Background

Introduction from Martin Caple, Chair, Joint Health and Social Care Regulators’ Patient and Public Involvement Group (PPI Group)

Our PPI Group was set up in January 2005. It’s a forum for the UK regulators of health and social care professionals to share ideas and promote good PPI practice. From the outset, all UK regulators expressed their commitment to embedding PPI within their work.

One of the first projects completed by the PPI Group was the publication, in February 2006, of a Handbook on PPI Good Practice. This current publication is the third edition of the Handbook.

Since 2006, health regulators have acquired more experience in achieving public and patient involvement. To capture and reflect this, we’ve added several case studies in Appendix 7 of the Handbook. We’ve also included project leads' contact details so any member of staff embarking on a project that would benefit from PPI can, if they wish, discuss their plans informally with them and exchange ideas.

I hope the Handbook continues to provide helpful guidance to our staff and Council members. I’d be very interested to receive feedback about it, so please take a moment to complete and return the form on page 89.

Martin Caple
Chairman, Joint Health & Social Care Regulators’ Patient and Public Involvement Group
capleh@aol.com

PPI Group member organisations

General Chiropractic Council www.gcc-uk.org
General Dental Council www.gdc-uk.org
General Medical Council www.gmc-uk.org
General Optical Council www.optical.org
General Osteopathic Council www.osteopathy.org.uk
General Social Care Council www.gscc.org.uk
Health Professions Council www.hpc-uk.org
Nursing & Midwifery Council www.nmc-uk.org
Pharmaceutical Society of Northern Ireland www.psni.org.uk
General Pharmaceutical Council www.pharmacyregulation.org

The Council for Healthcare Regulatory Excellence www.chre.org.uk
attend meetings of the PPI group as an independent observer.

Handbook originally compiled by Lindsay Mitchell, Prime Research & Development
About the PPI good practice handbook

Who and what is the handbook for?

The Handbook is for the staff and council members of the UK’s regulators of health professionals. It is a practical guide for those who want to find out what Patient and Public Involvement (PPI) is and how to achieve it. The PPI Group reviews the Handbook regularly so that it remains up to date and relevant.

What's in the Handbook?

The Handbook explores the ‘theory’ and values underpinning PPI. It contains practical suggestions on when, and how, to achieve particular outcomes. Lists of PPI toolkits produced by other organisations and consultancy and training organisations are appended, as is a summary of the PPI mechanisms in the four UK countries. It also contains electronic links to reference documents and websites. For the first time we have published case summaries of some PPI activities of the UK health regulators.

The Handbook is published in electronic format only.

Where did the information come from?

We have used existing information available on the Web. Much has been written about PPI and it is not our intention to reinvent the wheel. So, besides drawing the information together into a single source document and adding case studies, no new information has been developed in this work. Similarly, no guarantee can be given about the quality of information, organisations or services that are referenced in this handbook.

Tell us what you think

We would value your opinion on how to make this Handbook better. We'd like to know which parts of the Handbook you find helpful and those you don’t. Please use the feedback form at the back of this Handbook and tell us what you think.
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Principles and values

1 What is PPI?

'Patient and public involvement' is shorthand for involving individuals and the public in professional regulation in a number of ways. This Handbook looks at each of the areas of patient and public involvement in detail to help guide your work in a practical way.

The term ‘patient and public involvement’ has been used in this Handbook as a catchall term. You will need to learn and use the up-to-date terms that are appropriate to the different people you work with.

Terminology

The term ‘patients and the public’ is broadly taken to mean anyone who has an interest or stake in your work. These could be:

a. Patients
b. Users of health and social care services
c. Potential users
d. The public in general.¹

They could be people who use health and social care, such as patients, clients or service users, and their carers, who come into contact with the health and social care professionals that you regulate.

‘The public’ refers to everyone in the population who has a stake in health and social care as a public service.

‘Involvement’ means engaging with people at all levels in any aspect of your work such as planning, delivery and monitoring.

Within the NHS (particularly in England), ‘patient and public involvement’ means involving people in the design, planning, delivery and evaluation of services, whether they directly use those services or have an interest in them as a member of the public.

Other terms are used in different sectors such as: ‘service user and carer involvement’ in social care, ‘patient focus and public involvement’ in the NHS in Scotland.²

² NHS Quality Improvement Scotland (QIS), Patient Focus and Public Involvement Strategy 09-11 http://www.nhshealthquality.org/nhsqis/1843.140.186.html
2 Why do we need to involve patients and the public?

The main purpose of regulators is to protect the public, and so we should involve patients and the public in our work. Without having patients and the public involved, and at the heart of regulation, it would be impossible to understand their concerns and interests and act effectively on their behalf.

This is summarised well in the Kennedy report:

"Healthcare professionals on the ground have daily contact with patients and a strong sense of what patients want. Yet society is changing and involvement by proxy is no longer seen to be enough. The public are no longer prepared to be passive, trusting and grateful recipients of what is made available. They are no longer prepared to hope that their views will be fully reflected by the professionals. That is not a criticism of professionals; it is just a reflection of the way the world has changed. Increasingly, with public services as with commercial services, the public are ready to challenge, prepared to question, and have come to expect that services will be responsive to their needs. Thus the starting point for a consideration of how the public’s interests may effectively be reflected and safeguarded, is that the public itself, in some shape or form, must be directly involved. The public must be included. In the world of professional services, this is still a problematic proposition. The challenge is to find new ways of involving the public which will work and which are embedded in the fabric of the system. There must also be ways which take account of changes in society, whereby representative democracy appears to be less trusted than a democracy which is participatory: ‘leave it to others’ being supplemented or even supplanted by ‘do it yourself’. Moreover, the public who must be engaged is not some, largely notional, ‘general public’, conceived as a homogeneous entity with common views and needs. Such an entity may be relevant when truly national health issues arise, affecting, for example, the identification of national priorities or the introduction of a highly specialised service. But there are other, disparate publics, divided or grouped according to such criteria as where they live, their age, their gender, their ethnic background or their particular healthcare needs. These many sections and groups also need to be involved.

“As regards public involvement …two concerns are central: safety in the care of patients and high quality in the delivery of the service. What we contemplate here is effective involvement of the public, at national and local levels, both in setting and reviewing the standards to be met regarding the safety and quality of care, and in monitoring the observance of those standards. ... The public are entitled to be involved at all levels and stages: in both setting and agreeing the systems for assuring (the) competence (of healthcare professionals) and in their operation. As regards individual healthcare professionals, assuring competence embraces initial registration, the continuing monitoring of performance through continuing professional development (CPD), appraisal and revalidation, and the application of disciplinary measures when necessary. Historically, the public has only been involved in the last of these. However, we see them all as an interrelated whole in which the involvement of the public is essential if a truly patient-centred service is to emerge. In particular, we would expect the public to have a role in those bodies charged with setting standards for education and training and with controlling access to the professional register. Involvement of the public in these activities serves at least two valuable functions. First, the public can
participate in the process of setting and reviewing the criteria for admission to the profession. After all, the professional is going to be caring for the public as patients. Secondly, public participation in this process serves as a warranty that the public’s interests are being safeguarded and as a reminder that the profession exists for the public.”

A necessity not an option

Patient and public involvement is a necessity for health and social care regulators, not an option. Many regulators now have public involvement built into their constitution and the structures of their Councils and committees. There is also a need to involve people in other ways and this is the main focus of this Handbook.

The White Paper ‘Trust, Assurance and Safety – The Regulation of Health Professionals in the 21st Century’ stresses the need for public involvement in many areas. This includes the composition of Councils, the definition of ‘lay people’, systems for patient and public involvement panels within regulatory bodies, proactive programmes to engage more with the public and greater openness in regulatory bodies’ governance.

Implementing the White Paper: Enhancing Confidence in Healthcare Professional Regulators recommended that ‘All healthcare professional regulators should continue to participate in the Joint Health and Social Care Regulators Patient and Public Involvement Group and each regulator should have an agreed set of arrangements which demonstrates that they are actively engaged with and involving patients and the public.’

The Council for Healthcare Regulatory Excellence (CHRE) is a UK-wide independent statutory body whose statutory duties include:

- promoting the health, safety and well-being of patients and other members of the public in the regulation of health professionals
- informing and consulting the public.

CHRE reviews the performance of the nine healthcare regulators, sharing good practise and providing advice to the UK government and the governments of Northern Ireland, Scotland and Wales on health professional regulation.

The Alliance of UK Health Regulators on Europe (AURE), in its response to the European Commission Consultation regarding community action on health services, stated: “Public and patient engagement in healthcare regulation ensures that the regulatory process is transparent and better able to serve the needs of the society for whose benefit it operates. The European Commission should promote public and patient engagement as good practice in healthcare regulation.”

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The wider environment

Legislation is coming into force from April 2010, to require NHS organisations to audit and publish how public consultations have influenced their commissioning decisions - *Real accountability* - demonstrating responsiveness and accountability: guidance on the NHS duty to report on consultations.  

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3 On what principles should PPI be based?

The Kennedy Report sets out principles designed to lead to genuine patient and public involvement, and to more transparent and open decision-making. The principles particularly relevant to our work are

- a. The public and patients should have access to relevant information
- b. There must be honesty about the scope of the public and patients’ involvement, since the public cannot make some decisions
- c. There must be transparency and openness in the procedures for involving the public and patients
- d. The public and patients should have access to training and funding to allow them to participate fully
- e. A wide range of individuals and groups should represent the public; not particular ‘patient groups’
- f. The mechanisms for involvement should be evaluated for their effectiveness

This means that there are certain values that should underpin the involvement. The principles above see involvement being based upon the values of partnership – regulation is a partnership between professionals and the public where there is a need to negotiate to achieve the best outcomes. This is in contrast to a paternalistic model that assumes that ‘professionals know best’ and requiring patients and the public to trust in professionals’ skills, knowledge and ability. It is likely that there will be some people involved with the health and social care regulators whose central beliefs are still linked to the latter model, although all the drivers for change – reviews of regulation, Government policy, public opinion – are closer to the first partnership model.
4 Who benefits from PPI?

There is evidence to show that PPI benefits those involved and the wider public.⁷

The people who get involved, through

a. Improving confidence and self-esteem
b. Developing knowledge, understanding and skills
c. Encouraging people to take responsibility
d. The opportunity to make a difference e.g. improving services for others, influencing the agenda, ensuring that regulation in the future is appropriate to people like them

Health and social care regulators through

a. Exploring the differences between professional and patient views and between corporate and community views
b. Gaining a better understanding of the public’s needs
c. Improving quality of services that meet needs and reflect broad social values and so making services more efficient and effective
d. Improving governance – democratic legitimacy, accountability and trust
e. Building relationships – building networks, relationships and ownership
f. Capacity building and learning – building confidence, skills, understanding, awareness and knowledge

The wider public through

a. Improved public protection
b. Better focused regulation

See:

a. Patient and Public Involvement in Health: The Evidence for Policy Implementation, A summary of the results of the Health in Partnership research programme, Department of Health, Compiled by Christine Farrell (April 2004); and
c. Involving the public in NHS, public health and social care research – briefing notes for researchers; Hanley B et al (February 2004) INVOLVE;
5 Can we afford PPI?

Patient and public involvement incurs the following costs

a. Building relationships with organisations and networks that represent patients’ and the public’s views
b. Providing information on work, rules and activities in a variety of forms (e.g. through the media, in writing and on the web)
c. Responding to questions and issues from the public
d. Setting up specific events e.g. advertisements, venue costs, facilitator costs
e. Gaining patient and public input to specific pieces of work e.g. payments for contributions and expenses
f. Supporting the involvement of different communities e.g. facilitating access, translation and interpretation

Such costs – in terms of both time and money – can feel like an extra burden on an already large workload and it can feel difficult to focus on improving involvement when there are ongoing work demands. Individual members of the profession might also raise questions with you about spending their registration fees on involving the public.

An investment in the present, however, could save time and money in the future. It could also help regulators to undertake their duties to protect the public through 8

a. Offering different perspectives – better decisions tend to be made when more people contribute to them
b. Prioritising issues that are important to the public
c. Improved planning through seeking and listening to others’ views and making plans more transparent
d. Giving a greater sense of urgency and understanding of accountability
e. Making regulation more meaningful to patients and the public
f. Building trust
g. Raising awareness of regulation and the work of regulators
h. Helping to ensure effective use of money and resources and reducing waste
i. Providing access to other members of the public to contribute to the work (including those who are not usually reached or seldom heard)

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j. Helping to communicate outcomes and information  
k. Supporting people’s development and empowerment

In addition, it is possible for individual regulators to reduce their costs by, for example

a. Working jointly with other regulators on initiatives, for example consultations, sharing expertise and making joint appointments

b. Sharing exhibition stands and the costs of staffing them

c. Meeting the public in their own communities, or at their own events, rather than setting up specific events, therefore reducing the costs of venue hire and travel expenses
6 What can we do about people who argue against PPI?

Every organisation is likely to have some people who do not value the involvement of patients and the public. In the box below are some arguments you can use to counter these views.9

<table>
<thead>
<tr>
<th><strong>One or two people cannot be representative of patients</strong></th>
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<tbody>
<tr>
<td>Nor can one of two professionals be representative of professionals – if we need a bigger range then we need to involve more people</td>
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<table>
<thead>
<tr>
<th><strong>Trained or professionalised members of the public cannot reflect the views of a typical patient – it is always the usual suspects</strong></th>
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</thead>
<tbody>
<tr>
<td>This depends on what you want people to do. For example, if you want someone to sit on a steering group then they might not be typical but they will be able to contribute important insights and present a range of people’s views. Also just because they are actively involved and articulate does not mean they no longer use services</td>
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<table>
<thead>
<tr>
<th><strong>People won’t understand what we need to do</strong></th>
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<tbody>
<tr>
<td>Many people have been involved in the past and have made very useful contributions. There will be a need for the group to avoid jargon but this is useful to help everyone contribute</td>
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<table>
<thead>
<tr>
<th><strong>There are too many problems relating to confidentiality</strong></th>
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<tbody>
<tr>
<td>We need to raise such issues with patients and the public as we do with anyone else and help them understand the reasons behind confidentiality policies</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th><strong>It is the job of health and social care practitioners to act as advocates for patients</strong></th>
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<tr>
<td>Members of the public often have different priorities from professionals</td>
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<table>
<thead>
<tr>
<th><strong>How can people who are emotionally engaged in the topic be objective?</strong></th>
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<tbody>
<tr>
<td>Nobody is entirely objective or neutral. People who use services bring a particular knowledge base with them that is different from those who provide services. Both will have some form of emotional engagement</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th><strong>It is too expensive and time consuming to involve patients and the public</strong></th>
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<tbody>
<tr>
<td>It will take more money and time but not involving them is likely to compromise the relevance of the work and its quality. We will need to budget for it as we do with everything else.</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Members of the public may have unrealistic expectations</strong></th>
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<tr>
<td>This need not be a problem if we explain how long it might take, what will be involved and any issues that might be encountered</td>
</tr>
</tbody>
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9 Involving the public in NHS, public health and social care research – briefing notes for researchers; Hanley B et al (February 2004) INVOLVE.
Shaping involvement

7 What forms can involvement take?

There are a number of ways of thinking about PPI.

A useful distinction is whether involvement is reactive or proactive

a. Reactive involvement is asking people to respond to activities, services, plans, proposals and priorities. This would be, for example, sending fairly firm proposals out for consultation and there is little if any scope for change.

b. Proactive involvement is asking people as users of services and/or citizens to become involved in introducing and formulating definitions and making proposals for new or improved services.10

The distinction between reactive and proactive involvement relates to the

a. Approaches and methods of involving people
b. Purpose of involving people
c. Nature of the involvement

A development of this distinction Communication – establishing meaningful dialogue 11

a. Consultation – asking people’s views
b. Partnership – an equal relationship between the public and professionals

You can use either of these distinctions to consider the general approach taken in your organisation and how this might be improved.

It is also possible to look at the extent to which patients and the public (citizens) have any power within the relationship.12

Arnstein's ladder of citizen participation

<table>
<thead>
<tr>
<th>Degrees of citizen power</th>
<th>Degrees of tokenism</th>
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<tbody>
<tr>
<td>8 Citizen control</td>
<td></td>
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<tr>
<td>7 Delegated power</td>
<td></td>
</tr>
<tr>
<td>6 Partnership</td>
<td></td>
</tr>
<tr>
<td>5 Placation</td>
<td></td>
</tr>
<tr>
<td>4 Consultation</td>
<td></td>
</tr>
<tr>
<td>3 Informing</td>
<td></td>
</tr>
<tr>
<td>2 Therapy</td>
<td>Non-participation</td>
</tr>
<tr>
<td>1 Manipulation</td>
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</tbody>
</table>

At the bottom of the ladder, people have no say about what goes on but are kept informed about decision-making. Information goes one way. As you move up the ladder, there is more interaction so, for example, at rung 4 ‘consultation’ people are asked to respond to proposals whilst the organisation retains the decision-making power. Further up the ladder the organisation and citizens share decision-making power – this is seen as partnership. Finally, at the top of the ladder citizens take over the power of decision-making – citizen control.

Given the role, funding and constitution of the health care regulators, you might question whether the top of the ladder is appropriate. The ladder is useful, however, for getting people to talk about their expectations and be explicit about their intentions (i.e. not hiding behind words such as ‘partnership’ when there is no intention of sharing decision-making). It is better to consult well than to offer partnership and then fail to deliver.

The table on page 16 shows how the spectrum of activity (horizontal axis) from information provision to gaining feedback through to being able to influence change can be combined with who is being involved (vertical axis) – individually (likely to be patients, clients and service users) and collectively (the public as a whole and particular communities).  

Information to individuals about treatment, services and how to make a complaint

Individuals can feedback about their own care and treatments and raise issues of concern (e.g. complaints)

Trends in complaints, PPI issues and feedback on complaints and the patient experience

Shared decision making between individuals and professionals

Improvement in policy and planning

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**Individuals** are likely to be interested in the following types of questions:

a. Do I get the right information and explanations at the right time? For example, "Is this practitioner on the register?"

b. Does my view count? "I gave feedback on problems with accessing the support helpline; have they done anything about it?"

c. Is it easy for me to raise issues and concerns and get them sorted out? "How can I make a complaint about a particular practitioner?"

**Collectives – the public** – are likely to be interested in the following types of questions

a. Do we know how to make a difference in the work of this organisation? "This organisation says it is about protecting the public; how can we feed our views in and know they are listened to?"

b. Have people from all parts of the community been able to influence change? "Is this organisation run by people who are like the practitioners that are regulated rather than people from all different communities who use care services? Does this organisation promote equality and value diversity?"

c. Have things improved as a result of people giving their views? "How did our views change what you did? Was it worthwhile attending the public meeting?"
8 At what stage should people be involved?

Patients and the public should be involved as early as possible in the work so that they understand and own the process, and can influence its development.
9 What involvement methods are there?

You can view involvement on a scale ranging from minimum to maximum involvement.\(^{14}\) You need to match the level and type of involvement to the circumstances and context. Minimum involvement is sometimes appropriate such as when someone is seeking particular information. Generally speaking the greater the involvement the more links there should be to an organisation’s decision-making processes. This in turn should affect how the people who have been involved receive feedback.

Lay members of regulatory bodies are only one very specific way of involving patients and the public in professional self-regulation – albeit an important one. They can encourage and enable their professional colleagues to address patient and public views in the organisation’s work and in its decision-making, leading to changes in organisational culture.\(^{15}\)

The diagram on the next page sets out a scale of approaches and the methods you can use at different stages. It is good practice to consider a range of approaches, determine how they fit together to establish a pattern of ongoing involvement and dialogue, and be clear about how the feedback will be used.

You should also recognise that you can use any method in a more or less involving manner so it is possible for you to employ a large number of methods while still letting professionals drive the agenda. You should also remember that methods linked to planning and development do not lessen the need for effective communication and involvement on a day-to-day basis.

\(^{14}\) Much of the content in this section is taken from:
   a. Strengthening Accountability: Involving Patients and the Public Practice Guidance, Section 11 of the Health and Social Care Act 2001 (February 2003) Department of Health; and

\(^{15}\) Every Voice Counts – Involving Patients and the Public in Primary Care (2002) Anderson W et al.
Scale of Involvement and related methods

Public Involvement Scale

<table>
<thead>
<tr>
<th>Minimum involvement</th>
<th>Maxi involvement</th>
<th>Partnership</th>
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<tbody>
<tr>
<td><strong>Giving information</strong></td>
<td><strong>Getting information</strong></td>
<td><strong>Forums for debate</strong></td>
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<tr>
<td>Exhibitions</td>
<td>Citizens’ panels</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Leaflets and written documents</td>
<td>Open surgeries</td>
<td>Meetings with patients and carers</td>
</tr>
<tr>
<td>The press</td>
<td>Patient diaries</td>
<td>Public meetings</td>
</tr>
<tr>
<td></td>
<td>Phone-ins – radio or live</td>
<td>Seminars</td>
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<tr>
<td></td>
<td>Self-completed questionnaires</td>
<td>Targeting interested people</td>
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<tr>
<td></td>
<td>Semi-structured interviews</td>
<td>including the voluntary sector</td>
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<tr>
<td></td>
<td>discovery interviews</td>
<td></td>
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<tr>
<td></td>
<td>Structured one-to-one interviews</td>
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The approaches set out above are for illustration, not ones you have to use. You need to identify the approach that suits the questions you need answered, the purpose of involvement and the people to be involved. You will need to plan carefully so that people are involved at the right stages. It is important not to seek people’s views once major decisions have been made and cannot be changed.

Remember, there is no one right method that serves all purposes. You can also use one method to develop another. One example would be using a focus group to develop some initial thinking to form the basis of a survey.

Each of the different methods will need specific knowledge and skills to work effectively. You will need facilitation and conflict handling skills when you have direct contact with patients and the public in debate, participation and partnership. You will need research methodology skills when you are gathering and analysing information. You may well have many of these skills yourself or you might need to think about finding someone who has them – either in your organisation or hiring them in from outside.

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There are other ways of classifying PPI methods and approaches. These are set out in the table below with examples of how you might use them in your regulatory work.

<table>
<thead>
<tr>
<th>PPI methods and approaches</th>
<th>Possible uses by regulators</th>
</tr>
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</table>
| a. Qualitative research methods – to explore people’s perceptions, attitudes and ideas in depth and respond to participants’ own agendas | a. To find out views of the public in relation to specific issues at early stage of development (e.g. the education and training of practitioners, entry to the register) 
b. To evaluate the effectiveness of professional conduct proceedings |
| b. Quantitative research methods – to measure the incidence and significance of, for example, views, opinions or behaviours | c. To gain the views of the public on some set options 
d. To help to identify understanding of different aspects of regulation |
| c. Consultation techniques – written consultations, public meetings, and conferences | e. To gain the views of the public on proposed options 
f. To explain the purpose of regulation and developments and gain broad views on direction |
| d. Deliberative approaches – such as deliberative polling and referenda | g. To explore ideas about policy options and the allocation of resources |
| e. Community development approaches – long term processes of involving individuals and communities using a variety of participatory approaches including personal empowerment, positive discrimination, community organisation, and participation and influence | h. To assist the development of specific communities/organisations (e.g. voluntary) so they can contribute effectively to regulatory issues and developments |

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10 Which methods should we use?

You should not use one single method of involving patients and the public because different forms will be appropriate at different times. You need to be flexible and change your methods in response to feedback.

The main things to take into account are

a. No single approach will suit every situation, every member of the public, or every issue
b. Choose your approaches carefully and make sure the right people are involved
c. Always ask why you are involving people before you start to do so
d. Be clear about what you are going to do with the outcomes of involving people
e. The critical thing is ongoing dialogue and an improved working relationship with patients and the public

The quote below sums up the last point

“What makes most difference is the everyday, inconspicuous business of paying attention to people, providing information, giving feedback, treating them with respect and asking open questions. If we are doing this work in the background, then the special efforts to involve and engage people will build on the existing culture. If we only listen to people when we are making a special effort, the gap between rhetoric and reality will soon show.”

Involvement is not just about having a patient or a member of the public at a meeting. It is about the quality of the relationship they have with the work including

a. The quality of communication and information
b. The opportunity to actually contribute
c. Having contributions valued and incorporated
d. How the power of the regulator and its professionals is used

These issues become even more important when involving seldom-heard groups because there is a real need to consider whether the involvement actually benefits them or is just adding to the status quo.

You should always consider alternative methods if patients and the public advise you to do so. When you hold meetings you should make them as informal as possible and preferably hold them in locations that are familiar to the people concerned. You should also think about how you can make people feel more relaxed and so better able to participate. For example, providing lunch and opportunities for discussion outside of the meeting.

18 Involving the public in NHS, public health and social care research – briefing notes for researchers; Hanley B et al (February 2004) INVOLVE.
Further information about the different methods and approaches, their advantages and disadvantages are given in Appendix 1 (page 42).

Appendix 2 (page 57) provides information on PPI toolkits, guides and reports where you can find more detailed information on PPI and associated methods.

Appendix 3 (page 62) gives details of organisations that can support your work in PPI (e.g. by offering the necessary facilitation skills, providing training for staff).

Appendix 4 (page 67) provides information on consultancies and organisations that provide advice and support on patient and public involvement. This listing carries no assurance of quality as it was collated through internet searches.
11 How can we make PPI meaningful and not tokenistic?

There are many things you need to think about to make PPI meaningful. These things are not unique to PPI as they are also good practice when involving professionals; how you involve members of the public should be the same as how you involve professionals.

They include

a. Being clear about the aims and objectives of the involvement, how it relates to the overall programme/project and its timescales
b. The anticipated outcomes of the work and any constraints that operate
c. Identifying how and when you will involve individuals – checking that this will work for them
d. Explaining the terms and conditions of involvement (i.e. paid or on a voluntary basis)
e. Explaining the expectations of involvement if people will be paid for it
f. Identifying the support and training that you will provide for individuals
g. Always involving two or more people so they are not isolated, can support each other and their involvement is not tokenistic
h. Identifying and following through how you will give feedback on their involvement
i. Capturing lessons learnt as you go through and acting on them

When considering long-term involvement you also need to

a. Prepare a brief person specification to enable you to think about who you might involve, whilst also being flexible, setting out the range of experience, perspectives and expertise that you need
b. Develop a job description of what you want the person to do e.g. maintain an independent perspective, offer a personal perspective, work with other patients to present a broader view

You will need to explain in simple and unambiguous language

a. The particular work you are asking people to become involved in and its background
b. Why you are approaching them
c. What you are asking from them
d. The level of involvement they can expect in the work
e. The resources you can offer so they can contribute effectively. For example, expenses and, with longer term involvement, computers, printers and access to library facilities

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20 Involving the public in NHS, public health and social care research – briefing notes for researchers; Hanley B et al (February 2004) INVOLVE.
f. The benefits to them

g. How long the work is likely to take

h. Who will benefit from the work

i. The potential risks of involvement

j. The extent to which individuals need to set their own boundaries

To make the involvement meaningful and effective you will need to

a. Spend time developing a relationship with the participants

b. Visit people on their own ground

c. Expect some people to be sceptical about the work and their involvement in it

d. Look at examples of the work others have undertaken and use their work to influence yours

e. Ask participants to explain what they do

f. Find out about how and when people would like to be involved

g. Seek feedback on participant’s involvement and learn from it

h. Try new ways in response to feedback

You may need to contact a number of organisations before you get sufficient participants, or the right people, to be involved in different aspects of work.

Some people will not wish to be involved because: they have different aims and interests and so they cannot see the relevance of your work to them; they are too busy at that time, or because the emotional or practical costs of involvement are too high.
12 What hinders effective PPI?

The effectiveness of PPI can be limited by

a. The attitudes of professionals
b. The values of the organisation
c. The diversity and complexity of patients and the public, which can make it difficult to understand how to involve people effectively
d. The knowledge base of patients and the public – and also of professionals
e. Power relationships, which can mean that an organisation’s priorities dominate. Awareness and desire to share power can help redress the balance
f. Resources – a lack of time and money can prevent people from participating as can a lack of resources in an organisation to support effective PPI
g. Significant organisational change, which will dominate thinking and action
h. Policy that skews public involvement to short-term identifiable outcomes and undermines the development of more substantial ongoing forms of engagement

The publication Every Voice Counts discusses how to overcome problems with PPI

Negotiating across diverse interests

This is what partnership, and public involvement, is all about. But it remains one of the trickiest tasks, requiring a combination of sensitivity and leadership – valuing differences while also building a degree of consensus. Meetings can all too easily slide into unfocused discussions; but with too strong a chair, participants can feel undervalued or alienated.

Talk and action

Skill is also required in getting the balance right between the consensus-building discussion and the detail of implementation. If not enough time is spent sharing ideas and interests, public involvement initiatives may run their course without practical connections being made. Too little action, and disillusion and frustration soon set in.

21 This section has been drawn from:
   a. Small Voices Big Noises, Lay Involvement in Health Research – Lessons from other Fields, Baxter L et al; and;
22 http://www.kingsfund.org.uk/publications/the_kings_fund_publications/every_voice.html
Marginalisation

Bringing people together to develop collaborative approaches to public involvement work ought to reduce the risk of marginalisation. However, the creation of any new institution – such as a working group or partnership forum – always runs the risk of marginalising the issue from the existing institutions. Such groups have to be well-connected with the rest of the business of the organisation if they are to be effective in ensuring that such work brings about change.

Confusion of functions

It may be difficult for participants from outside the organisation, including voluntary sector representatives, to stick rigorously to the public involvement planning agenda if they have few other opportunities to talk to members and officers. In practice, it can be difficult to keep these functions apart. It is therefore important to regularly review the terms of reference of such groups, so that members’ perceptions of what they are for are not too divergent.
13 Are there any tips for effective PPI?

Yes.

1. Plan well in advance – work out the best method and the timing

2. Be honest – involvement can go badly wrong if people believe they are being invited to explore a wide range of options when there are only a few available

3. Use the results – just involving people is not enough, how you are going to use the results of involvement needs to be thought about at the planning stage?

4. Take it seriously – do it in the spirit of true involvement – otherwise it will waste everyone’s time and could be harmful

5. Spend time developing relationships, building trust and communicating with different user organisations and communities

6. Make communication simple and obvious

7. Keep people informed throughout

8. Involve people as early as possible

9. Be open to criticism and change

10. Work in partnership to ensure coordination, cost efficiency, effectiveness and shared outcomes

Overall, people think that a responsive public service is one that

a. Provides easy and appropriate access to services

b. Encourages the individual to use and shape services in ways that suit them

c. Actively seeks to learn from public involvement and develops services accordingly

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Practicalities

14 How best can we contact people?

You can contact patients and members of the public directly or through organisations that represent their interests. There are different types of organisations that seek to put forward the views of groups and communities. These include

a. Self-help groups
b. Voluntary organisations that campaign for improved services
c. Pressure groups
d. User-controlled organisations
e. Advocacy groups

Some organisations may concentrate on a specific condition (e.g. cancer, epilepsy) whereas others might concentrate on population groups (e.g. the elderly, children). In addition, some organisations are alliance organisations whose membership includes other autonomous national organisations (e.g. the Long-Term Conditions Alliance). All of these different groups are likely to have different views on a subject. You will need to think about whether all of these groups should be involved at any one time or whether the issue is more relevant to one group.

Voluntary and community sector groups are perhaps the most obvious and also the most neglected resource for public involvement as they are collective in nature. They range from being large and wealthy to small and entirely self-supporting but all offer opportunities for engagement.24 They are valuable as

a. Collective voices of patient and public interests
b. Sources of intelligence about patient and public needs
c. Partners in exploring and addressing needs
d. Sources of expertise in involving patients and the public
e. Routes of communication with different communities

When you engage with the voluntary sector you need to be sensitive to their capacity and interests. You might need to think about how you could help them to develop their capacity to work with you if they are interested in doing so.

When contacting patients and the public through organisations, it would also be worthwhile checking out the nature of the organisation concerned (such as the basis of their funding) as some might have benefactors with particular agendas to their work.

Appendix 4 (page 67) identifies some patient and public groups that can assist in your work.

Alternatively you can seek to contact individuals directly. You can do this in five main ways

1. Contact them directly
2. Advertise opportunities for involvement. For example, in local community settings, through newspapers and radio
3. Networking by attending events where the groups you want to involve are likely to be present
4. Promotional events
5. Groups and individuals may approach you and seek involvement

Think about social diversity and inclusivity before you contact people. For example: age, ethnic and social background, gender, sexuality, disability and geography, and how these factors may affect the people you plan to contact.

Whilst it can be pragmatic to contact the public through organisations, you need to do this with care as organisations are not necessarily comprised of people in the target audience. Ideally you should try to involve patients and members of the public directly and also through organisations and groups that represent their views.

However you initially contact people, effective relationships are based on trust and these take time to develop. Lots of seemingly small things will make a difference such as

a. Being willing to meet people in their own settings
b. Making an effort to answer their questions even if they do not seem directly relevant
c. Being as open as possible as to what is possible rather than just putting a positive spin on things
d. A commitment to sustained communication

Much literature recommends that there is a dedicated person, at a relatively senior level, within organisations to build up relationships with organisations and groups that represent patients and the public; someone who understands their interests and ways of working and the times that they would like to be involved. Such matters are likely to vary between different individuals and organisations and might also vary over time. It will be affected by how these organisations and groups work, their own internal issues and concerns, and the interest of the subject matter.
15 What prevents people engaging effectively?

A number of factors may prevent individuals from engaging effectively, such as

a. Not having the skills, resources and confidence to participate

b. Time constraints that affect people’s decision to participate. However, once individuals start to participate, time tends to become less of a concern

c. A feeling that public engagement exercises are just exercises in public relations

d. A sense of being a lone voice amongst professional experts

Factors which may deter the public as a whole include

a. The lack of a strategic approach within an organisation to working with the public

b. Organisational ethos and culture

c. Organisational skills and competence

d. Community capacity to engage

e. A lack of clarity about how to get public representation
16 How can we involve seldom-heard groups?

Involving groups whose voice is seldom-heard in regulatory discussions and debates will require extra thought, preparation, time and money. However, the outcomes are likely to be better because these groups have important expertise to offer. People from seldom-heard groups are likely to be embarking on an activity that is new to them, which means that they are on a steep learning curve. This will mean that at times it will be difficult for them to contribute and you will have to make adjustments to involve them effectively. There is no single way of approaching this and you will need to learn as you go along and adapt your approaches as you proceed.

It is necessary to remember that everyone can feel marginalised and vulnerable at times. It is essential that you value everyone as equals and experts in their own experience. There is a detailed checklist below which lists the issues to think through when involving seldom-heard groups. You can also use it for patient and public involvement more generally.

**Checklist on involving seldom-heard groups**

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<tbody>
<tr>
<td><strong>a</strong></td>
<td>Have you carefully considered the reasons for involving seldom-heard people, and are you clear about why you are doing it?</td>
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<tr>
<td><strong>b</strong></td>
<td>Have you explored every option to ensure that seldom-heard groups have had the opportunity to consider being involved (e.g. community networks)?</td>
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<tr>
<td><strong>c</strong></td>
<td>Is the information you are planning to give accessible and culturally relevant for those you want to reach and engage?</td>
</tr>
<tr>
<td><strong>d</strong></td>
<td>Is the information you have given sufficient for people to make a fully informed choice about whether or not they want to be involved?</td>
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<tr>
<td><strong>e</strong></td>
<td>Have you allowed for additional time depending on the needs of the person or persons concerned (e.g. for translation, broader discussion, medical needs and breaks in meetings)?</td>
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<tr>
<td><strong>f</strong></td>
<td>Have you budgeted for the additional resources needed to accommodate their needs whilst they are involved (e.g. signer, advocate, carer, special transport, accommodation and dietary requirements)?</td>
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<tr>
<td><strong>g</strong></td>
<td>Are the venues accessible to those you want to involve? Can you get better venues?</td>
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<td><strong>h</strong></td>
<td>Are the times of meetings suitable for the individuals you want to involve?</td>
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<tr>
<td><strong>i</strong></td>
<td>Where involvement is on a group, such as a project steering group, is the group chairperson fully aware that they must ensure everyone has an equal opportunity to participate?</td>
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</tbody>
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25 The information in this section is from *A Brief Summary and Checklist for Researchers, Research Commissioners and Research Groups for Involving Vulnerable and Marginalised People* (Based on ‘Involving Marginalised and Vulnerable Groups A Consultation Document’ (January 2003) Steel R, INVOLVE.

26 Checklist produced by INVOLVE and available in *A Brief Summary and Checklist for Researchers, Research Commissioners and Research Groups for Involving Vulnerable and Marginalised People* (Based on ‘Involving Marginalised and Vulnerable Groups A Consultation Document’ (January 2003) Steel R, INVOLVE.
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<tr>
<td>j</td>
<td>Will the group as a whole be aware that they must be proactive in ensuring that members of the public know that they can ask for clarification of anything they do not understand?</td>
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<td>k</td>
<td>Will you offer an advocate or mentor to help with this and other support needs where appropriate?</td>
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<td>l</td>
<td>Will the group be prepared to make adjustments to accommodate the level of knowledge, cultural familiarity, and learning ability of the individuals involved?</td>
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<td>m</td>
<td>Will papers be summarised in plain English?</td>
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<td>n</td>
<td>Are the professionals in the group aware that they should be self-conscious about using specialised professional language rather than using it spontaneously?</td>
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<td>o</td>
<td>Will you offer all group members training to help make the partnership successful for all involved?</td>
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<tr>
<td>p</td>
<td>Will you offer other training to members of the group?</td>
</tr>
<tr>
<td>q</td>
<td>Have you made arrangements to pay expenses?</td>
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<tr>
<td>r</td>
<td>Have you considered paying people for their time if they are otherwise unpaid?</td>
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<td>s</td>
<td>Will there be a process by which ground rules for the group can be developed and negotiated at the beginning?</td>
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<tr>
<td>t</td>
<td>Will there be an induction pack for people and will they have the opportunity to negotiate a ‘job description’?</td>
</tr>
<tr>
<td>u</td>
<td>For long term or ongoing groups, have you considered the possibility of a ‘rolling membership’ of people, with time limits (e.g. two years’ service) and overlaps between new and outgoing members to maintain continuity?</td>
</tr>
<tr>
<td>v</td>
<td>Have you considered the needs of individuals leaving a longer term or ongoing group?</td>
</tr>
</tbody>
</table>

You can contact seldom-heard groups through the organisations that speak on their behalf and ask them to contact individuals. It will be necessary to provide resources to these organisations for them to do this on your behalf. Some national organisations have produced guidelines on working with particular groups or communities.27

**Which people and groups are seldom-heard?**

Several organisations have defined those people and groups who are seldom-heard.

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The Department for Education and Skills

The Department for Education and Skills (since split into Department for Children, Schools and Families and Department for Business, Innovation and Skills) defined three types of seldom-heard groups:

**Type A:** the marginalised, economically disadvantaged or socially excluded.

**Type B:** the overlooked, ‘invisible’, or those unable to articulate their needs.

**Type C:** the suspicious, over-targeted or those disengaged from social, economic or educational opportunity. 28

The Learning and Skills Council

For the Learning and Skills Council the seldom-heard are “certain sectors of the community [who] find it difficult to take advantage of learning opportunities. This could be because of physical disability, language, financial constraints, cultural differences or social expectations, for example.” 29

Portsmouth City Council

Portsmouth City Council's award-winning consultation toolkit lists the following groups as being seldom-heard: 30

- People who have problems reading, writing and speaking English.
- Some people on low incomes.
- Some people from ethnic minorities.
- Some people who are generally ‘too busy’.
- Older people.
- Young people.
- People who are deaf or hard of hearing.
- People who are blind or partially sighted.
- People who have mobility difficulties.

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29 [www.lsc.gov.uk/](http://www.lsc.gov.uk/)
30 [www.portsmouth.gov.uk/media/COMMS_Consulting_People_toolkit.pdf](http://www.portsmouth.gov.uk/media/COMMS_Consulting_People_toolkit.pdf)
17 For what should patients and the public be paid?

It is difficult to be specific about payment levels. The aspects to consider are set out below.\textsuperscript{31} The following terms help to distinguish what is meant. \textit{Payment} refers to a fee to reward individuals for their time and expertise. \textit{Reimbursement} refers to the refunding of specific expenses or costs that individuals have incurred during their involvement. \textit{Volunteers} are people who choose to not be paid and offer their time and skills for free.

Why reimburse and pay?

Reimbursing costs and paying for time and expertise create an incentive for participation allowing a broader range of people to be involved. Specifically

\begin{itemize}
  \item a. Reimbursement and payment are material ways to acknowledge the value of public contributions
  \item b. It removes barriers that stop people participating (e.g. being able to cover the cost of transport, use of phone and childcare)
  \item c. It can indirectly lead to more effective and even-handed participation of people by easing financial burdens as there are likely to be financial implications to involvement
  \item d. It enables equal partnerships between members of the public and professionals
  \item e. It can be used to clarify the expectations and responsibilities relating to people’s involvement
\end{itemize}

In principle you should reimburse all expenses and it is best practice to pay for time and expertise. Rates will depend on a number of variables. Paying people need not influence the independence of their views. A ‘job description’ can be agreed to clarify and affirm their role as it should for all members of any formal group. This can help affirm the equal status of all participants, both professionals and the public. Payment should only be considered for specific pieces of work (e.g. peer review, report writing or attending a committee meeting) as this helps to reinforce independence.

Reimbursement

It is good practice to reimburse expenses to a member of the public when they have incurred these costs in undertaking a role previously agreed with you. This would include: taking part in a meeting, interview panel or training event; or undertaking a defined task in a project, programme or complaints procedure.

\textsuperscript{31} Department of Health, January 2006, Reward and Recognition The principles and practice of service user payment and reimbursement in health and social care A guide for service providers, service users and carers http://www.dh.gov.uk/assetRoot/04/12/68/65/04126865.pdf.

Involve and the Department of Health, \textit{A guide to paying members of the public who are actively involved in research: For researchers and research commissioners} (who may also be people who use services), INVOLVE (formerly Consumers in NHS Research) (2002, revised 2006).
It is not usual to reimburse expenses when a member of the public chooses to attend an open meeting, takes part in a consultation exercise or survey. However, your organisation might decide that it wishes to reimburse expenses for members of the public in these cases to encourage participation.

Organisations should have a policy covering reimbursement (and another separate policy for the payment of fees) and should make it available at an early opportunity to members of the public. Expenses should include

a. Travel – public transport, taxi fares, or an agreed private car mileage rate which includes wear and tear
b. Stopover – overnight accommodation
c. Subsistence – food whilst on ‘business’ or bought because the person has to be at a certain place at a certain time
d. Childcare
e. Telephone/fax costs
f. Stationery/equipment
g. Carer costs
h. Costs of a personal assistant of the individual’s choice
i. Conference fees
j. Participation in training

Expenses are generally not subject to tax unless they exceed the Inland Revenue ceiling (e.g. for mileage).

Payment for time, skills and expertise

You should pay patient and public representatives for their time and expertise at the same level as others involved in the work. This will depend on a variety of factors and circumstances (e.g. it is unfair to expect people to give their time for free when others are paid for their time as part of their day job, or through locum fees). However, when a committee or group is entirely voluntary, payment for time cannot reasonably be expected, although reimbursement of expenses may be essential to enable some people to attend.

Rates will depend on a number of variables. You should take the following into account

a. How does the principle of equity apply in this situation?
b. What level of skills, expertise, and experience am I seeking/expecting?
c. How much time is needed for this role (including preparation, reading, travel, communication and meetings)?

32 A guide to paying members of the public who are actively involved in research: For researchers and research commissioners, (who may also be people who use services), INVOLVE (formerly Consumers in NHS Research) (2002, revised 2003 and amended 2005).
d. What are the comparative levels of pay and responsibility of participating professionals?

e. How much responsibility am I expecting people to take?

f. What are the local and national pay conditions for the equivalent role?

g. What is the current national minimum wage?

Because employment law applies, you must provide terms and conditions to people if you are paying them for a service (but not for reimbursement of expenses). Staff in your Human Resources Department should be able to advise you about Employment Law.

Members of the public may be in receipt of social security benefits payments. It is vital to be aware that making a payment can affect these benefits. There are many different kinds of benefits and more than one kind may apply to a single individual. Each benefit has different conditions attached to it, including different ceilings on what additional income they can earn, if any, before benefit payment is affected. It is the responsibility of an individual of normal working age receiving benefit to find out about how payment may affect their benefit. They are also ultimately responsible for ensuring that they keep within their benefit conditions. However, you should make sure that you do not mislead people or put them in a difficult position33.

**Making payments**

When offering payment, give people the choice of whether to take the payment or not. There may be reasons why some people would prefer not to be paid; for example, because of altruism, financial circumstances, or because social security benefits are involved. It is important to make clear from the outset the payment that can be expected and when individuals will receive it.

**Timing of payments**

Payments, particularly the reimbursement of expenses, need to be made promptly, or in some cases in advance, or on the day. This is particularly important for people on low incomes and/or in receipt of benefits. Delays in payment will discourage participation, as will long complicated forms.

You should also remember that a proportion of the population do not have bank accounts so payment by cheque can cause difficulties.

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33 For more detailed information on Benefits rules in relation to user involvement, INVOLVE recommend the booklet 'A Fair Day’s Pay: A guide to benefits, service user involvement and payment' (July 2003) Mental Health Foundation.
Embedding PPI

18 How can we evaluate PPI?

Evaluation can help to plan and manage successful patient and public involvement. Evaluation of public involvement is relatively new but as engagement increases there is a related need to assess the effectiveness of different approaches, learn from experience and increase accountability.

Scope of evaluation

Evaluation does not need to be particularly extensive – at its most basic it can focus on three simple questions

a. Has the initiative succeeded? e.g. has it met its targets/objectives, resulted in other achievements?

b. Has the process worked? e.g. what happened, what worked well, what worked less well, what lessons are there for the future?

c. What impact has the process had? e.g. on participants, on the quality of policy, on policy makers?

The relationship between evaluation and engagement

Evaluation can help organisations improve patient and public involvement in four main ways

a. Clarifying the objectives of the exercise by identifying practical ways of measuring success

b. Improving project and programme management by building in review and reflection throughout the process

c. Improving accountability (e.g. of resource spend) by reporting what is done and what it has achieved

d. Improving future practice and policy by developing evidence about ‘what works’ and the effectiveness of different approaches

Who should do it?

Evaluation can be undertaken by

a. The people who are running the work themselves – this has the advantage of allowing changes to be made promptly as the process proceeds

34 This section has been drawn from: D Warburton with R Wilson and E Rainbow, 2007, Making a Difference: A Guide to evaluating public participation in central government, Department for Constitutional Affairs and Involve
b. By people from outside who have the specific role of acting as evaluators – this has the advantage of independence and the potential to identify issues that may go unnoticed by those directly involved

**When to evaluate?**

It is essential to start thinking about, and working on evaluation, early in the process. Many of the important outcomes of public engagement are intangible e.g. improved relationships and the evidence is often subjective and highly contextual. It is useful to get the evaluator involved in setting the objectives of the public engagement as this helps to ensure that the all of the objectives are explicit, clear and assessable.

**What should evaluation cover?**

The evaluation of PPI can take a similar form to any other type of evaluation. It can range from a simple audit to a more extensive examination of what happened and why.

The evaluation can usefully cover such aspects as

a. Objectives of the engagement e.g. what were the original objectives, who set them, did they change and were they met?

b. Context e.g. was it a one-off project or part of wider programme? What else relevant was happening at the same time? What geographical and historical factors might have affected the process?

c. Levels of involvement e.g. what type of involvement was sought? Was it achieved? Was it appropriate in the circumstances?

d. Methods and techniques e.g. what were they and who decided on them? Were they appropriate? What worked well and what could have worked better?

e. Who was involved e.g. what type of people (demographics)? How many?

f. Resources used e.g. staff time and costs of events and publicity; and non-monetary costs such as time contributed by participants, training and unpaid staff time

g. Output products and activities e.g. what useful information was obtained and new contacts made at participatory events? What were the outcomes of questionnaires and interviews?

h. Outcomes e.g. what policies changed has as a result? Or were there changes to the organisation or to staff development? Were there wider social changes such as greater public awareness and support?

It is also a good idea to consider general points such as

a. What are the main lessons we have learnt?

b. What should we never do again and why?

c. What was the best or the most successful aspect of the whole project and why?

d. What is the most significant change or biggest impact that the process has had and why?
What does evaluation involve?

There are number of basic steps to any evaluation which include

a. Scoping – deciding what to do, how and by whom
b. Collecting the data
c. Analysing the data
d. Testing the findings
e. Report writing
f. Communicating and using the findings – so that the organisation and others can gain from the evaluation (e.g. using the findings to improve future practice and building them into future staff development programmes.)

Where should we start?

The evaluation that you and your organisation decide to undertake will need to take into account

a. The resources available for evaluation
b. The size of the task and the benefits, or not, of having an independent evaluation
c. How patient and public involvement fits into other organisational strategies and any evaluation you may do of these

If it is not possible to have an independent evaluation of patient and public involvement, there are some practical steps that you can take yourself. For example, you can ask people how well the involvement has worked for them either at the end of a particular form of involvement or when starting a new form of involvement e.g. ask people what has and has not worked for them in the past and how involvement can be better planned.

If you wish to involve independent experts to evaluate your patient and public involvement, some of the organisations identified in Appendix 3 (page 62) will be able to help. Alternatively you could use individuals or organisations that specialise in evaluation.
19 How can we embed PPI in our organisations?

Patient and public involvement is a way of working, not a one-off activity. It needs to be embedded in your

- Organisational strategy
- How your organisation functions as a whole – it is not the responsibility of one department or one person
- How everybody in the organisation – employees and members – think and act

Patient and public involvement needs to include the following aspects.

1 **Planning**
   
   PPI strategies must be put into practice, not written and put on the shelf. This means
   
   - Developing relationships with, and linking to, existing user groups
   - Involving managers and staff in PPI
   - Carrying out a baseline assessment of what PPI is happening now and then monitoring developments
   - Building PPI into ways of working right across the organisation
   - Making sure that PPI is not an add-on but considered as a natural part of the organisation’s agenda
   - Identifying the benefits of PPI and demonstrating and communicating them

2 **Engaging leaders, members and senior management**
   
   The commitment of the Council and senior managers is essential. It is not just about believing that PPI is the right thing to do, but also understanding that it will contribute to improving your work as a regulator.

3 **Engaging staff**
   
   All staff have a role in involving patients and the public, while those charged with overseeing it need to be at a senior level within the organisation. The benefits of PPI need to be demonstrated to staff and success celebrated.

4 **Valuing staff so they can value the public**
   
   Develop PPI processes in conjunction with processes for involving staff. This means developing a clear purpose and a business case for PPI. “Value your staff who will then value the public”. The first step in achieving excellence in services is valuing the staff who deliver those services. In terms of organisations this means investing in internal
communication so that staff can champion improvement and be open to their ideas for innovation.36

5 Developing staff, Council members and the organisation

Any programme of change must address the knowledge, attitudes and skills of staff and members at all levels of the organisation. Staff and members will need help in tackling real (and imaginary) concerns about the consequences of PPI and how to take it forward effectively. Hands-on experience can be a powerful way to change attitudes as it can help people see the real value of involvement but more formal learning and development is also likely to be crucial.36

6 Mainstreaming PPI in the organisation

PPI needs to be supported with resources, staffing, training and development. How well PPI is done in practice should be monitored. When PPI has been implemented successfully, patients and the public are close to corporate decision-making, not isolated in small pockets of activity (such as reader panels) or on project groups that have no influence on decision-making. PPI must also be linked to other organisational activities such as audit and governance.

7 Using feedback to influence change

Finding out what matters to patients and the public must lead to change, otherwise it is wasted activity and will do more harm than good. Patient and public involvement without action to follow is wasteful and ineffective.37

Finally, enjoy involving patients and the public in your work – you will learn from them as an individual and as an organisation.

35 A playlist for public services; making all consumers matter (July 2005) Ed Mayo, National Consumer Council; PD 39/05.
Appendix 1 - Methods and approaches of public involvement

Approaches related to giving information

<table>
<thead>
<tr>
<th>Exhibitions</th>
<th>Key points</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Aims to present information in visual form</td>
</tr>
<tr>
<td></td>
<td>2. Possible to target specific audiences e.g. in workplaces, schools, community centres, outpatients</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Drawbacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>a</td>
</tr>
<tr>
<td>b</td>
<td>b</td>
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<tr>
<td>c</td>
<td>c</td>
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<tr>
<td>d</td>
<td>d</td>
</tr>
<tr>
<td>e</td>
<td></td>
</tr>
<tr>
<td>d Can use comments book to encourage people to put their views in there and then</td>
<td>c Resource intensive if staffed all the time</td>
</tr>
<tr>
<td>d Can use comments book to encourage people to put their views in there and then</td>
<td>d An unconstructive response in a comments book can set the tone for others that follow and does not allow opportunity to discuss reasons for the response</td>
</tr>
</tbody>
</table>

## Leaflets and written documents

### Key points
1. To present information about a specific issue
2. Style should depend on audience
3. Should be open and honest
4. Can be used to set out the organisation’s position, policies and processes
5. Can be used in writing or electronically

### Advantages
- a. May be seen as a starting point for consultation
- b. Accepted way of disseminating information
- c. Can be used for PR
- d. Keeps the public informed and aware of issues

### Drawbacks
- a. Documents can go out of date quickly
- b. May be seen as a fait accompli
- c. No guarantee the documents will be read
- d. Unsure whether the documents will lead to any change
- e. Can be resource heavy in terms of producing materials, distribution and potential wastage

## The press

### Key points
1. To publicise your work
2. Newspapers can carry your message as an advertisement – which you pay for and control
3. If an editorial, it is free but outside your control

### Advantages
- a. Fast and usually effective way of bringing issues to people’s attention
- b. Can reach a large audience in local or national newspapers
- c. Can target an audience through specialist press (e.g. minority ethnic newspapers)

### Drawbacks
- a. Only get simple message across
- b. Might not actually get the information into print after a lot of effort
- c. Cannot control what happens
- d. May be misquoted if you do not pay for advert
- e. Can be expensive
## Approaches related to getting information

### Citizens’ panels

#### Key points
1. Can build a picture of a community’s priorities
2. Can get a measure of public opinion on a specific issue
3. Can be conducted through telephone interviews and written or electronic surveys
4. Panel members usually recruited via the telephone, advertisements or writing to a random selection of the population
5. Panel members’ names and addresses held with their permission on a database
6. They are informed of the results of each survey e.g. through a newsletter
7. Topics and questions must come from the organisation and feed directly back into decision making processes
8. Many local councils have citizens’ panels that could potentially be accessed by the regulators

#### Advantages
- Panels can be made up of between 1,000-3,000 people depending on the size of the population
- Panel members recruited to reflect socio-economic make-up of a community and therefore broadly representative
- People must give consent to be a panel member and so there is a higher response rate
- If managed by an external facilitator then gives independence and credibility
- A steering group usually agrees the questions and links the panel with the organisation’s decision making forums
- Panel members can receive information in advance – electronically, by phone or in writing
- Panels can give a quick measure of public opinion on a specific issue that can be defined fairly and objectively
- Creates continuing dialogue with participants
- Special needs of particular members can be accommodated

#### Drawbacks
- Can take up lots of time and money
- Requires coordination and proper resourcing to manage the system effectively
- Requires research methodology skills to manage the system effectively
- Does not involve active participation in decision making or develop links to the community
- Language can be a problem and translation/interpreting maybe needed
- As panel members become more experienced they want to debate issues, which is time consuming and adds to the expense
- People move or lose interest, meaning that more panel members need to be recruited
- As panels do not encourage debate, answers might be superficial
- Panel members can become linked to the organisation, losing objectivity and stop being representative
Open surgeries

**Key points**
1. Provides an opportunity to discuss issues with organisational representatives

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Drawbacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>a  Can involve Council members</td>
<td>a  Has a political angle to it</td>
</tr>
<tr>
<td>b  Can build healthy partnerships with other organisations</td>
<td>b  Could be waste of time for those involved if no commitment from the decision makers to listen</td>
</tr>
<tr>
<td>c  Ongoing dialogue can be established</td>
<td>c  May be used only for complaints or problems</td>
</tr>
<tr>
<td>d  Allows people to challenge and question and boosts accountability</td>
<td>d  May get the same people all the time</td>
</tr>
<tr>
<td></td>
<td>e  Takes a senior member's time on a regular basis</td>
</tr>
<tr>
<td></td>
<td>f  Generates further work to feedback to planners/developers/managers particularly if the session is designed for problem solving</td>
</tr>
</tbody>
</table>

Patient diaries

**Key points**
1. Individuals follow a set of guide questions to keep a record of their treatment over time
2. Important to brief people well before they start and this is best done face-to-face

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Drawbacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>a  Gives patients and carers a feeling of being listened to and acknowledges that their own issues will be taken seriously</td>
<td>a  Usefulness for regulators not that clear</td>
</tr>
<tr>
<td>b  Allows patients and carers to reflect and expand on ideas and solutions</td>
<td>b  Those who have completed the diaries will want to see action as they have invested a lot of time</td>
</tr>
<tr>
<td>c  If used over time can be used to develop trust</td>
<td>c  Danger of collecting irrelevant information</td>
</tr>
<tr>
<td>d  Provides in-depth information of a qualitative nature</td>
<td>d  Can be time consuming to analyse</td>
</tr>
<tr>
<td>e  Guide questions can be used to probe further issues</td>
<td>e  Unless the guide questions relate to patient experiences and are written in their language then can be distracting and compromise the information</td>
</tr>
<tr>
<td>f  Records events and feelings as and when they happen</td>
<td>f  Need to read the whole diary to understand the information</td>
</tr>
<tr>
<td>g  Working from the patient’s perspective means that you can uncover other issues</td>
<td>g  Only applicable to those who are confident in their literacy skills</td>
</tr>
</tbody>
</table>
### Radio or live phone-ins

**Key points**

1. Radio stations cover stories/issues and invite people to phone in if they see it as important
2. They might offer you opportunity to answer questions live on the air
3. Alternatively some stations have community programmes where issues can be debated

**Advantages**

| a. | A fast and effective way of bringing things to people’s attention |
| b. | Opportunity to present individuals and the organisation with a human face rather than as a bureaucracy |
| c. | Opportunity for education/dissemination |
| d. | Can reach people who would otherwise be difficult to reach |
| e. | Usually resource light |

**Drawbacks**

| a. | Can be risky as may generate a negative response |
| b. | Can put individuals on the spot which might be uncomfortable |
| c. | Individuals might not give their best performance |
| d. | Might not be an appropriate radio station to use |

### Self-completed questionnaire

**Key points**

1. Allows the collection of statistical information
2. Sets of questions on a form to hand out or mail to people for them to fill in

**Advantages**

| a. | A way of getting relevant and usually quantifiable information |
| b. | Information obtained will relate to the issue |
| c. | If well done can collect useful information from large numbers or from representative samples |
| d. | If done face-to-face may increase response but will also increase cost |
| e. | Flexible and adaptable to a large number of issues |
| f. | Can give baseline data which can then be used to measure or monitor against |
| g. | Can use a professional organisation to do the work which would give it more independence |

**Drawbacks**

| a. | Not good for qualitative information |
| b. | Not in-depth as no opportunity to explore issues, ideas or experiences further |
| c. | Possible low response rate or biased response |
| d. | Provides only a snapshot at one point in time |
| e. | Can be difficult to administer |
| f. | Professional help may be needed to design and undertake the survey so that the results are valid and reliable |
## Semi-structured one-to-one interviews

### Key points
1. Aims to obtain feedback or explore an issue or service
2. Enables the interviewee to discuss and consider their own feelings and concerns
3. Can be face-to-face or over the telephone
4. Interviewer aims to cover set topics without asking the interviewee to answer specific questions from a limited range of possible answers
5. Produce qualitative data

### Advantages
- a. Obtains relevant information using a semi-structured approach
- b. Targets specific audiences which can ensure representative cross-section of the population
- c. Is structured enough to allow some comparisons
- d. Allows freedom to explore general views/perceptions in more detail
- e. Provides a framework for discussion
- f. Can use external organisations to do the work which will add independence
- h. Can be useful for exploring sensitive topics

### Drawbacks
- a. Requires good interviewing skills
- b. Need to meet sufficient people for answers to be generalised to the overall group under consideration
- c. Need expertise to prepare overall framework for interview
- e. Data analysis skills needed for qualitative data
- f. Can be difficult to organise interview times/dates
- g. Costly – time consuming and resource intensive for the number of people seen
Structured one-to-one interviews

Key points
1. Interviewer asks a number of pre-determined questions and allocates the answers to one of a predetermined set of possible responses
2. Can be face-to-face or over the telephone
3. Analysis relatively straightforward

Advantages
a. Approach lends itself to a wide topic area
b. Quick and less costly than semi-structured interviews
c. Can use a professional organisation to do the work providing more independence
d. Allows for tick box answers leading to easier data analysis that can be quantified
e. The people being interviewed do not need training/provision of information
f. The interviewers do not need to be as skilled as those who undertake semi-structured interviews

Drawbacks
a. Not very good for exploring people’s reasons, values or feelings about an issue
b. Rather prescriptive – may reflect own agendas, perceptions and prejudices
c. Only allows for minimum input from the respondent
d. Respondent may be influenced by the interviewer e.g. their age, gender, culture, ethnicity
e. Needs expertise to design the questionnaire
f. Can be costly but is less resource intensive than semi-structured questionnaires
### Approaches related to forums for debate

#### Focus groups

**Key points**
1. In-depth discussions of between 6-12 people focused on a specific set of issues or topics
2. Someone facilitates the discussion and ideally a note taker will be present

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Drawbacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Interaction between participants can produce new ideas</td>
<td>a Group norms might silence/inhibit individual voices – needs experienced facilitation</td>
</tr>
<tr>
<td>b Useful for providing an overview on issues about which little is known and for identifying issues to be explored later in more depth</td>
<td>b Does not generate information in terms of any quantitative data</td>
</tr>
<tr>
<td>c Possible to recruit participants on specific criteria e.g. sex, age and geography</td>
<td>c Mixed groups may not work well together</td>
</tr>
<tr>
<td>d Allows a framework for discussion to be identified whilst the content emerges from the interaction</td>
<td>d Not a rigid approach and therefore the information you get from each group might not be directly comparable</td>
</tr>
<tr>
<td>e Views of normally silent voices may be elicited by a skilled facilitator who will also manage the group dynamics and balance the contributions of different participants</td>
<td>e Can be costly to employ an experienced and skilled facilitator and note takers</td>
</tr>
<tr>
<td>f Facilitator can interact directly with the participants allowing for the clarification of responses. They can probe for further information interpreting body language</td>
<td>f Harder to ensure confidentiality in a group than in an individual interview – so the group must agree ground rules</td>
</tr>
<tr>
<td>g It can empower people by having their views endorsed by others and move them from a negative to a positive position</td>
<td>g When patients, the public and professionals are in the same group it is likely to need special handling</td>
</tr>
<tr>
<td>h Can include people with literacy difficulties</td>
<td>h Might be difficult to find experienced facilitators who can work in a range of languages/with interpreters</td>
</tr>
<tr>
<td>i Can provide in-depth information on views and the feelings behind them</td>
<td>i May need to hold a number of groups to validate findings</td>
</tr>
<tr>
<td>j Can include and gain views of people who think they have nothing to say</td>
<td>j Gender, culture, ethnicity or age of the facilitator might influence the discussion</td>
</tr>
<tr>
<td>k Can be a learning experience for the participants</td>
<td>k Can be difficult getting a group of the right size – ideally between 6-12 people</td>
</tr>
<tr>
<td>l Can bring similar people together which may result in the formation of a sustainable group</td>
<td>l Small sample limits general applicability of results</td>
</tr>
<tr>
<td>m Usually enjoyed by participants</td>
<td>m Group views can tend to go for the middle ground to keep everyone happy</td>
</tr>
<tr>
<td>n Difficult to prioritise issues</td>
<td></td>
</tr>
</tbody>
</table>
# Meetings with patient and carer groups

## Key points

1. Organised groups of people focusing around a common illness, condition, service or geographical area
2. Can be local groups or branches of national patient/care organisations. They can be support groups or groups set up to give a user view

## Advantages

<table>
<thead>
<tr>
<th></th>
<th>A captive audience of knowledgeable and committed individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Relatively easy and quick to make contact</td>
</tr>
<tr>
<td></td>
<td>Can put you in touch with users and carers for future focus groups</td>
</tr>
<tr>
<td></td>
<td>Can build up an ongoing partnership</td>
</tr>
<tr>
<td></td>
<td>Produces collective knowledge which does not rely on the views of one individual</td>
</tr>
</tbody>
</table>

## Drawbacks

<table>
<thead>
<tr>
<th></th>
<th>May only wish to offer feedback on issues that relate to their particular experience</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Could feel strongly about one issue</td>
</tr>
<tr>
<td></td>
<td>May need to involve other users to obtain a full range of views</td>
</tr>
<tr>
<td></td>
<td>Need to be clear about purpose at outset: involvement, consultation or lobbying</td>
</tr>
</tbody>
</table>
# Public meetings

## Key points
1. A meeting for which there is an open invitation
2. There may be a set agenda or discussion may focus on issues raised at the meeting
3. In the past, have tended to be used as a default position although are now being used more creatively and there has been more involvement and engagement e.g. market place events

## Advantages
- a. Opportunity for a wide range of people to comment or raise issues and directly challenge
- b. Opportunity for those organising the meeting to put their side of the story
- c. Has PR value
- d. Provides an opportunity for joint consultation on areas of common interest
- e. Offers public the opportunity to challenge issues directly which increases accountability
- f. Lay bodies and pressure groups like public meetings as they give an opportunity to challenge
- g. Provides an indication of the problem areas that may not have emerged previously

## Drawbacks
- a. May be a very low turn out
- b. Risky as no control over what happens
- c. May be a quick fix – perceived as tokenistic
- d. Needs organisation, time and money
- e. Voluntary sector needs lots of advance warning
- f. Audience might be hostile – police presence?
- g. Public meetings sometimes seen as the default position even though attendees are likely to be unrepresentative
- h. May only attract pressure groups/lobbyists
- i. Never a good time or place
- j. May need to hold more than one which means more resources
## Seminars

### Key points
1. A discussion group that aims to impart, exchange and receive information
2. More input from the facilitator than with a focus group

### Advantages
- a. Opportunity to provide information and seek views
- b. A way of securing partnership and involvement
- c. A way of creating a listening culture and gaining sympathetic views based on a better understanding of the issues
- d. A means of promoting partnership and equality between agencies and the public
- e. A way of identifying areas where information will help improve participation
- f. Specific representative groups are likely to find this process rewarding

### Drawbacks
- a. Can be boring for the public if not well done i.e. people talking at them rather than engaging them – need to use range of techniques
- b. Needs careful planning for best results
- c. May attract individuals who only want to air grievances
- d. Costly in terms of reimbursing expenses, room hire and organisation

## Targeting interested people

### Key points
1. Focuses on engaging with people where they come together for another specific purpose e.g. older people at lunch clubs, young people at clubs

### Advantages
- a. Potential to reach large mixed audience and identify trends and issues
- b. Obtains a wide cross-section of views
- c. Provides opportunity to gain feedback, give information, target existing activities/meetings, form a group that will act in the longer term, have a wide ranging discussion

### Drawbacks
- a. People may not be interested and therefore not wish to participate
- b. May be difficult to use all of the information obtained
- c. May be viewed as anecdotal and so too subjective
- d. Time consuming – are the people who need to listen prepared to go out and engage with people at a time that suits the group?
Approaches related to participation

Citizens' juries

**Key points**
1. Particularly appropriate for involving the public in wider decision-making especially about strategic planning choices or prioritisation
2. Jury consists of 12-16 people selected as a cross section of the community
3. Meet for several days to hear witness evidence and examine the issue in depth before making recommendations
4. Independent moderator/facilitator assists the smooth-running of the process
5. People participate as citizens not as patients, users or carers

**Advantages**
- People reflect broadly the characteristics of the wider population
- Jurors are given detailed information about the issue they are asked to decide on
- Possible for organisations to pose difficult issues around policy and prioritisation of services – they may be subjective involving value judgments in reaching decisions
- Jurors can call in other people to give evidence to them so they are able to get a rounded understanding
- Process is not rushed and jurors are able to justify and discuss their decision as a group
- If the organisation makes a decision different from a jury’s decision, it has committed itself to justify the reason why and make clear the basis on which the decision was made
- Aids openness in decision making as proceedings should take place in public

**Drawbacks**
- Although the jurors are drawn from the population their different views and values might not reflect those of the population
- You may attract jurors who find it difficult to articulate their views, concerns, experiences
- It may be difficult to clarify and focus on the exact question to be considered
- There might be a range of decisions that are needed and it might be difficult to decide which to open up to the jury
- Takes an enormous amount of planning to make it successful – might take one person all their time for a few months
- Costly at around £25,000 just for the jury not counting hidden internal planning costs such as staff time
- The organisation is not obliged to act on the jury’s decision and may choose not to but should explain its reasons for this
- As citizens' juries are split into cells to make decisions, might be more difficult to reach consensus

39 See also S Davies, S Elizabeth, B Hanley, B New and B Sang, 1998, Ordinary Wisdom Reflections on an experiment in citizenship and health, Kings Fund, London.
### Health panels

#### Key points

1. Primarily used to explore people’s views about policy issues and the allocation of resources
2. Usually made up of about 8-12 people recruited using a quota sampling technique to reflect socio-economic factors
3. Each member works for a set amount of time and is then replaced by a new member
4. Panels usually discuss live topics i.e. of genuine concern to the organisation that is running the panels
5. Panels can raise issues of concern to the members
6. Panels can also be run on the internet or by post – this allows organisations to reach those who would not normally wish to attend a session (e.g. young men)

#### Advantages

- a. Health panels offer the opportunity for complex issues to be discussed and considered by people in an informed way
- b. Panels are useful for views on resource allocation and priorities
- c. People on the panels gain information on a wide range of issues
- d. Panel members receive some information prior to the panel meeting and are asked to get views from their families and friends
- e. Panels reflect a cross section of the population and so provide an opportunity for minority ethnic communities and others to give their views
- f. Can be externally facilitated increasing independence and credibility
- g. Discussions are usually recorded and can be analysed and presented back to the organisation – this can be done independently to reduce bias
- h. People can meet regularly, providing an ongoing dialogue with the community
- i. Seen as an enjoyable experience by participants as they have a voice and can engage in meaningful debate
- j. Can move towards consensus as a group
- k. Panel members’ opinions can be used to contribute to the professional debate

#### Drawbacks

- a. If too many issues are discussed there will be little time for debate and members may end up just giving their views rather than the reasoning behind them
- b. As professionals draw up information for the panels beforehand they might be unknowingly selective – some panels employ an independent facilitator as a balance
- c. Additional information requested by panel members may not be available during the panel
- d. Organisation does not have to base its decision on the panel’s view but may suffer if the responses of the panel are dealt with in a patronising and tokenistic way
- e. Does not provide quantitative information because the number of members is too small
- f. Success of the discussion dependent on the skill of the facilitator
- g. Results of the discussion may be less credible if the facilitator is not independent
- h. Can be costly to maintain
- i. There may not be time to get the reasons for the panel’s views – often views are collected at the end using voting slips
## Approaches related to partnership

### Community development

**Key points**

1. Involves the community in identifying their own needs and finding ways to address them e.g. through influencing and informing organisations to help shape provision
2. Likely to involve supporting the community to set up systems and projects

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Drawbacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Strengthens community infrastructure and is a basis for leveraging in other resources</td>
<td>a Can be very local</td>
</tr>
<tr>
<td>b Can establish links with traditionally hard to reach groups</td>
<td>b Not about representativeness which can be a problem</td>
</tr>
<tr>
<td>c Focuses on lay rather than professional views</td>
<td>c Costs in the worker’s salary and in supporting the project</td>
</tr>
<tr>
<td>d Develops confidence and self esteem in communities and offers the opportunity to develop new skills and knowledge</td>
<td>d Results are unpredictable</td>
</tr>
<tr>
<td>e Allows cross-sector working and brings statutory and voluntary agencies together with local communities</td>
<td>e Identified needs cannot necessarily be implemented as may involve other agencies</td>
</tr>
<tr>
<td>f Is long-term, allowing in-depth understanding and commitment</td>
<td>f By the nature of the work there is a need to develop open and honest relationships which takes time, commitment and experience</td>
</tr>
<tr>
<td>g Can be a starting point to attract more and bigger funding packages</td>
<td>g Time consuming to get it right initially – requires long term commitment and funding</td>
</tr>
<tr>
<td></td>
<td>h Outputs might be costly to implement</td>
</tr>
<tr>
<td></td>
<td>i May not be an outcome for a long period of time</td>
</tr>
</tbody>
</table>
### Large group processes e.g. search conference, open space, team syntegrity

**Definitions**
Search conference, open space and team syntegrity are specific types of consultation methods that allow groups to be in charge of the agenda and direct the flow of the meeting.

**Key points**
1. Designed to work with a large number of stakeholders (30-120), over three to five days, in facilitated dialogue to establish shared objectives to manage change.
2. Appropriate for involving a motivated and diverse range of stakeholders.
3. Most effective on issues that affect a large number of people across communities.
4. Assumes that people are capable of taking some control and organise themselves for the task at hand.

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Drawbacks</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Speed of implementation of outcomes</td>
<td>a Time consuming</td>
</tr>
<tr>
<td>b Possible to involve people who are closest to the issue and exchange thoughts with other stakeholders</td>
<td>b Takes an enormous amount of planning and organising</td>
</tr>
<tr>
<td>c Highly participative assuming that people want to be engaged and have a voice</td>
<td>c Can be costly</td>
</tr>
<tr>
<td>d Emphasis on self management in small group work</td>
<td></td>
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<tr>
<td>e Openness</td>
<td></td>
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<tr>
<td>f Everyone is equal and expert</td>
<td></td>
</tr>
<tr>
<td>g Method upholds the idea that individuals are experts in their own lives</td>
<td></td>
</tr>
<tr>
<td>h Facilitators but no other experts</td>
<td></td>
</tr>
<tr>
<td>i Consensual processes</td>
<td></td>
</tr>
<tr>
<td>j Processes can bring together stakeholders who are often opposed to each other</td>
<td></td>
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</tbody>
</table>
Appendix 2 - PPI toolkits, guides and reports

Sources of information about PPI in the four countries:
Web-libraries, toolkits, guides and reports

1  **NHS Evidence**: The Patient and Public Involvement Specialist Collection
   www.library.nhs.uk/ppi
   “This specialist collection aims to support the implementation of patient, user, carer and public involvement in health care by providing access, in one location, to the best information which is freely available on the Web.”
   Links to reports, toolkits and organisations that focus on:
   - Introduction to PPI
   - PPI in practice
   - Involving particular groups
   - Education for PPI and
   - Organisations supporting PPI
   This resource is managed by the King’s Fund www.kingsfund.org.uk

2  **Advice Centre for NHS Patient Survey Programme**
   www.nhssurveys.org
   This relates to NHS surveys concerning patient experience but contains broader information that could be used for other purposes.
   “The NHS patient survey programme systematically gathers the views of patients about the care they have recently received. This website is for those involved in the survey programme including NHS trusts, survey contractors, and patients who have been asked to complete a questionnaire”.
   It lists approved survey contractors www.nhssurveys.org/approvedcontractors and contains information and advice on survey questionnaires, including number of useful guides and factsheets to help organisations analyse and interpret their data and act on the results:
   www.nhssurveys.org/improvinghealthcare
   - Using patient feedback: a practical toolkit
   - Understanding what matters: A guide to using patient feedback to transform services
   - A Guide to Sharing your Survey Results
   - A Guide to Understanding your Survey Results
   - A Guide to Action Planning
   - A Guide to the NHS Patient Survey Programme
3 **Health in Partnership**

www.dh.gov.uk


"Health in Partnership is a research programme supporting greater patient, carer and public participation in healthcare decision-making. The programme of 12 studies was funded by the UK Department of Health and launched in 1999."

4 **National Consumer Council (NCC):** now Consumer Focus

www.consumerfocus.org.uk

Engaging people in healthcare regulation: a route map for action by Abena Dadze-Arthur (National Consumer Council, January 2008) proposes a series of actions to help achieve effective PPI in the regulation of service provision. It makes a series of recommendations, some of which could as easily apply to the regulators of health professionals.


5 **Healthcare Commission,** now Care Quality Commission (England) and Healthcare Inspectorate Wales


A national study of how well healthcare organisations engage local people in planning and improving their services.

6 **Strengthening Accountability:** involving patients and the public (DH)


"This practice guidance is to help NHS staff address and share the why and the what of patient and public involvement in the context of Section 11 of the Health and Social Care Act - why it is important and what it entails."

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40 On 1 October 2008 the Welsh, Scottish and National Consumer Councils merged with Postwatch and Energywatch to form Consumer Focus, the new champion for consumers' interests in England, Scotland and Wales, and for postal consumers in Northern Ireland. Legacy documents published by the National Consumer Council (NCC) have been archived and are available through Consumer Focus’s website.

41 On 1 April 2009, the Care Quality Commission, the independent regulator for Health, mental health and social care services, took over the Healthcare Commission’s work.
7 Building Strong Foundations: involving people in the NHS (NHS Scotland)
www.sehd.scot.nhs.uk/involvingpeople/bsftoolkit.htm

The “toolkit” is a guide to some of the approaches available to facilitate involving people. The approaches are not only health related but generic in their use although they are becoming more widely used within the Health Service with a view to engaging the public in decision-making for the future of the Health Service”.

8 Signposts 1: A practical guide to public and patient involvement in Wales

9 Signposts 2: Putting public and patient involvement into practice in Wales
http://chwaraedysgutycymru.gov.uk/docrepos/40382/dhss/reportsenglish/signposts2-e.pdf?lang=cy

10 Improvement and Development Agency for local government (IDeA)
www.idea.gov.uk

“The IDeA supports improvement and innovation in local government”.

Connecting with Communities www.idea.gov.uk/idk/core/page.do?pageId=7816073

“This resource helps councils improve their communication with residents, staff and other stakeholders. It covers all the key topics and contains the latest tips on best practice and case studies – including two new sections on e-communications and communications in a recession”.

11 Office for Disability Issues
www.officefordisability.gov.uk

The Office for Disability Issues’ toolkit to help local authorities produce better information for disabled people:

a. Communications toolkit for local government
www.odi.gov.uk/working/improving-information.php

The toolkit encourages councils to involve disabled people, produce accessible information, test their products, signpost to other services and have a disability champion. It offers five principles for improving information, good practice points related to each and examples of success.

b. Images of disability

“This guidance draws on a range of good practice guidance. It is a summary of the law and existing best practice to the best of our knowledge”.
12 **International Teledemocracy Centre (ITC)**  
[www.itc.napier.ac.uk](http://www.itc.napier.ac.uk)  

“The International Teledemocracy Centre aims to develop and apply advanced information and communication technology to enhance and support the democratic decision-making process. ITC is part of the Faculty of Computing and Engineering at Napier University. It was set up in 1999 by Napier University in partnership with BT Scotland.”

The ITC e-democracy toolkit includes e-consultation:

“E-consultant is a web-based application that allows Internet users to make responses to a consultation, read related consultation documents, see who else has contributed and the nature of their response, and return to read feedback on the outcomes of the process. The website’s contents, appearance, structure and functions are tailored by ITC to meet the needs of consulting organisation. During the e-consultation ITC monitors the site using Conditions of Use agreed beforehand.”

13 **14Ps (Preparing professionals for partnership with the public)**  
[www.4ps.com](http://www.4ps.com)  

“4Ps – the specialist development agency working to implement the patient and public involvement agenda in health and social care”.

The website includes a helpful analysis of national ‘how to’ toolkits:  
[www.4ps.info/partner/swthamesrenal/files/toolkits.pdf](http://www.4ps.info/partner/swthamesrenal/files/toolkits.pdf)

[www.neweconomics.org](http://www.neweconomics.org)  

This handbook looks at what is meant by participation, drawing from examples around the world. It gives guidance on how to choose between them, how to use them properly and where to go for more information. It can be downloaded here:  

15 **A guide to actively involving young people in research**: for researchers, research commissioners and managers  
[www.invo.org.uk](http://www.invo.org.uk) (young people)  

Published by INVOLVE, Sept 2004 [www.involve.org.uk](http://www.involve.org.uk)

16 **National Institute for Innovation and Improvement 2005**: Improvement Leaders’ Guide to Involving Patients and Carers  

17 **Involving the public in NHS, social care and public health research**: Briefing notes for researchers  
[www.invo.org.uk](http://www.invo.org.uk)  

Published by INVOLVE, Feb 2004 [www.involve.org.uk](http://www.involve.org.uk)
18 The NHS Centre for Involvement (NCI) closed on 31st August 2009 at the completion of its contract with the Department of Health.

Published resources will continue to be available on this website for a limited period after closure. The Involvement Exchange has also closed, but the LINks Exchange will continue to operate as normal. After closure all enquiries about involvement or LINks-related matters should be directed to Melanie Smith at the Department of Health: melanie.smith@dh.gsi.gov.uk

The NCI website recommends that you might like to visit some other websites that deal with Patient and Public Involvement such as:

CHAIN (Contact, Help, Advice and Information Networks)
http://chain.ulcc.ac.uk/chain/index.html
An online network for people working in health and social care. It is based around specific areas of interest, and gives people a simple and informal way of contacting each other to exchange ideas and share knowledge. CHAIN is multi-professional and cross organisational.

NHS Networks
www.networks.nhs.uk
NHS Networks is a means of promoting and connecting the many networks which exist throughout the NHS - and encouraging the formation of new ones. PPI specific information and links: www.networks.nhs.uk/151

LINks Exchange
www.lx.nhs.uk
The LINks exchange (LX) is run by NHS Choices as a network for sharing best practice and supporting and developing those implementing Local Government Networks (LINks). The network provides access to information and guidance and will enable those involved in implementing LINks to share best practice.

19 Viewfinder: A policy maker’s guide to public involvement
www.nationalschool.gov.uk/policyhub/docs/Viewfinder.pdf
CabinetOffice, no date
This guide is about public involvement in government policy. It has useful information relevant to the work of the regulating bodies as it relates to policy development and planning.

20 Portsmouth City Council, Consulting people toolkit
www.idea.gov.uk/idk/aio/1716957
Useful, although it needs to be set against the advice that this is only one rather top-down method.
Appendix 3 - Organisations that support PPI (e.g. consultancy, training, research)

Academic/charitable organisations

1. **The Cochrane Collaboration Consumer Network**  
   www.cochrane.org/consumers/homepage.htm  
   "The Cochrane Collaboration undertakes systematic reviews of published research in healthcare. The Consumer Network promotes consumer involvement in research (including its own) and promotes the wider communication of its findings."

2. **ContinYou**  
   www.continyou.org.uk  
   "ContinYou is one of the UK's leading community learning organisations. We aim to offer opportunities to people who have gained the least from formal education and training. We work with a range of professional people, organisations and agencies to enhance what they do to change lives through learning."

3. **Institute for Public Policy Research**  
   www.ippr.org  
   One of the IPPR’s teams is the ‘Strategic Research Team’. They work as specialised consultants using and training on qualitative and public engagement techniques.
   
   "The Strategic Research Team's core aim is to identify emerging social justice issues and bring them to the attention of government, corporate and voluntary sectors via imaginative research techniques and high quality analysis. The SRT works very closely with research teams across IPPR, providing qualitative research advice, social trend mapping and innovative research ideas."

4. **Involve**  
   www.involve.org.uk  
   "Involve are public participation specialists; bringing institutions, communities and citizens together to accelerate innovation, understanding discussion and change. Involve makes a practical difference by delivering the highest quality public participation processes possible as well as undertaking rigorous research and policy analysis into what works.
   
   It is a not for profit organisation that receives funding from the Joseph Rowntree Charitable Trust and the Esmée Fairbairn Foundation."

5. **INVOLVE**  
   www.invo.org.uk  
   INVOLVE is a national advisory group, funded by the National Institute for Health Research (NIHR). Its role is to support and promote active public involvement in NHS, public health and social care research.
   
   The website includes:
   
   a. Publications such as a guide to involving young people and briefing notes for researchers for involving public in research (see list of toolkits/guides on page 57);
   
   b. A database of training providers in the field of public involvement in research; and
c. A links page – giving details of R&D websites and organisations that might be helpful for researchers and members of the public who have an interest in active public involvement in research.

6 **NHS Evidence - patient and public involvement**  [www.library.nhs.uk/PPI](http://www.library.nhs.uk/PPI)  
“This specialist collection aims to support the implementation of patient, user, carer and public involvement in health care by providing access, in one location, to the best information which is freely available on the Web.”

7 **NHS Networks**  [www.networks.nhs.uk/151](http://www.networks.nhs.uk/151)  
The patient and public involvement page lists PPI networks in the NHS Networks register and includes useful PPI links and downloads.

8 **NICE**  
[www.nice.org.uk/getinvolved/patientandpublicinvolvement/patient_and_public_involvement.jsp](http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/patient_and_public_involvement.jsp)  
“The views of patients, carers and the public matter to NICE. We want to involve them, as well as doctors, nurses, other healthcare professionals and managers in our work.

The Patient and Public Involvement Programme (PPIP) provides advice and support to NICE on patient, carer and public involvement. The PPIP currently works with NICE to develop opportunities for involving patients, carers and members of the public across NICE’s work programmes.”

9 **Participation Works**  [www.participationworks.org.uk](http://www.participationworks.org.uk)  
“Participation Works enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives.

We are a consortium made up of the following six agencies: the British Youth Council, Children’s Rights Alliance for England, National Children’s Bureau, The National Youth Agency, National Council for Voluntary Youth Services and Save the Children - England.

We offer: training and consultancy; a national network of participation workers (the Participation Works Network for England); and an online Gateway that offers a wide selection of information, the latest news and supporting resources on participation.”

10 **People and Participation**  [www.peopleandparticipation.net/display/Involve/Home](http://www.peopleandparticipation.net/display/Involve/Home)  
“People and Participation is based on Involve’s successful book by the same name which was launched in 2005. The book provides a useful summary of participatory methods and practice but given the number of methods and speed of the development of new methods it is impossible for a printed publication to stay accurate for long. The reason for transferring People & Participation to the web is to allow us to maintain more, and more up to date information about participation. It also allows use as the site user to add your knowledge and experience making the site a truly collaborative experience, something that a book simply cannot do.”

11 **Picker Institute Europe**  [www.pickereurope.org](http://www.pickereurope.org)  
“Picker Institute Europe is a not-for-profit organisation that makes patients' views count in healthcare.”
The institute's staff are qualified and experienced researchers and project managers who can provide you with strategic and technical support to:

a. Survey patients and staff
b. Improve quality through action planning and workshops to utilise patient experience
c. Involve patients and the public in commissioning
d. Understand what patients and local people want from their health services
e. Engage 'seldom heard' groups."

12 4Ps (Preparing Professionals for Public Participation)  www.4ps.com

"4Ps build on what health and social care staff do already and what they can do differently so providers, users and community all contribute to decisions"

Services are targeted primarily at NHS staff. 4Ps has produced a guide to toolkits (see toolkits list on page 57.

13 Research & Development Learning  www.rdlearning.org.uk

Its database gives details of training courses aimed at developing skills in involving users in research. The link that follows takes you to a web page (updated on a regular basis) which lists the courses on involving users in research.


Consultancies

1 Acton Shapiro consultancy & research  www.actonshapiro.co.uk

"Acton Shapiro has been delivering high-quality consultancy, evaluation and research services across health, social care and the third sector for more than 10 years. We are committed to finding practical solutions that work for individuals, organisations and communities.

Our clients include government departments/agencies, NHS organisations, local authorities, GP practices, independent health care providers, social enterprises and national voluntary organisations."

2 Commotion  www.commotionuk.com

"Established in 2004, Commotion helps to set up and run many projects that deliver a positive social and economic impact for society. These projects include:

- Community consultation and research
- Organising events and campaigns
- Fostering productive partnerships
- Developing new initiatives
- Training for staff"
We have a particular passion for initiatives that promote active and involved citizenship – and for projects that equip people with the skills, the confidence and the motivation to play their own part in strengthening democracy."

3 Finnamore Management Consultants  www.finnamore.net
Covers a variety of areas, including market analysis, partnership working and patient feedback. Finnamore Management Consultants – Planning Change

4 Opinion Leader Research  www.opinionleader.co.uk
"We draw on the widest range of research techniques to unpick complex and often controversial issues. We provide clients with insights and recommendations that are grounded in reality. We’re proud that our work helps them reach faster conclusions, make better decisions and develop more informed solutions.

Opinion Leader engages citizens using innovative techniques, enabling the public to explore complex policy issues and subjects deemed sensitive. Building effective dialogue between services and the populations affected by them helps our clients connect with their stakeholder audiences."

5 Participate  www.participate.uk.com
"With expertise in consultation, engagement, social research, communications and marketing, the team at Participate brings together all the skills public and private sector clients need for effective involvement and, more importantly, to encourage people to take part.

We believe in using innovative techniques that create a genuine desire in people to want to be involved and have their say. From traditional surveys to podcasts, deliberative events, stakeholder workshops, street events, online communities, focus groups, diary rooms and lots, lots more."

6 Silkap  www.silkapconsultants.co.uk
"Silkap Consultants specialise in research, user participation, service reviews, whole systems approaches, project management and diversity training for health and social care organisations. We combine our passion for equality with a belief that our work should have a practical value in improving the organisation, management and delivery of services and the overall experience for the user. We have stimulated pioneering work in the health and social care field in the last two decades on methods to engage diverse stakeholders, good practice in commissioning, quality assurance, language support services, ethnicity monitoring and HIV and sexual health. Our aim is to build confidence and capacity within your organisation and develop realistic strategies that move beyond the 'politically correct'."

7 Stakeholder Research  www.stakeholderresearch.com/index.htm
"Our consulting model is rooted in the belief that a stakeholder-inclusive approach to strategies and solutions can provide an organization with enduring competencies in value creation. Our core competencies include:

a. Engaging stakeholders in constructive dialogue that challenges established ways of thinking, brings fresh, multiple perspectives to familiar issues and seeks value-add solutions"
b. Building relationships that maximize economic and social gain throughout an organization’s value chain

c. Creating learning contexts that enable new ideas and actions to emerge

d. Communicating outcomes in support of continuous learning communities.”

8 **Vision Twenty One**  **www.visiontwentyone.co.uk**

“Vision Twentyone is an independent, professional consultancy offering strategic advice to clients from the public, private and third sectors, across the UK. Whether you are looking to:

- consult with local people about changes to services
- engage people in meaningful and deliberative discussions about key issues
- win community support for a planning application
- engage with local councillors to discuss a development
- conduct research that allows you to put your customers at the heart of your business
- use research results to lobby Parliamentarians and other decision-makers and influencers
- develop a marketing strategy or receive professional crisis management support.

Vision Twenty One has the professionals and expertise to tailor an approach to meet your needs and budget.”
Appendix 4 - Patient and public representative groups

This appendix focuses on groups that seek to represent the views of patients and the public. Most of these bodies are UK-wide although a few focus on one of the four UK countries.

Databases and website lists of patient/user organisations

1 Patient UK  www.patient.co.uk

"Details of 1852 UK patient support organisations, self help groups, health and disease information providers, etc. Each entry is cross referenced and details are checked annually."

A comprehensive database. Each entry gives brief description of the organisation, plus full contact details including web links

2 International Alliance of Patients’ Organizations  www.patientsorganizations.org

"IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world.

Our members are patients’ organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability."

The website includes a fully searchable Global Directory of Patients' Organizations, which is described as 'the most extensive and reliable listing of its kind'.

3 Scottish Council for Voluntary Organisations (SCVO)  www.scvo.org.uk

"The Scottish Council for Voluntary Organisations is the national body representing the voluntary sector. SCVO seeks to advance the values and shared interests of the voluntary sector."

The SCVO website includes a database (SCVO – Information – Voluntary Sector Database) of voluntary sector organisations that can be searched by the organisations’ name or main field of work. There are several relevant categories:

- Health care
- Hospitals and rehabilitation
- Mental health and crisis intervention
- Other health services
- Nursing homes
- Social care and development
- Social services
- Carers organisations
4 The National Council for Voluntary Organisations (NCVO) www.ncvo-vol.org.uk

“NCVO is a highly effective lobbying organisation and represents the views of its members, and the wider voluntary sector to government, the European Union and other bodies. We are also at the leading edge of research into, and analysis of, the voluntary sector.”

The NCVO has over 7,500 members and campaigns on generic issues affecting the whole voluntary sector. It focuses on influencing the English parliament and can give advice on UK-wide issues. It has an extensive website that includes an alphabetical list of members, with links.

5 Northern Ireland Council for Voluntary Action (NICVA) www.nicva.org

“The NICVA is the Northern Ireland Council for Voluntary Action, the umbrella body for voluntary and community organisations in Northern Ireland.”

NICVA has a database of voluntary organisations that can only be searched by keywords (i.e. there are no pre-defined categories to choose from). Searching on ‘health’ currently brings up 67 organisations.

6 Social Care Online www.scie-socialcareonline.org.uk

Social Care Online is an online database run by Social Care Institute for Excellence. It contains articles, journals and reports as well as links to other relevant websites. One section “contains links to hundreds of social care websites and related websites in England, Northern Ireland, Scotland and Wales. All sites are fully indexed and described by SCIE’s information managers.”

Individual organisations (not listed in Patient UK)

1 European Patients’ Forum www.eu-patient.eu

“EPF is the umbrella organisation of pan-European patient organisations active in the field of European public health and health advocacy.”

2 Scotland Patients Association www.scotlandpatients.com

“The Scotland Patients Association is an independent self-funding association which is there to help and support all patients in Scotland who need and request our help.”

Representative organisations that offer particular services

1 Carers UK www.carersuk.org

“Carers UK offers a wide range of consultancy services to health and social care sector organisations. This is based on our expertise of being at the cutting edge of policy development, our experience of helping organisations transform services and our knowledge of best practice, drawn from our network of over 1,000 organisations who work with carers.”

Consultancy services are targeted at local authorities, but they could be applied elsewhere.

2 Connect www.ukconnect.org

“Connect is a national charity. Our vision is a world where people with aphasia (communication disability) can find opportunity and fulfilment.”
We offer tailored training, mentoring, innovative resources, tried and tested service models, workshops and events. All of our work is in collaboration with people with aphasia, the real experts."

Connect provide training and consultancy to share knowledge, experience and expertise. They also produce publications and resources and undertake research.

3 **MENCAP**  [www.mencap.org.uk](http://www.mencap.org.uk)

"Mencap is the voice of learning disability. Everything we do is about valuing and supporting people with a learning disability, and their families and carers.

We are an individual membership organisation and our work is shaped by what our members tell us about their needs and wishes.

We also have strong relations with a local network of more than 500 affiliated groups. Our local groups are individual charities in their own right, but we work closely with them to ensure people with a learning disability and their families have support locally as well as nationally."

4 **RNID (The Royal National Institute for Deaf People)**  [www.RNID.org.uk](http://www.RNID.org.uk)

“Communication services – RNID provides a wide range of communication support services to individuals and organisations. These help deaf and hearing people to communicate with each other in many different situations.”

5 **RNIB (Royal National Institute of Blind People)**  [www.rnib.org](http://www.rnib.org)

Offers a range of products and services related to ‘good design’ and accessibility, including a guidance pack and consultancy services.
Appendix 5 - Patient and public involvement structures in the four UK countries

This Appendix describes the patient and public involvement structures in each of the four UK countries, with specific reference to the NHS. There are different, sometimes related, structures for social care.

Introduction

National PPI structures that primarily concern service provision rather than the regulation of individual health professionals, may appear to be unrelated to our work. It is, however, useful for regulators’ PPI and communications leads to know the different NHS PPI systems in each of the countries. This will help in planning some PPI projects when deciding who is invited to participate and/or how it might be possible to utilise their patient and public networks.

PPI mechanisms within the NHS have generally been put in place to involve patients and the public in the design, delivery and evaluation of public healthcare services. They also enable patients to complain about the service they have been given. The picture is complicated because, since the abolition of Community Health Councils in 2003 (except Wales) each of these PPI mechanisms has been subject to change.

Developments since 2000 have included

- NHS Plan 2000 placed an explicit duty on the health service to involve patients in how services are planned and developed
- NHS Act 2006 places a duty on Strategic Health Authorities, Primary Care Trusts, NHS Trusts and Foundation Trusts to ‘involve and consult’ patients and the public
- Local Government and Public Involvement in Health Act 2007 strengthened that duty to involve service users and their representatives and came into force in 2008,
- From April 2010 PCTs and SHAs will have a new duty to report on how people’s views have shaped commissioning decisions.
- From September 2011, NHS Trusts, Foundation Trusts and PCTs must prepare a ‘statement of involvement.

A changing picture

Following the Liberal Democrat-Conservative coalition formed after the May 2010 general election, it is likely that PPI mechanisms linked to NHS care will soon change again. The coalition government has stated that it intends to ‘increase democratic participation in the NHS and make the NHS more accountable to the patients that it serves’.

It has been reported that a new national body called Health Watch will be established to oversee feedback on GP practices. It is said that it will run a network of local bodies similar to Community Health Councils, which will include appointed officers, local volunteers, councillors and newly elected health officials. It will comprise a ‘network of local health watchdogs to monitor practice performance’.
Other reported government proposals include

- An independent NHS Board will be set up to allocate resources and provide commissioning guidelines
- SHAs will be abolished from April 2012
- GPs will have primary responsibility for commissioning services
- Primary Care Trusts will commission ‘residual services that are best undertaken at a wider level’ while acting ‘as a champion for patients’
- The Care Quality Commission’s role will be strengthened to become a ‘quality inspectorate’
- Monitor will become an ‘economic regulator’ focusing on access, competition and price-setting
- NICE is to be reformed and will focus on ‘value-based pricing’

Nothing is set in stone

Given the changing environment, before you use the information below, please check that it is up-to-date because it may be subject to change.

England

1 Local Involvement Networks (LINks)

PPI Forums which operated in every NHS Trust and PCT were replaced by Local Involvement Networks (LINks) in April 2009.

The role of a LINk is to:

- Encourage and support more people to get involved in shaping local care services; from helping to decide what services should be commissioned, to influencing the way they are run;
- Actively canvas every section of the community for their views and experiences of local care services;
- Provide the community with a mechanism for monitoring and reviewing local care services and the ability to hold them to account; and
- Tell those who commission, run and scrutinise local care services, what local people have recommended to help improve services.

LINks will build on the work of Forums but they will be open to anyone to join. They will cover all publicly funded health and social care services in an area, no matter who provides them (NHS, council, private sector or third sector). There are some exceptions such as children’s social services.
The idea of LINks is that they will make it easier for commissioners and managers to talk to communities and find out what they want. LINks are part of the local accountability and scrutiny arrangements and they will have powers requiring health and social care managers to respond to them. LINks will also be able to refer matters to Overview and Scrutiny Committees in councils that have social care responsibilities.

Each local authority (that provides social services) in England has been given funding and is under a legal duty to make contractual arrangements that enable LINk activities to take place.

2 Patient Advice and Liaison Services (PALS)

Each NHS Trust has a PALS to provide confidential advice and support to patients. PALS assist in resolving problems and concerns, give information on the NHS complaints procedures and how to access them.

3 Overview and Scrutiny Committees (OSCs)

OSCs were set up under the Local Government Act 2000. The Health and Social Care Act 2001 broadened their role to include the overview of issues affecting the health of local people and the scrutiny of the local NHS. An OSC may review and scrutinise any matter relating to the planning, provision and operation of health services in the area of its local authority. It can require the provision of information from a local NHS body and also require the attendance of an officer of a local NHS body to attend and answer questions. The OSC may make a report and recommendations to local NHS bodies and the local authority on any matter reviewed or scrutinised and require a written response within 28 days.

A local NHS body considering a substantial development of the health service, or a substantial variation in provision of the service, shall consult the OSC, which may comment on the proposals, focusing on whether consultation with stakeholders has been adequate. If the OSC does not believe the proposed changes are in the best interest of the health services in its area, or it believes there has been inadequate consultation, the OSC may refer the matter to the Secretary of State.

LINks have different, complementary, powers to the OSC and have the right to refer matters to the OSC and receive a response within 20 working days.

4 The Care Quality Commission (CQC)

The Care Quality Commission\(^{42}\) (CQC) replaced the Healthcare Commission, Commission for Social Care Inspection and the Mental Health Act Commission in March 2009.

As the new independent health and social care regulator for England, the role of CQC is to regulate health and adult social care services, whether provided by the NHS, local authorities, private companies or voluntary organisations. CQC also has the job of protecting the rights of people detained under the Mental Health Act.

The CQC’s main activities are:

- Registration of health and social care providers to ensure they are meeting essential common quality standards;

\(^{42}\) See www.cqc.org.uk
Monitoring and inspection of all health and adult social care;

Using their enforcement powers, such as fines and public warnings or closures, if standards are not being met;

Improving health and social care services by regularly reviewing how well those who arrange and provide services locally are performing. They also conduct special reviews on particular care services, care options or themes where there are particular concerns about quality; and

Reporting the outcomes of their work so that people who use services have information about the quality of their local health and adult social care services. It helps those who arrange and provide services to see where improvement is needed and learn from each other about what works best.

Voices Into Action is CQC’s charter on involving people. It commits the organisation to involving people who use health and adult social care services in everything it does, and to making sure that services involve people and respond to their views.43

CQC will also invite and take into account information about people’s views and experiences from LINks, Overview and Scrutiny Committees, Foundation Trust Boards of Governors, Learning Disability Partnership Boards and Local Children’s Safeguarding Boards, and has a legal duty to take into account information from LINks.

CQC is developing additional tools and guidance to help both providers and commissioners of services and its inspectors/assessors to evaluate involvement activities. This will cover the essential quality standards needed in order to be registered, and identifying any practice over and above essential standards, or any that falls below essential quality standards. This evaluation of involvement will not just include a review of policy and practice, but also the outcomes achieved for people.

The UK Parliament Health Committee undertook an inquiry into NHS PPI in England. It investigated:

The purpose of PPI;

The forms that are desirable, practical and offer good value for money;

The reasons that existing systems are being reformed after only three years; and

How LINks should be designed and how they should relate to and avoid overlap with other relating structures (such as OSCs, NHS Foundation Trust Boards, the Healthcare Commission).

It published its third report of session in mid-April 2007. It concluded:

“Throughout the inquiry we heard that what matters is not patient and public involvement structures but effective involvement of patients and the public. Structures and procedures, whether LINks, CHCs, PPIfs or Section 11 [Health and Social Care Act 2001], will have little effect if the health service is not prepared to listen and make changes as a result of what they learn. Indeed the existence of separate structures for patient and public involvement has tended to reinforce the NHS’ tokenistic approach. Effective patient and public involvement is about changing outcomes, about the NHS and social care providers putting patients and the public at the heart of what they do.

Many NHS and social care organisations have done patient and public involvement well. The existence of good practice shows that there is no reason why the NHS and social care providers cannot all effectively involve patients and the public.”

Scotland

In December 2000, Our National Health: A plan for action, a plan for change was launched in Scotland. Its focus was improving the health of the people of Scotland, delivering high quality health and social care services and more effectively addressing inequalities in health. The Scottish Executive has recognised that to achieve these aims there has to be a culture change in the way the service interacts with the people it serves and the way services are delivered - i.e. rather than do things to people; a modern healthcare service must do things with the people it serves.

NHS Quality Improvement Scotland (NHS QIS) was established as a special health board to improve the quality of healthcare in Scotland by setting standards and monitoring performance, and by providing advice, guidance and support to NHS Scotland on effective clinical care and service improvements. NHS QIS aims to:

a. Report to the public on the performance of NHS Scotland against nationally agreed standards; and
b. Support NHS Scotland in improving the quality of care and treatment it provides.

NHS QIS work closely with patients, the public, NHS Scotland and other organisations to:

- Develop standards that tell the public about the level of care they should expect;
- Review the quality and safety of healthcare services against the standards set;
- Identify and promote best practice to NHS staff to improve the quality and safety of patient care;
- Advise NHS Scotland on how effective healthcare treatments are; and
- Investigate incidents where NHS services significantly fail patients and the public.

44 www.publications.parliament.uk


46 www.nhshealthquality.org
NHS QIS also acts as an umbrella body for the Scottish Health Council (SHC)\textsuperscript{47}. The SHC has three main functions:

- Assessing the performance of NHS Boards in achieving a patient-focused NHS and involving the public in decisions about the design and delivery of health services;
- Developing the capacity of NHS Boards, patient and community representatives by developing and sharing best practice in patient and public involvement;
- Encouraging and enabling feedback from patients and carers about their experience of health services to NHS Boards.

In addition to a national office in Glasgow, the Scottish Health Council has a local office in each Health Board area supported by Local Advisory Councils. These have up to 15 volunteers who act as local ambassadors for patient and public involvement and advise the Scottish Health Council on how their Health Board is performing. The Scottish Health Council has ten members in total including the Chairman, six members appointed nationally and three nominated by Local Advisory Councils.

As well as the structure within the NHS in Scotland, there is a Scottish Partnership Framework that sets out the basis upon which the Scottish Executive and Local Government will seek to work together towards the common objective of serving the people of Scotland. It recognises that while they are both democratically elected and have their own legitimacy in the constitutional structure, they share a responsibility to serve the people of Scotland in partnership with each other.\textsuperscript{48}

**Wales**

In May 2005, the Welsh Assembly Government published ‘Designed for Life: Creating world class Health and Social Care for Wales in the 21st century’ which sets out its aims for the population of Wales in 2015.\textsuperscript{49} This plan focuses on promoting independence, service user involvement, and clinical and professional leadership. It is emphasised that implementation depends on engaging patients, service users, staff and the public.

Therefore, high levels of public and staff involvement must be achieved. The wider public and service users will be invited to join in the process. Members of the public have responsibilities in improving health as well as the NHS, and professional staff have a right to expect that patients keep their side of the treatment bargain. The National Assembly for Wales is committed to continue and improve the involvement and participation of the people of Wales in the National Health Service by putting patients first and building a health service around their needs. Patients and members of the public can become more involved in decisions about healthcare both as an individual and in a wider sense.

\textsuperscript{47} Scottish Health Council – www.scottishhealthcouncil.org


Community Health Councils in Wales, as the community’s statutory voice for health services, represent the interests of the public in the health service in their district. They are designed to give people an independent voice in their local NHS and its services. They are concerned with all aspects of healthcare, helping people get the services they need by offering advice and information, listening to what the public have to say about the quality of health services and helping, advising and supporting people who wish to make complaints about health services. Community Health Councils also have an important advocacy role in ensuring that informed discussion takes place in relation to redesigning services.

To find out more about Community Health Councils visit: www.wales.nhs.uk/sites3/home.cfm?ORGID=236

Similar to the structure in Scotland, Wales has a Partnership Council, which is an advisory body set up under the Government of Wales Act to promote joint working and cooperation between the National Assembly for Wales and local government. The 25 strong Council comprises members of the Assembly of all parties and members from local government – drawn mainly from the Welsh Local Government Association but also including representatives of the national park, police and fire authorities and Community Councils.

The Partnership Council’s remit is to:

- Give advice to the Assembly about matters affecting the exercise of any of the Assembly’s functions;
- Make representations to the Assembly about any matters affecting, or of concern to, those involved in local government in Wales; and
- Give advice to those involved in local government in Wales.

The Government of Wales Act 2006 is a further step in the devolution process and it will bring about a new style of government and political activity in Wales. The main changes are:

a. The legal separation of the Assembly Government (i.e. the Ministers) from the Assembly legislature (Assembly Members);

b. The opportunity for Wales to gain more powers from Westminster and to make more Welsh laws in Wales;

c. An enhanced scrutiny role for Assembly members who will spend more time scrutinising legislation and government policy; and

d. A statutory duty to promote the interests of the Voluntary Sector (i.e. the Voluntary Sector Scheme) is transferred to the Assembly Government only. This scheme will set out how it will in the exercise of its functions, promote the interests of relevant voluntary organisations

Northern Ireland

The Patient and Client Council (PCC) replaced Health and Social Services Councils on 1 April 2009. The PCC is a regional body and will be supported by five local offices operating within the geographical areas covered by the five integrated Health and Social Services (HSS) Trusts and Local Commissioning Groups (LCGs).

The overarching objective of the PCC is to provide a powerful, independent voice for patients, clients, carers, and communities on health and social care issues through the exercise of the following functions:

- To represent the interests of the public by engaging with the public to obtain their views on services and engaging with Health and Social Care (HSC) organisations to ensure that the needs and expectations of the public are addressed in the planning, commissioning and delivery of health and social care services;
- To promote the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care;
- To provide assistance to individuals making or intending to make a complaint relating to health and social care; and
- To promote the provision of advice and information to the public by the HSC about the design, commissioning and delivery of health and social care services.
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Appendix 7 - Good practice in PPI

The following case studies have been put together by members of the PPI group to illustrate ways in which involving patients and the public has enhanced our work. If you would like further information about any of the case studies, see individual regulators’ websites. A named contact for each of the organisations is provided at the end of each case study.

General Optical Council (GOC)

Helpful information

At a GOC consultation event held in April 2009, a deaf patient put forward some points about his experience at the opticians. The patient was given the opportunity to write about his experiences in the GOC’s quarterly Bulletin magazine. The Bulletin, received by all of their registrants, gave insight to all of GOC’s registrants about how patients with disabilities or communication problems can face difficulties at the opticians.

The article is on page 4 of the newsletter:

Contact: Simon Grier – sgrier@optical.org / 020 7307 3478

General Medical Council (GMC)

Case study: Developing guidance on confidentiality

In 2009 the GMC published guidance on Confidentiality. The guidance is addressed to doctors, but is also intended to help patients, members of the public, employers and others understand what is expected of doctors when fulfilling their obligations.

Prior to its publication, the GMC consulted on a draft of the guidance. Among the objectives of the consultation were to test that the new draft guidance contains principles and standards that are clear, relevant and achievable within the different environments in which doctors practise; and enable patients and the public to inform its content.

The main method for seeking views on the guidance was through a written, online questionnaire which was also available in hard copy format. This was supplemented by a shorter questionnaire aimed at individuals and smaller organisations. It did not require knowledge respondents to read the draft guidance, and instead drew on a summary of some key issues.

Meetings were held across the UK to engage public and patient representative bodies. These were attended by organisations such as the Terence Higgins Trust, Hepatitis C Trust, Stonewall and the Princess Royal Trust for Carers. Meetings were held in the four countries, with some meetings focusing on themes including secondary uses of information, vulnerable adults and serious communicable diseases. In addition, a focus group of patients was arranged with the help of the Minority Ethnic Women’s Network (MEWN).
Especially in the shorter questionnaire and at meetings, the GMC used scenarios outlining issues which doctors find difficult to deal with or have enquired about, to stimulate discussion. One of these scenarios asked whether doctors should disclose personal information about a competent adult patient whom the doctor believes to be at risk of serious harm – in this case from domestic violence – if no one else is at risk. Discussion of the scenarios revealed that there were often conflicting views, but with participants suggesting that the draft guidance represented a reasonably balanced approach for doctors to take.

Whilst the number of individual patient and public responses to the written consultation via the long questionnaire was a small proportion of the overall response, this was never intended to be the main way of seeking the views of patients and the public. It required familiarity with the draft guidance. The GMC knew that written consultation is not the most effective way of engaging with patients and members of the public. The shorter questionnaire (which was aimed at these groups) prompted more responses from members of the public and bodies representing patients and the public.

The meetings provided an opportunity to discuss difficult issues in much more depth and those attending said they found it valuable. For example, feedback from the focus group, which comprised a majority of members of the public, was that it had provided a helpful opportunity to air issues related to confidentiality and ask questions about the GMC’s position and expectations of doctors.

Discussions in the meetings with a mixture of professional and patient and public representatives produced lively and, at times, passionate discussion on issues which are widely acknowledged as being tricky. Discussions were rarely polarised along professional/patient lines.

Furthermore, the draft guidance was significantly improved through the consultation process - for example, through suggestions to strengthen encouragement to consent to disclosure through e.g. information about support services.

Contact: Paul Myatt – Pmyatt@gmc-uk.org / 020 7189 5147

**Nursing and Midwifery Council (NMC)**

**Case study: Development of guidance for the care of older people**

The Nursing and Midwifery Council (NMC) published *Guidance for the care of older people* in early 2009. Aimed at nurses, the guidance sets out the care that older people can expect to receive.

To ensure the guidance was constructed around the views of nurses, older people and their carers, a series of discussion groups were held around the country to talk about how the principles set out in the guidance could be applied in practice.

Numbers of people attending each group ranged from 15 to 85. The draft guidance, along with questions to be discussed in breakout sessions, was sent out to delegates prior to the groups. This enabled delegates to prepare, having had a chance to talk to colleagues if they wished.

Groups had a good mix of nurses, older people and carers as well as people from groups and organisations that represented service users and carers. Discussions were lively, with delegates...
A separate discussion group was held specifically for older people in association with the Thurrock Empowerment Network. A summarised version of the guidance was produced for participants and was the basis for discussion. This was because the main piece of guidance, although informative for nurses, may have proved too long and technical for lay people. This group gave the NMC the opportunity to focus on the content of the guidance from an older person’s perspective and speak to older people in their local community centre environment with which they were familiar. It also enabled them to raise issues which were particularly relevant to older people.

Feedback captured from the series of discussion groups included the following:

“It was good that so many expert ‘older persons’ were present”

“Interesting thoughts and ideas gathered from a variety of backgrounds”

“Thank you for including the voluntary sector which was useful and important as we have particular experience”

Case study: Care and respect every time

The NMC leaflet Care and respect every time, is based on the guidance. Its purpose is to inform older people and their carers about the level of care that they can expect to receive from a nurse.

To ensure that the leaflet would be accessible to older people, we asked some of the older people who had attended the discussion groups for comments on a draft copy. A number of people took the opportunity to circulate the leaflet amongst their networks and Greater London Forum which represents all older people’s forums in London collated feedback from their members on our behalf.

As well as providing constructive criticism, the period of user-testing also generated welcome publicity for the leaflet, with local and regional organisations such as local Age Concerns offering to distribute it via their networks and at events. In addition, a small article in Senior London magazine also raised awareness of the NMC’s work amongst some London-based older people’s groups.

Contact: Marie Saldanha – marie.saldanha@nmc-uk.org / 020 7462 5878

Health Professions Council (HPC)

Case study: ‘Be healthwise’ campaign

In November 2008 the Health Professions Council (HPC) launched its ‘Be healthwise’ campaign. The aim of the campaign was to raise awareness of the HPC amongst older people and those who care for them. The campaign came about after the HPC commissioned Ipsos MORI Social Research Institute to undertake research amongst older people aged 70+. The research revealed awareness of the HPC amongst older people and those who care for them is very low – even where they have used the services of HPC-regulated professionals. The
strategy for the targeted ‘Be healthwise’ campaign was therefore based on the Ipsos MORI research findings.

In November 2008 the HPC hosted an event titled ‘seminar on regulation and older people: what more can be done?’ The event was the third in the series of seminars organised by the joint UK regulators’ PPI group and was chaired by the HPC President. The seminar was attended by 32 participants in London and six participants via video link in Cardiff. Participants included a mixture of older people from in and around the London area, Community Health Council representatives from Wales, representatives from voluntary sector bodies such as Counsel and Care, Help the Aged, Justice for Health Network, and representatives from nine of the health and social care regulatory bodies.

The question for the seminar was “what more can be done?” and the HPC came away with a number of key messages regarding communication, such as making better use of publications aimed at older people. When working on policies and consultations, the older people at the seminar felt, “Nothing should be done about them, without them.” The event was successful and influenced the HPC’s strategy for its ‘Be healthwise’ ongoing campaign.

As part of the campaign the HPC exhibited and presented at:

- The National Care Forum’s annual conference;
- The English Community Care Association (network of independent care homes) annual conference;
- The National Care Show which took place in March 2009; and
- A number of other conferences aimed at older people care providers such as care homes and local authorities across the UK in 2009.

The HPC also conducted a direct-marketing element of its ‘Be healthwise’ campaign and mailed information packs to 22,000 care homes across the UK. This consisted of an introductory letter, poster and fold-out leaflet pack which contained a coaster for care home managers with HPC’s details. Following on from this, the HPC then focused on its regional media campaign based on local case studies, which used examples of HPC registrants and the older people they cared for. The HPC then targeted publications aimed at older people and their carers as well as regional and national press. The case studies generated positive coverage in numerous regional newspapers, professional body publications as well industry publications aimed at the target audience e.g. Disabled and Supportive Carer.

The HPC also explored ways of working with affinity groups and as a result secured coverage in the Help the Aged newsletter among others. Whilst attending the various exhibitions and conferences, the HPC found that awareness had increased significantly with a substantial number of carers and care home managers who had visited the stand as a result of receiving the information packs. The vast majority cited that they now visit the HPCheck.org website to ensure the health professionals entering their care homes are registered.

Contact: Ebony Gayle – Ebony.Gayle@hpc-uk.org / 020 7840 9784
General Dental Council (GDC)

Case study: Dental check-up – your views on protecting dental patients

To inform its corporate strategy the GDC organised a series of events to seek the views of patients, registrants and its stakeholders. This included a one-day public consultation event.

The GDC commissioned Glasgows to recruit members of the public, organise the event and facilitate proceedings. Glasgows worked with Meeting Magic Ltd who advised on the content and structure of the event and provided facilitators for each table group.

There was small group work at tables with a professional facilitator working as a host, a process guide and a recorder. Visual table templates and wireless laptop technology were used to capture participants' feedback.

The facilitator asked participants to complete an evaluation form at the end of the day. As well as collating raw response data, Meeting Magic produced a final report summarising responses and flagging up challenges to the GDC.

A table summarising the format of the event, the issues considered on the day and results and reflections is below.

Contact: TBC
## Dental check-up event

**Aims**
- Obtain a set of recommendations around the future work of the GDC.
- Allow the GDC to consider the implications for their organisation of what patients and the public say about dental professionals and regulation.

**Format**
- One-day stakeholder consultation event.
- Representative group of 111 members of the public
- Independently recruited from the four UK countries.
- Observed by GDC Council members and senior managers.
- Anonymised responses.

### Audience breakdown - 111 members of the public in total

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Urban/rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equal splits in terms of:</td>
<td>At least 30 to live in a rural area</td>
</tr>
<tr>
<td>Gender</td>
<td>At least 30 to live in an urban area</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NHS/Private</th>
<th>Visiting the Dentist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equal split of patients receiving the majority of their dental treatment on the NHS and privately.</td>
<td>Proportional numbers of patients regularly/occasionally/never visiting the dentist</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one representative of a black or ethnic minority group from all geographical areas (10% of total)</td>
<td>At least a third to have had invasive dental treatment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Socio-Economic Group</th>
<th>Satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>A quarter from Social Grades AB; C1; C2 and D</td>
<td>10 – 20% to have been unsatisfied with dental treatment they have received in the past</td>
</tr>
</tbody>
</table>
### Issues

<table>
<thead>
<tr>
<th>Patient expectations of professionals and treatment</th>
<th>Should newly registered professionals go through a probationary period?</th>
</tr>
</thead>
<tbody>
<tr>
<td>What patients value about dentists and dental treatment</td>
<td>What to do in the event of being unhappy with treatment</td>
</tr>
<tr>
<td>Judging the quality of treatment</td>
<td>How the GDC can give patients confidence that safety is at the heart of everything it does</td>
</tr>
<tr>
<td>Expectations of newly qualified versus more experienced registrants</td>
<td>How the public should be involved in, or contribute to our work</td>
</tr>
<tr>
<td>Requirements to a) join and b) stay on the register</td>
<td>Feedback on the event</td>
</tr>
<tr>
<td>Information required to make decisions about treatment</td>
<td></td>
</tr>
<tr>
<td>What the GDC Register should display</td>
<td></td>
</tr>
</tbody>
</table>

### Feedback on event

#### Participants

- Participants gave positive feedback and praised the facilitators for being well-informed and ensuring all who took part had the chance to contribute.
- The diversity of the participants was recognised.
- The sharing of work between tables was also highlighted as being helpful and thought-provoking and the use of technology was praised for allowing ideas to be captured in “real time”.
- Some participants would have liked to have had direct contact with GDC staff, and there were calls for a GDC Council member to answer specific questions.

#### GDC

- The event was identified as;
- A useful baseline for future patient perception surveys
- Providing clarity on the information patients want
- Providing tangible evidence of patient views of the dental profession and the GDC to address challenges to PPI within our organisation
- Both the raw data and final report are ongoing tools of reference for planning events and an evidence base for patient experience.
## Outcomes and reflections

### Key Findings from the event
- The GDC should promote itself more widely to increase public confidence and allow patients to access its services more easily. There is a call for regulation to have a “public face”.
- There is a “knowledge gap” in terms of the setting of professional standards and regulation of the dental team.
- The public want more information regarding the roles of dental care professionals within the dental team; the training of dentists; and more meaningful information on the GDC register regarding qualifications etc.
- There is limited public appetite for ongoing involvement in day-to-day GDC processes, with little interest in attending events or meetings. Consultation and engagement with patients should be “realistic” – around a specific issue.

### Advantages of this type of event
- Broadly representative (age, socio-economic group, geography, NHS/private, ethnicity).
- Lots of “new knowledge” as the GDC has not held an event on this scale before.
- No barriers to ideas because of GDC procedures, structure, budgets or professionals views.

## Next steps
- The development of a GDC wide Patient First Programme, lead by a Patient First Officer, with a proposed aim of “The means by which the GDC aims to proactively seek and build a continuous and meaningful public and patient engagement programme and at the same time to shape and inform regulation for the benefit of public protection.”
- The GDC’s External Relations Team is developing a patient information leaflet for dental surgeries to make patients “more confident consumers”. The leaflet will highlight their rights, what standards they should expect from their dentists and dental team, how they may wish to raise concerns and how they can access GDC services should they need to.
- More focused research on public/patient expectations, attitudes and experiences.
Appendix 8 - Feedback form

To tell us what you think about the Handbook, please complete and return this form to:
Philippa Barton-Hanson, PPI Handbook Review Coordinator, General Chiropractic Council, 44 Wicklow Street, LONDON WC1X 9HL
Email: communications@gcc-uk.org  Telephone: 020 7713 5155

1. Your name:

2. Your contact details:

3. How did you find out about the Handbook?

4. Why were you consulting the Handbook?

5. Overall, was the Handbook helpful to you or not? Please briefly explain why:

6. Were specific sections of the Handbook particularly helpful or unhelpful?
   If so, please state which ones:

7. Is there any topic or information not covered in the Handbook that should be added?

8. How could we improve the Handbook?

9. Other comments:

THANK YOU FOR YOUR HELP IN IMPROVING THIS HANDBOOK