Patient and public involvement – a toolkit for doctors

June 2011

Introduction

The BMA's Patient Liaison Group (PLG) believes that patient and public involvement (PPI) – also increasingly referred to as patient and public engagement (PPE) – is key in achieving a health care system that is responsive to patient needs and values.

The NHS defines PPI as the active participation of citizens, users and carers and their representatives in the development of health care services and as partners in their own health care.

The Government's widespread commitment to involving people in their own health care and in the commissioning, planning, designing, delivering and improvement of health care services has become a key element of policy.

This toolkit has been developed to provide guidance to General Practitioners (GPs) and Practice Managers on how to effectively involve patients and the public in healthcare planning and delivery.

> "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."

Department of Health

Why PPI is important?

What is patient and public involvement?

Patient and Public Involvement (PPI) 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 are patients and the public?

- People who use, or have used, health or social care services.
- Carers and families.
- Healthcare professionals.
- Members of the general public.
- Organisations which 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.

Patients and the public should be involved 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.
- Clarity of understanding of rights and responsibilities.
- Building strong relationships between patients and healthcare professionals.
- Clear information about care pathways.
- Ability to influence service delivery and future service provision.
- Involved in and an ability to influence commissioning decisions.

Benefits for doctors

- A greater understanding of what their patients want, so they can focus on what matters.
- An opportunity to celebrate success in all aspects of patient experience and involvement.
- Improved reputation through recognition that patients will have a positive experience.
- Being the patient’s choice for care and treatment.
- Understanding of current problems in care delivery and services.
- Informed continuous improvement and re-design of services.
- Delivering the NHS values.
- Enabling public accountability.
- Efficient use of resources.
- Contributions to effective clinical governance.
- Service appropriateness.

Benefits for the NHS

Greater openness, accountability and involvement of the public should all 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 is likely to have other benefits, for example, in helping 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 which 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

How can patients and public get involved?

There are two levels to PPI:

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

PPI is on a sliding scale – from having one person on a committee, to active outreach.

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

	Information	Feedback	Influence
Individual	Information to patients and carers about treatments and service: • Patient leaflets • Service prospectus • Patient held records • Internet provision • Access to patient correspondence	Patients can feed back on their own care and treatment, and raise issues of concern: • Individual complaints • Patient feedback • Comment cards • Patient diaries • Suggestion boxes • Compliments • Telephone surveys • Postal surveys	Shared decision making between patients, carersand professional: • Support to individuals • Advocates • Interpreters • Customer care
Collective	Information to the wider public about how well the organisation is doing: • Annual reports on PPI • Strategy for PPI • Annual plans • Performance information • Clinical governance reports • Press and media publicity	Patients can feed back on various issues and raise issues of concern: • Patient's panel • Complaints monitoring • Patient's surveys • Focus groups • Wider consultation about health needs and priorities • Internet discussion • Existing patient user groups	Involvement in policy and planning: • Citizens' juries • Stakeholder conferences • Local healthy alliances • Priority setting • Partnership forum • Lay representation on NHS bodies • Lay role in clinical governance • **Patient Participation Groups** • Public meetings

Please note this list is not exhaustive.

Patient participation groups

Patient participation groups in primary care

Patient participation groups (PPGs) offer GPs the opportunity to involve their patients in the running of their practices. Doctors, practices or patients can initiate a PPG. Get 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. Virtual groups are easy to recruit to, easy to manage and representative of diverse populations.

The Department of Health commissioned a 'Getting Started Guide' to help practices set up virtual Patient Groups. It contains a few simple tools that practices can use at the various stages of setting up a PPG.

Planning your approach

There are six fundamental steps to planning PPI:

1. Establish a planning team

- Create 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 participants engaged in PPI.

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 match 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.

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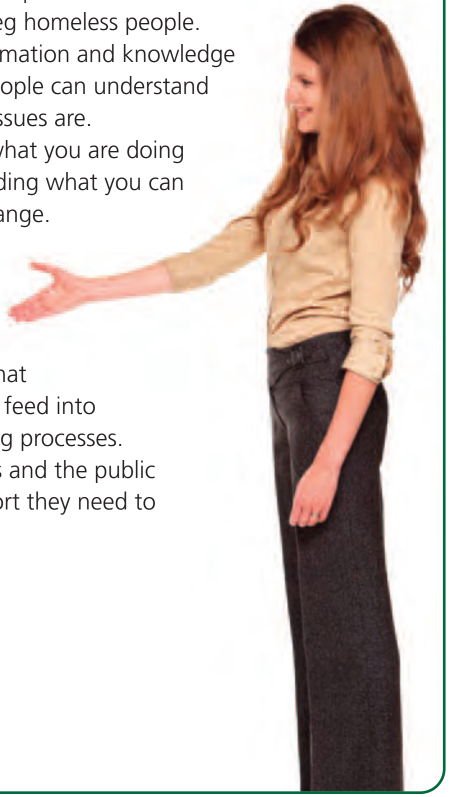
Planning your approach contd

4. Involve people

- Promote opportunities for people to be involved.
- Find out how people prefer to be involved.
- Reach out to people whose voices are seldom heard eg 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 their 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 over-estimated.
- 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

- Difficult to ensure that information from PPI work is available early enough in the decision-making processes.
- Lack of resources for PPI.
- Difficult to reconcile patient and public views and priorities with NHS priorities.
- Lack of PPI knowledge and skills.
- Executive-level culture – PPI isn't really supported or taken seriously.
- Difficult to engage beyond the 'easy to reach'.
- 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.

Recruiting participants

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 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, and distribute posters and leaflets.
- Target specific individuals to invite, particularly 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 that 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 on 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 who 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.
- Gay, lesbian, bisexual and transgender communities.
- Homeless people and travelers.
- Faith communities.

Tips for successful involvement

- Go to where your audience is.
- Think about who you want to attract & design the activity accordingly.
- Use language appropriate for the group (jargon free). 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.

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

Ethics

This section highlights the key ethical issues that you will need to keep in mind when involving patients and the public.

Individual	You will need to be clear with people exactly what you would like them to get involved in and explain that they are able to withdraw at any time.
Provide information	About what you would like participants to do, why you are doing the work, the subject you are working on, 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 exceptions you may need to make.
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.

Download a patient and public involvement consent form template.

Do you need ethical approval?

It is very important that patient involvement is implemented well and that patients' well being and dignity are defended. At present, there is no national framework for PPI governance (including ethical committee requirement). Normally, PPI work involves asking opinions or gathering feedback about the patient experience and as such does not require ethical approval. However, consult your Local Research Ethical Committee (LRC) if in doubt.

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 on-going basis.

Presenting your results

Remember your audience when presenting your results: different audiences require emphasis on different points!

- Prepare a report based on the raw data.
- Short newsletters and factsheets for patients and staff.
- Posters.
- Presentations in appropriate meetings or fora.
- Use the local media.
- Publish on your website.

Sharing your outcomes

Your outcomes should be available to everyone to access and 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 organisations.
- Directors of Trusts, Chief Executives and boards.

Evaluating your PPI

The plan for the evaluation should come in at the very earliest project planning stage. By carrying out an evaluation of your involvement work 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. Aims
- What was your primary aim?
- Did you achieve this aim?

2. Methods
- 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 on-going patient and public participation exercises?

Did you find this resource useful?

Please do provide us with any comments you may have on the toolkit at info.plg@bma.org.uk

References:

Communications toolkit for Patient Participation Groups
www.growingppgs.com

Patient and Public Engagement – The early impact of World Class Commissioning
www.pickereurope.org

Evidence-Based Digest
www.nhscentreforinvolvement.nhs.uk

Royal College of General Practitioners: Federations Toolkit – Involving patients and the public
www.rcgp.org.uk

Read further information

The National Association for Patient Participation (NAPP)

NAPP's role is to promote patient participation and to support new Patient Participation Groups to get started and share good practice.

INVOLVE

Involve is a national advisory group which supports greater public involvement in NHS, public health and social care research. INVOLVE is funded by the National Institute for Health Research.

Tools and techniques for involving patients, users and carers

A toolkit produced by the Modernisation Agency's, Clinical Governance Support team provides a brief overview of some of the techniques which have been successfully used for involving patients, carers and other users. The toolkit can be accessed from:

Improvement Leaders' Guide to involving patients and carers

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

Department of Health. (2006). Developing a stronger local voice

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

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.