

PATIENT PARTICIPATION GROUPS

TOOLKIT

Participation & Insight Team

**Julie Van Ruyckevelt
Ferne Haxby
Vicky Dyer**



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Introduction

Welcome to the Participation & Insight Team's 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 reflect the unique aspects of the practice and its population. This pack should help you get started.

NHS West Kent CCG is committed to involving patients and carers in the planning and decision making process around the services we commission. The NHS White Paper, Equity and Excellence: Liberating the NHS sets out the Government's long-term vision for the future of the NHS. It puts patients at the heart of everything the NHS does '**no decision about me without me**'.

Patients will be given more choice and control by having access to their health records, choosing their GP practice (without being restricted by where they live) and rating hospital and clinical departments according to the quality of care.

As GPs take control of the financial budgets within the NHS, they will be taking an active role in individual patient care in their consortium area. Determining the right range of services to be included in budgets needs to robustly balance with local needs. Most people have contact with the health service through their general practice. It is, therefore, natural to build patient and public involvement activity around GP surgeries. They are local to people and many patients have an ongoing relationship that gives them a stronger reason to participate:

- 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;
- In decisions about general service delivery, not just major changes.

The emphasis is on accountability and feedback. It is important to let people know:

- What has happened as a result of what they said?
- What is still to happen and when?
- What cannot happen and why?

This document gives practical ideas and an overview on how this document can 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 people.

The information provided by the National Association of Patient Participation (N.A.P.P.), available at www.growingppgs.com/get-involved, has been particularly valuable in developing the pack. N.A.P.P. is a registered charity and the umbrella organisation for Patient Participation Groups (PPGs) within primary care. PCTs and CCGs can affiliate to NAPP and receive support to effectively engage with and establish PPG Networks.

What is a Patient Participation Group?

A selection of patients and practice staff who meet at regular intervals to decide ways of making a positive contribution to the services and facilities offered by the practice to the patients.

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 health education activities within the practice
- To develop self-help projects to meeting the needs of fellow patients, such as befriending, help with transport and bereavement 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.

Benefits of a Patient Participation Group.

Good for the patient because:

- Patients will be more responsible for their own health
- Patient will have 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 patients in need
- Patients will be able to acquire an idea of what is needed to improve health care, and make sure the patient view is always represented
- Patients by maintaining an open dialogue with doctors and other health professionals will increase the accountability of the staff
- Patients will have an opportunity to become involved in other community initiatives e.g., health living centres

Step 1 – Getting Started

Who can suggest 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:

- Become a champion for patient involvement at the practice
- Call an open meeting of patients or approach selected individuals
- Approach surgery user groups (e.g., mums and toddlers, elderly screening clinics, wellwomen/man clinics)
- Contact the National Association for Patient Participation (NAPP)
- Read the literature already available about PPGs
- Talk to other practices with a PPG

A patient can:

- Approach the practice manager
- Follow the steps above
- Canvass the level of interest among other patients

Step 2 – Recruiting Your Group

There are two 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/flyers 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 area
- Put flyers in prescription bags for about 2 weeks and leave some on reception
- Put an article in the practice newsletter and on the website
- 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. They may also be 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 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 Child, Well Women/Man clinics or Carer's Groups.
- Ask the GP to speak to patients who they see in consultation
- Approach other local community groups and ask them to tell their members, such as the local WI

It is also possible to have a group which is a mix of open and invited representatives. Experience shows it can be better to 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
- Remember to make sure that you try and contact a diverse range of people so you get the views of people for example, from other ethnic communities, the travelling community, those with disabilities, all sexual orientations and those whose first language is not English.

Step 3 – The First Meeting

Keep it Informal

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 to leave with some consensus on what everyone wants to get from the PPG. It is a good opportunity for everyone, both patients and staff, 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 the 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 NHS West Kent Customer Services Department 0800-0-850-850

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 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.

Step 4 – The Second Meeting

Committee Members

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 issues that you will need to address:

- Elect a Chairperson – who manages the meetings and is usually a lay member rather than a member of the practice staff
- Elect a Secretary – responsible for taking minutes and general admin. This role may be undertaken by a member of the practice, if necessary. Discussions, decisions, attendees and any apologies for absence should be recorded in formal but brief minutes
- Decide if you group is going to do any fundraising. If so, a Treasurer will be needed to take care of funds and finances.
- Decide on the quorum – the minimum number of members of a patient participation group who must be present for the PPG to conduct business

Decide on how big a committee you need. Some groups have a large membership with a small executive committee who does most of the work and others who are co-opted for specific projects or who will turn out to support events for example. Remember there are no set rules but a group of six risks becoming a clique, while one bigger than fifteen would be cumbersome to manage as an executive committee

Terms of Reference

- 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
- Decide on the frequency, timing and venue of meetings

Set some Objectives

- Make sure you set some good short term objectives in your work plan so your group gets some 'quick wins' to boost confidence. Appendix 1 has a list of some examples of roles and projects adopted by PPGs
- Review the ideas for 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 plans to review these arrangements and the groups work plan annually to make sure everything is working properly
- Remember – make sure the practice gets a chance to feedback on any issues important to them

Step 5 – Keeping your group going

Ongoing Development

NHS West Kent 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 NHS West Kent for help.

NHS West Kent will be developing a PPG briefing to keep groups in touch with each other, keep them updated and let them know about new ideas and opportunities. Make sure you are on the distribution list by contacting the Head of Customer Services/Engagement at NHS West Kent

It might also be a good idea in the early stages at least to find a 'buddy' group. There are several other groups in the NHS West Kent area who would probably be happy to help you through the early stages or any difficult times. Find your nearest group by contacting the Head of Customer Services/Engagement.

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 etc., chairing meetings, fundraising
- Using a rota system e.g., for taking minutes

Funding issues

It is inevitable 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
- Jumble sales and raffles
- Applying for small grants

The Main Reasons Groups Fail

- Lack of focus
- 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
- Poor ground rules

Strength is 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

- Two way communication is important
- Representatives from the practice and patients should be present
- Make sure up to date information is shared – this informs what decisions can be influenced and what cannot
- The patient's perspective can be understood

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 everyone is aware of the activities of the group and may increase involvement and interest:

- Have a display in the waiting room about the PPG
- Newsletter
- A PPG section on the website
- Messages on the electronic noticeboard in the waiting area
- Parish magazines or freesheets produced locally
- 'Surgeries' in the waiting room where a PPG member can be present to answer any queries

Useful Links:

- National Association of Patient Participation N.A.P.P. www.napp.org.uk
- Growing Participation www.growingppgs.com
- NHS West Kent Clinical Commissioning Group/Commissioning Support Unit www.westkentccg.nhs.uk/www.southeastCSU.nhs.net

Appendix 1

What can a patient participation group do?

Helping the practice to improve services:

- Providing feedback from consumers e.g., appointment systems, consultation times need for notice board
- Monitor the accessibility of practice communications e.g., develop the practice booklet and leaflets, design of the website
- Carrying out surveys into a whole range of subjects e.g., measure patient satisfaction, health needs and expectations
- Practice help e.g., flu clinics in GP practices – making sure patients are happy in queues, giving information
- Improving practice facilities e.g., new toys for the waiting rooms, maintaining plants and gardens, fundraising for equipment
- 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. extended opening for GPs, changes in GP consultation times
- To explore the changing needs of patients within the area e.g. new housing, travellers, ratio changes in population

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 groups, exercise classes, creating babysitting circles, trips out for older people

Providing Information:

- Organising health fairs or evenings
- 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., diabetes etc
- Producing patient newsletters for the practice
- Ensuring patient information and advice is as user friendly as possible
- Representing the practice locally and nationally when patient voices are needed

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
- 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

There are, of course, many other opportunities for PPG groups to contribute.

Appendix 2

First Meeting Agenda

Name of Group

Patient Participation Group Introductory Meeting

Date

Agenda

Ground Rules

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

1. Welcome and Introductions
2. What do we want from this meeting?
3. What do we want from the PPG?
4. What don't we want from the PPG?
5. Being representative
6. Next Steps

Appendix 3

Second Meeting Agenda

Name of Group

Date

Agenda

Ground Rules:

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

Patient Participation Group

Terms of Reference

Purpose

The purpose of the Group is to facilitate the work of _____ surgery in its provision of services to patients as shall be determined from time to time by the partners of the practice and by the Group with a view to fostering an environment conducive within which the practice operates and to further the health and social needs of the patients. The Group shall not undertake any activity without the consent of the partners.

Objectives

The Group will:

- Provide a forum in which to discuss, plan and develop the most effective health services for the local population
- Create networks through which wider and more representative participation in local health care decisions can be established
- Develop creative means and methodologies for engaging local people
- Conduct surveys to capture patient experiences and insights as directed by the partners of the practice
- Deliver on-going dialogue with the public and support formal consultation when required
- Actively promote public awareness of health and social care issues
- Encourage and support activities within the practice and promote preventative medicine
- Liaise with other patient participation groups in the area and engage with groups connected with PCT/GP Consortia
- Feed back information about the community in general which may affect healthcare

Membership

The Panel will comprise representatives from its main localities and will be drawn from existing GP Practice Patient Participation Groups. The Consortium aims to draw representative of the diverse communities within its population.

Members will demonstrate the following criteria:

- Be actual/potential users of health services within the Consortium catchment area
- Be prepared to give the time and commitment to contribute actively to the Panel either virtually or through participation in a group or activity;
- Contribute to problem solving and offer ideas that will improve services for the people within the locality
- Be able to provide an individual and wider perspective on issues under discussion
- Participate in relevant training or development that will build their understanding of the PCT and the NHS and enhance their contribution to the Network.

The Group will meet quarterly but will conduct the agreed programme work outside of this.

Membership will comprise:

- 1 GP on a rotation basis
- Practice Manager or other staff member
- Patient representations
- PCT rep (when requested or approached)
- Additional co-opted members to be agreed and as defined by the agenda

?expenses

Key relationships

- Consortium Board and staff,
- Local Patient Participation Groups,
- LINks/Healthwatch,
- Local third sector organisations
- Providers
- NHS West Kent (in transition)

Appendix 5

Troubleshooting

Potential Problems

Whilst these points cannot be overlooked, they are all things that can be overcome if handled in the right way and the practice takes advantage of help that is offered to them when setting up the group:

- Practices fear the group becomes exclusive and it is not representative of the general make up of the patient population
- Patients think by joining such a group they will experience better service from the doctors, nurses and practice generally
- Fear patients will see a PPG as a forum for airing any moans they may have
- Fear the GP will spend a lot of time answering personal queries or complaints rather than achieving anything positive for the practice
- User involvement in the decision-making process calls for cultural and organisational change on behalf of the professionals
- Ensuring the groups are representative of their community
- Users take time to develop a sense of group identification that will be shared by the provider's from the outset and may initially lack a sense of competence/confidence
- A patient group takes time to plan, organise and support on an ongoing basis. Do not expect a successful group to arrive on your doorstep. Consider realistic work plan which is reviewed annually.

Overcoming the Difficulties

- Beware of dominance by a group or individual, have clear ground rules
- Try not to outnumber users with professionals or consult voluntary groups at the expense of genuine users
- Try not to take anyone for granted. Use every talent
- Try not to take anything for granted. Set up a formal system for communicating
- Ensure patients in the group have sufficient information and can understand it to make informed decisions. Their perception is important because if they are ill informed, it illustrates a need for clearer information.
- Recognise there will be differences in the perceptions of manager, professionals and lay representatives. Put in place mechanisms to balance these views

- If you want to avoid a problem with people who do not attend meetings, you should have a minimum attendance requirement built into your constitution e.g., non-attendance at three consecutive meetings
- Patients should serve on the group for a fixed term. Patients who become long-term members of the group may lose sight of the consumer agenda, and become too focused on the practice's priorities and problems
- Remember for some people meetings can be daunting. The purpose of meetings should be clearly defined:
 -
 - Always have an agenda
 - Avoid excessive discussion on unimportant details
 - Avoid the meeting dragging on
 - Make meetings accessible e.g., for people who work, have young children and do not have transport
 - Ensure decisions are made openly and after discussion meetings, decide not just what will be done, who will do it, how and to what time scale
 - Agree on dates for progress, and reports for long-standing projects
 - Remember to set the date for the next meeting

REFERENCES

Patient and Public Involvement and Engagement: An introductory guide for GP Commissioners; Report of north east advisory group for general practice commissioning: April 2011

NAPP, Growing Patient Participation 2009, www.growingppgs.com/get-involved/professionals