

Patient Participation Group Toolkit



Some useful
hints, tips and
guidance to help
you set up a
Patient
Participation
Group

What is a PPG and why are they needed?

How could you start one in your surgery?

*If you have one already,
how can you keep it going?*

Where can you get further help?

Oxfordshire LINK

May 2012



Every patient is unique and different. Every GP Practice is unique and different. It follows, then, that each Patient Participation Group (PPG) should also be unique and different. This Toolkit is not designed to give you a 'one size fits' all model to help you set up a PPG, but the means to help your PPG develop according to the needs and wishes of the patients in your practice.

Along with some ideas on how to set up and keep your PPG going, this booklet also includes some Useful Resources that you may wish to adapt for you own use.

We have also outlined further help that Oxfordshire LiNk could offer you, should you need it.

Oxfordshire LiNk is a Local Involvement Network, made up of individuals and community groups who care about health and social care services and work together to make improvements to them. One of the aims of **Oxfordshire LiNk** is to make sure your opinion is heard about how local services are planned and developed.

Oxfordshire LiNk has been set up to give communities a stronger voice in how their health and social care services are delivered. The LiNk promotes involvement and finds out what people think about those services, monitors the care provided and uses LiNk powers to hold the NHS and County Council to account. The LiNk is independent of the NHS and the Local Authority.

The goal of **Oxfordshire LiNk** is to be Your Voice on Social Care and Health, which includes finding out what you like and don't like about the services you use and what new services you need.

The role of **Oxfordshire LiNk** is to talk to and listen to local people in lots of different ways to find out people's opinions on local health and social care. The LiNk will collect this information and work to improve services based on what people have said.

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Background

What is a PPG?

PPGs work with the practice to offer the patient perspective on the service it provides. A PPG is a route for patients to advise the practice on what matters most to them and to identify solutions to problems. The PPG represents the needs of the whole practice and is made up of volunteer patients and representatives from the practice itself.



How do they work?

There is no set way in which they work, but most meet on a regular basis to discuss the services on offer and how improvements can be made for the benefit of patients. Many also involve the practice manager and one or more GPs to ensure actions from the meetings are followed up.

Why have one?

- Patients can influence the way in which practices are run, helping bring about improvements and a better service.
- Patients will be consulted about arrangements for their care before decisions are made.
- Patients will have a forum to suggest positive ideas and voice concerns.
- GPs and staff will be able to plan services jointly with patients in order to increase their effectiveness.



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What do they do?

- Improve communication between GPs and Patients
- Organise health promotion events
- Act as a 'critical friend' for the practice
- Signpost patients
- Research into what matters to patients
- Offer feedback on the patient perspective
- Help the practice make best use of its resources
- Provide practical hands-on support to the practice
- Represent practice views at Locality Clinical Commissioning Group (CCG) meetings

What are the benefits of joining?

It gives you the opportunity to have your say and take action to improve the way health services are delivered in the community. You have the right to send a representative to the Local CCG. It's also a great way to give something back and take an initiative in helping to make changes. It can also be a good way to meet new people and learn new skills.

PPGs are NOT:

- A forum for complaints - they are not a vehicle for patients to resolve their own personal issues
- A doctors' fan club
- Reliant on practice staff - they should be self-organising and patient led
- Just there to tick a box or to gain extra funding for the surgery



Starting Up

Recruiting members

It's a good idea to start by finding out how much support and interest there would be from your community to be for a PPG. You could visit community groups to tell people about it, put posters up, hold a meeting, be available in the surgery to encourage people to join. Ask the practice staff if they know of anyone who might like to be involved and invite them along personally. Remember, people like incentives, even if it's just free tea and coffee at meetings!



Getting your GP on board

Most PPGs have clinical and managerial staff on them as well. This is useful to provide two-way-feed back on what patients need the practice to change and also what the practice would like information on from the patients. If it's not appropriate for staff to be directly involved in meetings, you will need to agree how actions will be followed up with the practice and fed back to the group.

A starburst graphic with a black border and a white interior. The text inside is black and reads: "Be realistic about what you can achieve."

Be realistic about what you can achieve.

Establishing your PPG

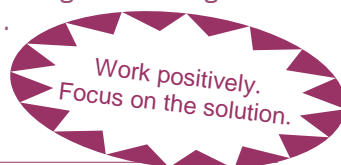
Be clear about what it is you are there to achieve. Set out objectives. Have two or three achievable goals that you can meet to start with. Always make sure that you have a clear list of action points from your meetings that will be followed up by the surgery. Keep patients informed on what you are working on and what you have achieved.

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Publicising your PPG

Create a 'brand' for your PPG that is eye catching and unique. Use this for all your publicity. Use posters to give people information or 'Calls to Action'. Make sure you keep advertising meetings and promote your recent successes.

You may want to think about a website or use social networking to get people involved.



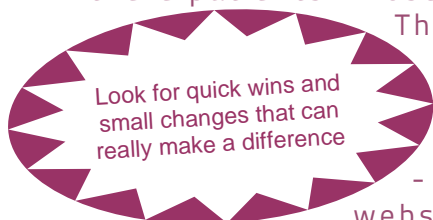
Working with others

Work with other PPGs in your area, sharing good practice - some problems can only be solved across a number of practices. Link with other groups and organisations within your community, including the Primary Care Trust, Oxfordshire Clinical Commissioning Group, local medical committees, local MP, The WI, CAB and others. And, of course, with Oxfordshire LINK.

Involving children, young people and other groups

Each practice has a diverse range of patients, so think about ways you can hear from ALL of them. You may want to have a direct link with the local Mother and Baby group and school. Or the local Lunch Club. Are there patients whose first language isn't English?

Think creatively about how you can reach a wide a range of people.



Ideas

- Create a Newsletter
- Set up a website
- Put up a notice board in the surgery to keep everyone up to date with what you are doing
- Set up a virtual patient group
- Run competitions for children
- Have a Facebook page!
- **If you are stuck, ask the LINK for practical tips and advice.**

Keeping Going

If a PPG doesn't succeed in its aims, it is usually due to one or more of the following reasons:

- A lack of focus and commitment
- Poor planning
 - Poor communication to and from the group
 - Hostility between group and practice
 - Relying too heavily on one or two people
 - Poor ground rules



Expanding the scope of your PPG

Looking for new ways to support the work of the practice will help to expand the scope of your PPG, keep it fresh and keep members keen and interested.

- Beef up your online presence.
- Use social media. Set up a Facebook page or a Twitter account. Get some young people involved to show you how it's done!
- Provide all round support to patients - social as well as medical. e.g. set up a bereavement support service; support for carers, e.g. a monthly social evening or coffee morning; set up a 'walking for health' group.
- Educate patients - set up free health education events to provide advice on healthy lifestyles.
- Think outside the box - involve new mums by putting on a 'pamper morning' at the surgery with crèche facilities, using the opportunity to educate them on child health issues.
- Time a local event to coincide with a national awareness day e.g. No Smoking Day.
- Meet with your Parish or Town Council to inform them of what you are doing



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How else could you gather feedback?

Get out into the community to canvass opinions. Target specific groups of people that are not represented, children and young people for example. Ask people to join the group for a short time for a specific piece of work. Visit groups already set up to ask for feedback.



Publicising your good work

Shout about the work you are doing! Tell practice staff and the wider patient population. Make use of online facilities, using the practice website or your own PPG one. Have your own notice board or put eye-catching photos up in the surgery. Hold regular 'surgeries' - one to one meetings with members of the PPG and patients. Create a newsletter. Have a regular article in your local magazine or paper.



Present your results and share your outcomes

Remember your audience when presenting your results. You could use reports, newsletters, factsheets, posters, presentations or a website to show what you have done. Make sure everyone can access information on what you have achieved, especially those involved in any consultation you have done.

Evaluate what you are doing

Carry out an evaluation of what you have done. Has it met your original aims and objectives? Has the work had an impact? This evaluation can help inform planning for the future.

Useful Documents

On the next few pages you will find a number of useful resources and documents to help you when setting up and running your PPG.

Ground Rules

Although nobody wants to talk about 'rules' before your group has started, it is important to outline some ground rules at your first meeting that everyone should agree to follow. They could include the following:

Ground rules

- Treat everyone with equal respect, courtesy and consideration, whether they are a patient or a member of practice staff, and act in a way which does not discriminate against or exclude anyone
- This meeting is not a forum for individual complaints or single issues
- We will be flexible, listen, ask for help, and support each other
- We will demonstrate a commitment to delivering results, as a group
- Silence indicates agreement - speak up if you don't agree with something
- All views are valid and will be listened to
- No phones or other disruptions
- We will start and finish on time and stick to the agenda
- Everything discussed at this meeting will be confidential

Roles within your PPG

There are certain roles and jobs within a PPG that you may wish to appoint people to at your first meeting. If you do not want to allocate roles formally, you will need to think about how to manage these tasks on an ongoing basis.

Chairperson - manages the meetings and should be a patient rather than a member of practice staff. You could take it in turns to be Chair, and also appoint a Deputy-Chair to help share this role, if there isn't one person willing to take it on.

Secretary - responsible for taking minutes and general administration. Again, people could take it in turns to do this.

Treasurer - If the group is going to do any fundraising, this will be the person who will take care of funds and finances.

Communications lead - it may be useful to appoint someone to be the main contact person for your group. This person's name can be given out to the press, as well as be the contact for general enquiries. If you don't appoint one person, you need to agree how people can contact the group. Will you have a generic email address and phone number? Or will all correspondence go via the surgery (with their agreement)?

Ensure the PPG selects a representative to attend important meetings on behalf of the group, such as the Locality CCG meetings.

Example Flyers

XXXX SURGERY

**Are you interested in finding out more about your Surgery?
Would you like to influence the development of local health
services?**

**We are keen to set up a patient participation group,
so why not come along and meet us?**

The meeting will take place at XXXX

**A date and time will be confirmed when a number of people
have expressed an interest.**

**If you would like to come along to the meeting or if you would
like to find out more, please contact XXXX**

TELL US WHAT YOU THINK

**WE ARE HOLDING THE FIRST
PATIENT PARTICIPATION GROUP
TO LISTEN TO YOUR VIEWS ABOUT**

XXX SURGERY

WHAT'S GOOD? WHAT'S BAD?

WHAT COULD BE BETTER?

WE WANT TO HEAR FROM ALL PATIENTS

WHEN? XXX

WHERE? XXX

Things to decide

At one of the first meetings, it might be useful to think about agreeing your Terms of Reference, an example of which is below. You might also want to set short, medium and long-term objectives, and think about priorities which could be put into a work plan.

Decide on the frequency, timing and venue for future meetings.

Decide on how big a PPG you need and if you want to adopt a membership scheme. You may wish to have a small committee and co-opt others on for specific projects. Remember, there are no set rules, but groups of between 6 and 15 tend to work best.

Make plans to review your arrangements and objectives annually.

Terms of Reference

This PPG will:

1. Contribute to practice decision-making and will consult on service development and provision;
2. Provide feedback on patients' needs, concerns and interests and challenge the practice constructively whenever necessary;
3. Assist the practice and its patients by arranging voluntary groups and support within the community;
4. Communicate information about the community which may affect healthcare;
5. Give patients a voice in the organisation of their care;
6. Promote good health and higher levels of health literacy by encouraging and supporting activities within the practice and promoting preventive medicine;
7. Influence the provision of secondary healthcare and social care locally;
8. Monitor services e.g. hospital discharge and support when back in the community;
9. Give feedback on NHS consultations;
10. Fundraise for medical equipment or other facilities to improve the practice and / or fund the activities of the PPG;
11. Liaise with other PPGs in the area

Tips

Groups to Involve

- Children and young people
- Older people
- Refugees
- Asylum seekers
- People with disabilities e.g. sight impairments, people who use mental health services, people with learning difficulties
- Carers
- Minority ethnic communities
- People whose first language is not English
- People in the justice system
- Gay, lesbian, bisexual and transgender communities
- Homeless people and travellers
- Faith communities

Tips for successful involvement

- Go to where your audience is
- Think about who you want to engage with and design the activity accordingly
- Use language appropriate to the group
- Provide refreshments
- Choose a suitable venue
- Consider timing
- Work with existing groups and voluntary organisations
- Always feed back to those involved
- Use an informal approach and reassure participants that their involvement will be confidential

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Tips for writing a press release

- Ensure the headline and first paragraph encapsulate the 'who, where, what, when and why' of your story
- Consider the three main messages you want to communicate and ensure they are prioritized
- Use short quotes to support your story
- Have a representative available to speak to the press if needed
- Always include contact details at the end and highlight what other information is available
- Constantly evaluate whether your press release is interesting to your target audience

Tips for funding your PPG

- Approach your PCT for financial support
- Set up a PPG membership scheme
- Approach a local business for donations
- Set up a book sale in the waiting room
- Run a cake stall at local events
- Run a Christmas raffle, selling tickets in the waiting room
- Run a coffee morning or afternoon tea party, with a small attendance fee
- Organise an event with an attendance fee
- Run a sponsored event
- Run a quiz night

You could look into gaining charitable status to support your work to raise funds.

Reporting

You may want to look at a way of ensuring the comments and suggestions raised at your meetings are recorded in a way that enables the practice staff to respond to them with a list of actions that can be monitored by the PPG. You could do this by putting all the priorities and suggestions for improvements discussed at each meeting into a table:

Priority 1 - ...		
<i>Space for comments from the Practice...</i>		
Suggestions	What the Practice is going to do (Actions)	By When
<i>Suggestions for improvements</i>	<i>Space for the Practice to comment on the actions they will take to help make improvements</i>	<i>A timeline for when Actions will be completed</i>

Under each main Priority, list a number of suggestions that could be made to help make improvements. The practice will then review this and complete the Actions part of the table, noting what they can and can't do under each suggestion, and list other possible solutions to help that they can think of. They also include a 'timeline' outlining when the Actions will be completed. If a suggestion can not be followed up, the practice must give a reason why. The practice then shares this at the next PPG meeting. The PPG then discusses the Actions and 'colour' codes them—'green' if they agree that the Action has been completed, 'orange' if it is ongoing and 'red' if not complete.

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Another column could also be added to this table to enable the PPG to record subsequent comments. If an Action has been completed, it can be removed from the table. Likewise, if the PPG agrees that a satisfactory reason has been given by the practice as to why a suggestion can not be followed up, i.e. has been marked in 'red' by the practice, it is up to the PPG to agree if this can be removed from the table as there is no more that can be done. The PPG could go back to the practice to ask for further information or to suggest alternate Actions that might be able to help - in which case the suggestion can be marked as 'orange'. A list of further Priorities that the PPG would like the practice to look into can be kept and added to this report as and when others are taken off.

This is a useful way to monitor the suggestions for improvements and the way the practice will try and make improvements. You will need to ask the practice to agree to working in this way, and to continue to report back to the PPG at every meeting. It would also work well if practice staff were unable to attend the PPG meetings. This is a working document that is changing and evolving. The Priorities should continue to reflect the needs of the practice. Consultation with all patients should feed into this process.

FOR MORE INFORMATION OR HELP ON THIS WAY OF REPORTING, PLEASE CONTACT OXFORDSHIRE LINK - link@oxonrcc.org.uk
01865 883488

Further Help

Oxfordshire LiNk is keen to provide help to new groups who would like some advice on how to set up a PPG; or to existing PPGs who would like some ideas on how to reinvigorate their group. We have listed some ways we could help below, but this is not a definitive list - please contact us and we will try and help in any way we can.

Social Networking - we could help you look at ways to use Social Networking as an engagement tool. We have access to a 'Guide on how to use Facebook' which we could provide and spend time with you looking at other options.

We have access to detailed information (via the Local Information System) on how best to consult with people living in your community. We can provide you with this information for your area - it will save you lots of time and effort!

If there is enough interest, we could look into setting up a Network of PPGs in your area. This could involve a virtual group, or regular meetings, where ideas can be shared and you can discuss ways of working together.

If you have already begun to gather information from Patients, but are unsure what to do with it next, we can help you put together an Action Plan.

***'Trust Me, I'm a Patient'** is a patient and public involvement role playing game, produced by the Department of Health. We could help facilitate this game with you and others in your area.*

Further information

Growing Patient Participation

www.growingppgs.com

Find out more about PPGs and how to get involved.

The National Association for Patient Participation

www.NAPP.org.uk

NAPP is the umbrella organisation for PPGs within primary care.

NHS Alliance

www.nhsalliance.org

The NHS Alliance provides support for Primary Care Groups and professionals working in Primary Care in the UK.

British Medical Association

www.bma.org.uk

The BMA is the doctors' professional organisation, representing doctors in all branches of medicine across the UK.

Department of Health

www.dh.gov.uk

NHS Oxfordshire

www.oxfordshirepct.nhs.uk

Oxfordshire Clinical Commissioning Group

www.oxfordshireccg.nhs.uk

01865 336795

oxon.gpc@nhs.net

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Oxfordshire LiNk

ORCC

Jericho Farm

Worton

Witney

Oxon

OX29 4SZ

Phone: 01865 883488

E-mail: link@oxonrcc.org.uk

Website: www.oxfordshirelink.org.uk