

# Patient Participation Groups

How to get started – A step by step guide to setting up a Patient Participation Group for General Practice and Patients



Title	A Guide to Setting up PPGs for General Practice and Patients
Description	The 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.
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# Welcome

Welcome to the NHS Milton Keynes 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 will help you get started.

NHS Milton Keynes is committed to involving patients and carers in the planning and decision making process around the services we commission. Section 242 of the Consolidated NHS Act 2006 and the Local Government and Public Involvement in Health Act 2007 places a duty on us to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes. This is a statutory duty, which means consulting and involving:

- 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.

NHS Milton Keynes Communication and Engagement Strategy sets out the commitment of NHS Milton Keynes to this process with guidelines and guiding principles in carrying out this work. It puts the emphasis 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?

Patient Participation Groups (PPGs) are seen as a significant way of involving people in local healthcare decision-making, and this document gives practical ideas and an overview on how the partners in Quality:MK will 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.

References and contact details referred to in this document can be found on page 17.



# What is a Patient Participation Group?

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 speaks for patients in general without being limited to any specific disease or condition. NAPP describes a PPG as a group of people who:

“work with their practices to provide practical support, to help patients to take more responsibility for their own health and to provide strategic input and advice. They are based on cooperation between the practice staff and patients. They help to improve communication”.

### 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 a 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 meet 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.

More information on the National Association of Patient Participation is available at: [www.napp.org.uk](http://www.napp.org.uk)





# What can a Patient Participation Group do?

## Helping the practice to improve services

- Providing feedback from patients e.g. appointment systems, consultation times, need for notice boards
- Monitor the accessibility of practice communications e.g. develop the practice booklet, leaflets and design of the website
- Carrying out surveys into a whole variety of subjects e.g. Measure patient satisfaction, health needs and expectations
- Practical help e.g. flu clinics in GP practices– making sure the patients are happy
- 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. Extended opening for GPs
- 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, Asthma, 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
- 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.



# Benefits of a Patient Participation Group

### Good for the patients because:

- Patients will be more responsible for their own health
- Patients will have a better understanding and knowledge of the practice and its staff
- 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 the 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 and social care issues
- They will be able to get help from patients in meeting targets and objectives
- They will have a forum to voice concerns, ideas and suggestions to patients
- They 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 patients needs
- 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 will maintain an open dialogue with doctors and other health professionals
- Patients will have an opportunity to become involved in other community initiatives eg LINK:MK.



# A Step by Step Guide to setting up a Patient Participation Group

## 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 a surgery can:

1. Talk to the Communications and Engagement Manager at NHS Milton Keynes at the contact given below for advice
2. Become a champion for patient involvement at the practice
3. Call an open meeting of patients or approach selected individuals
4. Approach surgery user groups (e.g. mums and toddlers, elderly screening clinics, well women/man 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
8. Canvas the level of interest amongst patients.

### A patient can:

1. Approach the practice manager
2. Follow the steps 5, 6, and 7 above

### If you need extra advice and information contact:

Communications and Engagement Manager

NHS Milton Keynes  
Sherwood House  
Sherwood Drive  
Bletchley  
Milton Keynes, MK3 6RT

Tel: 01908 278660

email: [allison.carlton@miltonkeynes.nhs.uk](mailto:allison.carlton@miltonkeynes.nhs.uk)

## Step 2 - Recruiting Your Group

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

1. Open groups
2. Invited groups

# 1

**Open groups** are formed from open meetings, which any patient may attend. You will need to advertise widely giving plenty of notice. (Appendix 1 has a suggested patient leaflet). 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:

# 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 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.

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

Here are some other ideas for contacting invited group members:

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

**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. You should 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
- Approaching 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 that you get the views of people for example, from other ethnic communities, the traveling community, those with disabilities, gay 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. 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 of what everyone wants to get from the PPG. It is a good opportunity for everyone, both patients and the practice, to discuss ideas and point out the skills and networks that they can bring to the group.



Appendix 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
- The NHS Milton Keynes Complaints Manager
- The NHS Milton Keynes Patient Advice and Liaison Service (PALS)
- The Independent Conciliation Advocacy Service (ICAS)
- Write to the Chief Executive of NHS Milton Keynes

Contact details for all of the above can be found on page 15.

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 – six 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.

## 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. **Chairperson** – who manages the meetings, and is usually a lay member rather than a member of the practice staff.
2. **Secretary** – responsible for taking minutes and general admin. This role may be undertaken by a member of staff from the practice. Discussions, decisions, attendees and any apologies for absence should be recorded in formal but brief minutes.

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 PPG you need. Some groups have a large membership with a small executive committee which 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 six 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.

## Step 5 – Keeping your group going

### On-going Development

NHS Milton Keynes can help with signposting to 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 Milton Keynes for help.

It might also be a good idea in the early stages at least to find a 'buddy' group. There are other PPGs in the NHS Milton Keynes area who would probably be happy to help you through the early stages or any difficult times. For further details contact the Communications and Engagement Manager at NHS Milton Keynes.

Contact details for the Communications and Engagement Department at NHS Milton Keynes can be found on page 7.







## 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
- Supporting members so that they can develop their skills and play a more active role
- 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 fundraising activities but should consider other funding opportunities.

Health:MK has agreed to provide each practice with £1k for start up costs.

## The Main Reasons Groups Fail

- Lack of focus and commitment
- Poor planning
- Poor communication to and from the group
- Hostility between group and practice or vice versa
- Relying to 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

### Communications 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 medical 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 patients. This will allow everyone to be 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 a 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.



## Examples of good practice

Patient Participation Groups (PPGs) give patients the opportunity to find out about what goes on 'behind the scenes' at their GP practice. It's also a chance for patients to tell their GP practices their views about areas of concern and suggestions for improving services.

The PPG at Whaddon House Surgery in Bletchley was one of the first to be established in Milton Keynes. Some really positive changes have been put in place as a result of the regular meetings, including:

- The introduction of a new appointments system, which is a considerable improvement on the old system with fewer patients not attending for their appointments
- An easy-to operate self check-in system
- The setting up of a website ([www.whaddonhousesurgery.co.uk](http://www.whaddonhousesurgery.co.uk)); a really useful part of this is the option to apply for repeat prescriptions online
- A quarterly newsletter, which includes GP and staff profiles and seasonal suggestions on how to keep yourself healthy
- 'Early Bird' appointment times to help people see a doctor at a time that was convenient to them. The practice was one of the first to offer extended hours appointments.



# 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](http://www.napp.org.uk)

**NHS Milton Keynes**  
[www.miltonkeynes.nhs.uk](http://www.miltonkeynes.nhs.uk)

**LINK:MK**  
[www.communityvoicesonline.org/links/home.aspx?id=38](http://www.communityvoicesonline.org/links/home.aspx?id=38)

**health:mk**  
[www.healthmk.org](http://www.healthmk.org)

**Quality:MK**  
[www.miltonkeynes.nhs.uk/qualitymk.htm](http://www.miltonkeynes.nhs.uk/qualitymk.htm)

**Patient and Public Engagement Toolkit**  
[http://www.institute.nhs.uk/images/documents/wcc/PCT%20portal/PPE TOOLKITwithlinksFINAL.pdf](http://www.institute.nhs.uk/images/documents/wcc/PCT%20portal/PPE%20TOOLKITwithlinksFINAL.pdf)

**The Department of Health**  
<http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/index>

## References

**Independent Complaints Advocacy Service (ICAS)**  
Kingfisher Exchange, 3rd Floor Kingfisher House  
Walton Street, Aylesbury, Bucks HP21 7AY  
(01296) 468170

**Patient Advice & Liaison Service (PALS)**  
Milton Keynes PCT HQ, Hospital Campus  
Standing Way, Milton Keynes, MK6 5NG  
(01908) 243633

**Chief Executive**  
NHS Milton Keynes  
Sherwood Place, Sherwood Drive,  
Bletchley, Milton Keynes MK3 6RT





# Appendix 1

Patient Flyer

## XXXXX Health Centre Patients' 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:  
XXXXXXXXX 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  
Patients' Participation Group then please contact  
XXXXXXXXX XXXXXX (Practice Manager) on 000 0000 0000

For suggested discussion topics see the reverse.

## Health Centre Participation Group

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  
Patients' Participation Group doing?
- Planning a community event at the Health Centre  
in the future
- 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

**Refreshments and travel expenses will be provided**



# 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
2. Open and honest communication and challenge between individuals
3. Be flexible, listen, ask for help and support each other
4. Demonstrate a commitment to delivering results, as a group
5. Silence indicates agreement – speak up but always go through the Chair
6. All views are valid and will be listened to
7. No phones or other disruptions
8. Start & finish on time, stick to the agenda.

### Aims and objectives

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

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

## 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

6. Arrange next meeting - date/time/location

# 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. Fundraising 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 area (NHS Milton Keynes and health:mk can help put you in touch with other groups).



# Appendix 5

## Troubleshooting and Potential Problems

They are all things that can be overcome if handled in the right way if the practice takes advantage of help that is offered to them when setting up a group.

1. Practices fear that the group becomes exclusive and that it is not representative of the general make up of the patient population.
2. Patients think that by joining such a group they will experience better service from the doctors, nurses, and practice generally.
3. Fear that patients will see a PPG as a forum for airing any moans they may have.
4. Fear that the GP will spend a lot of time answering personal queries or complaints rather than achieve anything positive for the practice.
5. User involvement in the decision-making process calls for cultural and organisational change on behalf of the professionals.
6. Ensuring that the groups are representative of their community.
7. 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.
8. A patient group takes time to plan, organise and support on an on-going basis. Do not expect a successful group to arrive on your doorstep. Consider realistic work plan which is reviewed annually.

## Overcoming Difficulties

1. Beware of dominance by a group or individual, have clear ground rules.
2. Try not to outnumber users with professionals or consult voluntary groups at the expense of genuine users.
3. Try not to take anyone for granted. Use every talent.
4. Try not to take anything for granted, e.g. set up a formal system for communicating.
5. Ensure that patients in the group have sufficient information, 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.
6. Recognise that there will be differences in the perceptions of manager, professionals and lay representatives. Put in place mechanisms to balance these views.

7. 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. nonattendance at three consecutive meetings.
8. Patients should serve on the group for a fixed term. Patients who become long-term members of the panel may lose sight of the consumer agenda, and become too focused on the practice's priorities and problems.
9. Remember that for some people, meetings can be daunting. The purpose of meetings should be clearly defined :-
  - Always have an agenda.
  - Avoid excessive discussion 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.
10. Committees
  - Try not to push people into jobs they do not really want.
  - Do encourage people to take on roles, but recognise when they are sincerely saying no.
  - Avoid re-electing someone who has not been doing the job well.
  - Officers should not carry on too long. Your constitution should define the length of the maximum term of each office, and also how long a committee member should serve.

## THANK YOU

To everyone who supported and helped in the development of this document.

If you would like document in large print, audio, braille, or in a different language, please contact NHS Milton Keynes on 01908 278801.

This document has been produced by NHS Milton Keynes Communications and Engagement Department with the support of



**health:mk Quality:MK**



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