information about the community, in general, which may affect healthcare.
6. Give patients a voice in the organisation of their care.
7. Health Education: encourage and support activities within the practice and promote preventative medicine.
8. Influence the provision of secondary health care 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. Fund-raising for medical equipment or other facilities to improve the practice or the group may prefer not to have the responsibility of fund-raising.
12. Liaise with other Patient Participation Groups in the a

This document has been produced by NHS Norfolk and Waveney ICB (previously NHS Norfolk and Waveney CCG) with the help of local PPGs and practices.

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