

# Patient and public involvement: a tool kit for GPs

Engaged and involved patients are key to achieving a healthcare system that is responsive to their needs and values. The BMA PLG (patient liaison group) wants to promote PPI (patient and public involvement), also known as PPE (patient and public engagement). GPs and practice managers can use this tool kit to involve your patients and the public in healthcare planning and delivery.

PPI is defined by the NHS as the 'active participation of citizens, users and carers and their representatives in the development of healthcare services and as partners in their own healthcare'

It is Government policy for people to be involved in the commissioning, planning, designing, delivering and improvement of healthcare services.

The Department of Health says: 'Effective patient and public involvement is fundamental to an NHS based on choice, responsiveness and equity. Delivering and designing health services around the needs of patients is key to the modernisation of the NHS and is integral to improving patients' experiences of health services.'

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## Why is PPI important?



PPI (patient and public involvement) gives people the chance to:

- Influence their own care and treatment
- Have a say in the way services are planned and run
- Help bring about improvements to the way care is provided.

## Who should be involved?

- People who use, or have used, health or social care services
- Carers and families
- Healthcare professionals
- Members of the general public
- Organisations that represent users of NHS services and community groups.

## Why should patients be involved?

- Patients are central to everything we do
- To improve clinical care and the overall experience patients receive
- Listening to patients will help deliver a better service
- Involving patients in their own care will help to reduce health inequalities
- It is government policy to involve patients and the public in the planning, monitoring and development of health services.

## What are the benefits of PPI?

There is clear evidence that PPI can make real, constructive changes to the provision of services, aiding the responsiveness of practices and providing services that truly reflect what patients want and need.

PPI also plays a key role in encouraging healthier communities, through the provision of information, advice and support to help local people lead healthier lives.



There are many benefits to involving, consulting and actively listening to your patients, including:

#### **Benefits for patients**

- Improved healthcare
- High-quality, patient-focused services and care
- Better informed access to care
- Clearer understanding of rights and responsibilities
- Stronger relationships between patients and healthcare professionals
- Clear information about care pathways
- Ability to influence service delivery and future service provision
- Involvement in and an ability to influence commissioning decisions.

#### **Benefits for doctors**

- A greater understanding of what your patients want, so you can focus on what matters to them
- An opportunity to celebrate success in all aspects of patient experience and involvement
- Improved reputation because patients will have a positive experience
- Improved care and services will mean your practice/clinic will be patients' first choice for care and treatment
- Understanding current problems in care delivery and services
- Feedback will inform the continuous improvement and redesign of services
- Delivering NHS values
- Enabling public accountability
- Efficient use of resources
- Contributions to effective clinical governance
- Making services appropriate.

#### **Benefits for the NHS**

Greater openness and accountability in the NHS and involvement of the public should help to create a better understanding of complex NHS and health issues. Effective public consultation and engagement can help to strengthen public confidence in the NHS and may help to achieve a more appropriate use of services and a better understanding of the reasons for planned changes to services.

#### **Benefits to society**

When people are involved in and can influence decisions that directly affect their lives, their self-esteem and self-confidence increases and this in turn improves health and well-being. There is growing evidence that having strong social networks and cohesion benefits health. Involvement in discussions about health and health services can help to encourage this social cohesion within communities.

# Your PPI toolkit

Levels of involvement (based on the Welsh Assembly Signposts Document)

## How can patients and the public get involved?

PPI has two levels:

- Individual – the extent to which patients and carers can have a say in their own care and treatment and share in decision-making about options open to them
- Collective – how patients, carers and the public can influence wider service delivery, policy and planning.

PPI may mean inviting one person to join a committee or active outreach to a community.

Please note this list is not exhaustive.

## Patient participation groups

### Patient participation groups in primary care

PPGs (patient participation groups) offer GPs the opportunity to involve their patients in the running of their practices. Doctors, practices or patients can initiate a PPG.

This resource provides practical advice on setting up and running a successful PPG, including:

- Why PPGs are beneficial
- How to set up a PPG
- How to run a PPG
- How to sustain a PPG.



## Patient participation directed enhanced service (DES) for GMS contract

Directed enhanced services are special services or activities provided by GP practices that have been negotiated nationally. Practices can choose whether or not to provide these services. The patient participation DES aims to promote the proactive engagement of patients through the use of effective PPG and to seek views from practice patients through the use of a local patient survey.

## Virtual patient groups

Effective and manageable patient participation can be achieved through a virtual group – an email community that they consult on a regular basis but which does not have regular face-to-face meetings. Virtual groups are easy to recruit to, easy to manage and representative of diverse populations.

# Planning your approach

There are six fundamental steps to planning PPI:

### 1. Establish a planning team

- Gather together a small team of people who are important to the exercise
- Be clear about the difference between working for and working with patients and the public
- Be clear about the different possible purposes of collective involvement
- Make sure there are adequate resources including money, time and people – skilled staff and engaged participants are needed.

### 2. Be clear about what is involved

- Are the objectives clear?
- What information is required?
- How is the information going to be used?
- What resources are available?
- Who will be involved?
- Who needs to be informed and who is likely to be affected by the issue under consideration?
- What method will be used?
- What can realistically change, what is not negotiable and why?
- How will the team be prepared?

### 3. Choose the right approach

- Your method of consultation should be suitable for both your purpose and your target audience
- Involvement is a means of improving services, not a problem to be solved
- Ensure commitment and leadership from the board, the chair, the chief executive, directors and clinical leaders
- Support staff and equip them with the necessary skills.

### 4. Involve people

- Create opportunities for people to be involved
- Find out how people prefer to be involved
- Reach out to people whose voices are seldom heard, such as homeless people
- Share the information and knowledge you have so people can understand what the real issues are
- Make it clear what you are doing and why, including what you can and cannot change
- Make it clear that people's views will feed into decision-making processes
- Ensure patients and the public have the support they need to get involved.

## 5. Communicate your plans and prepare your team

- The importance of good communication cannot be overestimated
- Consider how you will communicate your plans to everyone involved and throughout the organisation.

## 6. Evaluation

- Consider and plan how you will evaluate the process and provide feedback to all involved
- Find out more about evaluating PPI.

## Pitfalls

- It is difficult to ensure that information from PPI work is available early enough in decision-making processes
- Lack of resources for PPI
- It may be difficult to reconcile patient and public views and priorities with NHS priorities
- Lack of PPI knowledge and skills
- Executive-level culture – PPI may not really be supported or taken seriously
- Difficult to engage beyond the 'easy to reach' patients and public
- Not having the capacity to undertake the scale of PPI needed
- Conflict of patient/public view with clinical view
- Lack of effective systems to track PPI activities.

Successful PPI requires accurate and useful information from participants. Recruiting new members is one of the most challenging aspects of PPI – in particular, ensuring that the group represents the diversity of the local community and reflects a range of views.

## How can I attract new members?

- Hold an open evening or other event where patients and the public can find out about what PPI is and how it works
- Publicise PPI events and call for members through local media, posters and leaflets
- Target specific individuals to invite, particularly those in under-represented groups.

You may find it difficult to set up a group that exactly reflects the demographics of the local population, and volunteer roles tend to attract those who have a certain level of confidence and free time, and have flexibility about working and earning money.

## How can I maximise participation?

- Be proactive and get out into the community to canvass opinions
- Target certain groups of people not represented in the group to find out what they think
- Approach certain representatives to join the group for a short time or for a specific purpose
- Make sure that you try to contact a diverse range of people
- Contact organisations that represent users of NHS services and community groups.

## To get the best out of your PPI project, be sure to involve a range of people such as:

- Children and young people
- Older people
- Refugees
- Asylum seekers
- People with disabilities for example, people with sight impairment, people who use mental health services and people with learning difficulties
- Carers
- Partners
- Minority ethnic communities and/or people whose first language is not English

- People in custody – prison population
- Members of the 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 attract and design the activity accordingly
- Use language appropriate for the group and make it jargon free. When meeting people with disabilities, remember to talk to, and look at, the person not the advocate or supporter who may be present
- Provide refreshments
- Choose a suitable venue for the group
- Consider timing
- Work with existing groups and voluntary organisations
- Link in with issues of interest to your group
- Always feedback
- Use an informal approach and reassure participants that their involvement will be confidential, when appropriate

Find out how you can encourage participation among these groups using our pdf checklist.

## Ethics

Ethical issues that you will need to keep in mind when involving patients and the public include:

Individual	Explain exactly what you would like people to get involved in and assure them that they are free to withdraw at any time
Information	Provide information about why you are doing the work, the subject you are working on, what you would like participants to do, and what you plan to do with the information they give you
Confidentiality	Make it clear if information will be treated as confidential or anonymous and explain any circumstances in which exceptions may need to be made
Time to ask questions	Give the respondent time to ask questions and seek clarification
Documenting information	When recording what people say, try to capture it in their own words.

A patient and public involvement consent form template can be downloaded [here](#).

### Do you need ethical approval?

It is very important that patient involvement is implemented well and that patients' well-being and dignity are preserved. At present, there is no national framework for PPI governance. Normally, PPI work involves asking opinions or gathering feedback about the patient experience and as such does not require ethical approval. If in doubt, consult your local research ethics committee.

## How to ensure your PPI is effective

Throughout the process of PPI it is important to ensure that all participants are:

- Actively involved at every stage of the process and are kept informed of progress achieved
- Informed about action points and next steps taken, to demonstrate how PPI is influencing service change on an ongoing basis.

### Presenting your results

Remember your audience when presenting your results. Different audiences require emphasis on different points. Results can be presented as:

- A report based on the raw data
- Short newsletters and factsheets for patients and staff
- Posters for the GP surgery or clinic
- Presentations in appropriate meetings or forums
- An item in the local media
- An item on your website.

### Sharing your outcomes

Your outcomes should be available to everyone to access, specifically:

- Everyone who was involved in the consultation process. Don't forget to advise them of subsequent actions taken in order to demonstrate genuine commitment to PPI
- Patients and public involved in the consultation
- Managers and staff within the primary care organisation
- Directors of trusts, chief executives and boards.

## Evaluating your PPI

Plan how you will evaluate your PPI at the very earliest project planning stage. By carrying out an evaluation you will be able to assess whether your original aims and objectives defined during the planning stages of the process have been achieved. Evaluation should be an integral part of all involvement work, it can continuously inform planning and action. It is an important process to help establish how appropriate and useful the method was and to ascertain whether it and the resulting actions had a positive impact on the service.

### Framework for evaluating a PPI project

#### 1. What was your primary aim?

- Did you achieve this aim?

#### 2. What methods did you use?

- Were the methods used adequate to achieve your aims?
- What were the facilitators and barriers and how did context affect the initiative?

#### 3. Participants

- Were the participants representative?
- Were the participants proactive?
- What did the participants think of the process?

#### 4. Impacts

What impact did it have on:

- services
- patients involved
- patients receiving services
- staff
- Was the information collected used to inform service changes or planning?
- What lessons can be learnt for ongoing patient and public participation exercises?

## References

National Association for Patient Participation. *Communications Toolkit for Patient Participation Groups*.  
[www.napp.org.uk](http://www.napp.org.uk)

Picker Institute Europe (2009) *Patient and Public Engagement: The Early Impact of Word Class Commissioning*, Picker Institute Europe, Oxford

Royal College of General Practitioners: Primary Care Federations Toolkit: Involving patients and the public  
[www.rcgp.org.uk](http://www.rcgp.org.uk)

## Further information

### **The National Association for Patient Participation (NAPP)**

NAPP's ([www.napp.org.uk](http://www.napp.org.uk)) role is to promote patient participation and to support new Patient Participation Groups to get started and share good practice.

### **Involve**

Involve ([www.involve.org.uk](http://www.involve.org.uk)) is a national advisory group that supports greater public involvement in the NHS, public health and social care research.  
INVOLVE is funded by the National Institute for Health Research.

### **Improvement Leaders' Guide to involving patients and carers**

([http://www.evidenceintopractice.scot.nhs.uk/media/135286/involving\\_patients\\_and\\_carers\\_guide.pdf](http://www.evidenceintopractice.scot.nhs.uk/media/135286/involving_patients_and_carers_guide.pdf))

The guide shows how easily healthcare processes can be improved with a patient focussed approach. The methods and models used are illustrated with short case studies.

### **Trust Me I'm A Patient**

A patient and public involvement role-play game, produced by the Department of Health. The aim of the game is for participants to consider how patients and the public are involved in service changes.

### **The Quality of Patient Engagement and Involvement in Primary Care**

This report shows the result of a review the Picker Institute carried out on the quality of patient engagement in primary care and how to measure it, and developments in patient involvement in primary care.

([http://www.kingsfund.org.uk/sites/files/kf/field/field\\_document/patient-engagement-involvement-gp-inquiry-research-paper-mar11.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_document/patient-engagement-involvement-gp-inquiry-research-paper-mar11.pdf))

### **Developing A Stronger Local Voice**

This Department of Health (DH) report from 2006 sets out the Government's plans for the future of patient and public involvement in health and social care.

### **Other reports from the Department of Health**

Department of Health (2005) *Creating a Patient-led NHS – Delivering the NHS improvement plan*

Department of Health (2004) *The NHS Improvement Plan – Putting people at the heart of public services*

Department of Health (2004) *Getting Over the Wall – How the NHS is improving the patient's experience*

Department of Health (2003) *Strengthening Accountability – Involving patients and the public: practice guidance*. Section 5 sets out helpful guidelines and techniques for effective engagement.