

# Start-up Guide for General Practice

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## Patient Participation Groups in Scotland

December 2012

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## Section 1 – INTRODUCTION

This guide has been produced by the Scottish Health Council to assist primary care practitioners to improve or widen their current involvement with the public and engagement with communities by establishing a Patient Participation Group in their local community.

Involving patients, carers and the public is a very important part of improving the quality of service provided by NHSScotland. Effective public involvement can:

- act as a catalyst for change
- help achieve a major improvement in the health of the public, and
- help strengthen public confidence in the NHS.

### ➤ The Scottish Health Council

The Scottish Health Council promotes Patient Focus and Public Involvement in the NHS in Scotland. A key aspect of our role is to support and monitor how the NHS carries out its statutory duty to involve patients and the public in the planning and delivery of health services including primary care services.

In order for practices to fulfil their patient involvement expectation, we can provide guidance and support to assist you in establishing and developing a Patient Participation Group. Our advice and support is free and there is a local office in each NHS Board area in Scotland. To find contact details for your nearest local office see our website at [www.scottishhealthcouncil.org](http://www.scottishhealthcouncil.org) or telephone our national office on 0141 241 6308.

### ➤ What is a Patient Participation Group?

A Patient Participation Group is a patient-led group linked to a local General Practice. Ideally, the Patient Participation Group will be made up of a group of patients that reflect the diversity of the catchment population. They will work along with GPs and practice staff to provide a patient perspective on the healthcare services that are offered to the community.

The concept of having patient-led groups linked to primary and community care providers was first developed by the National Association for Patient Participation, an English-based organisation founded in 1978. Since then, Patient Participation Groups have become an established and recommended method of public engagement in the primary care sector.<sup>1</sup>

### ➤ Why have a Patient Participation Group?

A successful Patient Participation Group can help practices meet the Scottish Government's expectation that people will be involved in changes to primary care services as set out in Informing, Engaging and Consulting People in Developing Health and Community Care Services<sup>2</sup> and can also help to meet some of the person-centred aspirations set out in Clinical and Staff Governance for General Practice in Scotland.<sup>3</sup>

<sup>1</sup> National Association for Patient Participation (NAPP). Growing patient participation Getting started – A step-by-step guide for PCTs to setting up a Patient Participation Group in general practice [online]. 2009 [cited 2012 Jun 8]; Available from: [http://www.growingppgs.com/fileadmin/user\\_upload/Campaign/Getting%20Started%20Doc.pdf](http://www.growingppgs.com/fileadmin/user_upload/Campaign/Getting%20Started%20Doc.pdf)

<sup>2</sup> CEL4(2010) The Scottish Government. Informing, engaging and consulting people in developing health and community care services [online]. 2010 [cited 2012 Jun 8]; Available from: [http://www.sehd.scot.nhs.uk/mels/CEL2010\\_04.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2010_04.pdf)

<sup>3</sup> PCA(M)(2010)18 - Clinical and Staff Governance for General Practice in Scotland, The Scottish Government 2010 [http://www.sehd.scot.nhs.uk/pca/PCA2010\(M\)18.pdf](http://www.sehd.scot.nhs.uk/pca/PCA2010(M)18.pdf)

## **Key benefits of a Patient Participation Group to the patient**

- Patients will have a better understanding of the practice and can be involved in decision making, ensuring that the patient view is always represented.
- Patients can interact with the practice in a positive way, suggesting new ideas and expressing concerns.
- Patients will feel valued and empowered in the community which can lead to improved self-esteem.
- Patients will get to know the practice staff better and this will improve communication.
- Patients may have a larger interest in, and responsibility for, their own health.

## **Key benefits of a Patient Participation Group to the practice**

- A Patient Participation Group is an easily accessible resource for a practice to support wider community engagement.
- The reputation of the practice may benefit if it shows that it listens to patients, involves them in decision making and understand their healthcare needs and desires.
- GPs and practice staff can ensure that their service provision is more effective, efficient and tailored to the community which they care for.
- The practice may increase its understanding of key issues and problems in local health services enabling it to pre-empt and solve potential concerns.
- A Patient Participation Group provides the opportunity for GPs and practice staff to inform patients of the reality of running a General Practice, and the reasons behind some of the decision making.

Patient participation has been shown to result in improved patient safety, which leads to more effective and efficient health outcomes. These outcomes include improved service effectiveness, quality of life of patients, and patient and staff satisfaction, among others.<sup>4</sup> In the primary care sector, this can be accomplished by allowing and promoting a Patient Participation Group to represent the views of the community.

## **➤ Examples of how Patient Participation Groups are helping practices and patients:**

### **Communication**

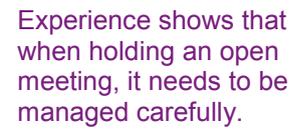
- Build two-way communication between patients and the practice.
- Help develop practice communications e.g. booklets, patient newsletter.
- Help carry out surveys or obtain patient views.
- Share good practice by networking with other Patient Participation Groups.
- Help ensure patient advice and information is user-friendly.
- Develop a patient library or information resource centre.
- Act as a representative group and take part in public consultations and events/meetings in order to influence the provision of healthcare both locally and nationally.

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<sup>4</sup> The Scottish Health Council. A Scottish Health Council report on improving quality through participation [online]. 2011 [cited 2012 June 8]; Available from: [http://www.scottishhealthcouncil.org/publications/research\\_reports.aspx](http://www.scottishhealthcouncil.org/publications/research_reports.aspx)

### **Treatments/services/facilities**

- Advise on the development of new or existing practice premises.
- Help capture issues for the practice to consider.
- Monitor services e.g. hospital discharge and the support provided.
- Promote awareness of and access to local health services.
- Provide practical help at special clinics e.g. registering patients at flu clinics



Experience shows that when holding an open meeting, it needs to be managed carefully.

### **Health promotion**

- Support the practice in its health promotion and education work e.g. provides additional resource and support for an 'open day' or 'health fair'.
- Raise awareness of key public health messages.
- Help the practice raise awareness of and share information on specific illnesses e.g. diabetes.

## Section 2 - BEFORE THE FIRST MEETING OF THE GROUP

Before establishing a Patient Participation Group, it may be worth getting together a few people from the practice to help with the preparation work that needs to take place. Considerations need to be given to the following:

- Who do we want on board to help?
- Have we got the time, resource and finance to get it started?
- What do we hope to achieve from a Patient Participation Group? Improving practice services, fundraising, a self managing Patient Participation Group, developing practice surveys and working with other areas are all practical and useful goals.
- Is everyone aware of what we aim to achieve?
- How are we going to communicate, update and feedback to the practice team?
- Who's doing what?
- What are our timescales?

Once the initial preparations have been taken on board and an action plan is established, the recruitment stage can take place.

### ➤ Who will represent the practice on the group?

Agree members of staff who will represent the practice on the Patient Participation Group – GP, the Practice Manager or other practice staff (it may be agreed that some staff attend on a rotational basis).

### ➤ Recruitment of patients to the group

#### Important factors to consider

- Be proactive in your recruitment efforts.
- The number of individuals to sit on the group.
- Ensure the recruitment process is fair and inclusive with people of all ages, ethnicity and background being considered. (See 'Be Representative and Keeping it Diverse' section below).
- The Patient Participation Group could potentially develop naturally from another group, for example, one that is already looking at a specific issue.
- Ensure that when recruiting, members have a clear understanding of what the Patient Participation Group is about and what is expected of them.
- Remember to keep engagement positive.

Experience shows around 12 to be the average number but it depends on the needs of the practice and is certainly not a prescriptive figure.

#### ***Suggested methods of recruitment:***

##### **By invitation**

Contacting individual patients directly and asking them if they would like to sit on the group. Some suggested ways of targeting patients are:

- where appropriate, practice staff could mention recruitment to the group to individual patients of theirs.
- practice staff could identify patients who they feel may bring value to the group.
- invite users of specific services (for example, people with long-term conditions or young mothers) by asking staff to promote the group during clinics.

## Encourage application from patients

People would be asked to 'apply' for a place on the group by stating what they could bring to the role.

Consider holding a coffee morning or open day to provide patients with background information about what a Patient Participation Group is, what it does, how it is beneficial etc. If using this method, it will need to be advertised widely, giving people plenty of notice.

Suggested ways to advertise recruitment within your practice catchment area:

- flyers
- practice waiting room, including electronic message board in reception
- practice newsletter and website
- social media
- practice open day or an open meeting
- ask staff to promote the group
- local community groups
- schools and local businesses
- local pharmacy and note on prescription slips
- local community newsletters
- receptionists raising awareness, and
- local press.

## ➤ Be representative and keep it diverse

Try to ensure membership is representative of your patients and aim to recruit as diverse a range of people as you reasonably can. To do this you will need to have a good understanding of your local community and think about how best to reach different groups.

Whilst every effort should be made to recruit and involve as diverse a group as possible, experience often shows how difficult it is to have a patient group that is truly reflective of the local population in terms of representation and diversity. Therefore it is important to have ways of ensuring all patients voices are heard and listened to whether or not people wish to join a Patient Participation Group.

Some suggested ways of doing this are:

- involve the whole of your patient community when recruiting and obtaining views, especially targeting groups of people not represented on the Patient Participation Group.
- use existing forums or groups (for example, local voluntary groups) to reach a more diverse group of people.
- where including users of a specific service would be beneficial, the Patient Participation Group could, on a temporary basis, involve individuals who do not wish to sit on the group permanently.

Recruiting people from 'hard-to-reach' or 'seldom heard' groups within society may require proactive effort. Some of these groups are listed below:

- those who do not use English as their first language
- people living in rural areas
- homeless people
- working people
- people living in residential care homes

- people with learning or physical disabilities, and
- people from deprived areas.

This list is not exhaustive. It is worth noting that local NHS Boards frequently carry out targeted work with specific groups that they find 'hard to reach' and may be able to recommend forums or other engagement methods. Likewise, the Scottish Health Council holds a database of a number of groups that fall under this category and would be happy to assist in promoting the Patient Participation Group to them.

## Section 3 – EARLY STEPS

This section of the guide will look at what to do in the early meetings of the group and set some ground rules for how to run the meetings.

### ➤ Write a working agreement/terms of reference

Developing a working agreement/terms of reference is an important step that can guide the group in the early stages and serve as a reminder of its purpose once it is up and running. This list may need to be amended from time to time and therefore the group might want to consider having this as a standing agenda item.

The document should identify:

- roles and remits - who should attend and what they should be doing.
- ground rules for taking part in the group.
- the purpose of the group - what are the aims and objectives?
- who the group reports to and how.
- a commitment by the practice to offer reasonable travelling and other expenses (Scottish Government Health Directorates guidance on volunteer expenses can be found at [www.sehd.scot.nhs.uk/mels/CEL2011\\_23.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2011_23.pdf) ).
- frequency of meetings.
- clear expectations for all.

It is important to include a statement emphasising that the Patient Participation Group is not to be used for pursuing individual personal complaints or issues and that there are other routes for people to give feedback, make comments, raise concerns or make complaints about NHS services.

**Why have a working agreement/terms of reference?** It helps bond people together and acts as a point of reference if things get difficult. Investing time and effort in preparing a good working agreement/terms of reference document can help to ensure the effectiveness of the group and pre-empt issues that might otherwise arise.

When the group first meets, they should write up a draft document for discussion and agreement. Experience shows this may take a few meetings to agree.

See appendix 1 for an example terms of reference/working agreement document.

### ➤ Ground rules

These are a useful way to ensure that meetings are properly run. Ground rules should be agreed at the earliest stages of the group and should be introduced at the start of each meeting as a reminder. Ground rules should be included as part of the terms of reference and will need to be continuously reviewed by the group.

Examples of essential ground rules would be:

- respect the views of others.
- the meeting is not a forum for individual complaints or personal issues.
- only one person speaking at a time.
- do not use jargon.
- we will stick to the agenda whilst starting and finishing on time.
- no mobile phones or disruptions.

It is a good exercise for the group to set their own ground rules; this way it's more likely that they will stick to them! It is also good practice to make round table introductions rather than presume everybody knows everybody else.

See appendix 3 for an example document.

## ➤ Agree chairperson and administration support

When nominating the chairperson, a group decision needs to be made on how they will be chosen and whether it should be a patient, GP or practice manager. The chairperson must be equipped to deal with controversial or delicate agenda items. This requires the ability to remain impartial and act in a diplomatic and sensitive manner where necessary.

The main role of the chairperson is to:

- organise and run the meetings
- ensure that the group is achieving its goals, and
- act as the official representative of the group.

Some groups have found that having a rotating chairperson gives everyone the opportunity to gain experience of this role. This helps to ensure everyone respects the chairperson and is aware of the importance of the role.

The main responsibilities of the chairperson are to:

- liaise with the administrator to agree arrangements, agendas and meeting dates
- ensure that each meeting is focused and does not get held up by irrelevant conversation
- act as a timekeeper for meetings ensuring reasonable time for each agenda item
- act as a facilitator during the meeting to encourage all members to get involved, and
- ensure all items on the agenda reach a conclusion giving a brief summary of key points and responsibilities to the group.

The administrator is responsible for:

- taking actions/minutes from the meetings
- supporting the chairperson to organise meetings, and
- maintaining membership lists.

As with the chairperson, this role can be carried out by patients, GPs or practice managers and again, this could be done on a rotating basis to keep it fair.

## ➤ Action plan

**Create an action plan** in the early stages to establish the group's goals. This can help group members to focus on their purpose and aims. The group and practice should discuss and agree short, medium, and long-term goals.

The following headings might be helpful to consider.

- Activity – what we will do.
- Outcome – what we want to achieve.
- Progress – what we have done so far.
- Deadline – when we want to finish.
- Evaluation – how well we did.

Each member of the group will have varying amounts of time which they can spend with the Patient Participation Group and various skills which can be utilised. Therefore, it is helpful to

have a range of projects and objectives which members can choose to work on in order to maintain their interest and maximise their potential and effect.

## ➤ Establish the experience of the group

This will establish the skills individuals have which may prove valuable for helping to create and maintain the group. In addition, if a practice in another area has an established Patient Participation Group, you could invite a member to come along and discuss what works well for them in order to share experience. Your local Scottish Health Council office can provide details of other Patient Participation Groups in your area.

## ➤ Meetings

**Location and timing of meetings** could affect attendance. Be sure to establish a convenient location and time for the meetings in order to accommodate as many people as possible as this will make development of the group more likely to succeed and ultimately be more effective. Be mindful of public transport to the venue and be sure to give the group advanced notice of meetings. Meetings should also be 'time limited', unless the group agree otherwise. This enables members of the group to understand their commitment time wise.

**Agendas:** It is essential to set an agenda before each meeting. This provides a goal for the meeting and also deals with standard issues like apologies and time and date of next meeting. Ensure adequate time is given to all items. Agree a system for setting agendas, for example who to send items to and by when. Try to keep meetings relatively short.

See appendix 4 for an example agenda.

**How to record the meeting:** Minutes which provide a summary of the discussion are the traditional way to take notes from meetings; however, shorter action points are becoming more popular. Action points allow group members to see at a glance, for example, what progress has been made at the meeting and who is responsible for what job.

See appendix 5 for an example of meeting action points.

## ➤ Feedback and communication

This is very important for the effective development of the group. Agreeing suitable methods for a two-way flow of information between patients, staff and the Patient Participation Group early on will help this become routine. One of the benefits of a two-way flow of information is that all those involved will feel empowered and valued.

Communicating information about the group's progress can be done in a variety of ways such as social media, newsletters, flyers or posters within surgeries.

An understanding of different communication methods for different groups of people may be advantageous so that implications of effective communication are overcome. Examples of this are:

- some people may have little knowledge of social media but would respond to direct mail or social clubs.
- isolated rural communities: many isolated rural communities have poor internet connection but close community resilience and often hold events and social gatherings.
- working people: rarely have the opportunity to attend events but may regularly use social media.

## Section 4 – KEEPING POSITIVE MOMENTUM

Once the Patient Participation Group is up and running it is important to keep the momentum going. Look at the short, medium and long-term action plans and decide on how to take this forward. Here are some suggestions that may help the group.

### ➤ **Remain focused<sup>5</sup>**

Once the group has set some objectives, it is important to keep track of them and keep working towards their completion. Once an objective is completed, it is always a good idea to set a new one as soon as possible to keep the momentum flowing. Ensuring that the group has objectives at all times can provide some really good motivation. This approach:

- maintains a sense of purpose for the members of the group
- gives everyone a role to play in the group, and
- lets prospective Patient Participation Group members see what they might be asked to get involved in.

### ➤ **Be open, honest, fair and constructive**

A Patient Participation Group works best when it works closely with the practice it serves. The Patient Participation Group and practice should be able to give one another constructive feedback and learn from each other.

- Share ideas for improvements in an agreed format for example in minutes of meetings, face to face, or by email.
- Always try to be constructive when presenting fresh ideas.
- Be honest about why certain ideas would improve things.
- Make fair decisions based on all relevant factors.

### ➤ **Recognise and reward success**

When the group has completed an objective or reached a significant milestone then it should celebrate that success. Recognising achievement will really help to keep the morale of the group high. Here are a few ideas which could be used:

- give credit to one another where it is due.
- design a poster to put up in the surgery to tell patients what has been achieved, and
- get in touch with the local newspaper<sup>6</sup> or TV station (STV has an online channel called STV local which is dedicated to local news stories) and share the story.

### ➤ **Many hands make light work**

Rather than assigning tasks to one individual, wherever possible try to assign tasks to teams of two or more people. This includes the Patient Participation Group chair and administrator.

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<sup>5</sup> NHS Norfolk. Patient Participation Groups (PPGs) [online]. 2010 [cited 2012 Jun 8]; Available from: <http://www.norfolk.nhs.uk/sites/default/files/A%20guide%20to%20setting%20up%20a%20PPG.pdf>

<sup>6</sup> National Association for Patient Participation (NAPP) Growing Patient Participation Communications Toolkit for Patient Participation Groups [online]. 2009 [cited 2012 Jun 8]; Available from: [http://www.growingppgs.com/fileadmin/user\\_upload/PDFs/Growing\\_Patient\\_Participation\\_communications\\_toolkit\\_for\\_PPGs.pdf](http://www.growingppgs.com/fileadmin/user_upload/PDFs/Growing_Patient_Participation_communications_toolkit_for_PPGs.pdf)

There are many benefits to working this way:

- if someone leaves the Patient Participation Group or is unable to attend a meeting then another person will know how much progress has been made on their task.
- two or more people working on one project will make it easier for them.
- people can share ideas and learn from each other.
- working within a group can help people to feel more confident.
- to make the most out of the team's abilities.
- it provides an opportunity for people to work closer together and build stronger working relationships.

### ➤ Further areas of work

**Healthcare challenges and activities**<sup>7</sup>: maintaining an awareness of the healthcare challenges and activity within the local community may help the group to come together to focus on a plan of work.

Current healthcare challenges may already be known by practice staff but it is always good practice to maintain a link with the local community so that the group are kept up to date with these. Examples of how to do this include:

- surveys
- patient feedback
- comment cards, and
- face-to-face contact.

In addition, the local NHS Board's Public Health Department may be a good contact to ensure that the group receives up to date information about local and national challenges.

**Attend community events** to promote the group and encourage membership. This can be used as an opportunity to carry out the examples above relating to local healthcare activity.

**A list of forthcoming campaigns** can be obtained from the local NHS Board's Health Improvement Team which may help the group to focus on specific health topics throughout the year.

**Setting tasks**<sup>8</sup> for group members could include, one member taking on the role of newsletter editor whilst another member may wish to take on the role of the group's information or publicity officer.

Other key roles, which members may be keen to take on, include chairperson, deputy chairperson or administrator. However, it is important to ensure that all members who take on such roles receive the necessary administrative support from the practice. To keep the momentum going, as previously stated, it is worth regularly refreshing these roles with new people in order to encourage new ideas to come forward.

**Training** should be sourced and offered to all group members as this may help to provide members with the necessary skills to be an effective member. It may also help members to build confidence to take on key roles or duties.

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<sup>7</sup> Patient Participation Groups: Getting Started The Royal College of General Practitioners Northern Ireland Patients in Practice Group 2011 <http://www.rcgp.org.uk/pdf/RCGP%20Booklet.pdf>

<sup>8</sup> NHS Norfolk. Patient Participation Groups (PPGs) [online]. 2010 [cited 2012 Jun 8]; Available from: <http://www.norfolk.nhs.uk/sites/default/files/A%20guide%20to%20setting%20up%20a%20PPG.pdf>

## ➤ Hold an open day

Consider holding an open day/evening to talk about the various issues relating to the practice and use this opportunity to promote the group (along with standard promotion activities - posters, website, on prescriptions etc). This may encourage new members to join and it could also be used to celebrate the achievements made by the group.

If there are a number of Patient Participation Groups within a particular geographical area, consider holding a regional or area networking event where representatives from each group could come together to share experiences, current practices and to build new relationships.

## ➤ Ongoing communication

Regular communication with members and the wider practice population will help to keep people informed of the group's activities. This in turn will help to keep the momentum going, maintain interest and attract new members. A variety of communication methods should be used to reach a wider audience, these include:

- leaflets and flyers
- newsletters
- social media sites
- minutes or action points from the meetings (which should be made available to anyone who wishes to see them)
- local press, and
- notice boards.

Group members may be keen to get involved in the development and maintenance of these. Displaying a poster within the practice is a good way to share with everyone the progress that has been made by the group. Posters should be refreshed on a regular basis to keep the momentum going.

## ➤ Take advantage of Scottish Health Council support

The Scottish Health Council has produced a Participation Toolkit, which contains a variety of tools for public engagement. Local office staff are able to offer support, guidance and advice around the use of these tools and other tools such as Visioning Outcomes in Community Engagement (VOiCE). Developed by the Scottish Community Development Centre, VOiCE is a planning and recording tool that can help to plan and record community engagement activities as well as the progress of the group.

Other areas of support include:

- sharing examples of best practice
- assisting with identifying gaps in the group's representation
- support to facilitate events and/or meetings
- assist with developing or updating working agreements/terms of reference, and
- help with networking.

In addition, the Scottish Health Council's electronic newsletter e-Connect highlights the latest policy and practice, research and resources in the field of participation. Subscription to e-Connect is available to all. To subscribe go to [www.scottishhealthcouncil.org/e-connect.aspx](http://www.scottishhealthcouncil.org/e-connect.aspx)

The Scottish Health Council's website contains a database of case studies which illustrate the approaches described in the Participation Toolkit. The Scottish Health Council has also

produced the Participation Standard which provides a way of measuring how NHS Boards ensure that people have a say in decisions about their care and in the development of local health services.

Details on all of the above methods of support can be found at [www.scottishhealthcouncil.org](http://www.scottishhealthcouncil.org)

### ➤ **Establish links with other relevant groups and networks**

When setting up the Patient Participation Group, it can be useful to contact other established Patient Participation Groups, as experienced groups may provide invaluable help, advice and support<sup>9</sup>.

Within the practice locality there may also be a number of relevant groups and networks that are already active, such as:

- youth groups
- Scottish Women's Rural Institutes (SWRIs)
- Community Councils
- British Legion
- locality planning groups/forums (Local Authority), and
- voluntary organisations and community groups.

Information about the many community groups that exist within the practice locality can be obtained from the local Council for Voluntary Organisations.

Going out to places where people meet to obtain their feedback can be helpful particularly where specific representation on the group is lacking. Existing groups that already meet locally could be used to ask for their opinions on issues relating to the practice.

Establishing links with local high schools and businesses may be beneficial in terms of obtaining feedback and raising the profile of the group. It may also be worth asking local businesses to promote the group on their website.

Local NHS Boards are a key point of contact as they will have a Patient Focus and Public Involvement (PFPI) Co-ordinator who may be particularly interested to hear about the group. They may also offer the group a number of opportunities to link in to various NHS Board committees that already exist.

The Scottish Health Council can advise of other relevant groups and networks that may be of interest to the Patient Participation Group. Partnership Forum may also offer an excellent opportunity for the group to promote itself, particularly if some of the PPF members already live within the practice's catchment area.

### **Where to get further support**

In addition to Scottish Health Council advice and support, the group may benefit from a variety of other local sources such as:

- local NHS Boards' Patient Focus and Public Involvement lead/team.
- the local Council of Voluntary Organisations office.

Another useful source of information is the National Standards for Community Engagement, produced by the Scottish Community Development Centre (SCDC). This and related documents can be found at <http://www.scdc.org.uk/what/national-standards/>

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<sup>9</sup> Patient Participation Groups: Getting Started The Royal College of General Practitioners Northern Ireland Patients in Practice Group 2011 <http://www.rcgp.org.uk/pdf/RCGP%20Booklet.pdf>

In addition, the National Association for Patient Participation (N.A.P.P.), is a UK-wide umbrella organisation for patient groups in primary care whose website [www.napp.org.uk](http://www.napp.org.uk) has a variety of regularly updated resources and examples of best practice for patient groups at all stages of their development.

A good place to start looking for advice and support is on the website of the local NHS Board. All NHS Boards should have a section on their website with information about how they involve people and/or support patient and public involvement.

Some NHS Boards offer funding for Patient Participation Groups so it is worth contacting the NHS Board's Patient Focus and Public Involvement team to see if the group can access this funding.

## Section 5 – REFLECTION

There is no right and wrong time to reflect on progress made. However, sometime in the near future, the group will want to evaluate its work and its effectiveness for the practice.

The Scottish Health Council has produced a toolkit on Developing a Patient Participation Group which can help and guide the group through the evaluation. The toolkit looks at areas such as involvement, planning, meeting the community need and sharing best practice to establish whether there are areas which need to be improved. It also highlights achievements so far and what the group would like to achieve in the future. The tool can be obtained from Scottish Health Council local offices and local staff will be happy to talk the group through this as it progresses.

At the outset, some of the issues the group may wish to reflect on are straightforward, and they will have probably been doing them already. Essentially the group should be considering what they have already achieved, what went well and what not so well.

The group should reflect on the members who have been recruited considering whether they are the right people, whether they are representative of the community, whether the recruitment process was done correctly and inclusively. The main thing is there is a group which can expand on its membership and the diversity of the group as it grows in confidence.

Consider whether the terms of reference and working agreement are correct. No group gets it right first time so the group can revisit this at a later stage. The main thing is that there is a working agreement/terms of reference in place so that people are clear about their roles and the functions of the group. Remember, this may take several meetings to get it right.

At this stage of the process remember to remain positive and recognise what the group has achieved so far due to the efforts of its members. Experience has shown that successful groups develop over time and learn as they progress. It is also worth remembering that what works for one group may not work for another. Even at this early stage if something is not working for the group, put it to one side and move on. This can be revisited later if necessary.

## References:

*Informing, engaging and consulting people in developing health and community care services*  
The Scottish Government 2010

[http://www.sehd.scot.nhs.uk/mels/CEL2010\\_04.pdf](http://www.sehd.scot.nhs.uk/mels/CEL2010_04.pdf)

*Growing patient participation Getting started – A step-by-step guide for PCTs to setting up a Patient Participation Group in general practice*

National Association for Patient Participation (NAPP) 2009

<http://www.napp.org.uk/gettingstarted.html>

*Growing Patient Participation Communications Toolkit for Patient Participation Groups*

National Association for Patient Participation (NAPP) 2009

<http://www.napp.org.uk/index.html>

*Patient Participation Groups (PPGs)*

NHS Norfolk 2010

[www.norfolk.nhs.uk/sites/default/files/A%20guide%20to%20setting%20up%20a%20PPG.pdf](http://www.norfolk.nhs.uk/sites/default/files/A%20guide%20to%20setting%20up%20a%20PPG.pdf)

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

NHS Milton Keynes 2009

[http://www.mkchs.nhs.uk/assets/\\_managed/editor/file/QMK/PPE/MK%20Patient%20Partnership%20Groups%20Guide.pdf](http://www.mkchs.nhs.uk/assets/_managed/editor/file/QMK/PPE/MK%20Patient%20Partnership%20Groups%20Guide.pdf)

*A Scottish Health Council report on improving quality through participation*

The Scottish Health Council 2011

[http://www.scottishhealthcouncil.org/publications/research\\_reports.aspx](http://www.scottishhealthcouncil.org/publications/research_reports.aspx)

*Guidance for setting up Patient Participation Groups in North East Essex*

North East Essex GP Commissioning 2011

<http://www.tollgatepractice.gpsurgery.net/Webdesk/documents/gpsTollgatepractice/Photos+and+Documents/Guidance+for+setting+up+PPG.doc>

*PCA(M)(2010)18 - Clinical and Staff Governance for General Practice in Scotland*

The Scottish Government 2010

[http://www.sehd.scot.nhs.uk/pca/PCA2010\(M\)18.pdf](http://www.sehd.scot.nhs.uk/pca/PCA2010(M)18.pdf)

*Patient Participation Groups: Getting Started*

The Royal College of General Practitioners Northern Ireland Patients in Practice Group 2011

[http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/\\_media/Files/Policy/A-Z%20policy/RCGP%20Booklet.ashx](http://www.rcgp.org.uk/policy/rcgp-policy-areas/~/_media/Files/Policy/A-Z%20policy/RCGP%20Booklet.ashx)

## **Example terms of reference/working agreement document**

NB: we have combined these two into one document for ease

**NOTE: This document is not prescriptive and sections should be adapted as required to suit each Patient Participation Group**

### **1. INTRODUCTION**

#### **1.1. Purpose of the document**

The purpose of this document is to set out the scope of the Patient Participation Group and provide guidance on how the group will function.

#### **1.2. Underlying principles of the group**

The Patient Participation Group will promote positive change in health services for the local community by adopting the following key principles:

- openness
- honesty
- transparency
- listening to one another and doing what we say we will
- agreed and consistent ways of giving and receiving feedback
- learning from each other and respecting each other's contributions, and
- joint commitment to ongoing health improvement.

#### **1.3. Scope of the group**

- Create a Patient Participation Group that is representative, equitable and, where possible, covers all sections of the practice population.
- Discuss and agree action plan with the practice. The plan should contribute to practice decision making and service provision and development.
- Provide feedback on patients' needs, concerns and interest and challenge the practice constructively whenever necessary.
- Assist the practice and its patients by arranging voluntary groups/support within the community.
- On behalf of the practice, communicate information about the community that may affect healthcare.
- Give patients a voice in the organisation and delivery of their healthcare.
- Promote good health and higher levels of health literacy by encouraging and supporting activities within the practice and promoting preventative medicine.
- Assist in the provision of secondary healthcare and social care locally.
- Monitor services e.g. hospital discharge.
- Liaise with other Patient Participation Groups in the area.
- Be offered the opportunity to be involved with the commissioning of services within the practice locality.

Note: The group is not a channel for raising individual complaints. The practice has a formal complaints procedure for individual complaints. Also, individual members of the Public Partnership Group must not act on behalf of the group, except where agreed by the majority of members.

## **2. ROLES, RESPONSIBILITIES AND CODE OF CONDUCT**

### **2.1. General membership**

- Application to the Patient Participation Group will be open to any patients of the practice.
- The term of membership will be for three years in the first instance.
- Individual members contact details will be stored on a database and will be kept in line with data protection guidelines.
- Any potential conflicts of interests should be declared by members.

### **2.2. Expected outcomes**

- Mutually enhanced health provision.
- Better informed public.
- Improved communication between practice and its patients.
- Increased public representation on decision-making bodies for health services.

### **2.3. Selection of chairperson**

- Selection Process: Nominations will be taken and in the event of more than two nominees for the positions then members will blind vote. The chairperson position will be awarded to the nominee with the highest number of votes.
- Term of Office: The length of the term of office to be agreed by the members by democratic process. The group may also ask the chairperson to step down before their term ends where the agreed code of conduct/working agreement has been breached.

### **2.4. Code of conduct**

- It is important that members can contact each other in between meetings. This will be done by providing members with each other's contact details, as agreed by each individual.
- The pace of the discussion/activity should be determined by the group.
- It is recognised that members will be from all walks of life and therefore experiences and subsequent views will be varied across the group. Each member is expected to respect the views of other members, while accepting they may not necessarily agree with these.
- The members need to recognise the importance of fostering an environment where individual members feel confident in expressing their own views, in the knowledge that they will be listened to.
- Informal chatting before and after a meeting is a useful way for members to get to know one another, however, when a meeting is in progress this is deemed unacceptable.
- Members need to appreciate that sometimes, for a variety of reasons, members are not able to actively contribute to discussions. Sometimes people will need to take time out of a meeting and this is acceptable.

### **3. MEETING ARRANGEMENTS**

#### **3.1. Frequency**

- This will be as required and agreed by the practice and the group.

#### **3.2. Duration**

- The meeting will be set for a maximum two-hour period unless otherwise agreed.

#### **3.3. Times**

- As agreed by group members.

#### **3.4. Venue**

- The meetings will be held at the practice.

#### **3.5. Agenda**

- The agenda and previous minute should be received two weeks in advance allowing time for the members to receive and read the information.
- Any items to be included in the agenda should be sent to the chairperson and administrator in advance of the agenda being issued.

#### **3.6. Meeting chair arrangements**

- It will be the responsibility of the chairperson to chair the meeting in a responsible and accountable fashion with the interests of the group in mind.
- With the full knowledge of its members, respond to letters and invitations on behalf of the group and sign off on any official correspondence on behalf of the group.
- Liaise with the group administrator to compile agendas and check minutes of meetings before distribution.

#### **3.7. Minute/Action points and reports**

- Key points, agreed actions and full names of responsible people will be the agreed approach.
- Minutes will be taken by the person providing administration support to the group.
- Information presented in minutes and reports is expected to be understandable and as far as is possible, jargon free.

### **4. ACCESS TO INFORMATION AND APPROPRIATE USE OF INFORMATION**

- 4.1.** Members will ensure proper use and handling of information e.g. confidentiality, data protection etc. This will be undertaken in accordance with the Data Protection Act 1998.
- 4.2.** The practice needs to support the members with the provision of information and this will include information being available in different formats e.g. websites etc.
- 4.3.** Where information is deemed to be confidential, the practice should make this known to the members.

### **5. SUPPORT FOR THE PATIENT PARTICIPATION GROUP**

#### **5.1. Administrative support**

Administrative support should ideally be provided by the practice and this function should:

- be the point of access and focus for communications – this will include access to the members by members of the public.
- produce the agreed agenda and minutes.
- arrange meetings (venue, refreshments etc).
- process claim forms.
- ensure web-based information is maintained and kept up to date.
- collect and disseminate information as and when required.
- attend meetings to take minutes.

## **5.2. Financial support**

- Financial support is to include all administration, publicity development and training costs. All barriers to participation should be removed.

## **5.3. Training and development for Patient Participation Group members**

- The practice needs to respond to the identified development needs, which the members may have.

## **6. COMMITMENT TO EQUALITY AND DIVERSITY**

- 6.1.** The practice will encourage representation of people from diverse backgrounds, but where this is not possible strategies will be put in place to support communication and participation through links with established community groups in the practice locality.

## **7. REVIEW OF THIS AGREEMENT**

- 7.1.** The agreement will be a standing agenda item.

*Reference used:*

*“Guidance for setting up Patient Participation Groups in North East Essex”, North East Essex General Practice Commissioning*

## **Sample role and responsibilities for members**

This document is designed to help members of Patient Participation Groups understand what is expected of them should they choose to become a member of their local PPG. It is important for both the practice and the PPG members that expectations are clearly set out and are agreed between both parties.

### **Role**

Patient Participation Group members will:

1. Contribute views and give advice to the practice on how to communicate and engage with the patients the practice serves.
2. Have an opportunity to share their opinions on proposed changes to the way that the practice works or provides additional services.
3. Highlight any healthcare issues/priorities or concerns within the local community that they feel are relevant to the work of the practice.
4. Be asked to play a part in any public engagement activities carried out by the practice for example by manning a stall at a local community gala.
5. Use their skills to help in the work of the PPG and practice for example by using their IT skills to help design a poster.

### **Responsibilities**

Patient Participation Group members will:

1. Attend meetings of the PPG. If the PPG member cannot attend a meeting then they should put their apologies into the chair or administrator prior to the meeting.
2. Play an active part in the group and take on roles such as: chairperson or administrator/note taker.
3. Respect confidentiality.
4. Not use the PPG as a forum for complaints or to raise personal issues which are not of relevance to the practice or the PPG.
5. Report back on any tasks that they have undertaken on behalf of the PPG.

### **Contact with the media**

If a PPG member is contacted by the media then they should refer them to the practice.

PPG members should not speak to the media on behalf of the PPG without first agreeing this with the rest of the PPG members and the practice. Of course PPG members are free to talk to the press as long as they make it clear that they are expressing their own opinions and not that of the PPG or the practice.

### **Conflict of interest**

In certain situations PPG members may feel that they have a conflict of interest with the topic being discussed and can not give an unbiased opinion. In these cases PPG members are expected to raise the conflict and will not be entitled to vote on any decisions to be made.

## **Expenses**

PPG members may be entitled to out of pocket expense incurred while carrying out tasks on behalf of the PPG. The PPG and the practice will decide together when this would be appropriate.

More information on expenses can be obtained by contacting the practice manager, the health board or by checking on the health board's website.

## **Term of membership**

Each PPG member will be asked to sign up to serve a term of 2–3 years on the group. This is to ensure that all patients of the practice get the opportunity to join the PPG. PPG members who have completed their term will be allowed to apply for an extension if they would like to stay with the group and if no one else has registered an interest.

## **What you'll bring to the PPG**

There is a great range of things that PPG members can bring to a group such as:

- Enthusiasm
- Skills & Abilities
- Opinions
- Experience
- Ideas

You will be able to play a part in some of the decisions that are being made by the practice. This will help the practice to make decisions that are based on the needs of their patients and will hopefully ultimately lead to the improvement of services for all patients served by the practice.

You will help the practice communicate with its patients and build a relationship that goes beyond the traditional doctor and patient relationship. With your help your practice will be able to respond to the wider healthcare needs of the community they serve and will be able to do even more to improve the general health of all of their patients.

## Example Ground Rules

- **Meetings should start on time, and keep to time, unless under exceptional circumstances**
- **Clear objectives should be set for each session with clarity on who should attend**
- **Meetings should be chaired effectively**
- **Everyone is responsible to adhere to and promote the ground rules**
- **Everyone's opinions should be heard and respected, but it is OK to disagree**
- **Only interrupt for the purpose of clarification**
- **Everything discussed during the meeting remains confidential unless agreed otherwise**
- **If jargon or acronyms are used they should be fully explained**
- **Everyone is responsible for ensuring the success of the meeting**
- **Everyone is responsible for removing papers/documents at the end of the meeting, to ensure confidentiality**
- **Actions should be recapped, recorded and circulated for implementation as soon as possible after the meeting**
- **Meetings should be evaluated for learning and development**

## **PATIENT PARTICIPATION GROUP**

**Meeting to be held on xxxxxxxxx in xxxxxxxxxxxxxx  
From xxxxxxam/pm – xxxxxxam/pm**

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### **AGENDA**

1. Welcome and apologies
2. Membership of group (1<sup>st</sup> meeting)
3. Terms of Reference (1<sup>st</sup> meeting)
4. Minutes of previous meeting held on xxxxxxxx (subsequent meetings)
5. Matters arising
6. SUBJECT 1
7. SUBJECT 2
8. SUBJECT 3
9. SUBJECT 4
10. AOCB
11. Confirm date and time of next meeting

**ACTION POINTS UPDATE**  
**Patient Participation Group meeting held on xxxxxxxxxxxx**

MEETING	REF.	HEADING	ACTION POINT	LEAD PERSON	Action by date	OUTCOME

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