PATIENT AND PUBLIC INVOLVEMENT

A HANDBOOK FOR THE HEALTH AND SOCIAL CARE REGULATORS

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Background

This handbook has been produced for the health and social care regulators to guide their work in Patient and Public Involvement. It is the outcome of a small contract and drew from existing information available on the Web. Besides drawing the information together into a single source document, no new information has been developed in this work nor has it been tested in practice. Similarly no guarantees can be given about the quality of information, organisations or services that are referenced in this document.

The regulators need to decide how they wish to take this work forward ie whether there is a need for further development work, how the handbook should be presented and how it should be disseminated. If there is a wish to publish the handbook, there may be a need to consider whether there is a need to obtain permission for the use of certain information.

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Patient and Public Involvement (PPI)

1 What is PPI?

Involvement
Engaging with people at all levels in any aspect of your work such as planning, delivery, monitoring.

Patients and the public
Anyone – individuals, groups, communities or populations – who have an interest / stake in your work. These could be patients, users of health and social care services, potential users, and the public in general[1].

2 What forms does PPI take?

There are a number of ways of thinking about PPI. Those that are likely to be of interest to health and social care regulators are outlined below.

Reactive or proactive involvement?
A distinction that is useful to think about is whether involvement is:

- reactive – people are asked to react to activities, services, plans, proposals and priorities
- proactive – people as users of services and citizens are asked to become involved in initiating and formulating definitions and making proposals for new or improved services[2].

This distinction relates to:

- the approaches and methods of involving people
- the purpose of involving people
- the very nature of the involvement.

Forms of interaction
A development of this distinction[3] is the difference between:

- communication - establishing meaningful dialogue
- consultation - asking users' views
- partnership - equal relationship between users and professionals.

Regulators could use either of these distinctions to consider the general approach that they take and how this might be improved.

Extent of participation
Arnstein developed the idea of a 'ladder of participation' (quoted in much of the literature[4]) which looks at the extent to which patients and the public (citizens) have any power within the relationship.

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[1] NHS Scotland, Building Strong Foundations – Involving People in the NHS: Some practical guidance on approaches

[2] Mullen and Spurgeon, 2000, quoted in User and Public Involvement in Health Services: A literature review

[3] The Scottish Association of Health Councils et al (1999) quoted in the same document ie User and Public Involvement in Health Services: A literature review

[4] Arnstein, 1969, quoted in User and Public Involvement in Health Services: A literature review and many other sources.

Arnstein's ladder of citizen participation

8 Citizen control	Degrees of citizen power
7 Delegated power	
6 Partnership	Degrees of tokenism
5 Placation	
4 Consultation	
3 Informing	
2 Therapy	Non-participation
1 Manipulation	

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 rungs of the ladder, there is slightly 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 decision-making power is shared between the organisation and citizens – 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 professions regulators, it might be questioned as to whether the top of the ladder is appropriate. However the ladder might be a useful tool for getting people to talk about their expectations. It would also be useful to ask organisations to be explicit about their intentions and not hide behind words such as 'partnership' when there is no intention of sharing decision-making. It would be better to do a good consultation than to offer partnership and then fail to deliver.

Forms of interaction and individual / collective input[5]
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– individual and collective.

	Information	**Feedback**	**Influence**
Individual	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 (eg complaints)	Shared decision making between individuals and professionals
Collective	Information to the wider public about what the organisation is doing and how well	Trends in complaints, PPI issues etc and feedback on complaints and the patient experience	Improvement in policy and planning

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OUTCOMES

Individuals are likely to be interested in the following types of questions:
- Do I get the right information and explanations at the right time?
- Does my view count?
- Is it easy for me to raise issues and concerns and get them sorted out?

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[5] Commission for Health Improvement, Involving patients in the NHS i2i – Involvement for improvement

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

- Do we know how to make a difference in the work of this organisation?
- Have people from all parts of the community been able to influence change?
- Have things improved as a result of people giving their views?

Values underpinning involvement
It is also possible to think about the values that underpin involvement:

1. Paternalistic model - which assumes that 'professionals know best' so patients/the public have to trust in the skills, knowledge and ability of professionals
2. Consumerist model - which assumes that individuals are in charge of getting the 'best buy' and that with internal competition, consumers can decide to take their custom elsewhere if they do not like what they receive. This model appears to be of no great relevance to regulators although might affect how patients and the public react to regulators
3. Partnership model - which views the giving and receiving of healthcare and related services as a negotiation
4. Autonomy model - which places respect for the individual first and recognises the different perspectives of patients and professionals.

In reality bits of all of these models are likely to be found in how health and social care regulators work and how individuals in those organisations think about patient and public involvement. The third – partnership – model is probably most in line with the current thinking on patient and public involvement although it is possible to see aspects of the autonomy model at work too. 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 first model while the second model is driving much healthcare provision in the UK today. They might be useful in thinking about how people react to involving patients and the public and for discussing experience.

3 Who are patients and the public?

There are different types of organisations that seek to represent patients and the public. These include:

- self-help groups
- voluntary organisations that campaign for improved services
- pressure groups
- user-controlled organisations
- advocacy groups.

There are also different categories of people who use health and social care services:

- patients/clients and potential patients/clients
- informal (unpaid) carers
- members of the public who might be targeted by health promotion programmes
- organisations that represent the interests of people who use health and social care services
- groups asking involvement because they believe they have been / will be exposed to risk.

Some organisations may concentrate on a specific condition (eg cancer, epilepsy) whereas others might concentrate on population groups (eg the elderly, children). In addition some organisations are alliance organisations whose membership includes other autonomous national organisations (eg the Long-Term Medical Conditions Alliance).

All of these different groups are likely to have different views on a subject. It is necessary to think about whether all of these groups should be involved in any one issue or whether it is relevant to one or more of the groups rather than others.

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[6]. They are valuable:

- in being collective voices of patient and public interests
- as sources of intelligence about patient and public needs
- as partners in exploring and addressing needs
- as sources of expertise in involving patients and the public
- as routes of communication with different communities.

Any engagement with the voluntary sector needs to be very sensitive to their capacity and interests. Potentially the regulators might need to think about how they could assist such organisations to develop their capacity to work in partnership on regulation (such as through using community development approaches).

4 What makes most difference to patients and the public?

> *"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."*[7]

5 What are the benefits of PPI?

There are very positive reasons for involving patients and the public[8]. These include:

- patients and the public are able to offer different perspectives - better decisions tend to be made when more people contribute to them
- involvement can help to ensure that the issues that are prioritised are important to patients and the public
- involvement will make the process more meaningful to patients and the public
- questioning by patients and public can give a greater sense of urgency and understanding of accountability
- it can help to ensure that money and resources are not wasted
- those involved can help provide access to other members of the public to contribute to the work (including those who are usually hard-to-reach)
- they can help to disseminate outcomes and information
- they can be advocates for the organisation and its work
- involvement can lead to people's development and empowerment

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[6] Every Voice Counts – User Involvement in Primary Care Services

[7] Scottish Executive, Building Strong Foundations – Opening Up

[8] This section has been drawn from a number of sources including: Summary of PC11 Report, An evaluation of consumer involvement in the London Primary Care Studies Programme, A Barnard et al; ....

- seeking and listening to others' views is an important element of planning
- services that take into account the public's views and needs will be better designed to meet those needs
- major decisions are more transparent and the process for reaching them is understood
- trust is built between the regulators and the public
- one of the prime purposes of the health and social care regulators is to protect the public enshrined in the relevant legislation that established the regulators - and so involving the public is arguably a necessity in doing this.

6 What hinders effective PPI?

There are a number of factors that limit the effectiveness of PPI[9]. These include:

- attitudes of professionals
- the values of the organisation and of professionals
- the diversity and complexity between different patient and public groups can make it difficult for people to understand how to involve people effectively – however there are different approaches that can be used to counter this
- the knowledge base of patients and the public – and also of professionals
- power relationships can mean that an organisation's priorities dominate - awareness and desire to share power can help redress the balance
- resources – lack of time and money of patients and the public can be a barrier although steps can be taken to change this
- significant organisational change
- policy which skews public involvement work to short-term identifiable outcomes and undermines the development of more substantial ongoing forms of engagement.

7 What can we do about those people who argue against PPI?

Every organisation is likely to have some people who do not value the involvement of patients and the public. The publication[10] *Involving the public in NHS, public health and social care research – briefing notes for researchers* offers some arguments that can be used to counter these views. These are produced in brief below.

One or two people cannot be representative of patients ….
Nor can one of two professionals be representative of professionals – if need bigger range then involve more

Trained or professionalised members of the public cannot reflect the views of a typical patient – it is always the usual suspects
This depends on what you want people to do eg 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 access 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

People won't understand what we need to do

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[9] This section has been drawn from: Small Voice, Big Noises, Lay Involvement in Health Research; and Every Voice Counts – Primary Care Organisations and User Involvement

[10] Involving the public in NHS, public health and social care research – briefing notes for researchers Roger Steele (ed) published by Involve February 2004

Many people have been involved in the past and made very useful contributions. There will be a need for the group to avoid jargon but this is useful to help everyone contribute.

There are too many problems relating to confidentiality
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.

It is the job of health and social care practitioners to act as advocates for patients
Members of the public often have different priorities from professionals (research based evidence)

How can people who are emotionally engaged in the topic be objective?
Nobody is entirely objective or neutral. People who use services bring a particular knowledge base with them that is different from those who provide them. Both will have some form of emotional engagement.

It is too expensive and time consuming to involve patients and the public.
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.

Members of the public may have unrealistic expectations.
This need not be a problem if you explain how long it might take, what will be involved and any issues that might be encountered.

8 On what principles should PPI be based?

The principles that are set out in the Kennedy Report on the Bristol Royal Infirmary Inquiry (2001) are designed to lead to genuine patient and public involvement and greater transparency and openness in decision-making. They offer a template for the values and beliefs that should underpin the patient and public involvement work in NHS organisations many of which appear relevant to the work of the health and social care regulators ie that:

- patients and the public are entitled to be involved wherever decisions are taken about their care
- the involvement of patients and the public must be embedded in all aspects of healthcare
- the public and patients should have access to relevant information
- there must be honesty about the scope of the public’s and patient’s involvement, since some decisions cannot be made by the public
- there must be transparency and openness in the procedures for involving the public and patients
- the mechanisms for involvement should be evaluated for their effectiveness
- the public and patients should have access to training and funding to allow them to participate fully
- the public should be represented by a wide range of individuals and groups and not by particular ‘patient groups’.

9 What involvement methods are there?

Involvement can be viewed as a continuum ranging from minimum to maximum involvement[11]. The level and type of involvement should be matched to the circumstances

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[11] Much of the content in this section is taken from “Strengthening Accountability: Involving Patients and the Public Practice

and context. Minimum involvement is appropriate for certain circumstances such as when someone is seeking particular information. Generally speaking the greater the involvement the more links there are to an organisation's decision-making processes. This in turn will affect the way feedback is given to those who have been involved.

The diagram below sets out a continuum and provides ideas about involvement at a range of levels. Good practice is to consider a range of approaches, determining how they fit together to establish a pattern of ongoing involvement and dialogue, and being clear about how the outcomes will be used.

It is worth noting however that any method or approach can be used in a more or less involving manner so it is possible for an organisation to be involved in a large number of involvement methods and approaches while professionals still in reality drive the agenda. In addition the approaches to involvement that are linked to planning and development do not lessen the need for effective communication and involvement on a day-to-day basis with individuals by the organisation.

Continuum of Involvement and related methods[12]

Public Involvement Continuum

Minimum involvement **Maximum involvement**

Giving information	Getting information	Forums for debate	Participation	Partnership
- Exhibitions - Leaflets and written documents - The press	- Citizens panels - Open surgeries - Patient diaries - Phone-ins – radio or live - Self-completed questionnaires - Semi-structured interviews including discovery interviews - Structured one-to-one interviews	- Focus groups - Meetings with patients and carers - Public meetings - Seminars - Targeting interested people including the voluntary sector	- Citizens' Juries - Expert patients - Health panels	- Community development - Large group processes

The methods and approaches set out in the diagram are illustrative examples. It is not designed to be a menu of approaches that must be used. Rather it is necessary to identify the approach that suits the questions to be answered, the purpose of involvement and the people to be involved. There is a need for careful planning and ensuring the people are involved at

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Guidance, Section 11 of the Health and Social Care Act 2001; User and Public Involvement in Health Services: a Literature Review Ridley J and Jones L, Scottish Health Feedback Partners in change.

[12] Based on a diagram produced by Bedfordshire Health Authority and quoted in: Strengthening Accountability Involving Patients and the Public Practice guidance Section 11 of the Health and Social Care Act 2001

the right stages ie not seeking the patients' and the public's views once major decisions have been made and cannot be changed.

There is no one right method and it is possible to use one method to develop another eg using a focus group to develop some initial thinking to form the basis of a survey. A key message from the literature is that no one method will meet all purposes.

Each of the different methods and approaches will need specific knowledge and skills to be applied to work effectively. Those where there is direct contact with patients and the public in debate, participation and partnership are likely to need facilitation and conflict handling skills. Those related to gaining and analysing information are likely to need research methodology skills.

There are other ways of classifying PPI methods and approaches[13] such as:

- Qualitative research methods – to explore people's perceptions, attitudes, ideas etc in some depth and to respond to participants' own agendas
- Quantitative research methods – to measure the incidence and significance of, for example, views, opinions or behaviours
- Consultation techniques – traditionally written consultations have been the formal means by which organisations ask stakeholders to comment on policies and proposals. This can also include public meetings, and conferences (eg community conferences and stakeholder conferences)
- Deliberative approaches – such as deliberative polling and referenda
- 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.

10 How do these methods relate to lay representation on regulatory bodies?

There is an important role for lay members on health and social care regulators as representatives of patient and public interests[14]. Lay members can encourage and enable their professional colleagues to address patient and public views in the work of the organisation and in its decision-making leading potentially to changes in organisational culture. However such roles are likely to require an expertise all of their own. Lay people on regulatory bodies need to be able to recognise the differences between professional interests and patient/public interests, and be able to advocate for the experience of the user whilst understanding the role of statutory professional self regulation. Support and investment is needed to enable lay members to fulfil their role effectively. Case studies of the work of lay members have found that they are most successful when they learned to play the corporate game but still continued to question the priorities that dominated the organisation's thinking.

Whilst lay members of regulatory Councils form one important aspect of patient and public involvement, they are only one very specific way of involving patients and the public, in professional self-regulation.

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[13] J Ridley and L Jones, ?, User and Public Involvement in Health Services: A literature review, Scottish Health Feedback Partners in Change

[14] Every Voice Counts: Primary Care Organisations and Public Involvement, 2002, W Anderson et al, Kings Fund, London

11 Which methods should we use?

The key messages are:

- there is no one approach that suits every situation and every patient and member of the public or issue
- choose your approaches carefully and make sure the right people are involved
- always ask why you are doing this before you start
- be clear about what you are going to do with the outcomes
- individual approaches or methods do not replace the critical thing – which is ongoing dialogue and an improved working relationship with patients and the public.

There is no single right answer to this question as different forms will be appropriate at different times[15]. 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: the quality of communication and information, the opportunity to actually contribute and have contributions valued and incorporated, and how professional and institutional power is used. It might also be about whether they are paid or not. These issues become even more important when involving hard-to-reach / marginalised groups as there is a real need to consider whether the involvement actually benefits them or just adds to the status quo?

Further information about the different methods and approaches, their advantages and disadvantages are given in Appendix 1.

Appendix 2 provides information on PPI toolkits, guides and reports that provide more detailed information on PPI and associated methods.

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

Appendix 4 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.

12 How can we make PPI meaningful not tokenistic?

There are a number of things that need to be thought about to make PPI meaningful[16]. These things are not unique to PPI as they would also be considered to be good practice when involving professionals ie how you involve patients and the public should be on the same basis as how you involve professionals and others helping you with the work. They include:

- being clear about the aims and objectives of the involvement and how it relates to the overall programme / project
- the anticipated outcomes of the work and any constraints that operate
- identifying how you will involve them and when – checking that this will work for them
- identifying the support and development that you will provide for them as well as for the professionals working with them

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[15] Involving the public in NHS, public health and social care research – briefing notes for researchers Roger Steele (ed) published by Involve February 2004; Clinical Governance Support Unit Modernisation Agency, Top tips for effectively involving and recruiting patients and carers

[16] Involving the public in NHS, public health and social care research – briefing notes for researchers Roger Steele (ed) published by Involve February 2004

- always involving two or more individuals so that these individuals are not isolated amongst a number of professionals, can support each other and their involvement is not tokenistic
- identifying and following through how you will give feedback on their involvement
- capturing lessons learnt as you go through and acting on them.

When long-term involvement is being considered then you also need to:
- prepare a brief person specification to enable you to think about who you might involve whilst also being flexible ie the range of experience, perspectives and expertise that you need
- developing a job description of what you want the person to do (eg maintain an independent perspective, offer a personal perspective, work with other patients to present a broader view)

You will need to be able to explain, in simple and unambiguous language, about:
- the particular work you are asking them to become involved in and its background
- why you are approaching them
- what you are asking from them
- the level of involvement they can expect in the work
- the resources you can offer to enable them to contribute effectively (including expenses and with longer term involvement such aspects as computers, printers, access to library facilities etc)
- the benefits to them
- how long it is likely to take
- who the work will benefit
- the potential risks of involvement
- the extent to which individuals need to set their own boundaries.

To make the involvement meaningful and effective you will need to:
- spend time developing a relationship with people
- visit people on their own ground
- expect some of them to be sceptical about the work and their involvement in it
- look at examples of the work they have undertaken and use their work to influence yours
- ask them to explain what they do
- find out about how and when they would like to be involved
- seek feedback on their involvement and learn from it
- try new ways in response to feedback from patients and the public.

You may need to contact a number of organisations before you get sufficient / 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 hence 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.

13 Are there are any tips are there 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 – it must be done in the spirit and ethos of true involvement - otherwise it will waste everyone's time and could be harmful.

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

6 Make communication simple and obvious – right tone, right channels, convenience

7 Keep people informed throughout – information, answers, responsibility, feedback

8 Involve people as early as possible – opportunities, making it interesting

9 Be open to criticism and change – feedback, acknowledgment, recall, improvement

10 Work in partnership with others to ensure coordination and cost efficiency

11 Shared responsibilities, shared outcomes – mutual support[17].

Overall, people think that a responsive public service is one that:
- provides easy and appropriate access to services
- encourages the individual to use and shape services in ways that suit them
- actively seeks to learn from public involvement and develops services accordingly.

14 Who benefits from PPI?

There is evidence to show that PPI benefits[18]:

a) the people who get involved through:
  - improvements in confidence and self-esteem
  - developing knowledge, understanding and skills
  - encouraging people to take responsibility
  - the opportunity to make a difference

b) the organisations they contribute to through:
  - exploring the differences between professional and patient views and between corporate and community views
  - better understanding of the public's needs
  - improved services
  - reduced health inequality

c) the wider community.

15 Why do individuals want to get involved?

There are a variety of reasons that individuals give for being involved. These include:

- to improve services for themselves and those who come after them (eg to ensure that others do not experience the problems that they have experienced)
- to influence the agenda
- to ensure that issues that are a priority for people are addressed
- to ensure that future regulation is appropriate for the needs of a specific group of people

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[17] National Consumer Council Future Services A Blueprint for responsive public services

[18] Department of Health, Patient and Public Involvement in Health: The Evidence for Policy Implementation A summary of the results of the Health in Partnership research programme Compiled by Christine Farrell April 2004

- altruism - wanting to give something back to the public as a whole, or to services from which they feel they have derived benefit
- sharing their knowledge, skills and experience from other related areas of work to the benefit of others
- having a right to involvement as key stakeholders[19].

16 What prevents people engaging effectively?

Individuals can be prevented by a number of factors such as:

- having the skills, resources and confidence to participate
- time constraints can affect people's decision to participate but once individuals start time becomes less of a concern.

The public as a whole can be prevented by factors within the organisation that is seeking to engage with them and factors within the communities themselves such as:

- the lack of a strategic approach within an organisation to working with the public
- organisational ethos and culture
- organisational skills and competence
- community capacity to engage.

17 How can we afford patient and public involvement?

The cost of PPI - in terms of both time and money - can feel like an extra burden on an already very large workload. It can be difficult to prioritise involvement when there is also a need to deliver specific services and when regulation is financed by the profession. However given the benefits of PPI outlined earlier, an investment in the present could save time and money in the future and also help to ensure that regulators are effectively undertaking their duties to protect the public[20].

18 At what stage should people be involved?

The basic message is that patients and the public should be involved as early as possible in the work so that they understand and own the process. The people running the work should consider alternative approaches and methods if advised to do so. When meetings are held they should be as informal as possible and preferably held in locations that are familiar to patients and the public. In addition thought should be given to other ways of making people more relaxed and hence better able to participate (such as providing lunch, giving opportunities for talking outside of the more formal meeting),

19 How can we best contact people/groups?

You can contact groups and individuals in five main ways:

1 contact them directly
2 advertise opportunities for involvement (eg in local community settings, through newspapers, radio etc)
3 networking (eg through attending events where the groups you are seeking to involve are likely to be present)
4 promotional events

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[19] Involving the public in NHS, public health and social care research – briefing notes for researchers Roger Steele (ed) published by Involve February 2004

[20] User and Public involvement in health services ..

5 groups and individuals will approach you seeking involvement.

It is important to think about social diversity and be inclusive when you are seeking to make contact with people. You need to think about: age, ethnic and social background, gender, sexuality, disability, geography etc and how these factors affect the contacts you make.

Appendix 4 identifies the patient and public groups and the databases they hold that can assist in your work.

Effective relationships are based on trust and these take time to develop. Lots of seemingly small things can make a difference such as:

- a willingness to meet people in their own settings
- a real effort to answer their questions however tangential they may seem
- being as open as possible as to what is possible rather than just putting a positive spin on things
- a commitment to sustained communication.

Much of the 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, understand their interests and ways of working, the time that they would like involvement etc. This is likely to vary between different individuals and organisations and might also vary over time as it will be affected by the context in which these organisations and groups work, their own internal issues and concerns and the interest of the subject matter.

20 How can we involve hard-to-reach/marginalised groups?

Involving hard-to-reach / marginalised groups requires extra thought, preparation, time and money[21]. However the outcomes are likely to be better as these groups have important expertise to offer. Individuals from hard-to-reach / marginalised groups are likely to be embarking on an activity that is new to them which means that they are on a steep learning curve and this at times may be difficult for them and those who are seeking to involve them, who are also likely to have to make adjustments themselves. There is no single way of approaching this and learning needs to take place in the organisation that is seeking to do this, adapting approaches as the work proceeds. It is necessary to remember that everyone can feel marginalised and vulnerable at times. Essential is to value everyone as equals and experts in their own experience. Below is a detailed checklist on the issues that need to be thought through in involving hard-to-reach / marginalised groups and for PPI in general.

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[21] 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' by Involve)

CHECKLIST ON INVOLVING HARD-TO-REACH GROUPS[22]

- Have you given careful consideration to the reasons for involving vulnerable people, and are you clear about why you are doing it?
- Has every avenue been explored to ensure that vulnerable or marginalised groups have had the opportunity to consider being involved (eg community networks)?
- Is the information you are planning to give in an accessible and culturally relevant form for those you want to reach and engage?
- Is the information you have given sufficient for them to make a fully informed choice about whether or not they want to be involved?
- Have you allowed for additional time depending on the needs of the person or persons concerned (eg for translation, broader discussion, medical needs, breaks in meetings etc)?
- Have you budgeted for the additional resources needed to accommodate their needs whilst they are involved (eg signer, advocate, carer, special transport, accommodation, dietary requirements etc.)?
- Will the venues you will be using be accessible to those you want to involve?
- Have you given due consideration to the suitability of the times of any meetings you may be planning in respect of the individuals you want to involve?
- 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?
- 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?
- Will an advocate or mentor be offered to help with this and other support needs where appropriate?
- Will the group be prepared to make adjustments to accommodate the level of knowledge, cultural familiarity, and learning ability of the individuals involved?
- Will papers be summarised in accessible/lay language?
- Are the professionals in the group aware that specialised professional language needs to be used self-consciously rather than spontaneously?
- Will training be offered to all group members in order to assist with making the process of the partnership successful for all involved?
- Will other training be offered to members of the group?
- Have arrangements been made to pay expenses?
- Has thought gone into the possibility of paying people for their time if they are otherwise unpaid?
- Will there be a process by which ground rules for the group can be developed and negotiated at the beginning?
- Will there be an induction pack for people who use services, and will they have the opportunity to negotiate a ‘job description’?
- For long term or ongoing groups, has the possibility of a ‘rolling membership’ of people been considered, with time limits (eg two years service) and overlaps between new and outgoing members in order to maintain continuity?
- Has thought been given to the needs of vulnerable individuals leaving a longer term or ongoing group?

One way of contacting hard-to-reach/marginalised groups would be to contact the organisations that speak on behalf of these communities and ask them to contact individuals. It will be necessary to provide resources for them to do this. Some national organisations

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[22] Checklist produced by Involve and available in: Involve, A Brief Summary and Checklist for Researchers, Research Commissioners and Research Groups for Involving Vulnerable and Marginalised People

have produced guidelines on working with particular groups or communities[23].

21 How much should members of the public be paid?

It is difficult to be prescriptive about payment levels. However *Involve* have produced a guide on the aspects that need to be considered[24].

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

- payment is a tangible way to acknowledge the value of public contributions
- it removes barriers that stop people participating (eg being able to cover the cost of transport, use of phone, childcare etc)
- it can indirectly lead to more effective and equitable participation of people by easing financial constraints as there are likely to be financial implications to involvement
- it supports equity of power in partnerships which involve the public and professionals
- it can be used to clarify the expectations and responsibilities relating to people's involvement.

In principle all expenses should be reimbursed. Payments for time and expertise should also be considered as best practice. Rates will depend on a number of variables. Paying people need not influence the independence of their views. A 'job description' can be drawn up with them to clarify and affirm their role as it should for all members of any formal group. This can help affirm the equitable status of all participants both professionals and the public. *Involve* suggest that payment is only considered for specific pieces of work (eg peer review, report writing or attending a committee meeting) as this helps to reinforce independence.

Expenses
In principle, all expenses should be reimbursed as this facilitates equal opportunities for participation. Expenses should include:

- travel - public transport, taxi fares, or an agreed private car mileage rate which includes wear and tear
- stopover - overnight accommodation etc
- subsistence - food etc whilst on 'business' or bought because the person has to be at a certain place at a certain time
- childcare
- telephone/fax costs
- stationery/equipment
- carer costs
- costs of a personal assistant of the individual's choice
- conference fees
- participation in training.

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[23] Baulcombe S, Hostick T, New T and Pugh H, 1998, Asking the Experts – A guide to involving people in shaping health and social care services, The Community Care Needs Assessment project (CCNAP) available to download from www.ccnap.org.uk.

[24] 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 and revised 2003)

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

Payment for time, skills and expertise
Patient and public representatives should be paid for their time and expertise to a level consistent with others involved in the work[25]. This will depend on a variety of factors and circumstances (eg 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/group is entirely voluntary, payment for time cannot reasonably be expected, (although payment for expenses may be essential for some people to attend).

Rates paid will depend on a number of variables and it is worth thinking about the following aspects:

- How does the principle of equity apply in this situation?
- What level of skills, expertise, and experience am I seeking/expecting?
- What are the time commitments involved in this role (including preparation, reading, travel, communication, meetings etc)?
- What are the comparative levels of pay and responsibility of participating professionals?
- What level of responsibility am I expecting these people to take?
- What are the local and national pay conditions for the equivalent role?
- What is the current national minimum wage?

Terms and conditions must be provided to people if they are being paid for a service (but not if it is just expenses) as Employment Law applies. Staff in your Human Resources Department staff should be able to advise you about Employment Law.

Members of the public may be in receipt of social security benefits payments. It is very important to be aware that these benefits can be affected if payment is made. There are a number of 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 can be earned, 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 their benefit might be affected[26].

Making payments
When offering payment people should be given the choice of whether to take the payment or not. There may be reasons why some people would prefer not to be paid (eg 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. Payments, particularly expenses, need to be made promptly, or in some cases even in advance. This is particularly important to people on low incomes.

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[25] Involve also cite different rates of pay for different types of work in their leaflet.

[26] For more detailed information on Benefits rules in relation to user involvement, *Involve* recommend the booklet 'A Fair Day's Pay' published by the Mental Health Foundation

22 What are the current PPI mechanisms in the four UK countries?

Each of the four UK countries has different PPI mechanisms related to the structures of the National Health Service within the country concerned. The picture is complicated in each in that these mechanisms are not necessarily stable and are likely to change with changes in the infrastructure of the NHS itself.

England[27]

In England there are four main mechanisms. These are:

Patient Advice and Liaison Services (PALS) in every trust help patients and their families resolve concerns on the spot - data from PALS helps trusts identify areas where patients' experiences need to be improved. PALS act as a signpost for other services such as the *Independent Complaints Advocacy Service* (ICAS) – a free service, independent of the NHS that supports patients and carers wishing to pursue a complaint about their NHS treatment or care.

Patient and Public Involvement Forums (PPI Forums) are working in every NHS trust and PCT area to get the views of local people about local health services and feeding these into trusts.

The Commission for Patient and Public Involvement in Health is responsible for appointing, supporting and providing advice and guidance to PPI forums. It will be abolished as part of the Department of Health's review of arms length bodies (although a recent article in the Health Service Journal has suggested that the abolition has been delayed).

Overview and Scrutiny Committees of local authorities are scrutinising health services across England and through the local election process, are a vehicle for whole communities to influence local decisions affecting health.

The *Healthcare Commission* has a new system for assessment – the annual health check – that will replace star ratings from 2006. Under the new systems NHS Trusts will need to invite comments on their performance from local stakeholders such as the Patient and Public Involvement Forums, local authority overview and scrutiny committees and their strategic health authority. As this is a new system in the first year there will only be a draft declaration stage in October 2005 when Trusts will be asked to submit a declaration covering 1/04/05 – 30/09/05 including any comments they have received. The Healthcare Commission is currently working with CPPIH and PPI forum chairs etc to provide more guidance on the annual health check. At the time of writing and in the resources available, we were unable to establish how the information gained in these ways will be made publicly available and might be used by regulators.

The structures in England can be shown in the diagram on then next page[28].

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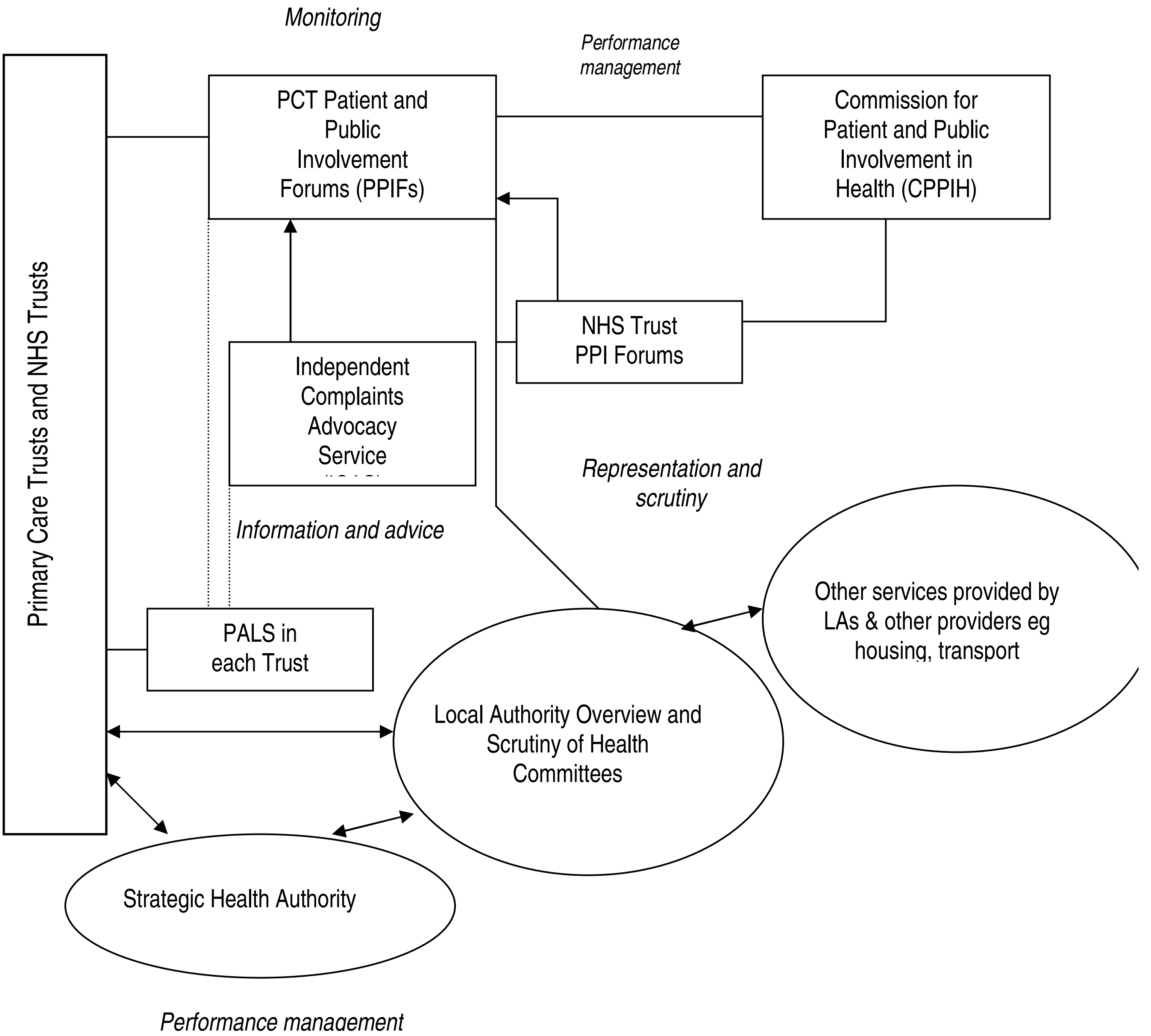
[27] Taken from DH website Patient and public involvement - a brief overview. Further information can also be found at: Patient Advice and Liaison Services; Independent Complaints Advocacy Services (ICAS); Patient and public involvement forums; The Commission for Patient and Public Involvement in Health (CPPIH); Arm's Length Body Review and the implications for PPI; Local authority Overview and Scrutiny Committees (OSCs)

[28] From Department of Health, November 2003, A guide to the NHS for members and officers of health scrutiny committees – this diagram is acknowledged to Barrie Taylor, Chair of Westminster scrutiny.



Patient and Public Involvement Structures in England

Appendix 5 contains more detailed information on the PPI mechanisms in England.

Scotland

In Scotland, 'PPI' is referred to as PFPI - Patient Focus and Public Involvement[29]. Work to develop new structures and processes for PFPI appears to be less well advanced than in England. It is being led by NHS QIS (Quality Improvement Scotland).

In 2003, NHS QIS consulted on a framework to guide their work on 'achieving and delivering an effective partnership with patients, carers and the public'. This framework was finalised at the end of 2003 and is being reviewed during 2005. A working group is looking at the framework that will be needed in the future to 'develop public involvement culture and practice'. We understand that Local Health Councils, which have performed a 'watch dog' role, are to be abolished, however we have been unable to find further information on this at the time of writing.

The new Community Health Partnerships that have been set up as the primary care arms of Scottish Health Boards have a duty to form a wide variety of partnerships in the interests of delivering effective services to patients and the public and to improve health[30]. These partnerships include directly working with patients and the public as well as partnerships with local authorities and the voluntary sector.

Wales

In Wales, there are 20 Community Health Councils[31].

> *"Community Health Councils work to enhance and improve the quality of your local health service. We are your independent voice in the NHS and we can:*
> - *provide help and advice if you have problems with or complaints about NHS services;*
> - *ensure that your views and needs influence the policies and plans put in place by health providers in your area;*
> - *monitor the quality of NHS services from your point of view."*

In Wales, there are also performance management arrangements for public and patient involvement through the Signposts framework, with Signposts Two, providing advice on organisational change and a self-assessment framework[32]. In Wales, the second stage in the complaints process will be the responsibility of lay people, independent of the NHS, appointed by the Welsh Assembly.

Northern Ireland

The consumer voice in the NHS in Northern Ireland is promoted by their four Health and Social Services Councils[33]:

> *"Independent consumer organisations, these councils have a duty to represent the public's views and interests, to review the work of health and social services and to recommend any improvements needed."*

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[29] From NHS QIS website nhshealthquality.org.

[30] Scottish Executive, 2004, Community Health Partnerships Statutory Guidance, Edinburgh

[31] From the Board of Community Health Councils in Wales website wales.nhs.uk/chc

[32] Welsh Assembly Government, 2003, Signposts Two – putting public and patient involvement into practice

[33] From NI NHS website n-i.nhs.uk/councils

23 How can we evaluate PPI?

The key message that comes through all of the literature is that organisations need to be flexible in their work in involving patients and the public and be prepared to change their methods and approaches as their work proceeds in response to feedback. There is also the key message that approaches need to be adapted to different purposes, circumstances and groups/communities. There are also some very practical steps that can be taken such as asking people how well it worked for them either at the end of a particular form of involvement or when starting a new form of involvement (eg what has worked for you in the past, what has not worked, how can we plan this involvement so it involves you better). There are also a number of studies which have been drawn from in the development of this handbook which look specifically at evaluation – each of these could be used to inform evaluation as could good practice in evaluation more generally.

24 How can we embed PPI in our organisations?

A key feature that comes through in all of the literature is that Patient and Public Involvement is a way of working not an occasional task. It is an approach that needs to be embedded in how the organisation functions as a whole not something that is delegated to one department or done in relation to particular projects or activities.

It needs to include the following aspects:

1. Planning – PPI strategies should not be written and put on the shelf they need to be put into practice. This means:
   a) developing relationships with and linking to existing user groups
   b) involving managers and staff in PPI
   c) undertaking a baseline assessment of what is happening now and then monitoring developments
   d) building PPI into ways of working right across the organisation
   e) making sure that PPI is not an add-on but considered as a natural part of the organisation's agenda
   f) identifying tangible benefits to PPI and demonstrating and communicating them.

2. Engaging leaders 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 believing that it will contribute to improving the work of the regulator and its services. PPI processes need to be developed in conjunction with processes for involving staff and provide tangible goals that mean something to staff. This means developing a clear rationale and a business case for PPI. The National Consumer Council[34] states: *"Value your staff who will then value the public".* This is based on the belief that 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 being open to staff and union ideas for innovation.

3. Mainstreaming PPI in the organisation with support for the work (eg resources, staffing, training and development) and also monitoring how well PPI is done in practice. 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

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[34] National Consumer Council, A playlist for public services, Ed Mayo

project groups away from mainstream decision making. In addition PPI is linked with other aspects of the organisation such as audit, governance and partnership working.

4 Engaging staff/members – 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. Staff will also need development to ensure that they can involve patients and the public effectively (eg learning and development in facilitation).

5 Developing staff/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. 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.

6 Using feedback to influence change - finding out what matters to patients and then the public must lead to change. Information gathering without action to follow it is wasteful and ineffective. Staff and others (eg Council and Committee members) will need help in tackling real (and imaginary) concerns about the consequences of PPI and how to take it forward effectively[35].

In addition organisations might need to think about how they can work effectively together on PPI (eg through sharing expertise through joint appointments, developing cross boundary working (such as consultations) and using the mechanisms set up by others (such as the voluntary sector)). The work undertaken by CHI on PPI suggests that national agencies should work more closely together at national level, speak with one voice about PPI and spread common messages. The production and funding of this handbook is perhaps a good start in this direction.

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[35] Commission for Health Improvement, ?, Involving Patients in the NHS i2i – Involvement for Improvement, Leaflet and Full Publication

APPENDIX 1
METHODS AND APPROACHES OF PUBLIC INVOLVEMENT[36]

EDITING NOTE – FURTHER WORK COULD BE DONE IN THIS SECTION BRINGING TOGETHER OTHER SOURCES OF INFORMATION

APPROACHES RELATED TO GIVING INFORMATION

<table>
<tr><th colspan="2">EXHIBITIONS</th></tr>
<tr><td colspan="2">Key points
• Aims to convey information in visual form
• Possible to target specific audiences eg in workplaces, schools, community centres, outpatients</td></tr>
<tr><td>Advantages
• Can reach members of the public might not normally reach
• If staffed provides an opportunity to talk to members of the public and exchange information
• Can be used to raise organisational/regulatory profile
• Can use comments book to encourage people to put their views in there and then
• Can be a way of providing additional information</td><td>Drawbacks
• Public can give their views on a wide range of aspects
• Wrong site will be waste of time and money
• Resource intensive if staffed all the time
• 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>
</table>

<table>
<tr><th colspan="2">LEAFLETS AND WRITTEN DOCUMENTS</th></tr>
<tr><td colspan="2">Key points
• To convey information about a specific issue
• Style should depend on audience
• Should be open and honest
• Can be used to set out the organisation’s position, policies and processes.
• Can be used in writing or electronically</td></tr>
<tr><td>Advantages
• May be seen as a starting point for consultation
• Accepted way of disseminating information
• Can be used for PR
• Keeps the public informed and aware of issues
•</td><td>Drawbacks
• Documents can go out of date quickly
• May be seen as a fait accompli
• No guarantee the documents will be read
• Unsure whether the documents will lead to any change
• Can be resource heavy in terms of producing materials and distribution and potential wastage</td></tr>
</table>

<table>
<tr><th colspan="2">THE PRESS</th></tr>
<tr><td colspan="2">Key points
• To publicise your work
• Newspapers can carry your message as an advertisement – which you pay for and have control
• If an editorial it is free but outwith your control</td></tr>
<tr><td>Advantages</td><td>Drawbacks</td></tr>
</table>

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[36] This section has been drawn from: Strengthening Accountability: Involving Patients and the Public Practice Guidance, Section 11 of the Health and Social Care Act 2001 – this document also provides a hints and tips section for each of the different approaches that it covers; Improving Health in Wales, 2003, Signposts Two Putting public and patient involvement into practice in Wales; Improving Health in Wales, 2001, Signposts A practical guide to public and patient involvement in Wales

• Fast and usually effective way of bring issues to people's attention • Can reach a large audience in local or national newspapers • Can target an audience through specialist press (eg minority ethnic newspapers	• Only get very simple message across • Might not actually get the information into print after a lot of effort • Cannot control what happens • May be misquoted if you do not pay for advert • Can be expensive

APPROACHES RELATED TO GETTING INFORMATION

CITIZENS' PANELS	
Key points • Can be used to build a picture of a community's priorities • Used to get a measure of public opinion on a specific issue • Can be conducted through telephone interviews and written or electronic surveys • Panel members usually recruited via the 'phone, advertisements or writing to a random selection of the population • Panel members names and addresses held with their permission on a database • They are informed of the results of each survey eg through a newsletter • Topics and questions must come from the organisation and feed directly back into decision making processes • Many local authorities have citizens panels which could potentially be accessed by the regulators	
Advantages • Panels can be made up of between 1000-3000 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 hence 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 be resource intensive in 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 cease to be representative

OPEN SURGERIES	
Key points • Provides an opportunity to discuss issues with organisational representatives	
Advantages • Can involve Council members • Can build healthy partnerships with other	**Drawbacks** • Has a political angle to it • Cold be waste of time for involved if no

organisations • Ongoing dialogue can be established • Assists accountability and gives a channel for people to challenge and question	commitment from the decision makers to listen • May be used only for complaints or problems • May get the same people all the time • Takes a senior member's time on a regular basis • Generates further work to feedback to planners / developers / managers particularly if the session is designed for problem solving

PATIENT DIARIES

Key points

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

Advantages	**Drawbacks**
• Gives patients and carers a feeling of being listened to & acknowledges that their own issues will be taken seriously • Allows patients and carers to reflect and expand on ideas and solutions • If used over time can be used to develop trust • Provides in-depth information of a qualitative nature • Guide questions can be used to probe further issues • Records events and feelings as and when they happen • Working from the patient's perspective means that you can uncover other issues	• Usefulness for regulators not that clear • Those who have completed the diaries will want to see action as they have invested a lot of time • Danger of collecting irrelevant information • Can be very time consuming to analyse • Unless the guide questions relate to patient experiences and are written in their language then can be distracting and compromise the information • Need to read the whole diary to understand the information • Only applicable to those who are confident in their literacy skills

RADIO OR LIVE PHONE-INS

Key points

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

Advantages	**Drawbacks**
• A fast and effective way of bringing things to people's attention • Opportunity to present individuals and the organisation with a human face rather than as a bureaucracy • Opportunity for education / dissemination • Can reach people who would otherwise be difficult to reach • Resource light usually	• Can be risky as may generate a negative response • Can put individuals on the spot which might be uncomfortable • Individuals might not give their best performance • Might not be an appropriate radio station to use

SELF-COMPLETED QUESTIONNAIRES

Key points

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

Advantages	**Drawbacks**
• A way of getting relevant and usually	• Not good for qualitative information

quantifiable information • Information obtained will relate to the issue • If well done can collect useful information from large numbers or from representative samples • If done face-to-face may increase response but will also increase cost • Flexible and adaptable to a large number of issues • Can give baseline data which can then be used to measure or monitor against • Can use a professional organisation to do the work which would give it more independence	• Not in-depth as no opportunity to explore issues, ideas or experiences further • Possible low response rate or biased response • Provides only a snapshot at one point in time • Can be difficult to administer • Professional help may be needed to design and undertake the survey so that the results are valid and reliable

SEMI-STRUCTURED 1-1 INTERVIEWS	
Key points • Aims to obtain feedback or explore an issue or service • Enables the interviewee to bring to light and consider their own feelings and concerns • Can be face-to-face or over the telephone • Interviewer aims to cover set topics without asking the interviewee to answer specific questions from a limited range of possible answers • Produce qualitative data	
Advantages • Obtains relevant information using a semi-structured approach • Targets specific audiences which can ensure representative cross-section of the population • Is structured enough to allow some comparisons • Allows freedom to explore general views / perceptions in more detail • Provides a framework for discussion • Can use external organisations to do the work which will add independence • Can be useful for exploring sensitive topics	**Drawbacks** • Requires good interviewing skills • Need to meet sufficient people for answers to be generalised to the overall group under consideration • Need expertise to prepare overall framework for interview • Data analysis skills needed for qualitative data • Can be difficult to organise interview times/ dates • Costly – time consuming and resource intensive for the number of people seen

STRUCTURED ONE-TO-ONE INTERVIEWS	
Key points • Interviewer asks a number of pre-determined questions and allocates the answers to one of a predetermined set of possible responses • Can be face-to-face or over the telephone • Analysis relatively straightforward	
Advantages • Approach lends itself to a wide topic area • Quick and less costly than semi-structured interviews • Can use a professional organisation to do the work providing more independence • Allows for tick box answers leading to easier data analysis that can be quantified • The people being interviewed do not need training / provision of information	**Drawbacks** • Not very good for exploring people's reasons, values or feelings about an issue • Rather prescriptive – may reflect own agendas, perceptions and prejudices • Only allows for minimum input from the respondent • Respondent may be influenced by the interviewer eg their age, gender, culture, ethnicity

• The interviewers do not need to be as skilled as those who undertake semi-structured interviews	• Needs expertise to design the questionnaire • Can be costly but is less resource intensive than semi-structured questionnaires

APPROACHES RELATED TO FORUMS FOR DEBATE

<table>
<tr><th colspan="2">FOCUS GROUPS</th></tr>
<tr><td colspan="2">Key points
• In-depth discussions of between 6-12 people focused on a specific set of issues or topics
• Someone facilitates the discussion and ideally a note taker will be present</td></tr>
<tr><td>Advantages
• Interaction between participants can produce new ideas
• Useful for providing an overview on issues about which little is known and for identifying issues to be explored in more depth at a later time
• Possible to recruit participants on specific criteria eg sex, age, geography etc
• Allows a framework for discussion to be identified whilst the content emerges from the interaction
• 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
• Facilitator can interact directly with the participants allowing for the clarification of responses and they can probe for further information interpreting non-verbal responses
• It can empower people by having their views endorsed by others and move them from a negative to a positive position
• Can include people with literacy difficulties as in the form of discussion
• Can provide in-depth information on views an the feelings behind them
• Can include and gain views of people who think they have nothing to say
• Can be a learning experience for the participants
• Can bring similar people together which may result in the formation of a sustainable group
• Usually enjoyed by participants</td>
<td>Drawbacks
• Group norms might silence / inhibit individual voices - needs experienced facilitation
• Does not generate information in terms of any quantitative data
• Mixed groups may not work well together
• Not a rigid approach and therefore the information you get from each group might not be directly comparable
• Can be costly to employ an experienced and skilled facilitator and note takers
• More difficult to ensure confidentiality in a group than in an individual interview – need to get group to agree ground rules
• When patients, the public and professionals are in the same group it is likely to need special handling
• Might be difficult to find experienced facilitators who can work in a range of languages /with interpreters
• May need to hold a number of groups to validate findings
• Gender, culture, ethnicity or age of the facilitator might influence the discussion
• Can be difficult getting a group of the right size – ideally between 6-12 people
• Small sample limits general applicability of results
• Group views can tend to norm
• Difficult to prioritise issues</td></tr>
</table>

<table>
<tr><th colspan="2">MEETINGS WITH PATIENT AND CARER GROUPS</th></tr>
<tr><td colspan="2">Key points
• Organised groups of people focusing around a common illness, condition, service or geographical area.
• 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.</td></tr>
<tr><td>Advantages</td><td>Drawbacks</td></tr>
</table>

• A captive audience of knowledgeable and committed individuals • Relatively easy and quick to make contact • Can put you in touch with users and cares for future focus groups • Can build up an ongoing partnership • Produces collective knowledge which does not rely on the views of one individual	• Only able to offer feedback on issues that relate to their particular experience • Could be biased or limited in range of views • Need to be clear of purpose – involvement, consultation or lobbying • Possible lack of objectivity and might be need to involve other users as well

<table>
<tr><th colspan="2">PUBLIC MEETINGS</th></tr>
<tr><td colspan="2">Key points
• A meeting for which there is an open invitation
• There may be a set agenda or discussion may focus on issues raised at the meeting
• 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 eg market place events.</td></tr>
<tr><td>Advantages
• Opportunity for a wide range of people to comment or raise issues and directly challenge
• Opportunity for those organising the meeting to put their side of the story
• Has PR value
• Provides an opportunity for joint consultation on areas of common interest
• Offers public the opportunity to challenge issues directly which increases accountability
• Lay bodies and pressure groups like public meetings as they give an opportunity to challenge
• Provides an indication of the problem areas that may not have emerged previously</td><td>Drawbacks
• May be a very low turn out
• Risky as no control over what happens
• May be a quick fix – perceived as tokenistic
• Takes organisation and involves time and money
• Voluntary sector needs lots of advance warning
• Audience might be hostile – police presence?
• Public meetings some times seen as the default position even though attendees are likely to be unrepresentative
• May only attract pressure groups / lobbyists
• Never a good time or place
• May need to hold more than one which means more resources</td></tr>
</table>

<table>
<tr><th colspan="2">SEMINARS</th></tr>
<tr><td colspan="2">Key points
• A discussion group that aims to impart, exchange and receive information
• More input from the facilitator than with a focus group</td></tr>
<tr><td>Advantages
• Opportunity to provide information and seek views
• A way of securing partnership and involvement
• A way of creating a listening culture and gaining sympathetic views based on a better understanding of the issues
• A means of promoting partnership and equality between agencies and the public
• A way of identifying areas where information will help improve participation
• Specific representative groups are likely to find this process rewarding</td><td>Drawbacks
• Can be very boring for the public if not well done ie people talking at them rather than engaging them – need to use range of techniques
• Needs careful planning for best results
• May attract individuals who only want to air grievances
• Costly in terms of reimbursing expenses and potentially room hire, organisation etc</td></tr>
</table>

TARGETING INTERESTED PEOPLE

Key points

- Focuses on engaging with people where they come together for another specific purpose eg older people at lunch clubs, young people at clubs

Advantages	**Drawbacks**
• Potential to reach large mixed audience and identify trends and issues • Obtains a wide cross section of views • Provides opportunity to gain feedback, give information, target existing activities / meetings, form a group which will act in the longer term, have a wide ranging discussion	• People may not be interested and therefore not wish to participate • May be difficult to use all of the information obtained • May be viewed as anecdotal and hence as too subjective • 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

- Particularly appropriate for involving the public in wider decision making especially about strategic planning choices or prioritisation
- Jury consists of 12-16 people selected as a cross section of the community
- Meet for several days to hear witness evidence and examine the issue in depth before making recommendations
- Independent moderator / facilitator assists the smooth running of the process
- People participate as citizens not as patients, users or carers[37]

Advantages	**Drawbacks**
• 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 rationalise and discuss their decision as a group • If the organisation makes a decision different from the juries 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	• 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 £25000 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 citizen's juries split into cells to make decisions might be more difficult to reach

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[37] 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

	consensus

HEALTH PANELS

Key points

- Primarily used to explore people's views about policy issues and the allocation of resources
- Usually made up of about 8-12 people recruited using a quota sampling technique to reflect socio-economic factors
- Each member works for a fixed term period and is then replaced by a new member
- Panels usually discuss live topics ie of genuine concern to the organisation that is running the panels
- Panels can raise issues of concern to the members
- Panels can also be run on the internet or by post – usually larger in size this allows organisations to reach those who would not normally wish to attend a session (eg young men)

Advantages	**Drawbacks**
• Health panels offer the opportunity complex issues to be discussed and deliberated by people in an informed way • Panels are useful for views on resource allocation and priorities • People on the panels gain information on a wide range of issues • Panel members receive some information prior to the panel meeting and asked to get views from their families and friends • Panels reflect a cross section of the population and hence provide an opportunity for minority ethnic communities and others to give their views • Can be externally facilitated increasing independence and credibility • Discussions are usually recorded and can be analysed and presented back to the organisation – this can be done independently to reduce bias • People can meet at regular intervals providing an ongoing dialogue with the community • Seen as an enjoyable experience by participants as they a voice and can engage in meaningful debate • Can move towards consensus as a group • Voices of the panel members can be used to contribute to the professional debate	• If too many issues are discussed there will be discussion and little time to allow debate and members may end up just giving their views rather than the reasoning behind them • As professionals draw up information for the panels beforehand they might be selective unknowingly – some panels employ an independent facilitator as a balance • Additional information requested by panel members may not be available during the panel • 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 • Do not provide quantitative information because the number of members are too small • Success of the discussion dependent on the skill of the facilitator • Results of the discussion may be less credible if the facilitator is not independent • Can be costly to maintain • 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 • Involves the community in identifying their own needs and finding ways to address them eg through influencing and informing organisations to help shape provision • Likely to involve supporting the community to set up systems and projects	
Advantages • Strengthens community infrastructure and is a basis for levering in other resources • Can establish links with traditionally hard to reach groups • Focuses on lay rather than professional views • Develops confidence and self esteem in communities and offers the opportunity to develop new skills and knowledge • Facilitates collaboration between sectors and brings statutory and voluntary agencies together with local communities • Is long-term allowing in-depth understanding and commitment • Can be a starting point to attract more and bigger funding packages	**Drawbacks** • Can be very local • Not about representativeness which can be a problem • Costs in the worker's salary and in supporting the project • Results are unpredictable • Identified needs cannot necessarily be implemented as may involve other agencies • By the nature of the work there is a need to develop open and honest relationships which takes time, commitment and experience • Time consuming to get it right initially – requires long term commitment and funding • Outputs might be costly to implement • May not be an outcome for a long period of time

LARGE GROUP PROCESSES EG SEARCH CONFERENCE, OPEN SPACE, TEAM SYNTEGRITY	
Key points • Designed to work with a large number of stakeholders (30-120) in sharing vision and change management • Appropriate for involving a range of stakeholders • Most effective on issues that affect a large number of people across communities • Assumes that people are capable of taking some control and organise themselves for the task at hand	
Advantages • Speed of implementation of outcomes • Possible to involve people who are closest to the issue and exchange thoughts with other stakeholders • Highly participative assuming that people want to be engaged and have a voice • Emphasis on self management in small group work • Openness • Everyone is equal and expert • Methods upholds the idea that individuals are experts in their own lives • Facilitators but no other experts • Consensual processes • Processes can bring together stakeholders who are often opposed to each other	**Drawbacks** • Time consuming • Tae an enormous amount of planning and organising • Can be costly

APPENDIX 2

PPI TOOLKITS/GUIDES/REPORTS

1) ORGANISATIONS/GROUPS OF REPORTS ETC:

Health in Partnership healthinpartnership.org
Good, useful site of background research/info.
"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."
Summary report produced in April 2004 summary doc
Site includes summary of all relevant policy policy

Also includes links many organisations involved in consumer involvement – these have been drawn from in the handbook and in identifying potentially relevant organisations.

Kings Fund kingsfund.org.uk
Website lists 8 reports on the topic of PPI. Most relevant seem to be:
Every Voice Counts
"Public involvement is at the heart of NHS modernisation, but putting it into practice is a challenge for many practitioners. This publication looks at the potential difficulties and offers solutions". (2002)
Ordinary Wisdom
"Shows how citizens' juries can be a useful way of involving members of the public in health care decision-making" (1998)
M Duman, 2005, Producing Patient Information: How to research, develop and produce effective information resources, Kings Fund London – designed to support professionals to develop the quality and impact of information.

National Consumer Council ncc.org.uk
"The NCC wants to encourage a shift in attitudes, policies and practices so that consumer involvement is at the heart of decision-making.
Our Involving Consumers project, under a remit from the Department of Trade and Industry, explores how representation arrangements can be better connected to consumers' views and experiences. A wide range of work has been carried out, including consumer research and case study descriptions of the state of play in the communications, food and health sectors. Although our reports are addressed primarily towards public bodies, many of the lessons are just as applicable to the private sector."
Site includes link to the final report of this project, plus other work including:
User Power: the participation of users in public services, A report prepared for the National Consumer Council by Johnston Birchall and Richard Simmons - this report explores how to increase user participation and make it effective by applying a more systematic and strategic approach.

4Ps (Preparing professional for partnership with the public) 4ps.com
Recent review of toolkits for PPI (April 05) – brief but to the point with links to other relevant sites. Aimed at health professionals. It covers 3 main national toolkits:

Strengthening Accountability: involving patients and the public (DH)

Strengthening accountability

Building Strong Foundations: involving people in the NHS (NHS Scotland)
Involving people - Opening up
Involving people - Practical guidance
Involving people - literature review

Signposts: A practical guide to public and patient involvement in Wales
Signposts 2: Putting public and patient involvement into practice in Wales
Signposts + Signposts 2

Also lists some 'Other Resources', including:

National Electronic Library for Health nelh.nhs.uk
Includes section on PPI – most things listed already covered elsewhere in the handbook.

NHS Clinical Governance Support team – web-based guide on 'How to involve people' cgsupport.nhs.uk

Advice Centre for NHS Patient Survey Programme nhssurveys.org *Includes list of 'Approved Survey Contractors' – consultancy organisations which presumably could run consultations etc. Also info/advice on survey questionnaires etc. Specifically aimed at statutory NHS surveys re patient experience, but could perhaps be applied to other purposes.*

2) INDIVIDUAL REPORTS/GUIDES ETC

Connecting with Communities www.idea.gov.uk/knowledge
"A detailed toolkit about communicating with local people, designed for local authorities but with much wider application. The site includes lessons from research, professional advice, best practice case studies and hundreds of free documents. The toolkit is a collaboration between the Office of the Deputy Prime Minister, the Local Government Association, the Improvement and Development Agency (IDeA) and the Audit Commission. Access to the site is through the IDeA website. You must register (free) on the IDeA site in order to get access to Connecting with Communities."
(From Health in Partnership)

DISCERN www.discern.org.uk
"An online tool for assessing the quality of health information, including printed materials and web resources. It is managed by the Institute of Health Sciences at the University of Oxford."
(From Health in Partnership)

e-democracy toolkit 'e-democracy toolkit'
International Teledemocracy Centre (ITC) 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."

New Economics Foundation, 1999, Participation works: 21 techniques of community participation for the 21st century, London
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. Available at www.neweconomics.org.

A guide to actively involving young people in research: for researchers, research commissioners and managers invo.org.uk (young people)
Published by INVOLVE, Sept 2004

Improvement Leaders' Guide to Involving Patients and Carers
(Modernisation Agency) www.modern.nhs.uk/improvementguides/patients
"The NHS Modernisation Agency has published several guides to improving the patient care and experience, including one specifically addressing the involvement of patients and carers. The guide includes the policy background, case studies and discussion of approaches."
(From Health in Partnership)

Involving the public in NHS, social care and public health research: Briefing notes for researchers. invo.org.uk (public)
Published by INVOLVE, Feb 2004

Making people's voices heard: Enabling people with long-term medical conditions to contribute to policy LMCA - Making people's voices heard
Long Term Medical Conditions Alliance, 2001
Also a 1997 report 'Patients Influencing Purchasers' –less relevant as related particularly to working with health authorities.

Sharing the learning on patient and public involvement from CHI's work : i2i Involvement to Improvement CHI PPI report
Published by CHI (no date)
A useful report – though couple of years old now (based on research in 2003 ie before PPI Forums were set up.

Healthcare Commission, ?, An A-Z of current Patient and Public Involvement issues and guidance
Provides a useful overview of the new structures and ways of working in England and Wales plus links to websites etc.

Speaking for Patients and Carers: Health Consumer Groups and the Policy Process
dmu.ac.uk
Research report by De Montfort University, funded by Economic and Social Research Council. "The team from the University's Health Policy Research Unit (HPRU) questioned more than 120 health consumer groups to find out how they represent and promote the interests of patients and carers at national policy level." *Report includes areas for improvement.*

Department of Health, Strengthening Accountability Involving Patients and the Public

Policy guidance Section 11 of the Health and Social Care Act 2001 (feb 2003)
This document sets out the duties placed on strategic health authorities, primary care trusts and NHS trusts in England under Section 11 of the Health and Social Care Act 2001 in relation to involving and consulting patients and the public in: planning services; developing and considering proposals for changes in the way those services are provided; and decisions to be made that affect how those services operate.

Department of Health, 2003, A guide to the NHS for members and officers of health scrutiny committees
Includes section on The new patient and public involvement systems plus various acts, structures etc including the healthcare regulators (although not GCC or GOsC).
Copies of this title can be obtained quoting 33420/A guide to the NHS for members and officers of health scrutiny committees and contact: DH Publications Orderline PO Box 777 London SE1 6XH Tel: 08701 555 455 Fax: 01623 724 524

Department of Health, Patient and Public Involvement in Health: The Evidence for Policy Implementation A summary of the results of the Health in Partnership research programme Compiled by Christine Farrell April 2004
A useful document that provides evidence on PPI in relation to policy development and implementation.

Department of Health, 1/10/04, 'Getting over the wall' How the NHS is improving the patient's experience
Describes the various DH policies and their impact on PI with relevant website addresses

Scottish Executive, Building Strong Foundations – Opening Up,
"This guide is the first part of the Building Strong Foundations Toolkit, which is part of the support from the Scottish Executive to encourage greater participation by people who use health services and the public in the NHS in Scotland. It has been compiled by the Partners in Change project and draws on ideas and experiences contributed by many people across Scotland. The guide is designed for: people working in the health service who want to find better ways to involve, consult and work in partnership with the patients and the public they serve and people who use the health service who are interested in shaping the way the service works for themselves, for someone they know, for people in similar situations or for the community as a whole."
This guide has some good cartoons and is presented in a user-friendly style.

Small Voices Big Noises Lay involvement in health research: lessons from other fields by Lisa Baxter, Lisa Thorne, & Annie Mitchell
Summary of a larger project report. Includes helpful hints on innovative ways of involving.

Viewfinder: A policy maker's guide to public involvement policyhub.gov.uk
(Cabinet Office, no date)
This guide is not related to health services but is about public involvement in government policy – however it has useful information relevant to the work of the regulating bodies as it relates to policy development, planning etc.

Summary of PC11 report, An evaluation of consumer involvement in the London Primary Care Studies Programme, A Barnard et al
This document summarises the contents of The PC11 Report. It is not intended to be a detailed account, but to present the essence of the research and its findings. For a copy of the full report there are details of how to contact us on the last page of this document.

User and Public Involvement in Health Services: a Literature Review Authors: Dr Julie Ridley and Lyn Jones, Scottish Health Feedback Partners in Change
A useful review of the literature in relation to PPI which has been drawn on to produce this handbook.

Every Voice Counts Primary care organisations and public involvement Will Anderson, Dominique Florin, Stephen Gillam and Lesley Mountford, Kings Fund 2002
A useful guide to effective PPI which has been drawn on to produce this handbook.

Portsmouth City Council, Consulting people toolkit
Useful for this particular approach – although needs to be set against the advice that this only one rather top-down method.

APPENDIX 3

ORGANISATIONS WHICH SUPPORT PPI (eg consultancy, training, research)

1) ACADEMIC/CHARITABLE ORGANISATIONS (as we understand)

The Carnegie Young People's Initiative www.carnegie-youth.org.uk
“This is an international organisation seeking to increase the participation of young people in policy making. The UK site includes information about the extent of young people's involvement in the UK and practical case studies.
The Initiative has recently embarked on a new project to make the NHS Patient Advisory and Liaison Services (PALS) relevant to young people and their patients and carers.”

The Cochrane Collaboration Consumer Network www.cochrane.no/consumers
“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.”

ContinYou continyou.org.uk
“Formed in November 2003 by the joining of two well-established charities, Education Extra and CEDC, ContinYou is one of the UK's leading community learning charities.
We use learning to tackle inequality and build social inclusion. Our work includes a range of programmes and services with a central purpose 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. We strive to link education and lifelong learning with health, and with work to regenerate communities.”
Various areas of work, including Health Improvement :
“ContinYou will work with its partners and service users to assist in maintaining health improvement. Underpinning this will be a capacity building approach both within statutory and non-statutory agencies, as well as communities, to enable them to work together to tackle health inequalities.” ContinYou - Health improvement

Health Quality Service (HQS) hqs.org.uk
“The Health Quality Service is the longest established health accreditation service in the UK and the rest of Europe. We work with UK and international healthcare organisations to improve the quality of patient care through consultancy services and the development of health care standards and assessment processes. …..
Mindful of the Government's drive for a responsive and reactive health service, and following requests from clients, HQS has designed a workshop programme to help professional staff groups develop a strategy and plan for effective patient and public involvement.”

Health Services Management Centre hsmc.bham.ac.uk
Public and Patients as Partners in Health and Social Care Programme
“HSMC has had a programme of work in the area of public and patient involvement for nearly ten years led by Dr Shirley McIver. During that time, government policy has shown an increasing emphasis on this area leading up to Section 11 of the 2001 Health and Social Care Act that placed a duty on all NHS organisations to involve patients and the public in planning

services, developing proposals for changes to services and decisions that affect how services operate.

This legislation together with that enacting the new structures for public and patient involvement at the national and local level, and the powers given to local authority overview and scrutiny committees in relation to health services means that many more NHS staff will be expected to develop expertise in this area.

The programme aims to meet this need with the following:

Teaching
Seminars, short courses and learning sets
Consultancy and Development
Research
Publications"

Could not get any more detail re consultancy and development and the brochure on seminars etc was for 2004.

Institute for Public Policy Research ippr.org.uk

One of the policy areas IPPR works in is 'Public attitudes and involvement.' As part of this they offer consultancy services:

"The People and Policy team has a strong track record in using our research skills and expertise to conduct projects for external clients. We undertake a range of projects, including: Strategic consultancy: helping organisations to develop a public involvement strategy or methodology for engaging stakeholders in decision-making; Managing and facilitating workshops and deliberative forums; Running large-scale innovative public debates; Qualitative research including focus groups and interviews; Programme evaluations; Peer research; Training in public involvement and deliberative techniques." ippr - Consultancy

INVOLVE invo.org.uk

"INVOLVE is a national advisory Group, funded by the Department of Health, which aims to promote and support active public involvement in NHS, public health and social care research.

INVOLVE is supported by a Support Unit based in Eastleigh, Hampshire which is managed under the umbrella of the National Cancer Research Network (NCRN) at the University of Leeds."

Site includes:

- *publications (eg Guide to involving young people; Briefing notes for researchers re involving public in research – see list of toolkits/guides)*
- *database of training providers in the field of public involvement in research*
- *links page – gives 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.*

NIHCE Patient and Public Involvement Programme

"On 1 April 2005, the National Institute for Clinical Excellence took on the functions of the Health Development Agency to form the National Institute for Health and Clinical Excellence (NICE), responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. As a result of these changes, the Patient Involvement Unit (PIU) is now known as the Patient & Public Involvement Programme (PPIP).

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."
May have advice/lessons to share?

Picker Institute Europe www.pickereurope.org
"Picker Institute Europe is committed to producing research evidence explaining patients' perspectives, experiences and involvement in health care. As well as carrying out surveys of patients' experiences for different health care providers and developing new survey instruments, we design and carry out research on:

- patients' or lay people's preferences, attitudes and perceptions of health care
- how patients are involved in their own health care
- how people are involved in and affected by health policy and service development."

This name is referred to in many places – they clearly do a lot of work in this field.

4Ps (Preparing Professionals for Public Participation) 4ps.com
"4Ps development programmes are for everyone involved in delivering health care - in hospitals, GP practices, the community, walk in centres, networks, collaboratives and Trusts."
Services geared primarily at NHS staff – questionable relevance to regulatory bodies. Have produced a guide to toolkits – see my toolkits list.

Research & Development Learning rdlearning.org.uk
Their database gives details of 5 training courses etc aimed at developing skills in involving users in research:

Health R&D Now
Involving Users in Research - (Workshop/Seminar)

Thames Valley University
Faculty of Health and Human Sciences
Leading, Management and Partnership Working - (Taught Course)

Trent Research and Development Support Unit
Part of the Solution: Involving Service Users in Research - (Workshop/Seminar)

UKHEP (UK Healthcare Education Partnership)
User and carer involvement - Distance Learning (Only)

University of Warwick
Patient and Public Involvement in Health Care - (Short Course)

2) CONSULTANCIES

Acton Shapiro consultancy & research actonshapiro.co.uk
"Acton Shapiro is a specialist independent company providing consultancy and research in the fields of health and social care. Directed by Liz Newbronner and Chris Acton, our team has a wide range of skills gained through many years of experience in health, social services and the voluntary sector.
Acton Shapiro can help you make patient, carer and public involvement manageable and

meaningful by:

- Working with staff to develop a patient, carer and public involvement strategy
- Designing, administering and analysing questionnaires
- Running focus groups, carrying out interviews and organising consultation events
- Planning and delivering involvement projects using a range of approaches
- Producing clear feedback reports for staff and the wider public
- Advising GP practices on approaches to involvement
- Training PCT and practice staff in approaches for effective involvement."

Finnamore Management Consultants finnamore.co.uk
Work in a variety of areas, one of which is 'Effective partnership working', including user/carer involvement. Finnamore Management Consultants - Partnership

Geronimo geronimopr.co.uk
"As a specialist provider of research, evaluation and consultation services, we work with our clients to engage stakeholders, user groups and the public in thought provoking consultancy. We combine breadth and depth of experience in health and education sectors and also have a broad understanding of consultation needs in other public sectors such as regeneration and economic development.
Our team of professional researchers are able to provide innovative, methodical and rigorous research meeting the needs of the public sector in the 21st century. Our approach offers clients an optimum mix of quantitative and qualitative research services and integrates more traditional research techniques with innovative on line consultation methodologies "

Harrogate Training & Development htd.org.uk
"Specialising in the design, management and delivery of professional and personal development events for the Health & Social Care sectors"

Newchurch Ltd newchurch.co.uk
"Consultation is integral to the Government's policy-making process. Newchurch has considerable experience in this field, having developed consultation proposals and collated and analysed responses on behalf of NHS and regulatory organisations.
We are also practised in engaging the public and healthcare providers in a range of less formal methods, such as one-to-one interviews."

Silkap silkapconsultants.co.uk
"Silkap Consultants specialise in research, user participation, whole systems approaches and diversity management and training for health and social care organisations. We combine our passion for equality with a belief that our work should have a practical application and 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 decade on methods to engage diverse stakeholders, good practice in commissioning health and social care services for diverse communities, quality assurance, advocacy, ethnicity monitoring and HIV and sexual health."
We offer training and consultancy for health, social care, voluntary organisations and charities, with specialist services in user involvement, diversity and equality. We conduct reviews, audits, evaluations, develop services and strategies, produce resources and facilitate learning within individual and group settings."

APPENDIX 4

PATIENT/PUBLIC REPRESENTATIVE GROUPS

1) DATABASES/WEBSITE LISTS OF PATIENT/USER ORGANISATIONS

Long Term Medical Conditions Alliance **lmca.org.uk**
"LMCA is the umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions."
Site includes list of member organisations (about 100) with links to web sites.

Patients Forum **thepatientsforum.org.uk**
"The Patients Forum is a network of national and regional organisations concerned with the healthcare interests of patients and their families and carers. Full membership is open to national and umbrella organisations representing the interests of users of health services and their families and carers. Associate Membership (non-voting) membership is open to other bodies such as professional and academic organisations, service providers and statutory and regulatory bodies."
About 65 full members are listed – links to their websites are given. Found several links that didn't work, so although more closely targeted at representative organisations, this site is perhaps less reliable than Patient UK.

Patient UK **patient.co.uk**
"Details of 1,973 UK patient support organisations, self help groups, health and disease information providers, etc. Each entry is cross referenced and details are checked annually. Browse by A-Z, by subject category, or search using the search box"
A very comprehensive database. Each entry gives brief description of the organisation, plus full contact details including web links. Very easy to use.

Patients Association **patients-association.com**
The Support Groups database provides contact details and background information on over 1,000 self help and patient organisations throughout the UK.
Not browsable – ie have to enter search criteria – so less easy to use than Patient UK.

2) INDIVIDUAL ORGANISATIONS (not listed in Patient UK)

Patient Concern **patientconcern.org.uk**
"Patient Concern is an organisation committed to promoting choice and empowerment for all health service users. Patient Concern is active in all areas of the health service, campaigning on issues that matter to patients and making the patient's voice heard in top level consultations."

3) REPRESENTATIVE ORGANISATIONS WHICH OFFER PARTICULAR SERVICES

Carers UK **carersuk.org**
"Carers UK provides consultancy services to assist local authorities in developing their work with carers.
Why choose Carers UK?
Carers UK as the only UK-wide organisation for carers, has unique knowledge and

experience of carers' needs, as well as detailed understanding of the legislative and policy framework in relation to carers.

Using our experienced consultants we can work with local authorities at all levels to ensure that their policies and procedures deliver measurable outcomes to carers.

Carers UK has a proven track record of working with local authorities, raising awareness of carers and their rights, assisting authorities to develop and improve the services that they provide to carers including carers assessment. Our research and campaigning work informs our consultancy and training."

Consultancy is geared to local authorities, but could perhaps be applied in other areas?

MENCAP mencap.org.uk

"***Mencap's accessibility services***

Mencap can help you to make your information more accessible to people with a learning disability.

How can Mencap help?

Mencap is the UK's leading organisation working with people with a learning disability. Through our daily experience of working directly with people with a learning disability, we have developed expertise in breaking down information into understandable concepts and language and presenting it in a way that aids understanding.

Our clients include the BBC, British Gas, and the Disability Rights Commission."

RNID 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. You can read more about these services in this section, and find out how they can help you and how you can book them."

RNIB rnib.org

Offers a range of products/services related to 'Good Design' and accessibility, including a guidance pack and consultancy services.

4) OTHER ORGANISATIONS / INITIATIVES

NCC, NCVO and CBI, Future services Are you being served? Launched in July 2004

"Future Services is a unique collaboration between NCC, NCVO and the CBI. For the first time these national representative bodies have come together to stimulate a debate about how future public service provision can be shaped by the people and communities that use them. Future Services will examine how greater diversity of provision in public services can build good practice, support the empowerment of users and the creation of more customer focussed public services."

APPENDIX 5

PPI STRUCTURES IN ENGLAND – DETAILED INFORMATION

Commission for PPI in Health cppih.org

“The Commission for Patient and Public Involvement in Health was set up in January 2003. It is an independent, non-departmental public body, sponsored by the Department of Health. The Commission's role is to make sure the public is involved in decision-making about health and health services in England. The Commission is responsible for submitting reports to and advising the Government on how the PPI system is functioning. It liaises with national bodies such as the Healthcare Commission on patient and public involvement issues, and makes recommendations to these bodies and the Department of Health as appropriate. The Commission gathers information and opinion from PPI Forums, channelled through its shared information system in order to ensure that the bodies it reports to are acting upon patients' and the public's views.”

Patient and Public Involvement (PPI) Forums

There are 572 PPI Forums in England, one for each NHS Trust and PCT. They replaced the old system of Community Health Councils in December 2003.

“They are made up of local people and have new powers. The Forums play an active role in health related decision making within their communities. Members of PPI Forums, are provided with training and development opportunities to enable them to participate effectively. Each PPI Forum is supported by a Forum Support Organisation and the Commission regional centre.

PPI Forums are a key vehicle for raising awareness of the needs and views of patients and the public, and placing them at the centre of health services. They have a number of primary roles, which include:

- Obtaining views from local communities about health services and make recommendations and reports
- Making reports and recommendations on the range and day to day delivery of health services
- Influence the design of and access to NHS services
- Providing advice and information to patients and their carers about services
- Monitoring the effectiveness of local Patient Advice and Liaison Services (PALS)
PPI Forums work together to share experiences and to address common issues.”

Forum Support Organisations

“Forum Support Organisations (FSO) are not-for-profit organisations that have been contracted through a competitive tendering process to support PPI Forums. These organisations, independent of the NHS, use their knowledge, experience and existing contacts within local communities to support PPI Forums.

They are single organisations or consortia that play a vital role in helping to shape the future of health provision throughout England. They are managed by a geographical basis by nine regional centres.

Each FSO support two or more PPI Forums by providing them with access to administrative and development support and a comprehensive knowledge management infrastructure. Specifically Forum Support Organisations:

- Help the Commission by supporting the recruitment and training of PPI Forums

- Help PPI Forums communicate with each other, the Commission and other external networks and organisations
- Arrange for information and guidance provided by the Commission to be available to the PPI Forums
- Help PPI Forums to monitor NHS services
- Help PPI Forums play an active role in health-related decision-making
- Provide administrative support to PPI Forums"

A full list of FSOs by region is given on the CPPIH website.

The future of CPPIH and PPI Forums

As a result of the DH's review of its 'arms length bodies', it was announced in July 2004 that the CCPIH will be abolished in August 2006. A new PPI resource centre/centre of excellence will be established in January 2006 via a contract with an existing organisation (tendering exercise currently underway). It will be managed by the new NHS Institute for Learning, Skills and Innovation. However a recent report in the Health Service Journal stated that the abolition of the CPPIH has been delayed until 2007 and the reorganisation of patient forums put on hold – although this is still to be confirmed.

"The Resource Centre will be an important source of information for patients forums, with its main role being to seek out existing and emerging PPI best practice and innovation and to communicate that information to stakeholders particularly the NHS and PPI Forums. The Centre will focus particularly on best practice for PCT patients forums about ways of working together to follow the patient's journey."

Following the decision to abolish CPPIH, a consultation exercise on the future of PPI Forums and their support needs was carried out in late 2004/early 2005. The government's response to this consultation was published in March PPI consult gov response The changes to be made are summarised as:

- "NHS Appointments Commission will be fully responsible for forum appointments from the abolition of CPPIH in August 2006
- In the future all forums will be required to have chairs who will be appointed by the NHS AC - forum members will be involved in this process
- The proposed 'centre for excellence' will become a resource centre for both forums and the NHS from December 2005
- Staff support will be provided under a limited number of contracts, focussed on the 9 existing regions
- Forums will be combined within PCT areas but retain a focus on every NHS trust in that PCT area
- The number of forum members across England will remain at least at the same level
- We will consider the development of regional and national networks for forums
- Forums will continue to be involved in the development of the work needed to make these recommendations happen."

Patient Advice and Liaison Services

"PALS are a central part of the new system of PPI in England. They are available in all trusts. PALS provide:

- confidential advice and support to patients, families and their carers
- information on the NHS and health related matters
- confidential assistance in resolving problems and concerns quickly
- information on and explanations of NHS complaints procedures and how to get in touch

with someone who can help.

- information on how you can get more involved in your own healthcare and the NHS locally
- a focal point for feedback from patients to inform service developments
- an early warning system for NHS Trusts, Primary Care Trusts and Patient and Public Involvement Forums by monitoring trends and gaps in services and reporting these to the trust management for action.

PALS act on behalf of their service users when handling patient and family concerns. They liaise with staff, managers and, where appropriate, other relevant organisations, to negotiate speedy solutions and to help bring about changes to the way that services are delivered. PALS will also refer patients and families to local or national-based support agencies, as appropriate."

Independent Complaints Advocacy Services (ICAS)

"The Independent Complaints Advocacy Service (ICAS) supports patients and their carers wishing to pursue a complaint about their NHS treatment or care. This statutory service was launched on 1 September 2003 and provides for the first time a national service delivered to agreed quality standards.

ICAS empowers clients by providing information, support and guidance helping them to articulate their concerns and navigate the complaints system. This may include assistance with constructing a complaints letter, drafting or attendance at meetings. ICAS supports the principle of local resolution and aims to help clients find a solution as close as possible to the point of the service that has caused dissatisfaction, maximising the chances of the complaint being resolved quickly and effectively."

From January 2003, Section 11 of the Health and Social Care Act (2001) in England has placed a mandatory duty on primary care trusts (PCTs), NHS trusts and strategic health authorities to involve and consult with patients, carers and the public – not just when a major change is proposed, but in the development of proposals and in ongoing service delivery. In Wales, there are robust performance management arrangements for public and patient involvement through the Signposts framework, with Signposts Two, providing advice on organisational change and a self-assessment framework (Welsh Assembly Government. 2003. Signposts Two – putting public and patient involvement into practice). About 98% of NHS trusts now have a PALS to support people and resolve individuals' concerns. While Wales will retain community health councils (CHCs), in England, the Commission for Patient and Public Involvement in Health, an independent non departmental public body will oversee new structures to empower patients, carers and the public to have a say in local and national decision making. At local trust level in England, there will be Patient and Public Involvement Forums (PPIFs) which, amongst other things will monitor the quality of services from a patient perspective. They will also and commission or provide Independent Complaints Advocacy Services (ICAS) to support complainants. Complainants will be able to access advice to help them articulate their concerns and navigate the complaints system. ICAS can also provide advocacy for those needing support with writing letters, or requiring someone to speak on their behalf at meetings. Information on ICAS is available at www.doh.gov.uk/complaints/advocacy.htm.

Local authorities with social services responsibilities have been given power (under 2001 Health and Social Care Act) to review the planning, provision and operation of health services through overview and scrutiny committees (OSCs). These committees will report to local NHS organisations, who must respond in writing within 28 days. NHS organisations have a duty to consult with their local OSC if they are considering any substantial development of health services, or any substantial variation in provision of services. Guidance on overview and scrutiny is available at www.doh.gov.uk/involvingpatients.

In April 2004, the new *Commission for Healthcare Audit and Inspection* (CHAI) will take over the responsibilities of the CHI, the healthcare value for money work of the Audit Commission, the National Care Standards Commission's work in private healthcare and later, subject to legislation, the work of the Mental Health Act Commission. In England, CHAI will also take over responsibility for the second stage of the complaints process. In Wales, the second stage in the complaints process will be the responsibility of lay people, independent of the NHS, appointed by the Welsh Assembly.

Instead of a rolling programme of local inspections across every trust, the vision for CHAI is that it will gather information from existing local and national sources and have a local presence. Information will be screened and there will be targeted in depth reviews. In terms of PPI, it will continue to assess the same things, such as the patient's experience and trusts' PPI arrangements, but in different ways. This provides the opportunity for different agencies, such as CHAI and CPPIH to work together, share data and coordinate inspections so as to reduce the burden of regulation on healthcare organisations. These new systems and structures make this a crucial period for the evolution of PPI. Our research has highlighted that local PPI activity has been a response to a convergence of these pressures, as well as a reaction to the NHS Plan and the recommendations of the Bristol Inquiry (Learning from Bristol. 2001. The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 – 1995. Command Paper CM 5207). People have reported that CHI's spotlight on PPI during a clinical governance review has also been a stimulus to work in this area.

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