

Signposts

A practical guide to public and patient involvement in Wales



Cynulliad Cenedlaethol Cymru
The National Assembly for Wales



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Contents

Acknowledgements	iv
About this guide	v
1. Setting the scene	1
1.1 Background	1
1.2 Key requirements of the National Assembly for Wales	2
1.3 Performance management	3
2. Building the foundations	7
2.1 A framework for public and patient involvement	8
2.2 Developing a strategy	15
3. Managing public and patient involvement successfully	21
3.1 Managing the work	22
3.2 Techniques	41
3.3 Capacity building: supporting the public and patients	65
3.4 Capacity building: supporting organisations	78
3.5 Capacity building: joint working	84
Appendix 1	89
Case studies	89
Contents in detail	91

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We would also like to thank all those who have contributed to the development of the guide, either by submitting valuable information and comments or by participating in consultation events and research.

About this guide

This guide to public and patient involvement provides information and advice to NHS organisations about how to develop work in public and patient involvement and how to meet the performance management requirements of the National Assembly for Wales as outlined in the NHS Plan *Improving Health in Wales*.

It is aimed primarily at those who are responsible for taking forward public involvement work within their organisations. However, the guidance may also be of assistance to others engaged in public and patient involvement where their activities impact either directly, or indirectly, upon the NHS. This includes community health councils, voluntary organisations, local authorities and others whose contribution has been invaluable in the preparation of this guidance, and who we hope will benefit in their turn from the messages contained in its pages.

The guide focuses on both the strategic and operational aspects of public and patient involvement, and draws heavily on research sponsored by the National Assembly and undertaken by OPM.[™]

OPM carried out a stock-take of public and patient involvement initiatives in Wales, undertook qualitative research on 10 case studies in Wales to find out 'what works when', and held two national stakeholder conferences that looked at the effectiveness of public and patient involvement in order to elicit levers and barriers to successful implementation. This work complements other Welsh initiatives that have sought to identify how the 'lay voice' can influence health and social care decision making best.

The resource guide draws on good practice principles from initiatives in the

rest of the UK which it is hoped will serve as useful background material for users of this guide. It also contains case studies that illustrate a range of different types of initiatives conducted across Wales and England.

There are three sections:

Section 1 is about **setting the scene** for public and patient involvement. It gives an account of why public and patient involvement is important, how it fits with the NHS Plan in Wales and the key elements of the work that must be completed in order to fulfil the performance management requirements of the National Assembly.

Section 2 outlines the work that needs to be undertaken in order to provide a **foundation for effective public and patient involvement**. It provides a framework for understanding what public and patient involvement means and guidance on how to: conduct a baseline assessment, take a strategic approach to the work, and develop annual plans.

Section 3 goes into more detail about **undertaking public and patient involvement** initiatives successfully. It takes a practical project management approach, identifies key success factors in implementation, provides signposts to further sources of information and support, and suggests how to build the capacity to carry out this work well.

This guide includes information about two dimensions of public and patient involvement – the 'individual' and the 'collective'. In this edition of the guide, sections 1 and 2 include references to both these dimensions when discussing the foundations for the work. However, section 3 outlines how to manage public

and patient involvement initiatives at the ‘collective’ dimension only (though some principles will be similar). The reason that the ‘individual’ level has been omitted from this edition is that work is currently being conducted in this area by NAFW and others and this will be incorporated into later editions (e.g. work on health and social care guide, patient support pilots and reform of complaints procedure).

Over time the intention is to add to and update the guide to incorporate future developments in practice in the field and in policy at the centre.

Copies

Users of the guide are encouraged to photocopy relevant sections for use by others. Further copies of the whole guide can be downloaded from the NAFW website at: <http://www.wales.gov.uk/signposts> or <http://www.cymru.gov.uk/signposts>

1 Setting the scene

This section looks at why public and patient involvement is important and what you need to do to fulfil NAFW's requirements.

The chapters are:

- 1.1 **Background to public and patient involvement**
- 1.2 **Key requirements of the National Assembly for Wales**
- 1.3 **Performance management**

1.1 Background

Public and patient involvement is a key element of *Improving Health in Wales – A Plan for the NHS with its Partners*. It contributes to creating a high quality NHS for Wales that is responsive to people's needs. Involving the public and patients is central to service planning and provision; it is a major driver for service improvement and leads to a better patient experience of care.

The plan for the new NHS is: 'created in partnership with the citizens of Wales, and will be driven by the views and involvement of individuals and communities in the design, delivery and monitoring of health services.' Chapter 3 outlines why public and patient involvement is important for improved health and health care and what responsibilities NHS organisations and staff have in undertaking the work.

The plan also provides for the development of a performance management framework that incorporates a new set of public service accountabilities. Included in these are requirements that NHS Trusts and LHGs:

- undertake a **baseline assessment** of arrangements to deliver public and patient involvement
- produce an **annual plan** for public and patient involvement.

It is also recommended that they:

- develop a **strategy** for public and patient involvement.

These aspects of public and patient involvement development will be subject to a **performance management** framework that will be monitored by the National Assembly for Wales.

1.2 Key requirements of the National Assembly for Wales

The National Assembly for Wales has specified in chapter 3 of the NHS plan its intention to build a framework focused on encouraging the NHS in Wales to:

- provide better information,
- listen to patients,
- provide advocacy and support,
- act on complaints,
- make the NHS accountable, and
- change the culture to achieve all the above.

It has also identified a number of actions and steps it expects NHS organisations in Wales to undertake in preparation for this work, including:

- making chief executives accountable for the implementation of public involvement activities;
- ensuring NHS organisations have a range of public involvement mechanisms in health service planning and service review;
- extending Local Health Group membership to include local authority representatives;
- requiring NHS Trusts and LHG to undertake a baseline assessment of their arrangements to deliver public involvement activities;
- ensuring NHS Trusts and LHGs publish an annual account of views received from patients and actions taken as a result;
- requiring all trusts and LHGs to publish an annual prospectus;

- providing patients with questionnaires to record their views about services;
- giving patients the right to receive copies of correspondence between clinicians about them.

By December 2001, NHS Trusts and LHGs will complete a **baseline assessment** of their arrangements to deliver public and patient involvement. This should help them review current activities and performance and meet the requirement for progressing this work in a systematic and coherent fashion. The NAFW monitoring process will focus primarily on the annual plans but it will want to see evidence that baseline assessments and strategic plans have been carried out.

Advice on how the work should be undertaken is provided in the relevant chapters in the guide. The following sections provide information on what needs to be provided to the NAFW in order to meet its performance management requirements. This includes standards expected, timescales of delivery, and evidence to demonstrate that the work is being undertaken effectively.

Welsh Language Act 1993

Organisations are reminded of their responsibilities under their Welsh Language Schemes to treat English and Welsh on the basis of equality in their dealings with the public. Although references to Welsh will not always be made specifically, readers should be aware that these requirements need to be applied to all aspects of activity outlined here. Ensure that appropriate questions are asked of Welsh speakers and that they are represented proportionally.

1.3 Performance management

Setting performance expectations

The wider *Performance Management Framework for NHS Wales* was published in March 2000. It was developed to provide a means by which NAFW, in partnership with local authorities, could monitor the performance of the NHS in Wales, while supporting the delivery of high-quality cost-effective services that address local needs and targets for health improvements, as well as tackling social inequalities. In addition to drawing up national performance indicators to underpin health improvement programmes, it also outlined seven core values (fairness, effectiveness, efficiency, responsiveness, integration, accountability and flexibility) as a foundation for health improvement work. Several of these have particular significance for public and patient involvement activities. The framework recognised and highlighted the importance of user and public involvement in monitoring performance and supporting service quality improvement, as well as helping strengthen wider accountability by the NHS in Wales.

A key benefit highlighted was: 'Patients and the public should be better informed about what services are currently delivered in their area, what future service changes/developments are being proposed and feel empowered to influence the future planning and delivery of health services. However there is (also) a need for NHS organisations to improve current mechanisms for engaging patients and the public in decision-making processes if these potential benefits are to be realised.'

(*NHS Wales: Performance Management Framework. The Framework Document*, page 21). Therefore public and patient involvement links into wider performance management aspects in the NHS in Wales – as well as being an objective in its own right.

In meeting the core values on responsiveness, integration and accountability (see figure 1 overleaf), effective public and patient involvement is integral to the performance expected from LHGs and NHS Trusts in Wales.

The performance framework is being revised in the light of discussions on implementing the NHS plan *Improving Health in Wales*. The updated version will continue to focus attention on delivering the key objectives of the NHS, including genuine improvements in public and patient involvement. In the meantime, the main requirements set are those specified in chapter 3 of the NHS plan. They are:

- completing a **baseline assessment** of public and patient arrangements (by December 2001);
- producing an **annual plan** on the work (by April 2002).

Baseline assessments and strategies

NAFW expects all NHS Trusts and LHGs to meet the requirements listed below as part of the work of undertaking a baseline assessment and developing a strategy for public and patient involvement over the coming three to five years. It does not want to see all the detail of the baseline analysis and the full plans of these strategies, but it does want to know that this work has been done

Figure 1. Performance management framework

VALUES	ASPECTS OF PERFORMANCE
Fairness	<p>The fairness of provision and access to services in relation to need on various dimensions:</p> <ul style="list-style-type: none"> • geography • socio-economic • demographic (age, ethnicity, sex) • care groups (e.g. people with learning disabilities)
Effectiveness	<p>The extent to which services are:</p> <ul style="list-style-type: none"> • clinically effective (interventions or care packages are evidence based) • appropriate to need • timely • in line with agreed standards • targeted and effective e.g. health promotion programmes • provided by organisations whose services conform to best practice • delivered by appropriate levels of trained, competent and educated staff
Efficiency	<p>The extent to which the NHS provides efficient services, including:</p> <ul style="list-style-type: none"> • cost per unit of care/outcome • productivity of capital estate • labour productivity
Responsiveness	<p>The extent to which services:</p> <ul style="list-style-type: none"> • are focused around the individual needs and preferences of patients • demonstrate patient involvement, good information and choice • address waiting times and accessibility • are progressively improved in line with local Health Improvement Programme priorities and the requirements of Long Term Agreements • provide the skill, care and continuity of service provision
Integration	<p>Evidence of:</p> <ul style="list-style-type: none"> • effective participation in the use of local Health Alliances • joint planning within Health Improvement Programmes and Community Plans of the Local Authorities e.g. development of joint training for ‘cross-boundary’ staff • joint use of resources through joint investment plans or use of new powers to pool resources • the developing role of Local Health Groups e.g. percentage of LHGs managing devolved budgets • integrated delivery of services both within and outside the NHS, reflected in Long Term Agreements
Accountability	<p>Evidence of:</p> <ul style="list-style-type: none"> • effective benchmarking practice aimed at consistently improving performance • effective management of services at a local level • Long Term Agreements which have a patient focus and reflect the key priorities of the local Health Improvement Programme • local performance management arrangements e.g. in relation to progressing the local Health Improvement Programme • implementation of corrective action plans where performance and efficiency fall short of expectation • open decision making processes • public involvement in planning, implementation and monitoring • measures to encourage the public to take responsibility for their own health and use of health services
Flexibility	<p>The extent to which the NHS provides flexible services which:</p> <ul style="list-style-type: none"> • respond to individual need and preference • adapt to changing needs • take advantage of joint working with local authorities and the voluntary sector
Promoting independence	<p>Evidence of:</p> <ul style="list-style-type: none"> • shifts in demand for services linked to the growing independence of users

Reproduced from *NHS Wales: Performance Management Framework. The Framework Document*, p16

properly and to see the main conclusions and development objectives for the future. This will need to be reflected in NHS Trusts' and LHG's annual plans to be produced each spring. (See section 3 for more about this work.)

The main requirements expected are:

- confirmation that NHS Trusts and LHGs have undertaken a baseline assessment of their public and patient involvement work;
- confirmation that NHS Trusts and LHGs have developed a three- to five-year strategy for future development of public and patient involvement;
- evidence that the baseline assessment and development of strategy was a thorough and inclusive process:
 - including a comprehensive assessment of past practice and future needs
 - involving input from key stakeholders
 - taking account of different needs and expectations
 - linking to the involvement work of other agencies in the patch;
- identification of the main strengths and weaknesses of current practice and main development objectives for the future;
- the output of this work embodies future plans for initiatives that:
 - address the need for work at both individual and collective levels
 - work along the spectrum of involvement – something at each level
 - build capacity internally and externally
 - have a strong focus on joint working and cross-agency collaboration
 - aim to use a range of methods
 - seek input from a broad range of interests

- seek involvement from marginalised and vulnerable groups
- lead to actions that aim to improve services/patient experience;
- confirmation that due regard has been given to the linguistic considerations of developing strategies;
- completion of the baseline assessment work by December 2001;
- completion of the strategy development work by April 2002.

Annual plans – key requirements

The second main requirement specified in chapter 3 of the NHS plan that NHS Trusts and LHGs will be expected to complete in the coming year is the drawing up of annual plans on public and patient activities. These will become the main vehicle through which NAFW will evaluate and monitor NHS Wales. In the first year (April 2002) the annual plan will build on the baseline assessment and strategy development of the previous six to nine months. These reports should not be lengthy documents but should convey the substance and priorities of what individual organisations are doing in this area. Subsequent reports from 2003 onwards will provide a retrospective assessment of the past twelve months' activities as well as future plans.

The annual plans will be expected to:

- translate broad aims and plans in the strategy into specific activities and initiatives for the coming year;
- target service areas and stakeholder groups;
- timetable activities;
- provide feedback on linguistic considerations;
- demonstrate how and where the results of public and patient involve-

ment work will affect decisions and impact on services – and that there are clear intended outcomes for the work;

- outline resource input (investment in activity, staff input, who does what, lead responsibilities);
- identify publicity and feedback arrangements;

Main steps of baseline assessment and strategy development work

1. Set up the project team.
2. Agree the main parameters: objectives; key activities; timetable; report back; and publicity arrangements.
3. Review available documentation (reports, data, other written evidence).
4. Conduct internal research interviews /discussions.
5. Conduct external research interviews /discussions.
6. Review all evidence and analyse key strengths and weaknesses of past practice and identify possible future development needs.
7. Draft outline strategy objectives for next three to five years.
8. Discuss and agree outline strategy with key internal groups.
9. Share outline strategy with main external groups such as partner agencies and other interest groups.
10. Finalise strategy and develop action and implementation plans.
11. Publicise final plans.
12. Report to NAFW.

- specify training and development activities to support the work (with staff and public);
- indicate any links with other relevant involvement work by other agencies and where and how collaboration will be pursued and information shared;
- report on the past year's activities and how work in the coming twelve months will build on this and take it forward (new areas/client groups);
- ensure that year 1 annual plans will report on 'foundation work':
 - baseline assessment
 - strategy development;
- update plans and review progress in subsequent years.

There is a common structure and format suggested for how NHS trusts and LHGs should present their annual reports to NAFW (see section 2.2).

2 Building the foundations

This section provides guidance for those leading the work on public and patient involvement at a strategic level on how to create the foundations for taking the work forward successfully. It outlines a framework for thinking about public and patient involvement that will help you to undertake the baseline assessment and lay the ground for developing strategy and preparing annual plans.

The chapters are:

2.1. A framework for public and patient involvement

- Dimensions of public and patient involvement
- Achieving the desired outcomes
- Capacity building
- Diagnostic analysis

2.2. Developing a strategy for public and patient involvement

- Taking a strategic approach and developing strategy
- Developing annual plans



PHOTO: ADAM SCOTT

2.1 A framework for public and patient involvement

- Dimensions of public and patient involvement
- Achieving the desired outcomes
- Capacity building
- Diagnostic analysis

Dimensions of public and patient involvement

In order to undertake work on public and patient involvement, it is important that NHS Trusts and LHGs have a common understanding of what the term means and take a consistent approach.

Public and patient involvement needs to be carried out across **two levels**:

- **the individual** – the involvement of patients in discussions and decisions

concerning their own individual care and treatment. It is closely linked to the overall care experience for individual patients.

- **the collective** – the involvement of patients and the wider public in decisions concerning the delivery and planning of services.

At both the individual and collective levels, there may be different **degrees of involvement** that reflect a spectrum of engagement that ranges from **provision**

Figure 2. Main dimensions of public and patient involvement

	INFORMATION	FEEDBACK	INFLUENCE
INDIVIDUAL			
COLLECTIVE			

of **information** to patients and/or the public, through **feedback** from patients and/or the public to patient and/or public **influence** over decision making. Figure 2 on the opposite page brings these different dimensions together in the form of a grid.

At the **individual** level, involvement might mean receiving information about access to services, what to expect from care and treatment and/or about health professionals and treatment choices (information); having the opportunity to ask questions, make suggestions, spell out needs and concerns, make a complaint about service or the experience of care (feedback); and/or getting involved in choices about care and treatment options (influence).

At the **collective** level, involvement might mean the wider public receiving information about health concerns, for example, health promotion, public health, local NHS organisations and services available and/or service performance (information). It also might include mechanisms for feeding back the

aggregated views of patients and/or the wider public to NHS organisations, for example through quantitative or qualitative research, audit, or clinical governance reports, and/or aggregating and learning from patterns in complaints (feedback). Finally, it might mean the capacity and opportunity to represent public and patient views at the planning and policy level, for example, service planning, budget setting, or priority setting (influence).

In the past, initiatives have tended to concentrate at the most basic level, usually information provision. All organisations need to evaluate what they are doing in all six spheres with a view to broadening and deepening activities. This not only requires the development of new areas of activity, but also developing the capacity to undertake the work and being prepared to change working practices and culture in order to deliver the benefits of public and patient involvement.

The grid incorporating the different dimensions of public and patient

Figure 3. Main dimensions of public and patient involvement – linking initiatives to key dimensions

	INFORMATION	FEEDBACK	INFLUENCE
INDIVIDUAL	<ul style="list-style-type: none"> • Patient leaflets • Service prospectus • Patient held records (smart cards) • Internet provision • Access to patient correspondence 	<ul style="list-style-type: none"> • Individual complaints • Patient feedback/comment cards • Patient diaries 	<ul style="list-style-type: none"> • CHC support to individuals • Advocates • Interpreters • Customer care practice
COLLECTIVE	<ul style="list-style-type: none"> • Annual reports on PPI • Strategy for PPI • Annual plans • Performance information • Clinical governance reports • Press and media publicity 	<ul style="list-style-type: none"> • Patients panel • Complaints monitoring • Patients surveys (by organisation/national) • Focus groups • Wider consultation about health needs and priorities 	<ul style="list-style-type: none"> • Citizens juries • Stakeholder conferences • Local healthy alliances • Priority setting • Partnership forum • Lay representation on NHS bodies • Lay role in clinical governance

involvement can be used as a diagnostic tool. NHS Trusts and LHGs can map their various activities across the **organisation as a whole** and within **individual services**. This can aid an assessment of whether there is adequate provision for public and patient involvement, through making explicit what initiatives are in place, identifying gaps where more initiatives are required and measuring the degree to which there is consistency of practice.

Figure 3 on the previous page gives examples of the kinds of activities that can be developed across the main dimensions of public and patient involvement. Several of these are included in the proposals in chapter 3 of the NHS plan, such as a service prospectus and an annual spring report.

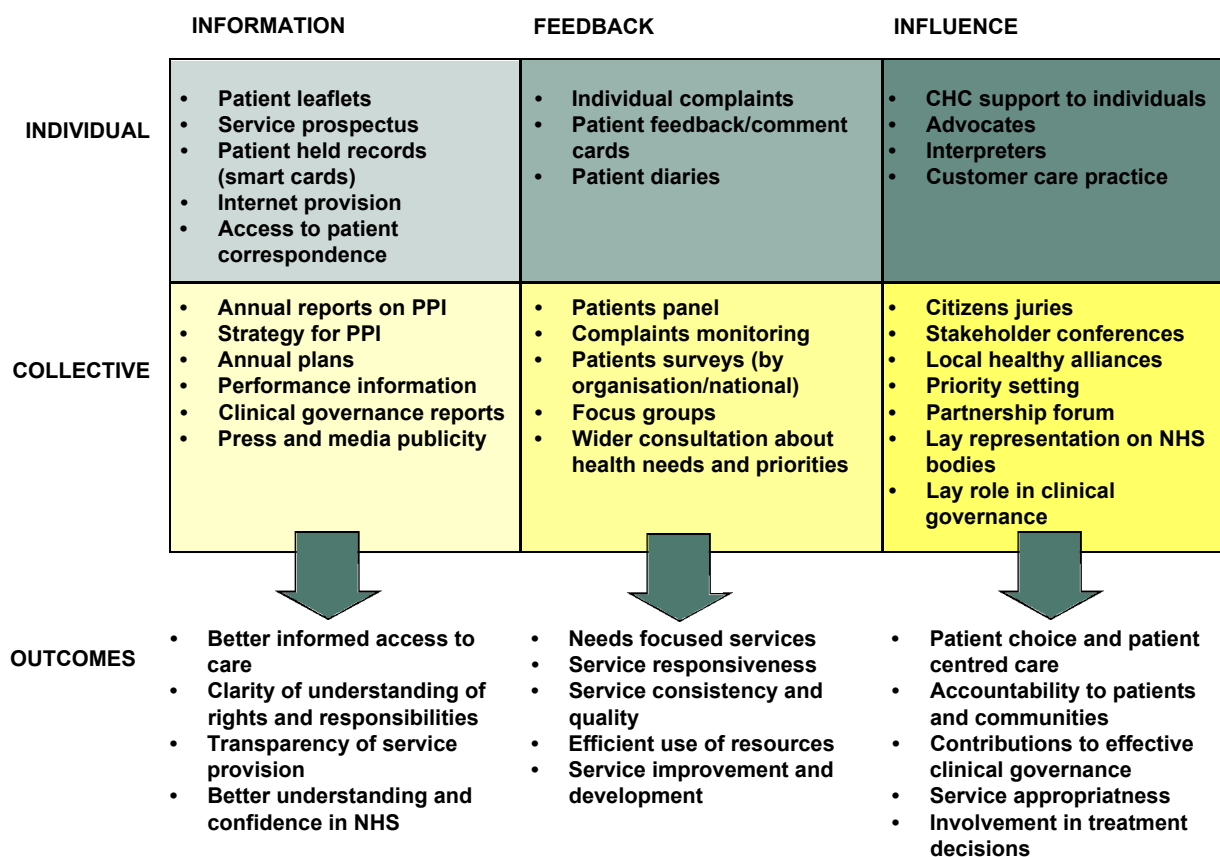
Achieving the desired outcomes

NHS Trusts and LHGs should be clear about the aims and objectives of this work. The possible outcomes for initiatives, presented in figure 4 below, attempt to make the link between means and ends.

Effective **information** provision to patients and to the wider public should lead to:

- better informed access to, and utilisation of, care,
- clarity of understanding about rights and responsibilities,
- transparency of service provision,
- better understanding and confidence in the NHS.

Figure 4. Main dimensions of public and patient involvement – linking purpose and outcomes



Effective **feedback** from patients and the wider public should lead to:

- services that are focused on needs,
- enhanced responsiveness of services,
- higher standards of service quality,
- greater consistency of service delivery,
- the efficient use of resources in delivering services,
- a developing capacity for service improvement and development.

Effective **influence** from patients and the wider public should lead to:

- patient-centred care,
- involvement in care and treatment decisions and informed choice,
- better accountability to patients and the public and enhanced clinical governance arrangements,
- integrated organisational systems and structures that are linked to improvements in outcomes and the patient's experience of care.

Feedback and influence share some common purposes and are not mutually exclusive arenas. The key difference is that feedback concentrates on obtaining public and patient perspectives on the **quality of service outcomes**, i.e. how good is the service that patients receive? Feedback is usually limited to obtaining information and views without any organisational obligation to take these on board during the **decision-making process**. Influence extends to bringing public and patient perspectives into the decision-making process itself in order to improve openness and accountability. It is when individuals or groups have a more active part to play in contributing to decision making or making the decisions themselves. Another way of putting it is that these initiatives should **improve both performance and governance**.

Capacity building

The research conducted into public and patient involvement across Wales suggested that building the capacity to undertake this work is the key to success. This capacity is the 'engine' driving the work forward and involves ensuring that any structures and systems created work properly, and are taken seriously, so that public and patient involvement processes lead to action and better outcomes for patients. There are three main areas for capacity building (more details on how to build capacity are to be found in section 3). In each of the following areas, organisations need to consider to what extent they are addressing the need to develop capacity for this work.

1. Supporting the public and patients

This is the ability to reach, and engage meaningfully with, a range of community interests and ensure that the work links with community development resources to enable people and non-statutory organisations to be involved. It is as much about providing opportunities for key interests to be taken account of as it is about providing useful information for organisations. Questions to be addressed when assessing capacity in this area include:

- Does the work reflect the social and cultural composition of the community?
- Does it include marginalised groups and more vulnerable people?
- Does it allow for perspectives on needs and aspirations to be articulated and acted upon?

There is more detail on how this area can be tackled in chapter 3.3.

Bro Morgannwg Inclusive Communication Initiative

Type of engagement: training and support for patients and carers

Context and objectives

The Total Communication Approach aims to provide a network of training and support to all carers and clients with learning disabilities to promote their involvement across the range of services that they use.

Process

The project seeks to establish a 'common language' between service providers, using visual strategies and symbols to support individuals' skills and needs. Four groups were established focusing on resources. Their remit includes:

- local development of signs and symbols and the production of documents in symbols;
- good working practices, for example how to provide active support to service users and carers;
- clinical effectiveness, in terms of assessing outcomes;
- providing training and advice for staff who elect to be co-ordinators in services.

The Inclusive Communication Initiative is evaluated through questionnaires with staff and service users, and through feedback provided by a representative body from supported user groups on relevant topics.

Partners

The project was initiated by the Bro Morgannwg NHS Trust Learning Disability Directorate, which works in partnership with seven major local authorities providing services to people with learning disabilities. A number of voluntary sector organisations such as Mencap, Cartrefi Cymru, DRIVE and West Glamorgan Housing Consortium are involved in the project.

Outcomes

The trust has received positive feedback regarding training provided through the project, and extra work generated by the project has resulted in the decision to develop additional full-time support posts, for which the trust is currently seeking funding. Evaluation of the project's effectiveness is ongoing. Successes include the production of West Glamorgan Housing Consortium's Tenant's Charter document in symbol form, and work on the complaint procedure for Bro Morgannwg.

Contact

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2. Supporting organisations

This incorporates the structures and systems that can support and integrate the work into everyday business, such as the resources available (financial, staffing, etc.), skills, expertise and the commitment of health professionals to do the work, organisational commitment and senior level support to make it all happen meaningfully. Questions to be addressed when assessing capacity in this area include:

- Are there clear roles and responsibilities in respect of who needs to do what regarding public and patient involvement work?
- Is this addressing behaviours and competencies internally as well as structures and systems?
- Are sufficient resources committed to supporting this work?
- Are there processes in place to assess whether this is being done well and is it meeting intended objectives and outcomes?
- Is the work integral to decision making, corporate objectives and everyday business?

There is more detail on how this area can be tackled in chapter 3.4.

3. Joint working

This means working in conjunction with partner organisations to ensure that public and patient involvement is co-ordinated and integrated so it adds value to the work and avoids duplication of effort and confusion on the part of the public. Questions to be addressed when assessing capacity in this area include:

- What activities are partner agencies involved in?
- How are these linked to NHS Trust and/or LHG activities?

- How far do different organisations draw upon each other's knowledge, expertise and networks, and learn from each other?
- Are initiatives in different organisations supportive and integrated?
- How far is information drawn from public and patient involvement initiatives shared between partner organisations?

There is more detail on how this area can be tackled in section 3.5.

Diagnostic analysis

You need to underpin your strategy for public and patient involvement with a diagnostic analysis of current and recent work in this area. Part of this could include a mapping exercise focused around the dimensions of public and patient involvement described above. This should identify initiatives and activities in place, as well as recognising gaps and deficiencies in current performance that suggest development needs and priorities for the future. The mapping exercise can be one part of a wider data gathering exercise. This can lead to an analysis of the situation and an assessment of your capacity to deliver on this work and, finally, to the development of priorities.

Data gathering

The data gathering element should include obtaining information on:

- structures, processes and activities for public and patient involvement currently in place (much of this information will have been obtained through the mapping exercise),
- needs and expectations in respect of public and patient involvement – internally and externally,

- an assessment of the effectiveness and impact of past and present initiatives,
- an assessment of the levers and barriers to success,
- the links between this work and wider organisational goals,
- your capacity to undertake the work (see section 3).

Analysis

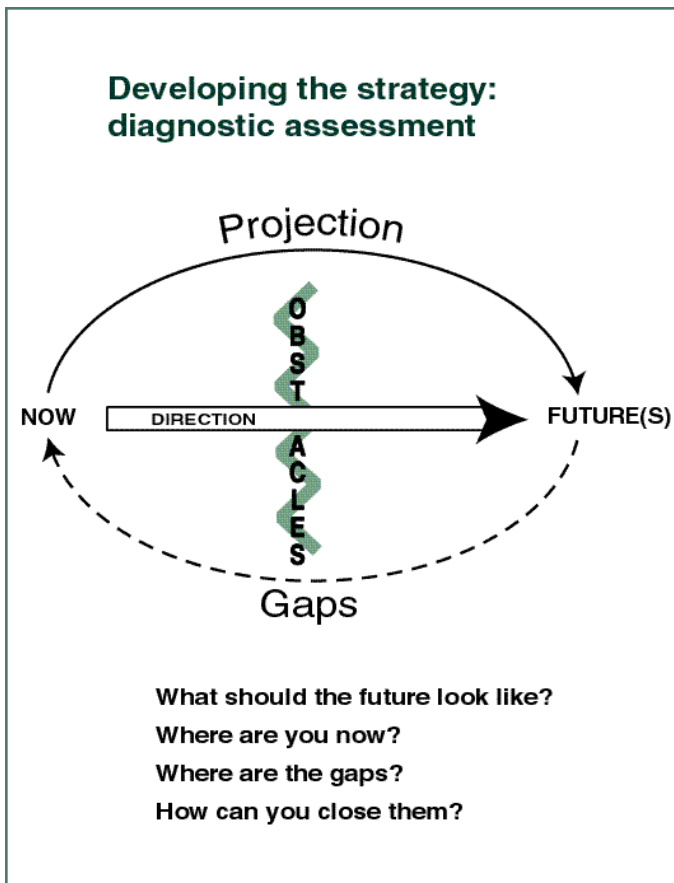
This can then lead to an analysis of an organisation’s context and a stock-take of organisational circumstances. There are various techniques available for this (see chapter 3.2). An organisation might then examine the **strengths and weaknesses** of its approach and assess the external environment in which it works to determine the way forward and develop priorities in conjunction with others.

Developing priority areas

Drawing on the mapping and diagnostic analysis, it should be possible to provide an overall assessment of an organisation’s current position with regard to public and patient involvement. This should lead to the identification of **priority areas for development** and allow the organisation to:

- set the **direction** in which the organisation wants to move in terms of strengthening, developing or extending its involvement work;
- make explicit the **obstacles** that need to be overcome to get there;
- recognise the **gap** between where the organisation is now and where it wants to be in the future and then think about actions that will help to close this gap (see figure 5 below).

Figure 5



Source: OPM

2.2 Developing a strategy

- Taking a strategic approach and developing strategy
- Developing annual plans

Taking a strategic approach and developing strategy

It is necessary to take a **strategic approach** to this work. This means being clear about why it is being undertaken and the expected benefits. This helps identify:

- *what* needs to happen organisationally to ensure success;
- *how* these changes will be brought about;
- *when* each action will be undertaken and over what timescale;
- *who* will be responsible for undertaking the work and managing its execution.

A **strategy** should:

- provide a sense of *purpose and direction*;
- *link* the work to the organisation's *wider aims and goals*;
- *take account of the environment* in which this work is being undertaken – the needs of others and the challenges to overcome;
- assess current work and specify what is needed in terms of *developing capacity* to undertake this work successfully;

- identify *clear objectives, measurable targets* and *realisable actions* to pursue;
- act as a *realistic plan for action* and not be just a paper exercise.

Visioning

All strategies, regardless of their focus, should provide a clear 'vision' – an aspirational statement, or picture – of what they aim to achieve in terms of outcomes and processes. This will help to determine what needs to be done to realise the vision. The NHS plan for Wales, and in particular chapter 3, provides aspects of the vision. But NHS Trusts and LHGs need to put this into their own context and link it with their own, their partners' and their communities' wider aims and goals. There must be a **shared vision** for public and patient involvement. Internal and external stakeholders must endorse, support and contribute to it.

There will be 'hard' elements of the work, such as developing the structures, processes and resources required. There will also be 'soft' aspects, such as developing values and a culture to guide the attitudes of staff towards the work. For the work to become meaningful, clinicians and managers need to believe in it and practise what is professed. The human capacity to deliver this relies on having not only the mind-set to endorse and support it, but also the skills and competencies to do it well.

The strategy document

The strategy should provide the long-term development plan for the NHS Trust or LHG in respect of its public and patient involvement work. It should draw upon and incorporate the work carried out as part of the baseline assessment and set out the future direction for the development of the NHS Trust's or LHG's intended work in terms of:

- **Vision and a set of core principles** that outline the organisation's aspirations for public and patient involvement. This might be a template for ideal practice, the values and beliefs that underpin its commitment to this work and how it relates to the vision and mission of the organisation. It could also include a set of standards and expected commitments for the work.
- **Assessment of current performance** based on the mapping and diagnostic analysis. This should recognise strengths that act as a foundation for good practice and deficiencies to be addressed.
- **Key priorities for development.** Decisions about priorities should incorporate resource factors and potential benefits, but also take account of the wider organisational and social context within the 'health patch'. Decisions made about priorities must reflect the needs and interests of external stakeholders, particularly those of patients, the wider public and partner agencies.
- **Objectives and targets.** The areas of activity to be developed, standards and commitments expected and how this will be measured.
- **Resources and support.** How the organisation will provide support for the implementation of the strategy.

These elements could form the elements or 'chapters' of a strategy document.

Test of a good strategy

A strategy for public and patient involvement needs to provide coherence and direction for the work and represent a meaningful blueprint for action and an essential tool for management. It should be a 'living document', that is one whose set of objectives and priorities is worked on and monitored continuously, revisited often, and updated when necessary.

A strategy should:

- have relevance and links to wider organisational goals and objectives;
- have relevance to wider community and partner interests and priorities;
- be founded in a sound and thorough diagnosis;
- have clear priorities and targets, with milestones for achievement;
- embrace an understanding of the dimensions of public and patient involvement;
- consider resource and capacity issues;
- be realistic and achievable;
- be widely endorsed and supported internally and externally.

Developing annual plans

The strategy provides the longer-term context in which annual plans are developed. The outputs of the strategy development work should be a small number of clearly articulated overall strategy aims or objectives (the outline strategy) supported by more detailed analysis of the actions that will support the realisation of each of these aims or

Figure 6. Public and patient involvement action plan

Organisation:					
Key strategy objective:					
Actions planned (including how it builds on past work)	Target groups/areas	Timescale	Links to other PPI work (co-ordination and support from others)	Resources	Expected outcomes (what and for whom?)

Format for annual plan reporting

Foundation plan (2002)

1. Purpose and vision
 - statement of where and how public and patient involvement fits into corporate priorities
 - vision of public and patient involvement for the organisation
2. Baseline assessment
 - process description and those involved
 - key findings on assessment of past practice – main strengths and weaknesses identified
 - main conclusions
3. Future development priorities
 - main strategy objectives for next three to five years (e.g. no more than 8 objectives)
 - how these are linked with, and take account of, other agencies' priorities
 - capacity building (internally and externally) and long-term resourcing and support
4. Next year's priorities and plans
 - key activities and initiatives planned
 - capacity building (internally and externally) and resourcing and support (suggested grid matrix for action plans)
5. Impact of the work and evaluating performance
 - main achievements so far
 - expected impact in coming year
 - process for monitoring and evaluating the work

Subsequent years' annual plans (2003 and beyond)

1. Strategy outline and priorities
 - restatement of key long-term priorities
 - how strategy guided last year's actions
 - any refinement of development priorities in the light of new circumstances
2. Impact and evaluation of past year's work
 - assessment of work completed
 - impact and outcomes to the work
3. Next year's priorities and plans
 - activities and initiatives planned
 - capacity building (internally and externally) and resourcing and support (suggested grid matrix for action plans)
4. Impact and evaluation of the work
 - expected impact and outcomes
 - process for monitoring and evaluating the work

objectives. This more detailed analysis will form the basis of the implementation plan that will include timescales, resourcing and accountabilities. It might be laid out in table or matrix format to support project monitoring and performance management.

Your annual plan should outline specific planned activities for the year. It should act as the equivalent of an annual business plan, timetabling the work, specifying who needs to do what and providing details of resources and support for the initiatives outlined. An integral part of the longer-term strategy, it is something that is reviewed and updated each successive year.

NHS trusts and LHGs will be expected to submit an annual plan on public and patient involvement each spring (see chapter 1.3). Your plan should include an assessment of the past year's work, including an account of how the organisation has responded to past public and patient involvement activities, as well as plans for the forthcoming year.

NAfW recommends that NHS Trusts and LHGs use a common format for these plans. Figure 6 provides a possible structure for annual reports that can also be the basis for public and patient involvement plans for 2002 onwards. The suggested structure incorporates the narrative content and substance of what goes into the annual report. Details concerning action plan activities, and initiatives for the forthcoming year, could usefully be drawn up outlining the main dimensions contained in figure 6. This is a well established grid or matrix format that many organisations regularly use in their business and service planning. Planned actions are listed against each of the main strategy objectives for public and patient involvement. This should be useful for internal monitoring and evaluation purposes as well as enabling efficient reporting on the work (both internally and to the NAFW).

3 Managing public and patient involvement successfully

This section is intended to be a practical aid for those who are leading, or are involved in, the taking forward of public and patient involvement initiatives at an operational level and who are responsible for implementing annual plans. It will also be of interest to those who take a more strategic approach and/or those seeking to integrate the work within an organisation or across a health community.

This part of the guide does not set out to duplicate the vast array of public involvement toolkits and other materials that already exist. Rather, it provides: a focus on a project management approach to public and patient involvement, an overview of the principles that should govern good practice, and references to sources of further support.

Each chapter below provides an overview of the steps necessary to ensure effective implementation of public and patient involvement initiatives. Some highlight key principles and contain references to materials that can support your work. Contacts that might be of assistance and examples of good practice are also included. The chapters are:

- 3.1. **Managing the work**
- 3.2. **Techniques**
- 3.3. **Capacity building: supporting the public and patients**
- 3.4. **Capacity building: supporting organisations**
- 3.5. **Capacity building: joint working**



PHOTO: ADAM SCOTT

3.1. Managing the work

- Planning the process
- Choosing the right approach
- Involving the right people
- Linking with clinical governance
- Monitoring and evaluation

Planning the process

Be clear about aims and objectives

Public and patient involvement requires careful planning. It should not be an afterthought or an add-on to core corporate aims and priorities. You should consider how public and patient involvement fits in with organisational priorities

and plans, and how money spent on involvement initiatives balances with spending on the provision of care. From the start, you need to be clear about the reasons for, and aims of, public and patient involvement. This requires an understanding of its benefits. You need to monitor and evaluate performance in respect of public and patient involvement from an early stage and the baseline assessment should be the

North West Wales NHS Trust

Type of engagement: assessing patient satisfaction

Context and objectives

This ongoing programme was set up in order to encourage nurses to work in partnership with patient and service users, aiming to provide patients with a greater understanding of the nursing process and ensure that they possess adequate information to make informed decisions regarding their care.

Process

Nurses and patients actively engage to agree problems, interventions and evaluate care. Intervention is in both primary and secondary care. Nurses work together with patients and

carers to complete initial and ongoing assessments, care planning, care delivery and evaluation of the effectiveness of care.

Partners

North West Wales NHS Trust runs the project.

Funding

The process is considered an integral part of the nursing workload and thus requires no additional resources.

Contact

Bethan Nickson, North West Wales NHS Trust, Ysbyty Gwynedd, Bangor, Gwynedd, LL57 2PW. Tel: 01248 384 959. Email: Bethan.Nickson@nww-tr.wales.nhs.uk

Cambridge City Council

Type of engagement: various techniques for engaging with young people

Context and objective

During 1999/2000 Cambridge City Council successfully developed an extensive youth participation programme designed to ensure that young people have a voice in local decision making. The project had a number of different stages, each aimed at encouraging young people to make their voices heard.

Process

Stage 1 involved a survey of 700 young people, gathering their views on priorities for local youth. Stage 2 saw a group of 40 young people brought together for two half-day sessions to form a grand jury. The jury used the survey results to debate the issues for young people in Cambridge. They decided that a formal jury should be set up to discuss 'things to do in Cambridge.' Fifteen jurors were then chosen from the grand jury to sit on the formal jury. The young people were selected to be broadly representative of the local youth population. The jury took place in March 1999 and ran four half-day sessions.

A jurors' training programme was designed to introduce them to Council decision-making processes and to enable them to participate in exercises to develop skills in questioning witnesses and processing information. They also participated in a fact-finding mission, comparing Cambridge with another regional centre. Participants of the grand jury were involved in a video project that was used as evidence. Focus groups, targeted at particular sections of the community not represented at the jury, also fed into discussions.

Funding

The young citizens' jury consultation project cost £26,000 and was funded by the city council. The council also put aside £20,000 to implement recommendations from the jury.

Outcomes

The jury's recommendations were presented to councillors. Actions arising from the project included:

- 'Party on the piece' – an annual one-day event for young people in Cambridge
- Young people's fare reduction on buses
- Funding for a youth bus that will visit all areas of Cambridge. This mobile youth resource centre has computers, games, equipment, youth workers, advice and information
- Cambridge now has an ongoing youth participation programme, which includes the establishment of a Young Consultants' Scheme and biannual youth conferences.

Contact

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Tel: 01223 457 004. Email: antoinette.jackson@cambridge.gov.uk

beginning of that process (see chapters 1.3 and 2.2). For all these reasons, organisations need to have a clear and coherent strategy for public and patient involvement. This should provide the rationale, the aims and objectives and expected outcomes, as well as a clear plan of action for delivering the strategy.

The aims and objectives might include one or more of the following:

- getting feedback on the quality of current services,
- learning more about patients' experience of care,
- improving the quality of care,
- identifying (unmet) needs,
- using information to inform the management of change and performance improvement,
- getting input into policy and planning,
- gaining ideas about priorities,
- obtaining public perspectives on different options for change,
- giving people increased ownership over provision of services.

It is important that organisations clarify which of these (or other) aims they have before planning the process.

Making a difference

In deciding on aims and objectives, you should recognise the potential impact of involvement. There is growing evidence that involving the public and patients can make a significant difference at a number of levels. As part of the work carried out by OPM for the National Assembly for Wales, 10 case studies of public and patient involvement were analysed using in-depth interviews with different stakeholders (public and health professionals). This looked at the impact of these initiatives and success factors – what helped and what got in the way.

It revealed that the impact of involvement can be at a number of levels:

1. Impact on service delivery
2. Impact on planning and policy
3. Impact on relationships between stakeholders

1. Impact on service delivery

- **Improvements in service delivery** – Changes resulting from initiatives can be at a basic but vital level, making a considerable difference to people's lives. These issues are often simple to address but can be missed by organisations. In the North East Wales Trust, involvement led to improving the delivery of hot meals to hospital wards. In Llangeni, changes were made to the opening hours of a pharmacy based in a local supermarket. Information provision was improved in terms of making it more user friendly in Blaenau-Gwent.
- **Development of new services** – Public and patient involvement initiatives can reveal gaps in services. For example, in cardiac care, public and patient involvement initiatives in England have led to the employment of specialist cardiac rehabilitation nurses to liaise with GPs, carers and patients when they come home from hospital. A Mental Health Services Review in the Swansea area showed that there was insufficient funding for community mental health, which prompted the funding of a patient advocacy service.
- **Impact on the interface between health professionals and service users** – Involving patients and the public can provide health professionals with greater confidence in delivering policies and ensuring there are fewer complaints. For example, in a consultation concerning assisted conception in Dyfed Powys, issues of

Dyfed Powys Health Authority: Assisted Conception Strategy

Type of engagement: one-day multi-stakeholder event

Context and objectives

The newly merged Dyfed Powys Health Authority needed to develop a shared policy and access criteria for assisted conception services. This policy needed to address the pressures of increasing waiting lists for services and the limited resources to meet demand. The involvement initiative sought to gather the views of a range of stakeholders in developing the policy and defining acceptable access criteria for services. The decision to involve the public was based on the recognition that the policy could not be developed solely on the basis of clinical evidence as this service touches on deeply held values and emotions within society. Public input was therefore necessary to anticipate objections and address the concerns of the local community.

Process

A one-day event was held, including hospital consultants, GPs, service managers, CHCs, user representative groups and service users. Participants were provided with information about current services and introductory presentations on clinical and scientific evidence and ethical considerations. As a result of their discussions, participants reached consensus on a number of issues. They also identified a number of value-laden areas on which agreement could not be reached, and decided that these should be left out of the policy and access criteria. Participants developed a set of recommendations which were presented to the health board some time after the event.

Outcomes

The process was helpful in enabling an informed debate of an emotive issue on which many people hold strong views. The fact that the recommendations were considered by the health board was important in making people feel that their views had been taken into account, although the board's decision did not follow the recommendations. Public involvement and the transparency of the process used to define the access criteria has also reinforced the confidence of professionals in applying and enforcing them, and fewer complaints have been received as a result.

Contact

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access criteria were debated openly and this led to increased understanding. The North East Wales NHS Trust reported that consultation as part of its Acute Services Evaluation led to better systems for sharing information with the public.

Powys Health Care NHS Trust

Type of engagement: focus groups and face-to-face interviews

Context and objectives

This project run from January to July 2000 and was conducted as part of a review of low-risk maternity services.

Process

The project team held 78 meetings with over 200 individuals. Five professional organisations were also contacted for views and comments. A long list of potential service model options was developed following meetings with a wide range of clinicians, managers and service users. These were assessed against pre-determined criteria and then against feedback from clinicians and service users. The shortlist of options and a list of underpinning core components were then shared with approximately 80 clinicians, service users, politicians and managers at a service summit. Further work with local clinical staff followed. Final recommendations of the steering group were presented to 35 clinicians, managers and local politicians in July 2000.

Funding

Powys Health Care NHS Trust

Contact

Andrew Hine, Director of Planning and Performance, Powys Health Care NHS Trust, The Courtyard, Bronllys Hospital, Bronllys, Breckon, Powys LD3 0LY. Tel: 01874 711 661. Email: Andrew.Hine@powys-tr.wales.nhs.uk

2. Impact on policy and strategy

- **Better information for organisations** – Involvement can lead to the provision of better information to organisations about the local community. This can enable them to identify grassroots priorities and see issues from a patient or public perspective. This is especially the case when initiatives run over a long period of time. Both the Local Health Forum in Llanasa and the Health Watch Group in Llangeni saw themselves as providing the opportunity for the community to set the agenda for discussions around health issues, and to provide a means for communities to feed into the policy process on an ongoing basis.
- **Measurable changes in policy or strategy** – There can be measurable changes in policy or strategy as a result of involvement initiatives. In the Diabetes UK Cymru project the objectives of the local diabetes strategy were updated as the result of consultation with the action group. In addition, new policies have been developed as a result of involvement initiatives. In Dyfed Powys the assisted conception strategy developed a new policy to address issues of geographical equity as a result of the consultation event. The Cardiff and Vale NHS Trust undertook to hold a ‘planning for real’ event to address transport issues that might relate to any service reconfiguration as a result of concerns raised by the patients’ panel.
- **Community generated proposals** – Sometimes, involvement can lead to totally fresh thinking on the way forward for service planning and development. The Powys Community Health NHS Trust submitted a service model to NAFW based on a patient generated preferred option that was put forward during the Trust’s Service

Summit. This was subsequently accepted and put in place.

3. Impact on relationships between stakeholders

- **Improving communication and understanding between key stakeholder groups** – The benefits of involvement can manifest as better communication and understanding between key stakeholder groups. Participants become better informed and gain greater understanding of services and the constraints under which they operate. Professionals benefit by gaining a real appreciation of the public or patient perspective, and having their own views challenged. Involvement initiatives can foster better understanding between these groups, and lead to more equal relationships governing their discussions on health service issues. Successful engagement processes can increase the confidence of health professionals in the value of public involvement, and encourage members of the public who might not normally get involved with health issues to participate.
- **The value to partnership working of joint consultation** – Involvement can add value to partnership working. Conducting joint initiatives supports organisations in identifying and meeting similar goals and agendas. Working in partnership helps to avoid over-consultation amongst some groups, and makes best use of agencies' limited resources (see also chapter 3.5).

Developing a shared agenda

Public and patient involvement – like many other initiatives for change – should be an inclusive process. It should provide 'ownership' for all those involved and affected through identifying people's

priorities for the work (a 'bottom-up' approach) as well as receiving senior support ('top-down'). This means developing a shared agenda early on with the relevant stakeholders – patients, carers and/or the wider community – and addressing their needs and concerns to identify a consensus about how to proceed. A shared agenda should focus on what type of work needs to be done in the short, medium and long term. It should be explicit about whether the work is focused in one particular area or across different areas. It may be that patients and others have identified concerns – here the work might focus on solutions. In other areas, diagnostic work may be required to identify the major concerns of patients and the public.

You need to create opportunities to allow others to influence the agenda. For example, an organisation might have a problem with people not turning up for appointments. Professionals might suggest sending out reminders to people. But if they engage the local community in discussions about wider issues concerning 'access', they might find more effective solutions, such as more flexible appointment systems or better local transport.

Building trust – creating good relationships

Building relationships and trust amongst stakeholders is helped by creating the conditions where an ongoing dialogue can develop. Through this, issues are picked up and addressed, responding to needs and expectations from all sides. It is also important in itself. This means valuing people's expertise and contributions. It is also about understanding that the patient contributes expertise concerning how to live with, and manage, ill-health or a particular condition, and about how it feels to use or try to access services. People who use health

services are more than patients with symptoms and need to be treated with respect and dignity. Their contribution should be valued. Equal partnerships imply that lay people need to be taken seriously – their views listened to and acted upon.

You need to create an atmosphere that promotes an honest exchange of views about what can and cannot be achieved. It is important to be realistic about the parameters of the process and what decisions are negotiable and non-negotiable. Though it may be tempting for organisations and health professionals to avoid uncomfortable discussions about controversial issues that have cost implications, it is better to confront these issues at an early stage. Sometimes, when consultations have not included discussions about finance, idealistic visions of the future have emerged. Then, later on, when financial considerations have been factored in, popular options get shelved.

It is essential to avoid consulting on changes that cannot be delivered due to lack of resources. In general, people respond positively to these sort of declarations. Though it may be tempting to do a lot of ‘blue-sky’ thinking about visions for the future, this needs to be balanced with practical (resource-constrained) discussions. There have been numerous criticisms of consultation processes being ‘tokenistic’, and there is some justification in these. Last, it is important to make the process as interesting and rewarding as possible. This encourages those who give their time and effort and strengthens potential opportunities for further engagement.

Learning lessons

It is important to understand the local and historical context of public and patient involvement in your area. Find out what has happened before and what

initiatives have been carried out successfully and unsuccessfully. What went right/wrong? What helped/got in the way? Part of this picture should have come through work on the baseline assessment.

Organisations need to acknowledge the past: people may feel distrustful of previous attempts to engage them, and/or feel that nothing will change as a result. Consultation ‘overload’ is a frequent complaint. So it is important not to go to the same people too often. But things are often made worse when people cannot see the impact of earlier involvement or consultation about similar or related issues. Getting over people’s low expectations is a major challenge in this scenario (see ‘understanding motivations’ below).

Understanding the context also gives you a sense of what loyalties there are in local communities to existing services and facilities and where the gaps are, so you can plan the right approach. This may require some additional work on identifying needs and expectations. It is also useful to read up on good practice elsewhere to inform your choice of approach.

Understanding motivations

There are several elements that influence why people get involved in this work. First, people need to feel motivated to do so. The topic addressed needs to be relevant to their experiences and concerns. While people are often motivated to discuss health issues, it is sometimes harder for them to feel engaged with the health service or system – something that may feel alien, bureaucratic and divorced from their everyday experience.

Some people will be motivated out of a negative experience – here the trick is to bring these views to the table in a constructive manner rather than simply avoid dealing with them. Others may

want to participate owing to a sense of gratitude. Here it is necessary to use techniques that elicit constructive criticism and get beyond people merely saying that everything is wonderful. Sometimes the use of an independent facilitator will help in this respect. The phrasing of questions addressed is another major consideration. Instead of using phrases such as ‘what was good or bad?’, there may be better alternatives such as ‘what works best from your point of view?’, ‘what most needs improving?’ or ‘what would help to make things better?’.

Capacity and opportunity

Even if people want to engage in discussions in this area, they may not feel able to. This may stem from a feeling that they lack the knowledge or expertise to talk meaningfully about the subject or they may not have an outgoing personality. Life circumstances (e.g. socio-economic and demographic factors, culture, ethnicity, age, gender, linguistic and other factors) may hinder people’s capacity to have a say. People’s distrust of what might change as a result of involvement often stops them from coming forward. Many of these factors can be overcome with active and formal support and encouragement from the organisation undertaking the work.

Finally, the lack of opportunities and communication about opportunities is another serious block to involvement. As well as developing mechanisms by which people can participate, organisations need to have a communications strategy that underpins these, including identifying specific dissemination roles and responsibilities within the team undertaking the involvement initiative. This also includes publicity about involvement initiatives to support efforts to get people involved and to widen the opportunities available to those inter-

ested. Your strategy should also reinforce feedback, both to those who were directly involved and to the public more generally about the impact and benefits of the work.

Choosing the right approach

Knowing what needs to be done

As discussed previously, there are different dimensions to public and patient involvement. Work to develop the strategy should reveal to an organisation its priority areas for development – what it is doing too little of and what it needs to concentrate more on in the future.

There may be work to be done across the different dimensions of involvement. You may wish to direct resources into identifying needs in particular areas where little public and patient involvement has been undertaken in the past, or where there is little known about the needs of service users. If activities have identified these needs and concerns, then there may be little sense in replicating the work. Instead, work could be done to engage the public and patients in identifying solutions and implementing change using the evidence of past involvement work to build improved services for the future. As well as undertaking different activities, you also need to build capacity across the organisation or health community to ensure that involving the public is part of everyday business.

Knowing where to start

Where there is a broad range of work to be done, choose the ‘right’ topic to start with. Where there are gaps, it is useful to start on a specific issue – one where the results can be applied to other areas that

Bargoed Project

Type of engagement: discussion/focus groups and in-depth interviews

Context and objectives

This engagement process, run between March 1993 and March 1994, involved face-to-face engagement with local primary school pupils as a health promotion exercise.

Partners

The project was run by the Caerphilly Health Promotion Department and involved community interest groups and the public. Nine schools and a range of external partners were involved.

Funding

Local industry, the local NHS Trust, other local organisations, schools and the community provided funding. The project was staffed from within schools, including health visitors, fitness instructors and other partners.

Outcomes

The process was successful in establishing links between health promotion and the local authority, and saw the launch of a multi-agency programme of health related activity. A number of aspects proved to be self-sustaining, allowing expansion of the project to include further health promotion activities throughout the county borough, securing funding through a major local employer and the trust. It was also useful in terms of creating lasting alliances, including support from the schools involved, and a close working partnership with the local county borough council.

Contact

Rhymney Valley Health Promotion Unit. Gwent Health Authority, Mamhilad House, Mamhilad Park Estate, Pontypool, Gwent NP4 0YP. Email: Samantha.Clarke@gwent-ha.wales.nhs.uk

Note: staff members involved in the original project are no longer with the unit as the project took place during the early 1990s.

may provide ‘quick wins’ and may be transferable in terms of the process used. It could be one where the lessons cut across different parts of the organisation and/or local partner remits. Take the work in small chunks and create the possibility of incremental changes and quick responses. This builds the trust needed to develop the work further.

It makes sense to engage people at an early stage on feedback on service quality – an area likely to have immediate relevance for those suffering from a particular condition. From this one can build up towards getting involvement in planning and policy. It may be that those involved in initiatives on improving quality will be interested in coming back to be involved in more strategic issues. One approach that incorporates this principle is the ‘Patients as Educators’ model, where delegates from patient focus groups that met to focus on ‘what works’ from a patient point of view go forward to meet with health professionals to discuss improvement (see Gillam and Brooks on page 44).

‘Horses for courses’

Be flexible – You will need to mix and match methods depending on the nature of the initiative. There is some evidence (though not a lot) of what works best in different circumstances and there are well known advantages and disadvantages of the different techniques (see chapter 3.3 for more details). Many decisions also depend on local circumstances. Knowing what works in which circumstances will determine how much you and the public gain from consultation.

Be creative – Do not hold open meetings when these are unlikely to attract people, or send out lengthy questionnaires that might put people off. It is essential to prepare the ground for whatever approaches are going to be used. This means thinking through how

Blaenau Gwent Social Care Plan

Type of engagement: targeted consultation meetings

Context and objectives

Blaenau Gwent Local Health Group undertook a formal consultation process to obtain feedback from the local community regarding its existing Social Care Plan. The process was used to identify gaps and issues raised around the current plan to inform the Community Services Plan for 2001.

Process

The LHG and local authority held four main meetings, targeting four different groups. Consultation took place with the service users of a day-care centre, voluntary sector representatives, carers, and finally the wider public. Each meeting saw the LHG present the Social Care Plan to the group. This was followed by discussion between the group and LHG representatives who were able to answer questions and provide explanations about priorities and service delivery. Sections were tailored to address the specific needs of the group being addressed. In addition the plan was made available in a wide variety of public venues, such as council offices, health centres, leisure centres and libraries, and a helpline was provided to answer questions.

Partners

The LHG worked collaboratively with the local authority in presenting the Health Improvement Action Plan to the public in order to maximise public interest and avoid over consultation through unco-ordinated initiatives. Voluntary sector representatives were also active in leading some of the meetings.

Outcomes

The consultation process was seen to be successful in a number of ways. It increased the number of people attending consultation events and heightened interest in consultation initiatives. This interest has carried over to further involvement initiatives. The process helped to improve public understanding of the types of services provided, and of the changes under consideration. From a service delivery perspective, the consultation highlighted a number of gaps in the service, which informed the development of objectives for the 2001 plan, with consequent improvements in service provision.

The formation of a patients panel is planned to consider issues concerning a new community hospital for Blaenau Gwent. The LHG is also working with the local CHC to develop closer relations, and a Health Watch public network is shortly to be introduced into five community areas covering the whole of Blaenau Gwent.

Contact

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North East Wales Acute Trust: Acute Services Evaluation

Type of engagement: questionnaires and interviews with patients

Contexts and objectives

The North East Wales Trust sought with this initiative to evaluate the acute services it provides from a patient perspective. It wanted to know whether service users had a particular view of what an ideal service would look like, and what their expectations were in terms of quality.

Process

The trust, in conjunction with a researcher from the North East Wales Institute of Higher Education, developed a questionnaire based on a standard service evaluation questionnaire, but focusing on evaluating services from the patient's perspective. In order to achieve the results, the researcher conducted interviews to gather patients' views on what they considered were the elements of a good quality service. The results of these interviews formed the basis of the final questionnaire, which was distributed to a random sample of patients when they were discharged from hospital.

Outcome

This initiative brought about a number of changes in service delivery, for example working practices changed in some departments to remedy small, but important, issues like ensuring that patients receive their meals hot. The evaluation also pointed to gaps in current services such as inconsistent information provision, and the need for better foreign language interpreting services. It also highlighted organisational issues or themes that needed to be addressed by multidisciplinary teams within the trust.

More broadly, the process built understanding within the trust about effective public involvement which led to the formation of a patient and public involvement steering group.

Partners

North East Wales Institute of Higher Education, Clywd CHC

Contact

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people might want to be involved. Moreover, there may be lack of clarity about the aims and objectives of consultation meetings and events. Professionals may come expecting strategic discussions. Members of the public might see them as an opportunity for questions and answers about individual problems. It

may be helpful to hold events in local community centres, religious centres, schools or supermarkets, or to combine with other local events.

Be professional – The work needs to be undertaken by those who know what they are doing and who display good personal and professional skills. If this

does not happen, there is a real danger that people may be turned off and will never come back.

Involving the right people

Deciding who needs to be involved

Organisations should be clear about who to involve in order to get positive results. You should consider three sets of people:

1. those who have direct experience of services (patients or carers),
2. members of the wider public,
3. those who represent community interests.

Different people might be needed in various areas or phases of work. For example, learning from patients' experiences should focus on involving patients and carers, though the other two groups will have valuable perspectives to offer. Involving people in planning and policy might include working with all three sets of stakeholders. Organisations need to have specific systems in place in order to include people from marginalised groups (see also 'supporting people from marginalised groups'). There is also a need to develop networks in the community and with community interest groups in order to support the work.

Getting 'good enough' representation

Think about representation but do not be paralysed by the notion. Do not use the understandable demand that lay representatives should 'represent' their community as an excuse to exclude them. One can work with a 'good enough' cross-section. This is not an excuse for being lazy in recruitment, but is a way of ensuring that efforts are

made to be inclusive without consulting a cast of thousands.

Involving carers

Carers (family members, friends) have special needs in relation to involvement initiatives and should play a key part. In many cases, they are an important advocate for patients, especially when patients' particular conditions or circumstances affect their ability to speak on their own behalf. In other cases, they are important members of the clinical team itself. They should be enabled to contribute their own perspectives on issues concerning the patient experience, and have needs in their own right. They can thus make a vital contribution towards planning, evaluating and developing services.

Reaching out beyond the 'usual suspects'

It is easier to sustain public involvement where you can clearly identify different client groups. It can be tempting therefore to go to those groups or representatives you already know about and have clearly identified as speaking on behalf of 'particular groups'. However, you need to resist this and reach out to others beyond the 'usual suspects'. You will specifically need to target those who do not come forward.

Including people from marginalised groups and promoting social inclusion

The principles of inclusion apply in all aspects of life – whether it be in health services decision making or employment. It includes fairness and equal opportunity, accessibility and citizenship, having a voice and a choice, and receiving respect. People who are socially included are those empowered to make decisions, have the opportunity to fulfil ambitions and potential, can access

Anglesey Health Watch Groups

(based at Llangefni and Holyhead)

Type of engagement: group membership and consultation initiatives, e.g. surveys

Context and objectives

The aim of the Health Watch Group (HWG) is to access grassroots perspectives about what is needed from local services, and how service delivery is perceived. The purpose of this kind of initiative is to let the public set the agenda by raising their own concerns.

Process

The groups were set up by the local CHC, based on a model from South Wales which has been adapted to the local environment, drawing on identifiable communities for building network arrangements.

The health watch groups are composed of lay people but are supported by CHC representatives who attend meetings and provide information about local health service developments. Members rely on their own networks for engaging with the public to raise issues or get feedback. HWGs have been encouraged to get involved in research projects, surveys and visits to local health service providers. They help in raising awareness of public health issues, such as breast screening. A CHC member from each HWG sits on the executive committee of the CHC.

Outcomes

The activities of the health watch groups have improved some aspects of local service delivery, for example, assuring the opening hours of a local pharmacy within a supermarket are maintained and identifying gaps in service provision. There is some scope for extending the remit of HWGs to linking with other local service providers like the council. The groups have also improved links between the CHC and the community. This means that CHC members now have a better understanding of the views of a broader cross-section of the community, and local people are more aware of current changes within health services and the NHS. The initiative has also created better working relationships between the CHC and other local statutory and voluntary organisations where they have worked together on collaborative projects with HWGs.

Contact

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services, and have expectations and the confidence to ensure they are met.

There is a spectrum of inclusion based on the perceptions of wider society. It is often based on the value judgements of others or social and economic circumstances. Those excluded are often those perceived to be 'different from the norm'. These might include the homeless, refugees, people from black and ethnic minorities, older and younger people. In certain circumstances these might include Welsh speakers, so ideally you should list groups and organisations that specifically represent Welsh speakers.

Involving people who are socially excluded and who have difficulty relating to formal structures poses particular challenges (see also 'supporting people from vulnerable and marginalised groups' in chapter 3.3).

Finding people who can help

Local leaders, or 'champions' can make the project work. Early involvement of key people from the grass roots is vital (though one should beware of over-dependence on single individuals). Use existing structures and networks. Voluntary sector organisations can provide a rich seam of good advice, commitment, expertise and support – use them (but do not over-burden them without valuing their time). There may be specific agencies or groups who can help, such as CHCs, the National Association of Patient Participation, the legal service, CABs, citizens advice bureaux, etc. They can gather information and pursue individual and collective concerns.

More will be said about how to support the public and patients to be involved in chapter 3.3.

Linking with clinical governance

Clinical governance is 'a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.' (NHS Wales: *Putting Patients First: quality, care and clinical excellence*, Welsh Office)

The purpose of clinical governance is to ensure that patients receive the highest quality of NHS care possible. It covers the organisation's systems and processes for monitoring and improving services, including:

- strategic capacity to deliver clinical governance
- public and patient involvement,
- clinical risk management,
- clinical audit,
- research and effectiveness,
- staffing and staff management,
- education, training and continuing personal and professional development,
- the use of information about the patients' experience, outcomes and processes.

Effective clinical governance should therefore ensure:

- continuous improvement of patient services and care;
- a patient-centred approach that includes treating patients courteously, involving them in decisions about their care and keeping them informed;
- a commitment to quality, which ensures that health professionals are

up to date in their practices and properly supervised where necessary;

- the prevention of clinical errors wherever possible and the commitment to learn from mistakes and good practice, and share that learning.

Clinical governance poses special challenges and opportunities for public and patient involvement. Patient input should be a key element in bringing about improvements in the quality of health care and incorporating the patient's view into its heart.

Tools to capture the patient experience, i.e. finding out what patients themselves see as important and what they believe is in need of improvement, is core to the process of public involvement within NHS Wales. A recent audit of progress on the implementation of clinical governance in Wales has shown that public and patient involvement in this area is patchy and inconsistent.

The Commission for Health Improvement (CHI) undertakes clinical governance reviews in NHS organisations across England and Wales. As part of these, it takes into account the views of stakeholders (voluntary and community organisations and partner agencies) and patients concerning the 'patient experience', and assesses the capacity of organisations to involve patients and the public in decisions on treatment. Several recently published CHI reports reveal that organisations could and should do far more in this area and the expectation is that NHS organisations will take account of this development need. In the future, CHI has expressed an interest in drawing on the concepts and tools in this guide to help its work in Wales and England.

As part of an organisation's clinical governance arrangements, there is a need for a strategic framework for: understanding how feedback from patients, or any input to or from the wider community, plays a part in

internal systems and structures; how this work can be made part of everyday business; and how the concerns of health professionals can be tackled (chapter 3.4).

Many health professionals are already familiar with, and committed to, clinical governance. As a result they will recognise that public and patient involvement should be part of clinical governance arrangements. Using clinical governance as the 'way in' to public and patient involvement may be a useful route.

References

- Kelson, M. *Patient Involvement in Clinical Governance*, 2001
- Chapter 2 in Lugon, M. and Secker Walker, J. (eds) *Advancing Clinical Governance*, RSM Press, London
- NHS Wales, *Putting Patients First: quality care and clinical excellence*, Welsh Office, 1998.
- Clinical Governance: developing a strategic approach*, NAFW, September 2001.
- O'Brien, J. Mount, B. (1987). *Renewing organisations through person centred planning*, US, Responsive Systems Associates and the Center on Human Policy. Available on the web: <http://soeweb.syr.edu/thechp/rsapub.htm>
- National Patients' Access Team, *Learning from patient and carer experiences – a toolkit*. NHS Executive, Coronary Heart Disease Partnership Programme.

Contact

Consumers in NHS Research Support Unit, The Help for Health Trust, Highcroft, Romsey Road, Winchester, SO22 5DH. Tel: 01962 872247. Fax: 01962 849 079. Email: conres@hfht.org; web site: <http://www.hfht.org/ConsumersinNHSResearch> This unit provides information, advice and support to consumers, researchers and those working in the NHS on consumer involvement in NHS research.

Clinical Governance Support and Development Unit – Wales. NHS Quality Division, NAFW. Tel: Wendy Chatham, 02920 801147. Email: wendy.chatham@wales.gsi.gov.uk

Monitoring and evaluation

Know why you are evaluating

Organisations evaluate initiatives and strategies for a number of reasons. First, they need to assess and demonstrate the impact of public and patient involvement to ensure that they are accountable to internal and external stakeholders. The latter includes NAFW and the local community. NAFW will require evidence that the work has had demonstrable impact through its performance framework requirements.

Secondly, organisations should be aiming at continuous improvement: – they need to know that what they are doing in this field is effective; that they are getting what they want out of it; and that it links into ongoing systems and processes for improving the treatment of patients. Evaluation is essential so that your organisation can learn from its public and patient involvement initiatives and determine how to involve people better in the future.

Know when to monitor and when to evaluate

Although the terms are often used together, monitoring and evaluation serve different purposes and you need to be clear about which is appropriate for your needs:

- **Monitoring** is used to assess the progress of an initiative or strategy while it is going on. It is used to keep tabs on the management projects and the use of resources. It is helped by the setting of milestones and targets that mark stages of progress, such as those included in your annual plans (see section 2). The purpose of monitoring is to support project management and accountability.

- **Evaluation** is an assessment of the impact of public and patient involvement. It is generally undertaken at the end of an initiative or at a key point in the lifetime of a project, at a time determined in advance. Evaluation focuses on whether involvement has achieved its aims and objectives, such as those set out in your strategy (see section 2). The purpose is to determine what works and what does not, in order to learn from each experience so that better initiatives can be designed in future.

Be clear about what you are evaluating

Evaluation can, and should, be carried out both for individual involvement initiatives and for the public and patient involvement strategy as a whole. In either case, the focus should be determined by the aims and objectives defined for the involvement before or during the planning stages of the work. The first step in developing an evaluation framework should be to identify what you are aiming for in terms of relevant outcomes. Monitoring and evaluation arrangements should be put in place early, and not added later once an initiative is under way.

To measure how things have changed as a result of involvement, it is important to have a clear view of how things were before the initiative or strategy was put into place. The baseline assessment, which is required as a first step to developing your public and patient involvement strategy, will provide a good basis for assessing the current state of progress and the impact of involvement, and will provide a benchmark for future work. As involvement strategies take effect it will be necessary to refer to the baseline in order to assess the impact of involvement in the future.

Use the right tools

Once you have identified what you want to evaluate you will need to define meaningful ways of measuring these outcomes. Some evidence of the impact of public and patient involvement will be easy to measure and quantify (e.g. assessing how many people from socially excluded groups have been included, or identifying significant changes in policy or services which have been influenced by involvement). These could be done by collecting either statistical data or documentary evidence.

More important and more challenging is to assess the impact involvement has on attitudes and behaviours of individuals and organisations. These kinds of changes can be difficult to measure and will require different methods for collecting and analysing evidence, e.g. determining whether greater trust has developed between patients and professionals could be assessed using interviews with participants or observation by evaluators.

Evaluating the involvement process

This level of evaluation requires gathering information about how well involvement initiatives have worked. Evaluating involvement processes should focus on the way that the involvement was designed and delivered. This should include some or all of the following:

Why?

- Were aims and objectives clear?
- Were people clear about what they were being asked to get involved in?

How?

- Was it the right approach?
- Were roles and responsibilities clear?
- Were partners involved appropriately in planning and delivery?

- Was it clear how the results of involvement would feed into decision-making processes and how feedback would be provided to participants?
- Were timescales realistic and clear to those involved?

What?

- Were the right techniques used?
- Did the method chosen meet the needs and expectations of participants and commissioning bodies?
- Did the method provide or collect appropriate information or enable people to express their views adequately?

Who?

- Were the right people involved?
- Did those involved reflect the social and cultural composition of the target population, i.e. users of a particular service or the whole community?
- Were people supported appropriately to participate, i.e. were venues and timings appropriate? Was enough information provided in appropriate language and formats?

A variety of methods can be employed for this kind of evaluation. The most common are surveys, interviews and observation by evaluators.

This kind of evaluation might also take an initial look at the way in which the involvement process has influenced the views and attitudes of participants or commissioning bodies who use the outputs. Evaluations of this kind are sometimes done using a 'before' and 'after' approach where participants are asked about their expectations of involvement, or their views on an issue, before the event, and again afterwards. The results are then compared to assess the effect of the involvement process on the views of those who took part.

Evaluating the outcomes of involvement

Evaluating the outcomes of public and patient involvement requires a much longer term view than evaluating involvement processes. Some outcomes may follow relatively quickly after the involvement initiatives, while others may take much longer to become apparent. This is why it is important to fix a timeframe in advance for evaluating outcomes.

Outcomes of involvement may occur at a number of different levels, so you will need to have a clear framework to help you focus on which kinds of outcomes you want to assess. Longer term changes that affect service delivery, patient experiences and, ultimately, health outcomes will need to be judged by a variety of indicators of health and service performance. Evaluations of outcomes should cover some or all of the following areas:

- **Service delivery.** Has involvement led to improvements in service delivery, or the development of new services?
- **Planning and policy.** Have changes been made to policies or strategies as a result of involvement, or have changes been made to the way in which policies and strategies are developed, i.e. do they take greater account of public perceptions and concerns?
- **Relationships between stakeholders.** Have people's attitudes shifted in a lasting way as a result of involvement, e.g. do professionals, patients and/or the public have greater understanding of each others perspectives? Is there better communication and/or greater trust between these groups? Do organisations work better together, or with the community, as a result of involvement initiatives?

Evidence on some aspects of outcomes can be gathered from documentary sources, e.g. minutes of board meetings where involvement initiatives were discussed and decisions were taken. But much evidence, particularly about shifts in attitudes, you will need to gather from individuals who have been involved in acting on the results or recommendations generated by involvement initiatives. This is most commonly done using surveys or interviews.

References

Each of the texts below outlines the range of approaches used to evaluate services and programmes, differentiating between the focus of different methods of evaluation (including qualitative and quantitative approaches).

Connell, J. Kubisch, A. Schorr, L. and Weiss, C. (eds) *New Approaches to Evaluating Community Initiative*, Washington DC: The Aspen Institute, 1995. Downloadable at <http://www.aspenroundtable.org>

Outlines the 'theories of change' approach to evaluation which focuses on the explicit links between the chosen method of intervention and its intended outcome.

Fitz-Gibbon, C.T. and Morris, L.L. *How to Design a Program Evaluation*, Newbury Park, CA: Sage, 1987

Herman, J.L. Morris, L.L. and Fitz-Gibbon, C.T. *Evaluators Handbook*, Newbury Park, CA: Sage, 1987

King, J.A. Morris, L.L. and Fitz-Gibbon, C.T. *How to Assess Program Implementation*, Newbury Park, CA: Sage, 1987

Ong, B.N. *The Practice of Health Service Research*, London: Chapman and Hall, 1993

Patton, M.Q. *How to Use Qualitative Methods in Evaluation*, Newbury Park, CA: Sage, 1987

Pawson, R. and Tilley, N. *Realistic Evaluation*, London: Sage, 1997

Proposes a framework for evaluating initiatives which links the context of the initiative with the mechanism chosen to achieve change and the outcomes which emerge over time.

Roberts, H. 'Performance and Outcome Measures in the Health Service,' in Cave M., (ed) *Output and Performance Measurement in Government*, London: Jessica Kingsley, 1990

Rossi, P.H. and Freeman, H.E. *Evaluation a Systematic Approach*, London: Sage, 1993

Stecher, B.M and Davies, W.A. *How to Focus an Evaluation*, Newbury Park, CA: Sage, 1987

St Leger, A.S. Schnieden, H. and Walsworth-Bell, J.P. *Evaluating Health Services' Effectiveness*, Buckingham: Open University Press, 1997

Involvement in audit

Marcia Kelson, *Promoting Patient Involvement in Clinical Audit: Practical Guidance on Achieving Effective Involvement*, College of Health/Clinical Outcomes Group, 1998.

Practical guidance for NHS organisations about how to promote patient involvement in clinical audit activity. Includes examples of good practice.

Involvement in research

Involving Consumers in research and development in the NHS.

<http://www.doh.gov.uk/research/rd3/nhsrandd/consumers.htm>, Consumers in NHS Research and Support Unit, January 2000. Includes: Why involve consumers in R&D, types of consumer involvement, who should be involved, when and how to involve consumers, checklist for involving consumers in committees and for budgeting consumer involvement in R&D.

Involvement Works. Consumers in NHS Research and Support Unit, March 1999. <http://www.doh.gov.uk/research/rd3/nhsrandd/consumers.htm>

Describes work done during 1999 and plans for the future.

The Standing Group on Consumers in NHS Research was set up by the Director of Research & Development in 1996, and is a sub-group of the Central Research & Development Committee. Consumers in NHS Research aims to ensure that consumer involvement in research and development improves the way that research is prioritised, commissioned, undertaken, disseminated and used.

3.2 Techniques

- Things to think about: theoretical concerns and practical considerations
- General texts on public and patient involvement
- An overview of methods: quantitative, qualitative, deliberative, large-scale, community development

Things to think about

Organisations are faced with a wide range of options to consider when engaging in public and patient involvement. You need to choose techniques that can be tailored to the circumstances or context of the involvement initiative. First of all, it is important to think through your aims, objectives and overall approach before deciding what sort of technique to use (see also chapter 3.1).

Often, people get too bogged down in the technicalities, trying to figure out what particular method is necessary before they are clear about why and what they want from the process. Sometimes individuals raise concerns about the validity of the method used and the data likely to be produced. It is useful to identify whether these concerns are in themselves valid, or whether there are some underlying fears about engaging with patients and the public in the first place (see also chapter 3.4 on creating the organisational culture).

Once you are ready to think about techniques, there are several aspects to consider before choosing. Some of these have been dealt with in the previous section on choosing an approach. For example, the level of engagement necessary may dictate that some methods are more likely to yield useful

findings than others. If you want to develop a more participatory approach, a method that brings people together over a period of time, such as a forum or panel, is probably more useful than a one-off survey or focus group.

In general, the main aspects to think about are:

- **Theoretical concerns.** These include aims and objectives and the topic of interest. Some methods lend themselves better to particular topics or outcomes than others. It also includes thinking about who the relevant stakeholders are and who you want to hear from. The numbers or type of people to be involved can dictate the choice of technique.
- **Practical considerations.** The method selected is often dependent on the resources available. The budget for the project, including payments for participants and organisational arrangements, is one factor to consider. But time is another major factor in success and you may find that you need a lead project manager to take an overall view of the initiative, good administrative support, and a small team that includes relevant internal and external stakeholders to steer the project.

Theoretical concerns

Quantitative versus qualitative

If you are looking for statistically significant data or are trying to obtain ‘off-the-cuff’ responses from a broad range of people, then quantitative methods, such as surveys and questionnaires, are likely to be useful. But if you are trying to identify the underlying reasons why people hold certain views, or want to explore things in more depth, then a qualitative method, such as one-to-one interviews, are likely to be more useful.

Large or small numbers

Sometimes it is necessary to bring all stakeholders together in order to debate a cross-community issue in depth and to explore the different perspectives of a wide range of people. This can be done by consulting separate groups and then bringing them together in a large event, or you can bring people together for a day-long event. Some methods, such as whole system events and open space, are particularly good at eliciting people’s priority concerns without imposing a management agenda.

Complexity and controversy

If the issue is complex and/or if it concerns getting a public and patient view on planning and policy issues (such as priority setting or budget decisions), then people need time to think through the issues in order to come to an informed judgement. Deliberative methods might be the best way to achieve this.

Sometimes, a high-profile issue (such as service reconfiguration) is contentious. It is important then to use a process that can, and can be seen to, engender trust and confidence. Particular deliberative approaches that elicit principles and criteria for decision making and apply them to focused questions can be useful in these cases. One example of this sort of approach is the citizens’ jury.

Practical considerations

Below are examples of some of the more common practical considerations to be borne in mind when planning public and patient involvement initiatives.

Money

Some forms of engagement are more expensive than others. Costs should reflect the resources at stake and the strategic importance of the exercise to the public and the community as well as the money actually available to do the work. This means a more direct link is established between investment in the involvement work and the wider value of undertaking it. It is impossible to put a precise cost to different approaches and techniques. As a very rough guide, running a focus group may cost between £500 and £2,000, while running a citizens’ jury may cost over £20,000.

Obvious factors that affect costs:

- the number and range of initiatives selected, and
- the type of initiatives selected in general. Those that are large scale and/or those that use ‘deliberative techniques’ are likely to be more expensive.

Other variables include:

- the need for translation services
- whether, and from where, external facilitators and/or researchers are used,
- the costs of administration and support,
- whether existing individuals, databases and facilities can be used,
- whether external agencies are used in planning (e.g. for recruitment or organisation of events),
- incentive fees and additional expenses (e.g. travel, childcare). It is good practice to pay people for their time.

Time

Again, there are no hard rules on how long an initiative can take. It will depend on many of the factors that affect expense (see above). Obviously, the more time you spend on planning and preparing an initiative the better. In general, logistical problems are as important, if not more so, in the run up to an event. You may want to estimate how long things should take and then add some more time to your calculations.

Common problems that can occur with timings include:

- Planning events at times when people will be away (religious festivals, school holidays, etc.).
- Holding meetings at the wrong times. If people are working, think of holding an event at the weekend or during the evening. But the day time might be better for older people or those not working due to illness, or if the venue is in an urban location that might feel unsafe at night. Childcare arrangements will be an important consideration either way.
- Underestimating how long it will take to recruit people to attend events. You will need to allow at least three to four weeks between sending out invitations, getting them back and sending out confirmation letters, even if good administrative procedures are in place.
- Getting health professionals to come. If you want health professionals to come or to make presentations, make sure that the event is in their diaries early on.
- Not thinking about logistics early on. Hiring (and checking out) venues and audio-visual requirements, getting location maps, ordering refreshments – all these may take a lot longer than you expect.

General texts

The following section provides a number of references to general texts on public involvement, some of which are specific to health and patient involvement.

Audit Commission, *Listen Up! Effective community consultation*, <http://www.audit-commission.gov.uk/ac2/SSfirst.htm>

Wall chart showing a summary of various methodologies and techniques

Barker, J, Bullen, M, de Ville, J. *Reference Manual for Public Involvement*, NHS Development Unit/South Thames Regional Office, January 1999

Includes sections on conducting public meetings, focus groups, interviews, open surgeries, self-completed questionnaires, rapid appraisal, participatory observation, ethnographic enquiry, community development, citizens' juries, panels.

Cabinet Office, *How to consult your users: an introductory guide*, <http://www.cabinet-office.gov.uk/servicefirst/1998/guidance/users/users.pdf>

Includes why services should consult, making consultation work, how to choose the right approach, evaluating the consultation, piloting changes. Covers use of representative groups, focus groups, user panels, citizens' panels, citizens juries, questionnaire based surveys, ballots etc. Includes references for further reading. Copies may be ordered from Service First Publications Line: 0345 22 32 42 or Tony Singleton 020 7270 6274

Primary Care Groups Public Engagement Toolkit, DoH. Downloadable at <http://www.doh.gov.uk/pub/docs/doh/toolkit1.pdf>

Describes how PCGs in England can ensure involvement of users of local health services, carers and the wider public through various processes and structures.

Primary Health Care Teams: Involving Patients, examples of good practice, NHS Executive, February 1997.

Sections include informing patients, consulting patients and working in partnership with patients. Includes references for further reading, contact details of primary care teams developing work in involvement.

Gillam, S. Brooks, T. *New Beginnings. Public involvement in Primary Care.* London, King's Fund, 2001.

Outlines the need to move from public involvement that is limited to communication and consultation toward more participatory or community driven forms of involvement, requiring greater resources and a long-term shift in organisational and professional values. Includes chapters outlining why and how to involve patients and the public and in-depth chapter case studies on particular initiatives.

Goss, S. (ed.). *Managing working with the public*, Kogan Page, 1999.

Chapters on approaches to public involvement across the public sector and organisational development and change management issues.

NHS Executive, NHS Confederation, Institute of Health Services Management. *In the Public Interest: developing a strategy for public participation in the NHS*, Department of Health, June 1998. Includes models for involvement, framework for a strategic approach, recommendations for effective public participation.

Virtual Resource Centre, *Public and Patient Involvement*, <http://www.doh.gov.uk/ppvrc/index.htm>

The VRC is being set up to contain tools, techniques, sources of evidence, information and expertise, and examples of good practice to assist with the practicalities of implementation.

Walker, Perry and Lewis, Julie (eds), *Participation Works! 21 techniques of community participation for the 21st century*, London, New Economics Foundation, <http://www.idea.gov.uk/bestvalue/consult/main.htm>

Looks at consultation as part of Best Value, and provides a comprehensive summary of methods together with their strengths, problems and costs. Designed to provide an overview for members and officers. Includes ways of involving vulnerable and marginalised groups. Available from New Economics Foundation, Vine Court, 112-116 Whitechapel Road, London E1 1JE.

Chambers, R. *Involving Patients and the Public*, Radcliffe Medical Press. A useful basic guide.

An overview of techniques

The following sections of this chapter describe some of the methods and techniques that can be used in different contexts, with a brief description of the type of initiative, suggestions of when it may be appropriate to use the particular technique, and associated advantages and disadvantages. It is not possible to include every method that can be used on particular occasions. But the following sections provide a range of some of the techniques that have been used most often in the field of public and patient involvement.

Quantitative techniques

Quantitative techniques are useful when gathering information from a large sample of the population in order to quantify the amount, or proportion, of people who hold different views on a subject. These techniques can provide a snapshot of opinion or measure levels of satisfaction with a service. They typically involve sampling through a survey.

Benefits associated with quantitative approaches include:

- statistically reliable and representative information about a community
- give clear results to communicate
- repeating surveys allow changes to be tracked over time
- can compare views of participants
- comparative surveys allow evaluation against other authorities.

Disadvantages include:

- unable to provide background as to why views are held
- generally use 'closed' or 'forced choice' responses (i.e. 'yes' or 'no'; 'agree' or 'disagree' statements or

fixed measures on a scale of such items)

- respondents are unable to express their views on their own terms
- not very suitable for examining complex or personal issues

Opinion surveys

Surveys can be conducted as postal or interview surveys with a sample of local people or service users. They can cover a wide range of perspectives on issues and can be used to get a random sample of public opinion. They can provide statistically significant data (if sample sizes are adequate) and are appropriate for finding out public opinion on broad policy issues or measuring satisfaction. Surveys of service users (e.g. through face-to-face methods or through using routinely issued forms, such as benefit applications) can be useful tools for assessing reaction to changes in services, concentrating on user experience.

Self-completion postal surveys

Advantages:

- relatively inexpensive and easy to conduct in large numbers
- respondent can reply in own time
- relatively easy to survey people with mobility problems and people in different geographical areas
- systematic way of measuring opinion
- standardised questions allow for benchmarking
- ability to reach a representative sample of the population
- can be used with service users or with wider public
- can be targeted quite accurately
- widely used and recognised as a social research tool

- most valuable for service assessments and consultation on specific service changes

Disadvantages:

- often low response rates (typically 20-25 per cent or less)
- respondents are self-selecting (i.e. only those motivated will fill it in, and these are those likely to have the most strong or extreme views)
- difficult to ensure representative sample
- surveys of users can omit people who do not use the service and/or those who may be dissatisfied with it
- may be problems for people with special needs (e.g. language, visual impairment)
- difficult to use for technically complex subjects that need more background information to be provided
- limited scope to explain and clarify questions asked and survey purpose
- require arrangements for business reply or pre-paid postage or relying on the respondent to pay for postage
- some people resent receiving questionnaires
- time required to design and analyse
- size and complexity affects cost
- need to allow time for completion and return

In recognition of low response rates, you need to provide as much assistance as possible to promote returns (e.g. keep the questionnaire design simple and provide a covering letter, a help line for assistance, and a pre-paid envelope for returns).

Face-to-face surveys

These require participants to complete a structured questionnaire in the presence of a trained interviewer. Surveys may be conducted in the street or in the participant's own home.

Advantages:

- face-to-face questionnaires can be designed to be more sophisticated and the interviewer can concentrate on those questions that are relevant
- interviewers can explain more complex subject areas
- flexible – can explore responses
- allow targeting of specific groups
- response rate is higher

Disadvantages:

- relatively costly
- time consuming and labour intensive
- require trained interviewers or the hiring of a consultant if expertise is not available in-house
- may exclude sections of the population (e.g. relies on people opening their homes to strangers, or being out and about for street surveys)
- may exclude those who do not speak English or Welsh
- may be concerns about the lack of anonymity

Telephone surveys

These are like face-to-face surveys, but are conducted by telephone.

Advantages:

- relatively cheap and quick
- convenient and easy to complete
- can target specific groups
- easier to contact elderly or ill participants

- booking telephone time is easier than arranging face-to-face meetings
- allow for explanations and things to be explored

Disadvantages:

- high refusal rates
- require trained interviewers
- exclude people without telephones or who are ex-directory
- need to be conducted in the evening to ensure representative response
- language barriers
- lack personal approach

References

- Bryman, A. *Quantity and Quality in Social Research*, London: Unwin Hyman, 1988
Discusses the comparative values of quantitative and qualitative approaches to research and their usefulness in different contexts.
- De Vaus, D.A. *Surveys in Social research* (4th Ed), London: UCL Press, 1996
Provides advice on how to plan, conduct and organise surveys including the interpretation of statistics.
- Fowler, F.J. *Survey research methods* (2nd Ed), Applied social research methods series, Vol. 1, Sage. London, 1993
Focuses on the survey approach including collecting analysing data. This includes sampling, interviewing designing and analysing survey questions.
- Cohen, G. Forbes, J. and Garroway, M. 'Can different patient satisfaction methods yield consistent results? Comparison of three surveys', *British Medical Journal*, 313: 841-844, 1996
- Dixon, C. & Carr-Hill, *The NHS and its customers II, Customer feedback surveys – An introduction to survey methods*, York, Centre for Health Economics, 1989
- Fitzpatrick, R. 'The assessment of patient satisfaction' in Jenkinson C. *Assessment and Evaluation of Health and Medical Care*, Buckingham, Open University Press, 1997

The chapter focuses on patient satisfaction with health care. Other chapters in this book relate to a variety of approaches used in the assessment and evaluation of health and medical care

Qualitative techniques

These techniques aim to identify and explore themes in detail and can provide a good basis for revealing public and patient perspectives on quality of services and/or health services and/or health concerns more generally. Qualitative methods look at why participants hold certain views and aim to describe attitudes, behaviour and motives. They can also provide the foundation for quantitative techniques, for example, scoping issues that will form the basis of a questionnaire.

Because this work is more in-depth, it involves fewer participants at a time than quantitative methods. Techniques may include one-to-one work, such as semi-structured interviews with different types of people (e.g. patients leaving hospitals, the public). Qualitative work can also be undertaken in small or large groups, for example through the use of structured group discussions (focus groups).

The benefits associated with qualitative research include:

- detailed information about participants' views is obtained
- participants are able to articulate their views in their own words
- complex matters can be explained face to face
- face-to-face research can help to develop understanding among group members

However, because of the more labour intensive and time-consuming nature of qualitative research, numbers are smaller and samples are thus less representative of the larger population or target group.

Using these techniques relies heavily on good interviewing and/or facilitation skills. In group sessions, the ability to handle the group dynamic and bring quieter individuals into the discussion is a vital skill. This ensures a more balanced and representative perspective from the whole group, not just from particularly vocal individuals.

References

Bryman, A. and Burgess, R.G. *Analysing Qualitative Data*, Routledge, London, 1994.

Denzin, N. and Lincoln, Y. (eds) *Handbook of Qualitative Research*, Thousand Oaks: Sage, 1994.

Covers a wide range of applications of qualitative research and their theoretical grounding.

McCracken, G. *The Long Interview*, London: Sage, 1988.

Covers approaches to qualitative interviewing

Miles, M.B. and Huberman, A.M. *Qualitative Data Analysis*, Sage, London, 1994.

Mays, N. and Pope, C. *Qualitative Research in Health Care*, BMJ, London, 1996.

Silverman, D. *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, Sage, 1993.

Outlines qualitative methods and analysis approaches to data collected using these methods

Focus groups

Focus groups are informal ad hoc groups of approximately eight to 15 people, brought together in discussion sessions to give in-depth responses to a particular issue, providing opportunities to explore the background to different views. A trained facilitator or moderator – usually neutral or third party – takes the groups through a series of themes or topics. The group then develops its own ideas and shares experiences and understanding.

Advantages:

- relatively cost effective to organise
- can be used to consult different sections of the community and on different topics
- useful for consulting specific target groups
- allow complex issues to be tackled and promote a wider exploration of issues
- allow you to find out what is important to people
- groups allow people to spark ideas off one another
- can include people who do not read and write or who do not speak English or Welsh if an appropriate facilitator is used
- usually enjoyed by participants

Ceredigion Accommodation Research Project

Community team for people with learning disabilities

Type of engagement: interviews and focus groups

Context and objectives

This project, established in July 1999, focuses specifically on people with learning disabilities. It was developed to improve service delivery for those either in residential accommodation, cared for at home, or requiring high levels of support.

Process

The process involved the collection of data regarding the accommodation needs of clients. Information was collected from key workers, individual interviews with clients, self-completion questionnaires for 120 carers, and interviews with some carers. Group work took place with 17 clients in three groups. An independent housing consultant compared the accommodation needs to existing best practice and sources of funding.

Partners

The Community Team – learning disabilities (CTLD) ran the project, assisted by the Family Support Team.

Funding

Funding was provided by the Ceredigion Social Services Department

Outcomes

The project identified 114 clients rated as priorities in terms of accommodation needs, and developed a report as a strategic framework to plan accommodation options over a ten-year period.

Contact

Jim Crow, SCOVO, 5 Dock Chambers, Bute Street, Cardiff CF10 5AG. Tel: 029 204 92443.
Email: Cardiff2@scovo.demon.co.uk

Disadvantages:

- small sample limits general applicability of results
- care needed in group composition to ensure a good cross-section of target group
- qualitative result, not intended to be quantified
- require care in analysis and interpretation
- require experienced facilitator which may be expensive
- possible for one or a few people to dominate the group and others to be excluded
- group views can tend to the norm
- difficult to prioritise issues
- lack of confidentiality within the group may inhibit some participants

References

Krueger R.A. *Focus Groups as Qualitative Research*, Sage, London, 1998

Bloor M, Frankland J, Thomas M & Robson K (2000) *Focus Groups in Social Research*. London: Sage

Bloor M. Frankland J. Thomas M. & Robson K. *Focus Groups in Social Research*. London: Sage, 2000
 Outlines the use and organisation of focus groups as a research method including their practical operation.

Citizens' panels

A citizens' panel comprises a statistically representative sample of an area's population and is used by organisations as a 'sounding board' on key issues. A panel can meet regularly to assess local services and develop views about future needs and goals, or to test specific options and proposals. It usually involves 750 to 2,500 people and can be used for regular surveys, repeat surveys, surveys for

several organisations, to select specialist samples, recruitment for qualitative research, and consultation events.

Advantages:

- combines formal research methods with a wider participatory approach
- representative sample of local residents and a reliable cross-section of local population are involved
- can be repeated to tackle different issues and/or track changes in opinion over time
- time is saved by not having to draw a new sample for each survey
- people have agreed to take part, hence response rates are higher
- can give relatively quick feedback
- since information is held about panel members, this allows identification of specific groups within the population for particular initiatives
- creates a continuing dialogue with participants
- provides a research resource that can be shared between local organisations if the panel is a joint initiative or a shared resource
- special needs of specific panel members can be accommodated

Disadvantages:

- setting up a panel can be time consuming and resource intensive
- requires co-ordination and proper resourcing to manage the system effectively
- requires research methodology skills – if badly sampled, can be unreliable
- not suitable for consultation about services used by limited numbers of people

Iechyd Morgannwg Health Authority

Type of engagement: citizens' panel

Context and objectives

The project was set up in 1996 and is ongoing. The aim is to improve service delivery in the domain of public health.

Process

The project aims to develop an extensive local database of people and organisations with direct or indirect interests in the field of primary care, with a view to contacting them for future consultation exercises of various kinds. The database now holds over 9,000 records, including national bodies with a local base and local groups. On this basis the project will develop a methodology for a dynamic consultation network, i.e. a process of ongoing consultation with the community through focus group discussions, periodic surveys and in-depth interviews.

Partners and funding

The project is managed and funded by the health authority.

Outcomes

The dynamic consultation methodology has been developed and applied in consultations on the five-year strategy for developing primary care and mental health care issues.

Contact

Jan Williams, Chief Executive, Alan Wilson, Director of Patient Care, The Oldway Centre, 41 High Street, Swansea SA1 1LT.
Tel: 01792 458066.

- less likely to include people who speak another language or with poor literacy
- does not involve people actively in decision-making or develop community links
- requires commitment on behalf of participants to stay involved
- people who agree to get involved may have an atypical level of motivation or interest
- panel members can become too closely linked to the authority, losing objectivity and ceasing to be representative of the 'general population'

References

Jo Dungey, *Citizens' Panels: A new approach to Community Consultation*, Local Government Information Unit, December 1997.

Includes advantages and disadvantages, setting up and running a panel, and six case studies.

Bradford Speak Out! A guide to establishing a research panel, City of Bradford MDC, Bradford Strategic Management Unit.

Includes methodology, panel usage, use of research panels in the health sector, public and private sector. The Bradford Speak Out! Citizens' Panel consists of 2,500 residents, representatives of the district's population.

More information from: Directorate of Corporate Services, Strategic Management Unit, Research Section, Room 201, City Hall, Bradford BD1 1HY. Tel: 01274 752221. Email: research section@bradford.gov.uk

Deliberative techniques

Deliberative approaches are designed to enhance the informed involvement of citizens in the planning and decision making process. People make an informed judgement concerning a complex issue. The core elements of deliberation are:

- reason = informed discussion
- reflection = time to think about what is seen and heard
- revision = the opportunity to refine views

Deliberative models constitute a 'family of approaches' sharing key features but with specific characteristics. An independent facilitator usually runs the exercise. Techniques include citizens' juries, deliberative opinion polls, standing panels, community issue groups, consensus conferences and electronic methodology. Issues suitable for consideration using these techniques tend to be characterised by a requirement for value-based judgments, complexity and controversy.

Advantages:

- allow representation of a diverse range of views
- allow complex issues to be tackled
- develop an understanding of the issues
- allow establishment of future priorities
- involvement assists the empowerment of communities
- effective in involving citizens in considering policy and strategic decisions, rather than detailed service design
- exposure to this method can improve the responsiveness of those in the public sector to the contribution citizens make.

- help to generate commitment and ownership of health and health care issues among those involved
- enable access to understanding of why people think in a particular way, providing a basis for more constructive dialogue between decision makers

Disadvantages:

- limited number of participants are unlikely to provide a statistically representative view
- less useful for taking decisions, as opposed to contributing to the decision making process
- less useful when day-to-day operational decisions are involved (may be more appropriate to work directly with service users to obtain their expert input)
- less useful when exploring views on broad, unfocused issues

References

See website: Models of Public Involvement, <http://www.pip.org.uk/models.htm>

Sykes, R. and Hedges, A. (eds) *Panels and Juries: New Government, New Agenda*, Social Research Association. Includes information on citizens' juries, citizens' panels, deliberative polling, and health panels, with case studies.

Citizens' juries

A citizens' jury provides a structured approach to obtaining citizens' views on controversial issues or an issue of local importance where choices have to be made concerning planning and policy. A jury consisting of 12 to 16 people, selected as a cross-section of the community (e.g. in terms of demographics, gender, ethnicity, employment status) meet over several days to hear 'witnesses' providing different perspectives on the issue. The jury brings explicit criteria to

bear on the issue and examines it in depth before making (usually non-binding) recommendations to the relevant authority. An independent moderator assists the smooth running of the process.

Advantages:

- offers people an active role, learning, developing and revising their view and perhaps reshaping the original question
- means of finding out what people think while simultaneously involving them in the process of democratic decision making
- aids openness in decision making, as proceedings should take place in public
- outcome is hard to ignore
- can be used for controversial topics
- allows time to pursue things in depth
- provides a breadth of views

Disadvantages:

- requires commitment of time and effort from jurors. Can be expensive (up to £20,000) and requires considerable support for the process
- jurors need to be convinced that their views will count, yet public authorities may be reluctant to commit themselves in advance to taking account of unknown recommendations
- results are not necessarily binding
- tendency for authorities to expect jurors' views to be subjective and lack depth
- tendency for jury process to encounter opposition from politicians and local media accusations that juries are merely a 'talking shop' and a waste of money

- scope can be very limited because of the need to look at very specific questions
- Works best where organisations have already made substantial progress in their consultation
- Expertise is required to run them
- May be influenced by personal agendas
- Media interest and publicity may be unpredictable and less favourable

References

- Declan Hall & John Stewart, *Citizens' Juries in Local Government: Summary for the LGMB on the Pilot Projects*, Local Government Management Board, 1996.
- Stewart J. et al *Citizens' Juries*, IPPR, London, 1994
- Anna Coote and Jo Lenaghan, *Citizens' Juries: Theory into Practice*, IPPR, 1997.
- Clarke, R. Rennie, R. Delap, C. and Coombe, V. *Using People's Juries in Social Inclusion Partnerships, Guidance for SIPs*, Edinburgh: Scottish Executive Area Regeneration Division, 2000.
Downloadable at <http://www.scotland.gov.uk/library3/social/upji-00.asp>.
Practical guide to designing and running citizens' or peoples' juries including a process for developing interagency responses through a stakeholder jury.
- Davies, S et al *Ordinary wisdom: reflections on experiments in citizenship and health*, King's Fund, 1998.
Looks at the potential for the public in shaping healthcare policy and planning through citizens' juries, and how this might differ from the involvement of service users.
- Shirley McIver, *Healthy Debate?* King's Fund, 1998.
An evaluation of six juries run by IPPR and the King's Fund from initial planning through to implementation.

***Big Issue* in the North Trust**

Type of engagement: citizens' jury

Context and objectives:

The *Big Issue* in the North Trust held a citizens' jury with 16 vendors of the *Big Issue*, all users of illegal drugs, about drug treatment services. Jurors heard from a range of expert witnesses, visited a treatment centre and spent time in small groups formulating their views.

Process

The jury were asked to consider the question: What would make ideal drug treatment services? Vendors were recruited through posters and application forms displayed in each of the *Big Issue*'s three offices for a week. The jury took place over six days in Manchester in November 1999.

The jurors spent the first two days taking part in a variety of role play and group work exercises. This aimed to allow the jurors to form a cohesive group and to develop their confidence and skills in listening, questioning and debating in an assertive and effective manner.

Two further days were spent hearing the views of, and questioning, a number of expert witnesses, including the Government's Deputy Drug Czar, a local MP, a senior police officer and a variety of health professionals.

The fifth day was spent visiting a private hospital specialising in treating addiction. This allowed jurors to consider whether there were any lessons for other service providers. The final day was spent debating and agreeing recommendations. The jurors met again a few days later to agree the final report.

Funding

The *Big Issue* in the North Trust paid an independent organisation £16,000 to organise and facilitate the jury.

Outcomes

The *Big Issue* in the North Trust used the jury's recommendations to inform the development of a premier drugs service, fast-track access to drug detox and rehabilitation. The *Big Issue* has also run a second jury on financial services, using lessons from the first to, for example, allow more time for discussion in small groups.

Contact

Stuart Bowman, 135-141 Oldham Street, Manchester M4 1LN.

Tel: 0161 279 7813. Email: stuart.bowman@bigissueinthenorth.com

Deliberative polling

There are two main types of deliberative polling. One type seeks an immediate response from a representative sample of people. The other provides for a poll of views before discussion and consideration of briefing materials take place, followed by a re-polling. The latter is more useful in determining policy since reactions to the question are informed by better knowledge of the relevant issues. These polls involve more people than citizens' juries but the level of deliberation is less intense.

Advantages:

- easy to interpret results
- relatively easy for people to participate
- insight into what people think about a particular issue

Disadvantages:

- no qualitative information
- results can be swayed by the amount, quality and balance of information provided by supporters of each option, rather than by the issue itself
- often gets low turnouts
- can be very expensive
- can be difficult to get representative sample

References

Fishkin, J.S. *The Voice of the People: Public Opinions and Democracy*, Yale University Press, New Haven, 1995

Roger Sykes and Alan Hedges (eds), *Panels and Juries: New Government, New Agenda*, Social Research Association/Local Government Association
Report of a seminar looking at the options of citizens' juries, citizens' panels, and deliberative polls.

Health panels

Health authorities have often used health panels to look at health care policy issues. These consist of a number of separate panels, each comprising about 12 members of the public, who meet on several occasions (often about three times a year) to discuss issues put to them by the commissioning organisation. Members are chosen by quota sampling to ensure that key social and demographic characteristics are represented, for example, socio-economic status, ethnicity and age. They allow consultation on complex issues, such as how primary care could be organised. Members may have a limited term of office to ensure that new perspectives can be brought into the process.

Advantages:

- enable people to reflect on an issue before indicating a position
- useful when discussing a matter people have not considered before

Disadvantages:

- high level of advance briefing required
- the small numbers involved make it hard to ensure a representative sample
- more expensive than an ordinary focus group, but less expensive than a citizens' jury

Large-scale events

Whole system events, open-space events

These techniques allow people to be involved in planning and policy processes, to map out services and gain information about people's views and experiences of services, and to inform needs assessment. They aim to involve the public, service users, carers, and the voluntary and independent sectors as well as statutory service providers. Using

Cardiff and Vale NHS Trust: Patients Panel

Type of engagement: four to five full-day meetings per year over three to five years

Context and objectives

The patients panel was set up by the newly merged trust, the third largest in the UK, at a time when it was about to embark on developing a three to five-year strategy for clinical services within the trust, which would be designed to improve the delivery of clinical services throughout the area. From the outset, the initiative sought to involve local people in thinking about how services should be delivered, and in evaluating the delivery and implementation of the strategy. The purpose of involving patients in this way was to ensure that the strategy was acceptable locally, to make trust decision-making processes more open and transparent to the public, and to build relationships between the trust and external interests.

Process

Following a notice in the local press inviting the public to come forward, and working closely with local CHCs, the panel was set up in January 2000. It initially consisted of over 40 members and included members of the public from across the area, alongside representatives from patient and community groups. The initial full-day workshops were facilitated by an independent agency.

The panel continues to hold regular meetings throughout the year to discuss a range of service issues related to specific clinical services. The meetings follow a format of presentation, question and answer sessions and panel-led workshops with a central theme of interaction throughout. Panel members are also involved in the planning of the panel days. Panel discussions and outcomes are regularly reported to the strategy board, which is committed to taking the panel's views into account when considering service reviews.

In parallel to the patients panel, the trust has introduced a staff panel to seek their views on service changes and a very positive interaction between the two panels has developed.

Outcomes

Since its inception, the patients panel has increasingly come to be seen as a resource for the trust and beyond. The trust has delayed decisions pending further information as a result of the panel's influence and has also become a sounding board for other partner agencies. This has led to the agreement to 'plan for real' around all issues affecting the delivery of health care.

Contact

Peter Welsh, Head of Strategic and Service Planning, Cardiff and Vale NHS Trust, The Grange, Whitchurch Hospital, Cardiff CF14 7XB. Tel: 029 2033 6051. Email: peter.welsh@cdffcom-tr.wales.nhs.uk

a 'holistic' approach, these events usually look at health and health care issues from whole system multi-interest perspectives. They take account of prevention and health promotion as well as treatment and care and can also help to identify pressure points, gaps, new opportunities and how isolated changes might impact on other parts of the service system.

Techniques involve listening to the individual opinions of local people on current health/social care needs, sharing views on needs and services, looking at ways in which current services could be changed or new services developed to meet these needs more effectively. Participants are asked to work together to choose priorities and negotiate and agree on outcomes.

Advantages:

- can involve large numbers of people
- can bring a varied mix of people together
- wider dialogue is possible

Disadvantages:

- dependent on who wishes to attend
- likely that a few people will want to dominate
- could become politicised by particular interest groups
- require careful chairing/facilitation

References

Jan Stevenson, Debra Blake, Peter Binns, Jonathan Berry, *Seeking the views of local people on health and social care services for older people in Trafford South*, King's Fund Rehabilitation Programme, March 2000.

A description of the process adopted by Trafford South PCG as a first step towards involving local people in service planning, inviting groups of interested people to consider whole service systems. Describes planning and running of events.

Bunker, B. and Alban B, *Large-Group Interventions*, Jossey-Bass, San Francisco, 1997.

Parston, G. Cowe, I. *Making the Connections: citizens mapping the big picture*, PMF, 1998.

Describes a mapping exercise to look at how relationships between people, public services and wider community resources combine to achieve health, safety and learning for individuals and communities.

Planning for real

This is a structured consultation method focused around a three-dimensional plan of the neighbourhood. The technique is available as a tailored package from the Neighbourhood Initiatives Foundation, The Poplars, Lightmoor, Telford TF4 3QN; Phone: 0870 770 0339; Web site: <http://www.nifonline.org.uk>

Advantages:

- useful for planning and capital spending issues
- stimulating for participants, making it easy to get honest and wide ranging opinions
- can deal with complex issues

Disadvantages:

- difficult to ensure that attendees are representative of the whole community
- very structured approach may limit usefulness for some issues
- size of the community consulted is limited by the size of the 3D model
- expensive to set up, but can be good value in light of the complexity of the model, which can be used again for future consultations

Simulations

Simulations bring together people who are already working in the relevant policy or service area. They involve real players either acting in a fictional context or one that is an approximation of reality to build a picture of what will happen in the future. They provide a safe environment in which a large

number of people can learn how complex issues will evolve. These events draw on the experience of practitioners, and through this participants are able to understand the dynamics of the whole system change and develop shared policy ideas and models that can be applied in the real world.

Pembrokeshire Local Health Group

Type of engagement: large-scale event

Context and objectives

These events were held for the purpose of consulting with the public and service users to learn about the views of the local community regarding their health needs: how well current services met those needs and what changes they would like to see in the future. This information was used to inform development of the local health action plan and Health Improvement Programme (HIMP).

Process

Consultation events included:

- Three all-day workshops, held in different parts of the country
- A community groups' forum of service users, carers and the general public, with members recruited through the local press and involving around 750 community organisations
- A one-day residents association workshop, representing communities throughout Pembrokeshire, as well as a voluntary services forum
- A second round of half-day meetings to consult on the draft health action plan

Partners

Stakeholders included the general public, services users, and carers and the voluntary organisation in Pembrokeshire.

Funding

Resources, in terms of staffing for the events, venue and lunch costs, travelling costs, stationery and postage costs were covered by the Local Health Group.

Contact

Ifor Evans, Assistant General Manager, Penffynnon Hawthorn Rise, Haverfordwest, Pembrokeshire SA61 2AZ. Tel: 01437 765 865. Email: ifor.evans@pembroke-lhg.wales.nhs.uk

References

OPM, *Creating the Climate: Health Futures for Wales*, OPM, 2001

A report on four open simulations organised by OPM for NHS Wales.

OPM, *Step Change: Modernising Primary Care*, OPM, December 1999.

A report of two simulation events designed to explore public/private partnerships in primary care.

GPower: The impact of locality commissioning, OPM/Wakefield Health Authority, 1997.

Report of an open simulation for Wakefield Health Authority, exploring the impact of the commissioning of health services through GP localities.

Community development

Community development approaches aim to strengthen local community infrastructure, allowing communities to identify their own issues and needs and ways of addressing these. They can help to develop positive relationships between the community and public and private sector agencies by enabling people to contribute to the way in which public services are delivered. Local people can set up sustainable networks and projects which respond to their needs, often in the form of self-help groups and local community associations. The community may be understood as a geographic area, a community of interest, or of identity. The focus can be on disadvantaged communities and groups. This model takes a holistic view of health and makes connections between the range of factors impacting on health and inequalities.

Advantages:

- empowers and informs participants
- promotes access to information and resources
- explicitly focuses on reducing inequalities

- starts from the perspective and experiences of the community itself
- builds confidence and self-esteem in local people and offers opportunities for learning new skills and developing expertise
- assists collaboration between sectors and brings local community and public, private and voluntary sectors together to address shared priorities

Disadvantages:

- as it is a long-term process, it will not show 'quick wins'
- may be difficult for health service professionals to embrace the concept and requires communities to be encouraged to take the lead
- many problems addressed by this model cannot be solved within local communities, e.g. inequalities, poverty, environment
- requires skills that are scarce within the NHS and need to be developed
- requires significant resources, such as money for crèches, information resources, training for local people, provision of community venues
- challenge of involving hard-to-reach groups, likely to need language translation and interpretation
- may deal with an emotive issue, with associated tensions, or an uninspiring concept

References

London Borough of Southwark, Southwark Action for Voluntary Organisations and OPM, *Toolkit for Community development*, Southwark Strategic Services, 2000.

A collection of tools, techniques and best practice in community development. Includes list of contacts.

North Glamorgan NHS Trust – The Gurnos Community Health and Resource Centre, Merthyr Tydfil

Type of Engagement: focus groups, group discussion, planning workshops, participatory appraisal exercise

Context and objectives

The project was established in September 1999 and is ongoing. The original aim was to establish a Community Health Resource Centre for the local residents of Gurnos Estate.

Process

The project involves various forms of community engagement in order to explore local perceptions of health, services provided and expectations of the planned Community Health Resource Centre. Consultation takes place through group discussions and workshops. Recruitment relies on awareness generating publicity and building on local networks of community groups.

Partners

North Glamorgan Trust and Gurnos and Glan Uchaf Regeneration Strategy Partnership steer the project. Other partner organisations included the local authority, Groundwork Trust, local schools, the NSPCC, Safer Merthyr Tydfil, Community Development Foundation, Local Community Groups, and the police. Efforts have also been made to raise the interest of a wide network of stakeholders across statutory and voluntary agencies and the community.

Funding

The community elements of the project are funded by the European Regional Development Fund (ERDF), while North Glamorgan NHS Trust provides free accommodation to the project's community partners. The project was originally part of the Regeneration Strategy Partnership. This developed into the 3Gs Development Trust (Old Gurnos, New Gurnos and Galon Uchaf), a company limited by guarantee and a registered charity. The Communities First programme is a potential source of future funding, and the potential also exists to sustain the project through the use of new pooled fund flexibilities between local government and the NHS.

Outcomes

The project has resulted in the establishment of the Healthy Living Resource Centre, with active community involvement.

Contact

Mel Jones, Community development manager, Prince Charles Hospital, Gurnos, Merthyr Tydfil. Tel: 01685 728 299. Email: Mel.Jones2@nglam-tr.wales.nhs.uk

Good Practice Working in partnership with voluntary organisations and communities, North Thames NHS Executive Briefing Paper, <http://www.doh.gov.uk/pub/docs/doh/unlosup2.pdf>

Highlights issues impacting upon the development of effective local partnerships between the statutory and voluntary sectors, aimed at individuals working with community stakeholders, including service users, voluntary organisations, CHCs, community groups.

Health needs assessment

Participatory appraisal techniques aim to enable local people to become partners in identifying their problems, participate in setting priorities and have a voice in decision making process about services and interventions that affect their lives. Local people are involved in information collection, in the analysis of their situation and in seeking possible solutions which would become the basis of planning processes.

Advantages:

- relatively quick and cheap
- aim to address problems of ill health in the community rather than on the individual level
- designed to provide information for action, rather than to accumulate data for academic research

References

Vicky Nicholls, *Welcoming Local Voices: The Role of involvement in health needs assessment in London*, Greater London Association of Community Health Councils, Health Education Authority, 1999.

Details the lessons learned from past experience in involving communities in health needs assessment in London.

Changing Practice, Learning Lessons, A Health Needs Assessment and Training Toolbox for Primary Health Care Teams; <http://www.trent-net.org.uk/hna/>

The toolbox is divided into four sections, each of which examines different aspects concerning health needs assessment,

training, and planning around addressing health and training needs. It provides information and guidance, as well as examples that illustrate the information provided.

Forums

Forums may take the form of community forums or area based neighbourhood committees, i.e. regular meetings with local people to consult about local issues. Alternatively, interest and user group forums may be used, comprising groups of service users or their representatives.

Advantages:

- may provide an effective means for representing the views people from marginalised and vulnerable groups
- can consider public sector activities or respond to particular proposals
- community forums are particularly helpful in geographically large authorities

Disadvantages:

- difficult to ensure that attendees are representative of the whole community and can become dominated by particular individuals
- relatively expensive to set up, requiring dedicated staff resources

Ethnographic enquiry

Ethnographic enquiry is concerned with understanding 'the process and structure of a social setting'. The ethnographer aims to gain insights into people and groups by both listening to what they say and by observing their behaviour. The process requires the observer to participate in the group, experiencing activities directly, to develop an understanding of the group's perspective and record his/her own perceptions.

Ethnographic research emphasises the subjective reality of individuals, recognising that the world as experienced by a

particular group can be understood only by adopting the point of view of those particular individuals.

Reference

Spradley, J.P. *The Ethnographic Interview*, New York: Holt, Reinhart and Winston, 1979

Describes the ethnographic approach to the interview situation.

Participatory observation

Participatory observation techniques may make use of notebooks, tape recorders or video cameras to observe people within a particular context. A researcher/observer takes part in the daily activities of a particular group, detailing observations throughout the day. Empirical data is collected in the form of diary notes, project documents, conversations and audio/video recordings. Data is then analysed using qualitative methods.

Advantages:

- The technique allows the person involved to observe a group or person in their real life setting, in real time with real responses. It allows a window into the status quo, rather than generating an engineered event such as a focus group.

Disadvantages:

- A stranger or a group of visitors taking notes on an individual or group may be viewed with reservation, suspicion and resentment. This is especially true if the reasons for the note-taking are not well understood or if permission has not been given. To avoid suspicion or resentment, a 'warming up' period should always precede participant observations, involving notebooks, videos, and audio recorders.
- The mere presence of a video camera may have a negative effect on inter-

actions, making the environment more like an experiment than is desirable.

Reference

Spradley, J. *Participant Observation*, New York, Holt, Rhinehart and Winston, 1980

Rapid appraisal

Rapid appraisal is a survey approach for developing a preliminary, qualitative understanding of a situation. It involves three basic concepts:

- a system perspective;
- 'triangulation' of data collection;
- iterative data collection and analysis.

These provide a conceptual foundation for rapid appraisal and a rationale for the selection of specific research techniques. The basic concepts, and their related research techniques, provide a flexible but rigorous approach for data collection and analysis by a team of two or more individuals, usually with backgrounds in different academic disciplines.

The triangulation process is a means of cross-checking performance from one source against another. The method uses key individuals, groups and organisations in a community – 'key informants' – to assist in the identification of health and social needs based on their experience of living and working in that specific community. These are generally drawn from three groups:

1. health and social service professionals who work within the community;
2. people who can be seen as community leaders;
3. local members of the community or community groups or those important in informal networks.

Llanasa Community Local Health Forum HIA Project

Type of engagement: long-term involvement to gather community input into planning decisions

Context and objectives

Llanasa Community Local Health Forum has identified the Health Impact Assessment (HIA) tool as a means of ensuring that local community views are taken into account by decision makers across a range of activities from environmental planning to the development and delivery of local services. The use of the HIA tool has enabled the group to assert the point of view of the local community through a statutory process. Local authorities have been obliged to take these views into account as a result.

Process

Members of the local health forum conducted background research to produce baseline profile information on the local area. The group convened a number of public meetings to identify issues of concern to local people, and to draw together a list of key informants and stakeholders on particular issues in the community. This process formed the basis of the group's 'kaleidoscope' approach – drawing on targeted individuals according to the particular issue under consideration.

Partners

The Local Health Forum, a voluntary organisation, initiated and steered the process.

Outcomes

The HIA process has enabled the Local Health Forum to influence service changes in the local NHS Trust by establishing liaison groups to work with managers and clinicians on a number of issues. These include problems experienced by disabled people in using hospitals and the use of specific gastric procedures. It has also identified cancer hotspots in the local area and is working with appropriate agencies on ways to support people. The Health Impact Assessment tool has increased public interest in involvement in public health issues and the deliberative dialogue that is an integral part of the process and has raised confidence in the local community that their views do count.

Contact

Roger Seddon, Secretary, Llanasa Community Local Health Forum, The Poplars, Abbey Drive, Gronant, LL19 9TE. Tel: 01745 887 449. Email: rogerseddon@yahoo.com

Health Impact Assessment

Health Impact Assessment (HIA) is based on a broad concept of health, embracing policies that cover the social and quality-of-life aspects of people's health. As a decision-making tool, it is designed to take account of the wide range of potential effects that a given proposal may have on the health of its target population. The process:

- considers the scientific evidence about the relationships between a proposed policy/project and the health of a population;
- takes account of the opinions and experience of those to be affected by a proposed policy decision;
- highlights and analyses the potential health impact of the proposed decision;
- enables decision makers to maximise positive and minimise negative health impacts;
- enables consideration of effects on health inequalities.

HIA emphasises the need to work towards sustainable development; aims for fairness and equity for all; targets disadvantaged and marginalised groups; encourages the full participation of those likely to be affected by the policy, programme or project; and makes use of qualitative as well as quantitative evidence. There are essentially three types of HIA:

1. Prospective (conducted before a proposal is implemented) offers the opportunity to consider potential health impacts before a policy is implemented – and thus make adjustments that will maximise the beneficial effects and minimise any harmful effects on health.
2. Retrospective (conducted after implementation) provides learning to guide

the future development of proposals and enlarges the evidence base for future HIAs.

3. Concurrent (conducted during implementation) allows prompt action to counter any negative effects associated with implementation of the proposal and monitors for accuracy of predictions about potential health impacts.

Advantages:

- HIAs' recommendations can be based on the participation of a wide range of stakeholders, working on an equal footing to provide a fully considered view on issues affecting the health of the local community.
- They have intellectual and democratic legitimacy.

Disadvantages:

- Each HIA is uniquely located in time, space and local conditions. Uncertainties encountered while undertaking it will frequently dictate the need to make assumptions which may result in challenges to the HIA's validity (such assumptions must be stated explicitly).
- The financial and opportunity costs of this method require careful screening of potential candidate projects.
- A HIA needs to be undertaken by competent and trained individuals and agencies in liaison with local public health departments.
- It is inappropriate for collecting detailed information on a particular health problem.

References

Marsaili Cameron, *A short guide to health impact assessment: informing healthy decisions*, NHS Executive London, August 2000, download at: <http://www.doh.gov.uk/london/shortguide.pdf>

A concise guide to HIA.

Ison, E. London Health, *A Resource for Health Impact Assessment*, NHS executive, October 2000

Includes introduction to HIA, applying HIA and resources for HIA – available in sections or as a full document to download at <http://www.doh.gov.uk/london/resource.htm>

3.3. Capacity building: supporting the public and patients

- Patients, carers and members of the public
- Vulnerable and marginalised groups
- Community representatives
- Non-statutory organisations
- References and contacts
- Community Health Councils in Wales

A key test of the effectiveness of public and patient involvement is how much effort is devoted to supporting the capacity of people in the community to take up opportunities to get involved. All organisations need to think about this in order to make engagement with communities a reality.

NHS Trusts and LHGs need to consider the following:

- the potential reach and breadth of their public and patient involvement activities across the community;
- the political, social, cultural/linguistic composition of their communities;
- their ability to engage with hard-to-reach groups;
- the effectiveness of the various methods of engagement with different groups and how far this promotes or prevents active involvement;
- the things they can and should do to make it easier for people to get involved.

Organisations must do all they can in order to ensure that people can be involved in health-care decision making. One of the factors that often prevents an effective contribution being made by patients, carers or members of the

general public is paying insufficient attention to their support needs.

There are at least three types of groups that need support:

1. **Individuals** (patients, carers and members of the public) need support when they take part in initiatives that aim to learn from their experiences of health and social care.
2. **Representatives of community interests** – those who reflect the interests of a wider community – need support when they contribute to decision making.
3. **Community interest organisations** need collective support to be involved.

You should identify the variety of support needs of different people and how these change over time and/or as people become involved in different phases or levels of initiatives. But some support needs are common to whoever is involved – whether they are an individual member of the public, a patient, or a carer who is asked to be involved in qualitative research about the quality of services, through to a community representative on a committee.

Effective involvement means it is often necessary to involve people from more than one of these groups during an

initiative and also to provide opportunities for them to meet together, as well as with health professionals.

Overall, it is important to:

1. make people feel valued so that they know that their views count, includ-

ing making things safe and accessible so that people are able to contribute;

2. provide people with relevant information so that they have the knowledge and understanding to make informed decisions;

South Ayrshire Council

Type of engagement: stakeholder conference. Client group: learning disabilities

Context and objectives

South Ayrshire Council organised three stakeholder conferences involving people with learning disabilities, their carers and a range of other partners from the private, public and voluntary sectors to develop the South Ayrshire Joint Learning Disability Strategy. Both service users and carers were involved in planning the conference, which had three main aims

1. to enable service users to express their views and articulate a vision for the future.
2. to enable other stakeholders to listen to service users expressing their views.
3. to provide a platform for carers and other stakeholders to express their views

Process

Prior to the event, preparatory sessions were held with people with learning disabilities to help them to understand how the conferences would work. 350 people attended the three events; over 100 of the participants were service users with learning disabilities, ranging from mild to complex disabilities. The recruitment process was designed to be as inclusive as possible, and made use of the existing council database of local people with learning disabilities and their carers, all of whom were invited.

At the conferences, participants spent most of the day in small groups. Trained facilitators used visual aids to explore the hopes, fears and ambitions of participants with learning disabilities. Participants were supported, if required, by staff from a range of different agencies.

Funding

The three stakeholder events cost £3,500.

Outcomes

The views expressed at the conferences have a central place in the South Ayrshire Learning Disability Strategy, which is currently being implemented.

Contact

Annabel Sinclair, South Ayrshire Council, Wellington Square, Ayre KA7 1DR.
Tel: 01292 612000 ext. 612024.

3. develop the skills of individuals so that they have the confidence and capacity to contribute effectively.

Organisations should develop systems and structures to identify, recruit, support and train lay people to be involved in health and social care decision making.

Patients, carers and members of the public

Making people feel valued

Best practice dictates that organisations should provide financial incentives and expenses in order to motivate people to participate in involvement processes. You should consider carefully the timing and location of events in order to make participation convenient for local people.

Organisations need to ensure that initiatives and events are designed with the lay person in mind and make people feel that they can safely voice their views. There should be special consideration for those from vulnerable and marginalised groups. For example, those with disabilities and special needs, sensory impairment, language difficulties or learning difficulties. Participants should be able to bring with them an advocate, friend or relative.

People need to know that their views count – that during the process they will be able to get their views across. Organisations should be able to demonstrate that they will take on board people's views *and* act on them. Successful initiatives have highlighted the importance of organisations believing that patients and the public have legitimate and valuable perspectives on key issues, rather than simply involving people to meet some statutory obligation for consultation. Effective organisations must be open to acting on issues identified and raised in this way.

Information and communication

It is essential to provide resource materials beforehand for participants that use clear language, avoid jargon and explain any technical terms and acronyms. There must be a clear explanation of the process, its aims and objectives and the parameters of the initiative (i.e. what is and is not open to negotiation regarding outcomes). People need to have key points of contact during the process and be kept up to date with progress and feedback on actions taken.

The communication strategy underpinning the work must address the needs of those who are not directly involved as well. This means a targeted dissemination strategy using local networks (e.g. GP surgery, library, religious centres), open information sessions, using the local press and linking with multi-agency groups.

As well as facilitating the involvement of English and Welsh speakers in their chosen language, you may have to cater for other special communication needs. This may mean providing sign language or braille facilities, hearing loops for those with sensory disabilities, or interpreters.

Vulnerable and marginalised groups

Organisations must identify which groups are currently excluded (both in terms of service delivery and with regard to public and patient involvement) and how many people from socially excluded groups are, or could be, affected by the initiative. Statutory organisations should demonstrate that they have sought the assistance of local community groups and joint agency partnerships to advise them in this area.

Carmarthen Youth Project ('Dr M-Z')

Type of engagement: questionnaire survey

Context and objective

The Carmarthen Children's Society Youth Project was established in June 1995, with the aim of strengthening the local community.

Process

The process involved young people consulting other young people through questionnaire surveys

Partners

The Children's Society and Carmarthen Youth Project steered the project, with involvement from youth council representatives from three secondary schools, the Youth Task Group, consisting of parents and agencies, parent teacher associations, community education, the police and the local MIND project.

Funding

Funding was provided in the form of grants from Health Promotion Wales, West Wales TEC, St David's Diocesan Team and the Children's Society. The Lottery Charities Board provided additional funds of £136,000 over three years, while national grant making trusts and the police contributed £11,100. It is currently funded by banks.

Outcomes

The project achieved strong youth involvement in pilot project clubs, with funding for two full-time staff. It saw the establishment of an alcohol free bar in the town centre, long-term funding for a young person completing a training-for-work programme, and the involvement of many volunteers in running pilot projects. Links with young people in other districts running similar projects were also established.

Contact

Gail Harris, Carmarthen Youth Project, 4 Queen Street, Carmarthen SA31 1JR.
Tel: 01267 222 786

People who are socially excluded require approaches that are particularly sensitive to their needs. These groups include those 'excluded' because of their defining 'health problem', such as mental health service users, people with physical/sensory disabilities, HIV positive people, and drug and alcohol abusers; those from particular communities or social situations, such as people from black and ethnic minorities, travellers,

non-English speakers, lone parents, ex-offenders, homeless rough sleepers; those from deprived communities and/or who are unemployed or on low incomes; and those 'excluded' by age i.e. the young or the elderly.

People from these groups may find it hard to participate in public and patient involvement initiatives for various reasons. They may have difficulties accessing initiatives because they are

poorly publicised or are held in locations that are far away from where they live and/or work. Where recruitment to groups or events relies on advertisements and volunteers, they do not attract participants from a broad enough range of social and ethnic groups.

Community representatives

Those who represent community interests may be members of the voluntary sector or community health councils, or are 'lay representatives' on statutory committees or groups. They may also be 'lay members' of formal bodies or boards, such as LHGs and, as such, have corporate responsibilities as well as articulating the community voice.

In general, they need the same basic support as individual members of the public, patients and carers. But they will also require additional specific types of support, training and development linked to their representative role and the likelihood that they will be asked to become involved in a wider range of things. Organisations in both the statutory and the voluntary sectors need to clarify the knowledge, expertise and skills required for those who are trying to reflect and/or represent the public or a community interest.

Identification and recruitment

The identification and recruitment of community representatives on to committees or groups requires special consideration. Thought should be given to finding a balance between representatives who have been involved in the past and those from groups or communities who have not. With regard to the latter, supporting people who can reflect the views of vulnerable and marginalised groups and/or communities must be a high priority. You must ensure that there

are mechanisms to enable committees and forums comprising lay representatives to draw upon the views of patients, carers and the wider public.

It may be that patients and members of the general public involved in recent initiatives express a willingness to participate further. For example, if focus groups are held to get feedback on services in one area, participants might volunteer to be consulted again on related issues (such as design of patient information leaflets, or other 'one-off' projects) or to participate in planning and policy issues. Organisations should be able to support these people to take part in further processes and thus create a larger 'pool' from which to consult.

Functions of the lay representative

The main functions of community representatives are twofold:

1. To identify and reflect the views of the community or communities they represent: '**community channel**'.
2. To articulate these concerns effectively within the committee, forum or organisation: '**community advocate**'.

The former requires an understanding of methods that involve patients, carers and the public and having close links to, and networks within, the community. The latter requires a range of skills, such as influencing skills, communication skills, understanding of organisations and committee structures and the ability to ask challenging questions. With this range of expertise, community representatives can carry out a number of functions within a committee or group. They make a special contribution to public and patient involvement initiatives, but care should be taken to avoid having them solely responsible for these activities. This can lead to public and patient

Bristol City Council, Education and Lifelong Learning Department

Type of engagement: community development

Context and objectives

Bristol Community Education has developed an innovative model of action research. The programme involves members of different communities in Bristol who are currently excluded from or under-represented in decision making. Since 1998 Bristol has carried out a total of nine research programmes that have had a main emphasis on parental involvement in schools and lifelong learning.

Process

Members of specific communities were recruited, trained and employed as local consultants to carry out research into specific issues in their community. These local consultants worked with an experienced facilitator to identify the main issues in the community, to determine the questions that need asking, to produce research tools (mainly a questionnaire), to carry out interviews with other local managers, and to analyse data and produce reports. Their findings were presented to key managers, funders and decision makers. In each research project, the local consultants formed an advisory group, often with other key stakeholders, to oversee the research process. In some cases, these advisory groups have continued after the initial research process has been completed – group members have continued to work together to put findings into practice, providing a foundation for sustained community involvement.

Funding

The overall budget for each research project is around £6,000.

Outcomes

The research programmes have fed directly into local decision and funding strategies. One exercise resulted in the establishment of a New Community Learning Fund, to enable local parents and community/voluntary groups to apply to increase access to learning. In all cases, the research findings have been used to inform major funding proposals, such as Sure Start, New Deal for Communities and Single Regeneration Budget, ensuring they are a reflection of what local communities need and want.

Contact

Jane Taylor, Bristol City Council, Education and Lifelong Learning Department,
PO Box 57, The Council house, college Green, Bristol BS99 7EB. Tel: 0117 903 833.

Diabetes UK Cymru: Local Diabetes Services Advisory Groups

Type of engagement: supported group membership and patient questionnaires

Context and objectives

The local diabetes services advisory groups aim to involve users and carers in the monitoring of diabetes care and the development and implementation of local diabetes strategies through a partnership approach.

Partners

The impetus for the groups came from a joint Department of Health, British Diabetes Association (now Diabetes UK) initiative, which then received support from the local health authorities and professionals.

Process

LDSAGs bring together patients, carers, members of multidisciplinary teams, including health and social care professionals, and representatives of local Diabetes UK voluntary groups and local CHCs. The groups focus on improving local diabetes services with an emphasis on empowering people with diabetes in their own self-care. User representatives are supported to enable them to contribute effectively to the group, and multidisciplinary training is provided to group members by Diabetes UK Cymru.

Outcomes

LDSAGs have been successful in increasing patient involvement, with the number of groups reporting the involvement of service users almost doubling between 1994 and 1996. The groups are seen to be a good practice example for involving people with long-term medical conditions in service development. Improvements in services at local level have also been reported by both professionals and service users.

Contact

Andy Misell, Policy and Public Affairs Officer, Diabetes UK Cymru, Quebec House, Castlebridge, Cowbridge Road East, Cardiff CF11 9AB. Tel: 029 2066 8276. Email: wales@diabetes.org.uk

involvement processes being marginalised from mainstream business.

Community representatives need specific training and development. There is, at present, little opportunity for this. Often, there are few systems for bringing people together and there is much

‘tokenistic’ representation. Out of these considerations organisations can develop common service and role/job descriptions for lay representatives. This should lead to the development of standards, monitoring and accountability mechanisms, training and capacity building.

Reference

Jane Bradburn, Gillian Fletcher, Catherine Kennelly, *Voices in Action: Training and Support for lay representatives*, College of Health, DoH 1999.

Report on project to create a training and support scheme for lay representatives.

Contact

Wales Council for Voluntary Action
Baltic House, Mount Stuart Square, Cardiff
CF10 5FA; Tel: 02920 869224

Non-statutory organisations

There is a vast range of groups and organisations that can support this work and who can contribute in various ways. In addition to community health councils and patient support groups, there are numerous organisations within the voluntary sector that can contribute to involvement strategies – either by being able to contribute views, or by co-ordinating initiatives. The statutory sector needs to do more to recognise, value and utilise the contribution of these groups. At the same time, they should not use them as a ‘free resource’. Non-statutory organisations require ongoing support to contribute effectively.

Non-statutory organisations could do more to ensure their effective participation in decision making. They have a responsibility to develop their own strategic decision making and development needs with regard to this work. This means prioritising efforts, joining up with other organisations, linking effectively with statutory organisations and listening to the views of socially excluded communities. They should also identify which specific skills and competencies they will need to acquire and become more proficient at.

Responsibilities and accountability

Voluntary organisations play an important role in keeping communities informed by using their extensive networks. Many initiatives developed within the voluntary sector and by CHCs might be extended, for example patient participation groups and health watch groups. CHCs and the voluntary sector might wish to raise their profile, explain clearly their role and do as much as they can to reach those who may feel they are not represented within their structures.

References and contacts

Engaging hard-to-reach groups

British Deaf Association Wales
Shand House, 2 Fitzalan Place,
Cardiff CF2 1BD
Tel: 02920 462929

Welsh Council for the Deaf
Glenview House, Court House Street,
Pontypridd.
Tel: 029 20485687

Wales Council for the Blind
Shand House, Newport Road, Cardiff
Tel: 029 20473954

British Diabetic Association Wales
Sophia Close, Cardiff CF1 9TD
Tel: 029 20668276

Royal National Institute for the Deaf
<http://www.rnid.org.uk/>
Third Floor, 33-35 Cathedral Road, Cardiff
CF11 9HB
Tel: 029 2033 3034
TextTel: 029 2033 3036
Fax: 029 2033 3035

Regional Communications Officer:
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North Wales
Ysgol Brynglas School, Clayton Road,
Mold, Flintshire CH7 1SU
Tel: 01352 759 966
TextTel: 01352 759 949
Fax: 01352 759 961

Royal National Institute for the Blind
<http://www.rnib.org.uk/>

RNIB Cymru
 Trident Court
 East Moors Road
 Cardiff CF24 5TD
 Tel: 02920 450 440
 Fax: 02920 449 550

Diabetes UK
<http://www.diabetes.org.uk/>

Diabetes UK Cymru
 Quebec House, Castlebridge, Cowbridge
 Road East, Cardiff CF11 9AB
 Tel: 029 2066 8276
 Fax: 029 2066 8329
 Email: wales@diabetes.org.uk

Social exclusion

Heriot-Watt University School of Management and Edinburgh College of Arts School of Planning and Housing have jointly launched a Centre for Research into Socially Inclusive Services (CRSIS) to investigate problems associated with social exclusion, including financial, retail and local public services. Web site:
<http://www.crsis.eca.ac.uk>

The Guide to Effective Participation,
<http://www.communities.org.uk>.

Includes 10 key ideas about participation, a framework for consultation, assessing the appropriate level of consultation, how to consult, signposts from theory to practice, guidelines and references to further reading.

Black and ethnic minority communities

Shirley McIver, *Obtaining the Views of Black Users of Health Services*, King's Fund Quality Improvement Programme, 1994.

Aims at helping health professionals obtain the views of black people who use health services. Outlines different methods and details four areas of concern: communication, information provision, diet, religious and cultural beliefs.

Consultation Update, Policies and Equalities Unit, Lewisham, August 1999 and December 1999.

Highlights key issues around consultation with customers and citizens.

Cabinet Office, *Involving Users: Improving the delivery of health care*,
<http://www.cabinet-office.gov.uk/servicefirst/1999/consult/health.pdf>

Describes how the Leicester Royal Infirmary NHS Trust worked with black and minority ethnic communities to draw up a service improvement action plan.

Contact

AWETU Black and Minority Ethnic Mental Health Group
 41a Lower Cathedral Road, Riverside,
 Cardiff CF11 6LW
 Tel: 02920 394141

Young people

Carolyn Willow, *Hear! Hear! Promoting Children and Young People's Democratic Participation in Local Government*, Local Government Information Unit, February 1997.

Describes case studies of good practice, including in both local government and the health services – brief description of the initiative, timescale, and points to consider for application elsewhere.

DTZ Piedad Consulting, *Involving Communities in Urban and Rural Regeneration: involving young people*, p39-51.
<http://www.dtzpiedaconsulting.co.uk>

Julian Cohen and Judith Emanuel, *Positive Participation: consulting and involving people in health related work, a planning and training resource*, Health Education Authority, 1998.

Outlines the value of involving young people in health related activities. Promotes effective involvement methods and principles. Includes practical workshop exercises for facilitators and trainers.

People with learning disabilities

Values into Action – UK-wide campaign with people who have learning disabilities,
<http://www.viauk.org/general@viauk.org>
 Tel: 020 7729 5436.

Publications include:
What is community care?

A 12-page pamphlet with some common

questions about community care for people with learning difficulties.

Who's in Control? Decision making by people with learning difficulties who have high support needs

Drawing on the results of 18 months of research with people with high support needs, this publication demonstrates how to enable people with learning difficulties to be in control of their lives.

Older people

Jan Stevenson, *Involving Older People in Health Developments*, King's Fund Rehabilitation Programme, Briefing Paper no. 4, December 1999.

Reviews literature and lessons learned regarding involvement, specifically in primary care. Aims to help strategy development and plans for consulting the public. Includes references to further reading.

Contact

Age Concern Cymru
4th Floor, 1 Cathedral Road,
Cardiff CF1 9SD
Tel: 02920 371566

People with mental health problems

Jane Thompson, *User Involvement in Mental Health Services: the limits of consumerism, the risks of marginalisation and the need for a critical approach*, Mental Health Foundation.

Examines different approaches to user involvement, recognising that while a consumerist approach to involvement currently dominates practical efforts to develop user involvement, such an approach fails to address power imbalances or address deeper issues.

Terry Philpot, *Managing to Listen: a guide to user involvement for mental health service managers*, Mental Health Foundation.

Offers practical assistance to mental health service managers who want to initiate or develop user involvement. Aims to: draw on the experiences of managers, staff and users; identify problems and offer solutions and ideas based on those experiences;

and find ways of promoting and supporting good practice with both staff and users.

Vivien Lindow and Jenny Morris, *Service User Involvement: synthesis of findings and experience in the field of community care*, Mental Health Foundation.

Recognises that the assumptions and behaviour of community care workers, or the way services are organised, can prevent/make it difficult for people to make choices. Examines barriers to collective involvement, and looks at moving toward user-led services.

NHSTD in Collaboration with Survivors Speak Out, MINDLINK and the National Advocacy Network, *Training and User Involvement in Mental Health Services*, Mental Health Foundation.

Looks at common issues and differences in the user movement across the country, focusing on issues for women, black and minority groups. It aims to inform, support and strengthen local networks of users, health professionals and managers trying to develop user involvement; encourage sharing across localities; provide a practical working tool to stimulate involvement; identify potential difficulties and signpost other sources of information. Source of handouts, check-lists, guidance, contacts.

Contacts

MENCAP in Wales
Unit 31, Lambourne Crescent,
Llanishen, Cardiff
Tel: 029 20747588

MIND Cymru
23 St Mary Street, Cardiff CF1 2AA
Tel: 029 20395123

South Wales Mental Health Advocacy
PO Box 745, Cardiff CF14 2YF
Tel: 02920 625777

Supporting carers

Banks, P. 'Carers' contribution in primary care' in Gillam and Brooks (ed). *New Beginnings: towards patient and public involvement in primary care*, London, King's Fund, 2001.
Provides examples.

The Carers Compass: directions for improving support to carers, Carers Impact, London, King's Fund, June 1998. Aimed at NHS commissioners and managers, working in local partnerships. Sets out the policies and practices that need to be in place to support carers, and provides suggestions for how to measure the success of these.

Department of Health, *Caring about Carers: a national strategy for carers*, London, The Stationery Office, 1999.

Outlines the first national strategy for carers that directs all organisations to identify carers and provide them with information, assign posting to support services, and help them to maintain their own health.

Contact

Carers National Association in Wales
River House, Ynysbridge Court,
Gwaelod y Garth, Cardiff, CF15 9SS
Tel: 02920 811 370

Community representatives

Jane Bradburn, Gillian Fletcher, Catherine Kennelly, *Voices in Action: training and support for lay representatives*, College of Health, DoH 1999.

Report on project to create a training and support scheme for lay representatives.

Non-statutory organisations

Good Practice – Working in partnership with voluntary organisations and communities, North Thames NHS Executive Briefing Paper, <http://www.doh.gov.uk/pub/docs/doh/unlosup2.pdf>.

Highlights issues impacting on effective local partnerships between the statutory and voluntary sectors, aimed at assisting those planning and carrying out work with community stakeholders, including service users, service user groups, voluntary organisations, community health councils, community groups, and the wider public.

Community Health Councils in Wales

CHC Web site:
<http://www.patienthelp.wales.nhs.uk>

Association of Welsh Community Health Councils

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3.4 Capacity building: supporting organisations

- Systems and structures
- Roles and responsibilities

Involving patients and the public may be a worthwhile end in itself, but it must also act as a stimulus to change. In order for public and patient involvement to make a real impact it needs to be linked to decision making processes in NHS organisations. Managers and health professionals need to be responsive to the wider community's opinion about its needs and expectations in respect of health care and how it judges current provision. This is not just an issue of encouraging feedback and supporting involvement – it means actually doing something with the results. There will inevitably be raised expectations about what will happen next. The real litmus test for those who become involved is seeing what happens as a result.

Systems and structures

Valuing the work

For public and patient involvement work to flourish, organisations need to be committed to the importance of it, be able to create the right context and climate for it to be effective and be clear about what needs to be done and who should do it to achieve success. All this needs to be built into performance management arrangements.

Valuing involvement means providing the resources – time, money, staff, skills, support, structures and systems, commitment and leadership – to do the job

properly. Creating the infrastructure for involvement means investing resources in order to get the expected return in valuable information to do something with. However, it should be recognised that change is not easy, and that it may take time. At the moment, it often appears to the wider community that nobody within a service or organisation wants to take responsibility or listen to needs. There is a strong sense that those who commission involvement initiatives only do so because they think they should. There is a feeling that organisations remain unconvinced of the benefits and/or do not put incentives into place to encourage the work to be carried out effectively.

Culture change

Part of public and patient involvement is about developing a strategy and vision for the work (see part two) and structures and systems to support it. This needs to be accompanied by work on the organisational culture – the informal symbols and behaviours that reveal the values of the organisation. Culture may be affected by the make up of health professionals who carry powerful assumptions about 'how things should be done' (see section on 'involving health professionals'). It is also affected by systemic pressures that occur within a public sector that has to manage demand and make 'rationing decisions'. This can lead to a 'we know best' attitude and one that suspects that individual user groups will

demand things for themselves to the detriment of wider collective needs.

In the absence of a 'profit motive', public sector organisations have not had so much incentive to look for efficiency gains and can find it harder to measure performance. In turn they can tend to measure inputs rather than outputs and outcomes. Public and patient involvement can help reverse this trend by ensuring feedback on quality and pressure for improvement. Through involvement, the culture can move from one that treats people as 'passive' (and sees them as complaining) to one where patients and the public are 'co-producers', able to take more responsibility for what happens, to recognise what can and cannot be done and to make trade-offs.

Make a start by exploring your organisation's culture. Learn to recognise it and face the problems and attitudes of 'the way we do things round here' and identify the assumptions and behaviours that get in the way of improving the culture. There are many processes and techniques that can be used, including culture audits, challenge groups, organisational raids, exploratory project teams, learning sets and the like that tap into the cultural currents of the organisation and the values and beliefs that underpin them. But the technique is less important than involving members of staff and managers, and helping them to feel confident and safe when identifying problems and working on solutions.

Inevitably the pursuit of meaningful public and patient involvement will necessitate some changes in attitudes and behaviour of staff and some remoulding of organisational culture as a result. Successful cultural change only comes about if the staff affected by it have some way of reflecting, learning and developing and this is supported by an appropriate process – usually some form of organisation development to support the process of change that

recognises the importance of their role and contribution.

Dispelling myths about involvement

In the past, both health professionals and community representatives have felt that there is a tension between organisational goals and the services that patients or the public might want to see in place. Health professionals and managers may also argue that they are constrained by central guidance on what their priorities for action may be. The Guidance produced by the National Assembly for Wales concerning public and patient involvement creates the opportunity to prioritise this work. At a more local level, it is possible to create a shared agenda for the work that allows for professional and public/patient priorities to be addressed together in a meaningful way.

Ironically, it is often the very lack of meaningful engagement with the wider community that fosters false assumptions about 'what the other side' wants and creates fears and concerns within organisations about 'raised expectations'. If there has been little experience of involving patients and the public, then an organisation may view involvement as something to manage or manipulate rather than an opportunity to learn and make practical improvements.

Linking to decision making

During consultations, many members of the public and representative groups think that decisions have already been made, or that public and patient involvement presents a *fait accompli* to participants, and that whatever options for change are developed within a project will not get considered or resourced. To change this, engagement needs to be integrated with decision making. For example, it may be possible to identify

‘patient-centred’ outcomes – those things that matter most to service users – as indicators within clinical governance arrangements and then to use these to monitor change.

Who decides on the outcomes of the work? Are they part of the project from the start? What happens to the results of the project? Who is accountable for the effectiveness of the project? These are questions that need answers. There has to be a senior level commitment to share results and take action – even if it is only to explain what can and cannot be done. For example, trust and LHG boards need to demonstrate how this work is being undertaken within their organisations. This all underlines that involvement needs to be central to planning and decision making.

Taking action

Demonstrate the benefits – public and patient involvement needs to be linked with results in terms of improved care and treatment. Modest expenditure at the beginning of an initiative, or during the early phase of strategy development or piloting service development or improvement, may bring ‘quick wins’ and be cost-effective. Some aspects might be immediate – making public meetings more accessible for people with disabilities, providing translation services so that people can be involved in focus groups, involving users in staff training and/or recruitment, developing information, making changes on the ward.

These can demonstrate commitment to action and improvements in outcomes. But this needs to be balanced by work leading to more systematic changes and input into planning and commissioning services. One way of doing this is to undertake an initiative in one area and/or for a particular client group that cuts across departmental boundaries (e.g. older people). This can also generate

cross-disciplinary learning and be applied to other areas or groups.

Mainstreaming the work

As well as doing one-off work on particular priority issues, public and patient involvement should be integral to your ongoing strategy development and planning. It should be linked to other work, so that when a developmental priority is set, the organisation does not have to scramble around to create a one-off project. Systems of participation cannot just be grafted on to a planning system that is unclear or lacking transparency. Time should be allowed in order to link the work into a wider process of strategic development.

You can use the learning from one aspect of the work and apply it to others. For example, work on individual complaints can be integrated with looking at the pattern of complaints and therefore be used as a catalyst for an involvement project that seeks to improve things. Linking audit and R&D departments to the involvement agenda, involving patients in training programmes for health professionals on communication skills, having public and patient representatives on research funding committees; all these are ways of ensuring that involvement is linked in practical ways to everyday business.

Roles and responsibilities

Understanding professional concerns

Many of those who have been involved in this sort of work report that overcoming 'resistance' from health professionals can be a real problem. They say that clinicians and managers may have a negative attitude to the work and a patronising attitude towards the public and patients that can impede progress. A common accusation is that they 'protect their own ground' and are unwilling to 'let go' of their power.

On the other hand, public and patient involvement is a pressure for change. It can signal or pre-empt changes in relationships between health professionals and patients, and therefore it is not surprising that health professionals may fear the unknown effects of the work. This is to be expected, as there may be a prevailing culture of 'blame' and fear of litigation.

Health professionals may fear that greater patient involvement will open the 'floodgates' of increased demand. But one clear message that leaders of involvement initiatives should provide is that the outcomes of good public and patient involvement initiatives are basic, practical suggestions that have not been thought of before. These might even save money and time! For example, user groups can pass on their learning and help educate others in self-management. Patients involved in developing information can ensure that it is better targeted to answer the questions that patients need answered (and save wasting professional time).

There are signs that many health professionals now acknowledge the need to involve patients in both their own care and treatment decisions and more

generally at a collective level. The question is not so much 'why?' should the public and patients be involved so much as 'how'? Health professionals want to know the benefits of involvement, what it means to their own work (and workload) and how they can be supported to deliver improvements. It is no good harassing people to change in a confrontational manner without recognising peoples' fears and concerns.

Weighing the evidence

Health professionals may not see the validity of information produced from involvement initiatives. The expertise and evidence that patients and the public bring to the table is often different in nature to that relied upon by health professionals when building a case for change. For example, evidence-based practice relies heavily on quantitative data and systematic reviews of outcomes. Health professionals may feel they need this sort of data in order to be convinced of the need for change. They may label the experience of individual patients as 'anecdotal' and classify those taking part as 'unrepresentative'. These are all ways that health professionals can undermine involvement initiatives. But they are understandable concerns and ones that you need to take seriously.

So, how can they be responded to? There is some evidence that involving patients in their own individual care and treatment decisions leads to improvements in the quality of care. But at the collective level, there is as yet a lack of evidence about the benefits. This should not be used to argue that it does not work or that it is not helpful to organisations that need to change. However, the 'involvement movement' is in its infancy and will take a while to generate enough hard data to convince sceptics.

On the other hand, one can argue that involvement initiatives should not

require this sort of hard evidence – that the values underpinning involvement are sufficient in themselves to make it a top priority. Arguments concerning accountability and openness have proved sufficient in the realm of clinical governance. They may be enough to convince organisations that involvement is also an impetus for change at this level. In addition, monitoring the impact of involvement is a complex business and it may be difficult to evaluate.

Much of the work undertaken during involvement exercises will be qualitative (see section 3.2) and is not intended to provide quantitative data. A patient's story – or 'testimony' – is valid in its own right. If a patient reports a problem in his or her own care, it may or may not be a representative view, but it can signal problems and reveal that underlying processes are awry.

Another issue is whether patients and health professionals agree on what constitutes good practice. In some cases the answer will be 'yes', in other cases, 'no'. Sometimes, health professionals will concentrate more on the science of medicine and hard evidence of what works. Often, patients and the wider public will put more store by the 'human' aspects of care – dignity, respect, information, communication. But in many cases the two aspects coincide. In any case, this does not obviate the need for difficult (sometimes political or financial) decisions on how to solve the problems. But it can bring together valuable perspectives to provide a rounded picture of what good practice should be like.

Engaging health professionals

If the first step in engaging health professionals is to tackle their concerns, then the second is to involve them in the work itself. Staff are an essential resource for this type of work. They do not choose to be unhelpful or resistant to change, but

if they have no decision-making power themselves, they often feel unable to help. Unempowered people cannot empower others. They can and should be enabled to make a positive contribution.

Health professionals may have multifaceted perspectives to contribute if they have been patients or carers themselves. But often they are not encouraged to put themselves forward. Involvement needs to become part of everyday practice. The same lessons of public and patient involvement apply to staff involvement – people need to understand the purpose of it, receive valid information, be involved in creating a strategy and understand how the health system works as a whole.

It is essential that staff do not see the work as (yet another) administrative task. To make it integral, you might start with systems for monitoring patient views at ward or general practice level. This sort of project might also provide a 'kick-start' which could lead to mainstream work once the learning has been assimilated. Public and patient involvement does not necessarily mean identifying what is going wrong. It can focus on supporting and sharing good practice, and improving the quality of services.

It is worthwhile to have someone who can lead the work on a dedicated day-to-day basis. But it is vital to avoid it being seen as one person's job only and therefore marginal to all other people's responsibilities. There are some important lessons and parallels with clinical governance work in this respect. All staff are likely to need to learn new skills. They will need to feel confident in order to present issues to patients and/or the public and have to find ways to get other staff to respond to public and patient initiated activities. Specific skills, such as how to conduct focus groups, surveys, and other relevant methods require training and development programmes, dedicated resources and opportunities.

A number of NHS organisations have already invested in developing competencies in the 'human aspects' of care (e.g. treating patients with respect and dignity). The royal colleges and medical schools are putting more emphasis on communication skills as part of medical education and training. Some organisations are going further in providing 'customer care' training and development programmes to improve the delivery of care.

It may be easier to engage some individuals and professions than others. And there are significant benefits to be had in involving health professionals in key positions of responsibility, such as GPs or consultants. This may be hard, but can be done through getting senior level support for the work and, once again, demonstrating its benefits.

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3.5 Capacity building: joint working

- Benefits of joint working
- Making joint working effective

A universal theme of most public and patient involvement work is that it should be wide-ranging and inclusive, both across communities and within NHS organisations. To secure the greatest potential benefits, NHS Trusts and LHGs, along with their partners in other agencies and in the non-statutory sector, should be aiming to work together to:

- maximise the potential gains of tackling this work in a more coherent, co-ordinated and integrated way;
- minimise the prospect of ignorance and misunderstanding, confusion on all sides, and wasted resources as well as missed opportunities.

Benefits of joint working

Many of the issues arising under the theme of joint working are common to involvement more generally (e.g. supporting the public and patients to be involved, creating the internal organisational climate, etc). These topics are tackled in the relevant chapters above. However, some issues are particularly pertinent to joint working because different organisations in health and social care need to be aware of what the other is doing in the area of public and patient involvement and how their individual activities connect and interrelate. Moreover, the public and patients do not regard the boundaries and distinctions between the different agencies as

important – they are more interested in the delivery of ‘seamless’ care.

Public involvement to support joint working

People’s needs are multi-faceted. Concentrating on delivering quality services necessitates a joint agency approach both towards delivering people-centred services and involving people in planning. Public involvement can be the glue that binds organisations and agencies together. It can ensure that organisations get a coherent message rather than being confused by messages arising from unco-ordinated pieces of work. Having a common task can promote mutual understanding between agencies and legitimacy for their work. It can foster dialogue between the different agencies and create a shared agenda about what needs to be done. This can create a more seamless service from a public and patient perspective which has benefits for all sides.

Through joint working, organisations will get a picture of the whole and be able to plug gaps and develop better and more imaginative use of resources. For example, a trust may want to get a more rounded picture of patient and carer needs in a particular clinical service. Feedback from patients in this area will often highlight discontinuities in the system of care, both within single health organisations and between different agencies.

Trafford South Primary Care Group

Type of engagement: whole systems approach

Context and objectives

Trafford South Primary Care Group, working in conjunction with the Kings Fund, used a 'whole systems approach' to review health and social care services for older people living in Trafford South. Public and private sector professionals, voluntary agencies, service users and carers attended two stakeholder events held in June and August 1999. The event was externally facilitated. Participants worked in small groups of 6-8 and sometimes in pairs.

Process

Seventy people, of who just under 40 were service users or carers, attended the first whole systems event. The event focussed on participant's views on existing services and ideas about future service provision. During the first day, participants were briefed about key trends (e.g. demography, developments in IT, factors influencing social exclusion). The outcomes were discussed at the Primary Care Group board workshop and developed them into a set of 15 priorities in four broad service areas.

Seventy-five people attended the follow-up event, where participants reviewed the outcomes of day one. Twenty of the attendees were older people and carers, fifteen represented voluntary agencies. Participants were each asked to choose their top three priorities from the fifteen developed by the PCG Board. The background to each of the priorities was explained and the extent to which a proposed intervention was known to be effective.

Funding

The overall budget for the project was £30,000, exclusive of the support of an experience project manager.

Outcomes

Feedback from participants at the end of the first event was used to implement changes to the second event, for example to improve the acoustics and to reduce the length of the day. The exercise generated a list of issues prioritised by participants. The PCG's commissioning intentions for the period 2000- 2003 reflect the issues prioritised by the whole systems event's participants.

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Joint working may also highlight the variety of information needs and provide an incentive to developing joint information. Information about treatments (usually obtained through health professionals within trusts) may need to be augmented by information about other services available outside the health service when people come home (e.g. welfare advice, employment services, access to home help).

Joint working to support public involvement

Joint working (and joint funding) can promote better ways of involving the public. It helps to avoid duplication of initiatives and public involvement ‘overload’ and confusion. Organisations can then speak with one voice and bring a more strategic approach to planning the initiative, making decisions and taking follow-on action. It also means that ‘intelligence’ garnered about the public’s needs and expectations of public services are shared more widely between different agencies and more full and effective use is made of it.

Making joint working effective

Inclusiveness and ‘buy-in’

Joint working needs to be inclusive from the start. All the relevant organisations should be identified and involved in an equitable manner. You need to be clear about what the joint working aims to do – is it about exchanging information, or really working together? What added value does it bring to those around the table?

To ensure effectiveness, there needs to be proper co-ordination. The real challenge is how to get all organisations on-board. This may mean certain organ-

isations taking a lead role in defined areas or appointing key people to act in a co-ordinating capacity. It also means setting clear boundaries for work as well as recognised linkages and protocols for sharing information.

Developing a shared agenda is hard but there are many techniques that are especially suitable for a joint working approach, such as those included under the heading ‘large-scale events’ and ‘panels’ in the chapter on techniques.

Assumptions, expectations, working methods, policy cycles, and power differences all differ widely between organisations and individuals, making the promotion of ownership particularly difficult. You need to be explicit about aims and objectives, co-ordinate the work properly, clarify roles and (individual and joint) responsibilities, reveal differences and find some way forward through consensus. Independent facilitation can sometimes help in this regard.

Implementation and effectiveness

There needs to be clear evidence of independence within the process and resources available to take action in order to build public trust so they can see that involvement matters and makes a difference. There needs to be a clear link between people within the relevant organisations and integration of accountability structures. But the way large organisations are currently set up make them unwieldy and sometimes unsuitable to joint working – they need to evolve quickly to meet changing needs (see also ‘structures and systems’). There are challenges in securing the buy-in of particular types of individuals, for example, councillors and GPs. Incentives and support for involvement need to be in place (see also ‘roles and responsibilities’).

Financial issues

Legislation allowing joint funding has recently been passed and may help matters in the future. At a local level, organisations are not used to working together and have not as yet developed flexible and coherent systems for pooling resources. Different funding streams mean that savings or costs in one area are not shared equitably within or between organisations. This can be a real disincentive to implementing changes that might follow an involvement initiative. However, there may be good models of working in particular fields in other areas (e.g. patient disability groups in England) that provide examples of combining resources, legislation and work on care pathways through public involvement. In some cases part of the solution may be to tie funding to support grassroots intervention.

A partnership approach

As with other partnership initiatives, organisations need to work collaboratively with other key stakeholders on their public and patient involvement strategies. As such they need to be driven by the same approaches, disciplines and protocols that guide other aspects of joint working. Of course this cannot happen overnight, but needs to be developed gradually and sustained by an ongoing commitment in terms of time, energy and commitment on all sides. Joint initiatives such as surveys, panels or events (see chapter 3.2) will need careful planning and preparation together with proper resourcing and support. Effective partnership and joint working has to be built on a mutual understanding of different needs and expectations, shared goals and objectives and respect for the limitations and constraints on all sides.

This all helps to set some boundaries for roles, responsibilities and accountabilities between the different parties. It

also requires clear structures and processes for joint working, backed up by a commitment to regular and full communication to sustain the working dialogue and maintain the relationship.

Good communication requires sharing information in a climate of mutual openness and taking a non-proprietary attitude towards information gathered from involvement work. This means ease of access to reports, databases, networks and contacts. Joint appointments of personnel with recognised expertise in public and patient involvement may provide a useful vehicle to promote closer working and a partnership approach. Such individuals could become a focal point for integrating and coordinating public involvement work, as well as acting as a common resource and a key intermediary between several organisations and the wider community.

Partnership approach

- Shared understanding
- Shared goals and objectives
- Shared information
- Shared resources
- Shared responsibilities and accountabilities

The role of local authorities (LAs)

Accountability

As they are democratic bodies and accountable to the wider electorate, local authorities have a special role in being able to bring democratic legitimacy to a public and patient involvement strategy. LAs are charged with a wider responsibility for the social, economic and environmental well-being of their

community. Their role in the scrutiny of health and health care is likely to grow significantly in the future and provide an additional avenue for public and patient involvement work.

Health and social services

LAs can bring the wider (public) health debate to the attention of health services, for example, by making sure that housing and environmental issues are part of the picture. They can co-ordinate services in particular areas and ensure that the work covers issues such as prevention, intermediate care, after care and home care. LAs are also in a good position to identify socially excluded groups and promote partnership working. They often have developed networks in communities and have in place recognised community development activities. One problem for local authorities could be that health issues are only a small part of their agenda.

Developing expertise

Many LAs have expertise in involvement techniques and could do more to extend the use of, for example, citizens juries. They could help other agencies by sharing their expertise in these areas and promote joint working through sharing and pooling information and networks, and developing joint databases.

Using existing networks

Many local authorities already have well developed networks of contacts in local communities and health professionals working in community development and support roles, as well as established relationships with the voluntary sector and community groups. These are valued resources for NHS organisations to make good use of. Public services can waste a lot of energy trying to create their own networks when perfectly good routes (and roots) into communities already exist. These are not just useful for building links and relationships, they

are also a valuable source of expertise and intelligence about local communities in their own right.

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Appendix 1

- Case studies
- Contents in detail

Case studies

North West Wales NHS Trust	22
Cambridge City Council	23
Dyfed Powys Health Authority: Assisted Conception Strategy	25
Powys Health Care NHS Trust	26
Bargoed Project	30
Blaenau Gwent Social Care Plan	31
North East Wales Acute Trust: Acute Services Evaluation	32
Anglesey Health Watch Groups	34
Ceredigion Accommodation Research Project	48
Iechyd Morgannwg Health Authority	50
Big Issue in the North Trust	53
Cardiff and Vale NHS Trust: Patients Panel	55
Pembrokeshire Local Health Group	57
North Glamorgan NHS Trust: The Gurnos Community Health and Resource Centre, Merthyr Tydfil	59
Llanasa Community Local Health Forum HIA Project	62
South Ayrshire Council	66
Carmarthen Youth Project ('Dr M-Z')	68
Bristol City Council, Education and Lifelong Learning Department	70
Diabetes UK Cymru: Local Diabetes Services Advisory Groups	71
Trafford South Primary Care Group	85

Contents in detail

Acknowledgements	iv
About this guide	v
1. Background	vi
1.1 Setting the scene	1
1.2 Key requirements of the National Assembly for Wales	2
1.3 Performance management	3
Setting performance expectations	3
Baseline assessments and strategies	5
Annual plans – key requirements	5
2 Building the foundations	7
2.1 A framework for public and patient involvement	8
Dimensions of public and patient involvement	8
Achieving the desired outcomes	10
Capacity building	11
1. Supporting the public and patients	11
2. Supporting organisations	13
3. Joint working	13
Diagnostic analysis	13
Data gathering	13
Analysis	14
Developing priority areas	14
2.2 Developing a strategy	15
Taking a strategic approach and developing strategy	15
Visioning	15
The strategy document	16
Test of a good strategy	16
Developing annual plans	16
3 Managing public and patient involvement successfully	21
3.1. Managing the work	22
Planning the process	22
Be clear about aims and objectives	22
Making a difference	24
1. Impact on service delivery	24
2. Impact on policy and strategy	26
3. Impact on relationships between stakeholders	27
Developing a shared agenda	27
Building trust – creating good relationships	27
Learning lessons	28
Understanding motivations	28
Capacity and opportunity	29
Choosing the right approach	29
Knowing what needs to be done	29
Knowing where to start	29
‘Horses for courses’	30
Involving the right people	33
Deciding who needs to be involved	33

Getting ‘good enough’ representation	33
Involving carers	33
Reaching out beyond the ‘usual suspects’	33
Including people from marginalised groups and promoting social inclusion	33
Finding people who can help	35
Linking with clinical governance	35
Monitoring and evaluation	37
Know why you are evaluating	37
Know when to monitor and when to evaluate	37
Be clear about what you are evaluating	37
Use the right tools	38
Evaluating the involvement process	38
Evaluating the outcomes of involvement	39
3.2 Techniques	41
Things to think about	41
Theoretical concerns	42
Quantitative versus qualitative	42
Large or small numbers	42
Complexity and controversy	42
Practical considerations	42
Money	42
Time	43
General texts	43
An overview of techniques	44
Quantitative techniques	44
Opinion surveys	45
Self-completion postal surveys	45
Face-to-face surveys	46
Telephone surveys	46
Qualitative techniques	47
Focus groups	48
Citizens’ panels	49
Deliberative techniques	51
Citizens’ juries	51
Deliberative polling	54
Health panels	54
Large-scale events	54
Whole system events, open-space events	54
Planning for real	56
Simulations	57
Community development	58
Health needs assessment	60
Forums	60
Ethnographic enquiry	60
Rapid appraisal	61
Health Impact Assessment	63
3.3. Capacity building: supporting the public and patients	65
Patients, carers and members of the public	67
Making people feel valued	67

Information and communication	67
Vulnerable and marginalised groups	67
Community representatives	69
Identification and recruitment	69
Functions of the lay representative	69
Non-statutory organisations	72
Responsibilities and accountability	72
References and contacts	72
Community Health Councils in Wales	75
3.4 Capacity building: supporting organisations	78
Systems and structures	78
Valuing the work	78
Culture change	78
Dispelling myths about involvement	79
Linking to decision making	79
Taking action	80
Mainstreaming the work	80
Roles and responsibilities	81
Understanding professional concerns	81
Weighing the evidence	81
Engaging health professionals	82
3.5 Capacity building: joint working	84
Benefits of joint working	84
Public involvement to support joint working	84
Joint working to support public involvement	86
Making joint working effective	86
Inclusiveness and ‘buy-in’	86
Implementation and effectiveness	86
Financial issues	87
A partnership approach	87
The role of local authorities (LAs)	87
Accountability	87
Health and social services	88
Developing expertise	88
Using existing networks	88
Appendix 1	89
Case studies	89
Contents in detail	91