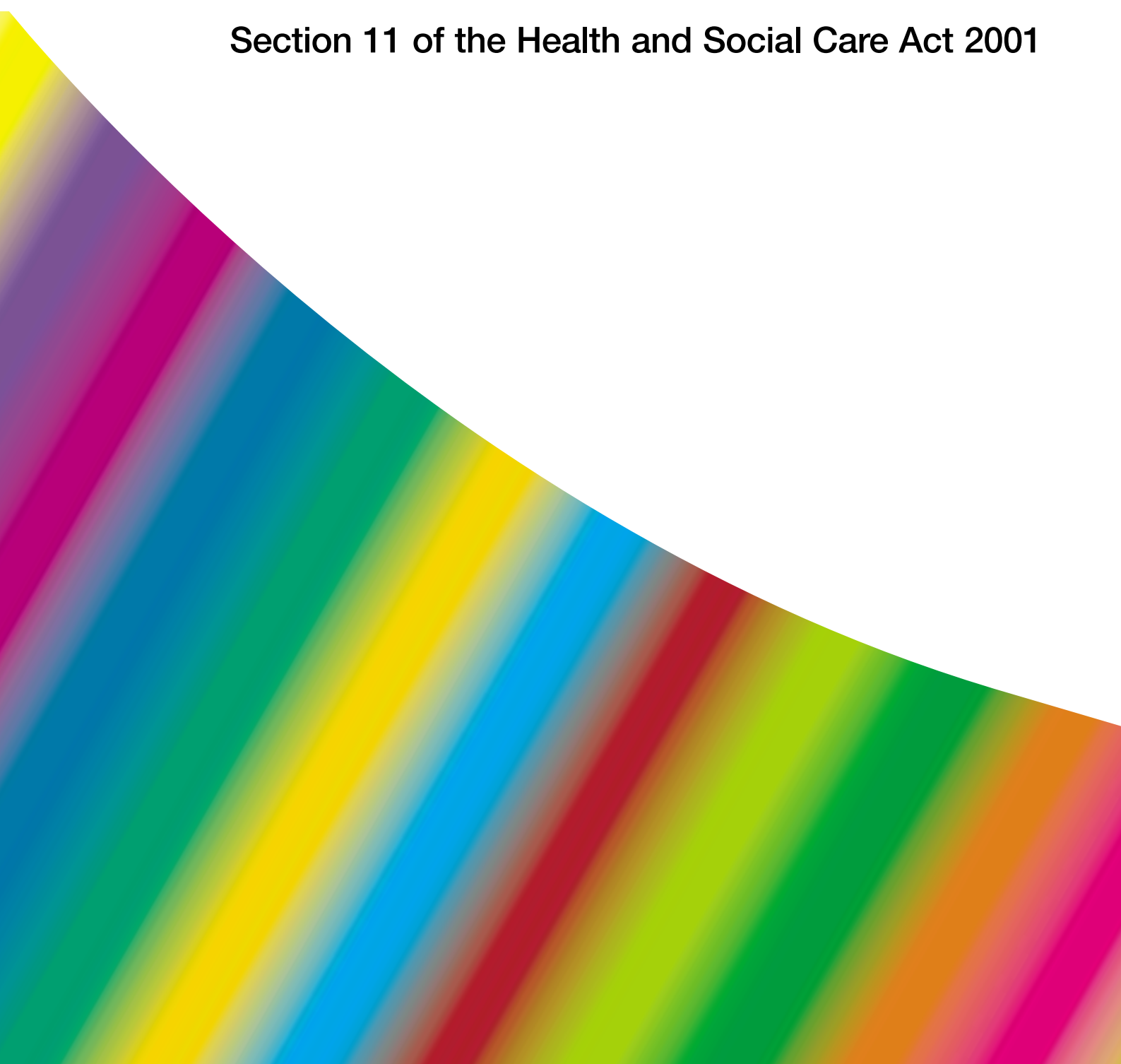


Strengthening Accountability

Involving Patients and the Public

Practice guidance

Section 11 of the Health and Social Care Act 2001



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Introduction to the practice guidance

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

It also addresses the **how** and the **how to** questions that are concerned with the implementation of Section 11 of the Health and Social Care Act, 2001.

The practice guidance will only be helpful to staff if they can address the context in which it is to be applied:

- how can you ensure that patient and public involvement becomes a priority within your organisation?
- how can your organisation overcome any resistance to change?
- how will relationships change?
- how will you support others to work in different ways?

These are questions about organisational and personal development; about changing ways of working.

When reading and exploring the practice guidance it is important to reflect on and address issues at board level and with local partners in the NHS, other public services, and the voluntary and community sector. Successful use of the practice guidance will depend on the complementary development of the context within which it will be applied. It is for all staff who are responsible for involving patients and public. It gives you:

- best practice baseline measures to use as a self assessment tool;
- a wide range of helpful information, suggestions and approaches; and
- help to understand what is meant by on-going patient and public involvement.

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The context

The major drivers behind Section 11 of the Health and Social Care Act (2001)

The core principles of the NHS and the NHS Plan

‘Patients are the most important people in the health service. It doesn’t always appear that way. Too many patients feel talked at, rather than listened to. This has to change.’¹

Four of the ten principles underpinning the NHS Plan directly support the patient and public involvement agenda and should be used as values to determine options for involvement. They are, that the NHS will:

- shape its services around the needs and preferences of individual patients, their families and their carers
- respond to different needs of different populations
- work together with others to ensure a seamless service for patients and
- respect the confidentiality of individual patients and provide open access to information about services, treatment and performance.

The Kennedy Report

The principles that are set out in the Kennedy Report on the Bristol Royal Infirmary Inquiry (2001) will lead to genuine patient and public involvement and greater transparency and openness in decision-making. They provide a template for the values and beliefs that should underpin the patient and public involvement work in PCTS and trusts.

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

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Different ways of working

Why involve and consult patients and the public

There are many reasons why it is important to involve and consult patients.

First and foremost – it is the law. The Health and Social Care Act places a legal duty on NHS organisations to involve and consult patients and the public in the planning of service provision, the development of proposals for change and decisions about how services operate.

However this is not just about fulfilling a duty or ticking boxes, it is about understanding and valuing the benefits and positive outcomes, both financial and non-financial, of involving patients and the public in the planning and development of health services

Section 11 and the wider patient and public involvement system, of which it is part, will help to make sure the principles set out in the Kennedy Report (page viii) are acted upon throughout the NHS, and that there is transparency and openness in procedures for involving and consulting patients and the public.

Beyond this there are other valid reasons to involve and consult.

- Seeking the views of others and having mutual regard for them is an important element of planning
- Services are designed and adapted to respond better to people's needs
- A consultation allows alternative proposals to be developed
- It demands that proper time and thought is given to patient's and the public's views on a proposal and ensures the development of an evidence base for important decisions
- The experience of patients', the public and local communities knowledge can be used to benefit others
- Better decisions are made because more people's views, perspectives and suggestions are heard

- Major decisions are more transparent and the process for reaching them is understood
- Trust is built between communities and the health service.

On-going involvement of patients and the public will also strengthen reporting mechanisms to the patients' forums (when established) and overview and scrutiny committees (OSCs). In addition it will develop the accountability of the trust or PCT board as it will be able to demonstrate how it has listened and responded to feedback from local people and show how patients and the public have influenced service improvement.

The best practice baseline measures (pages xi – xv) are a self-assessment tool that will help NHS organisations to improve the process for involving and consulting patients and the public. Patients' forums (when set up), OSCs and Independent Reconfiguration Panels (IRPs) will use them in their respective roles. Commission for Health Improvement (CHI), which routinely assesses patient and public involvement as part of its clinical governance review process, will take account of the trust's self-assessment as part of this.

Best practice baseline measures for involving and consulting patients and the public

Preliminary work – A

There is an understanding that good patient and public involvement is not about one-off events but an ongoing body of work embracing many approaches

- Evidence of:
 - partnership working with the local authority and voluntary sector through the Local Strategic Partnerships, local compacts and with other local NHS organisations
 - sharing of information about patients' and the public's experiences and views of health services across health economies

Preliminary work – B

A baseline has been established

- Evidence that:
 - a baseline assessment of work to involve patients and the public has been undertaken by the PCT/trust
 - the baseline assessment was a thorough and inclusive process that:
 - included a comprehensive assessment of past practice and future needs
 - relates to the local demography
 - involved input from key stakeholders including the local authority
 - took account of different needs and expectations
 - links to the involvement work of other agencies in the area
 - the PCT/trust has assessed its arrangements to involve patients and the public
 - patient and public involvement work and consultations are recorded on a system which provides information on who has been involved/consulted, the methods used and what has changed, e.g. an involvement and consultation diary/database
 - it informed the Local Delivery Plan

1

A strategy for involving and consulting patients and the public is in place

- Evidence that:
 - the systematic involvement and consultation of patients and the public is part of the PCT/trust's Local Delivery Plan
 - the strategy includes:
 - a) clear aims and objectives for on-going involvement and statutory consultation
 - b) planning arrangements for obtaining a consensus on whether a consultation is required
 - c) systems for evaluating the impact of on-going involvement and consultation on decision making processes
 - patient and public involvement is built into the PCT's/trust's strategic decision making processes e.g PPI is a regular item at board meetings
 - there are clear lines of accountability and responsibility for this area of work and a designated director to oversee the implementation of the strategy

2

There is a planning process for patient and public involvement that identifies work that could lead to changes in service

- Evidence that the planning process:
 - focuses on the 'big picture' and leads to an on-going body of work rather than a series of stand-alone events
 - is integral to the PCT/trust's Local Delivery Plan and other organisational strategies

Link OSC Regulations

3

A strategic/partnership approach to planning and implementing patient and public involvement and consultation

- Evidence that:
 - a representative cross section of people, community groups and key stakeholders have been involved from an early stage
 - that specific groups the NHS has traditionally found hard to reach have been involved and consulted
 - partnership working has avoided duplication and reduced involvement and consultation overload
 - patients' forums (when set up), the OSCs or other representative bodies as appropriate, have been involved

4

Staff appropriately trained, involved and consulted

- Evidence that staff:
 - working at all levels have been trained to involve patients and the public e.g. on-going staff training programmes on PPI
 - understand and value the benefits of involving and consulting patients and the public
 - have themselves been involved and consulted by their own organisations

5

There are corporate performance measures for involving and consulting patients and the public

- Patient and public involvement built into staff performance appraisal at all levels
- Processes in place to amend policy and recognise good practice

6

There is a whole system approach and the nature of involvement and consultation work is clearly defined and understood

- A clear statement of the organisation's commitment to putting patient and public involvement at the core of service planning and development
- Evidence that:
 - involvement and consultation take place throughout the process of planning, developing and changing services.
 - there is a clear understanding of the rationale, scope and scale of the work
- Evidence of links with the race equality schemes, PALS, patients' forums (when set up), OSCs and the LSPs as appropriate
- Cabinet Office Guidance has been taken into account

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7

A range of methods used

- Evidence that a range of methods, that are appropriate to the target audience, have been used to involve and consult patients and the public, particularly specific groups that the NHS has traditionally found hard to reach and main stakeholders

8

Relevant information made available to patients, the public and stakeholders

- Evidence:
 - of effective communication at all levels
 - that consideration has been given to people who have specific communication needs e.g people who do not speak English, people with learning or physical disabilities or sensory impairment.

9

Adequate time for the whole process

- Evidence that:
 - consideration has been given to: the time it will take to involve the identified audiences taking into account the cultural events calendar and holiday times
 - Cabinet Office Guidance has been taken into account

Practice guidance 6

10

Open, transparent public decision making

- Evidence:
 - of a clear process/mechanism for informing the PCT/trust's decision making processes identified in their strategic planning documents
 - that there was flexibility to negotiate i.e. a proposal is not a 'fait accompli'
 - that best use has been made of outcomes of involvement and consultation
 - that the PCT/trusts has listened and responded appropriately
 - that the results of involvement and consultation have been properly considered before making decisions

11

The PCT's/trust's communication strategy incorporates ways of communicating the implications and outcomes of its PPI work with a range of audiences

- Evidence of:
 - a communication strategy that includes a range of media to:
 - provide comprehensive feedback to patients, the public and stakeholders throughout the process
 - report on how the outcomes of involvement and consultation processes have impacted on decisions taken
 - the feedback mechanisms in action

12

The impact of each involvement and consultation process is evaluated

- Evidence of:
 - measures against which the success of a process has been determined
 - an iterative process
 - how the learning has been used to inform the organisations' planning processes

Baseline assessments – building on existing foundations

Baseline assessments – building on existing foundations

A baseline assessment is a review of current patient and public involvement work. It is an opportunity to find out what is going on in the PCT/trust at all levels of involvement, from giving information through to partnership working and for organisations to assess their own arrangements for meeting the requirements to progress the PPI agenda in a systematic and coherent fashion. It should include all of the work related to NSFs, Collaboratives, Modernisation Agency initiatives, the clinical governance agenda and other key work. and needs to be incorporated at the highest level into the PCT's/trust's strategic and clinical governance planning activities.

Before you launch into this you should consider if the organisation has recently undertaken a baseline assessment of patient and public involvement. For example, Phase I of the Local Modernisation Review required old health authorities to undertake a baseline assessment of patients' and the public's experience in the task force areas. Wherever possible PCTs and trusts should build on work that has already been done and link it with ongoing work such as the race equality schemes.

One way of undertaking the **baseline assessment** would be to set up a project team with a clearly identified project leader and key stakeholders to:

1. agree the parameters; objectives; key activities/headings; timetable and report back mechanisms
2. collate and review available documentation (reports, data, other written evidence)
3. identify current work in progress
4. obtain feedback on past practice from staff, patients and the public
5. analyse key strengths and weaknesses of past practice.
e.g. methodologies used, reporting formats, the outcomes achieved
6. use the results of the assessment to inform the first draft of the **strategy**.

Or you may wish to work in a less prescriptive way and run a workshop with key players that may deliver the same if not richer results.

The following example is a snapshot of the PPI work being undertaken in one hospital. It was undertaken by a newly appointed PPI lead to identify where and how patients were being involved, both at an individual and collective level, throughout the hospital. It identifies the wide range of involvement work being undertaken by staff across many departments and provides a comprehensive foundation for a baseline assessment.

This is a snapshot of the PPI work undertaken in one trust at a point in time and provides a comprehensive foundation for a baseline assessment.

Nottingham City Hospital – Patient Involvement by Directorate/Dept

Directorate/Dept.	Detail	Example of action
Oncology & Radiotherapy	Patient views of hospital transport 50 patients interviewed by radiographers regarding complaints about the transport system. Results showed that patients needed more information about transport and public access to the hospital.	<ul style="list-style-type: none"> ● Developed patients information leaflet with details of public and hospital transport etc. ● Audit planned for 2001 to identify if complaints have been reduced
Oncology Outpatients	Patient held communication booklet. A joint project with the CHC, district nurses & Oncology OPD. The booklet was developed to aid continuity of communication regarding treatment between professionals within and external to the hospital. The booklet contains a section for patients to record their own information (how they felt etc)	<ul style="list-style-type: none"> ● Well received by patients. ● Patient views to be formally audited Dec 2000
Oncology	Early complications of treatment for CA cervix patients. Research states that there is a 10% toxicity with this treatment combination. Patient given a diary to record daily effects of treatment. The patient experience will be used to evaluate effects.	<ul style="list-style-type: none"> ● The project is still in the data collection phase

Directorate/Dept.	Detail	Example of action
Palliative Care – Hayward House	Patient information audited to check if timely and accurate.	<ul style="list-style-type: none"> ● Review enabled appropriate changes
Palliative Care – Hayward House	Breathlessness audit. Patient questionnaire to identify if patients with CA lung had physical and emotional problems with breathlessness and if patients would prefer to be seen in a dedicated clinic.	<ul style="list-style-type: none"> ● The need for a dedicated clinic was identified, however the amount of patients is quite low to be cost effective. The lung specialist team will now explore delivering the service in a community setting.
Cancer Services	The patient experience. Joint project NCH & QMC. A ongoing qualitative initiative to look at information and communication for patients with lung cancer to meet NHA cancer standards	<ul style="list-style-type: none"> ● Piloted a questionnaire with patients to identify if standards being met ● Patients identified a satisfaction with the service and needs for information ● Results fed back to NHA and Network Audit group.
Mobility Centre	Electrically powered indoor wheelchairs (EPIC) . An evaluation to assess if chairs had improved quality of life	<ul style="list-style-type: none"> ● 83% of patients confirmed improvement. Where patients were not satisfied further work which identified environmental problems. Changes to allocation process were made to ensure equipment matched patient and environmental requirements.
Mobility Centre	Electrically powered <i>outdoor/indoor</i> (EPIOC) wheelchairs. An evaluation to assess if chairs had improved quality of life	<ul style="list-style-type: none"> ● 93% rated chair highly and 7% were satisfied ● Info sheet developed to meet concerns raised by patients about delivery of chair

Directorate/Dept.	Detail	Example of action
Occupational Therapy	Audit via questionnaire of wheelchair voucher scheme to evaluate how well the system was received	<ul style="list-style-type: none"> 100% of patients said that they would use the system again Identified that there was a lack of information about the scheme. Recommendations are being put in place to address this.
Occupational Therapy	Carers views of the service. Standards developed in conjunction with the National Strategy for Carers and the National Fed. Of Carers. Carers were interviewed and an analysis of case notes undertaken to identify whether standards met (if carers had been involved in the treatment process).	<ul style="list-style-type: none"> Carers felt included in treatment, however there were inconsistencies within the case notes – all OTs now document relevant information.
Physiotherapy	Lower back pain audit and back fitness programme. Direct observation of patients and questionnaires to identify whether the programmes improved their mobility and quality of life.	<ul style="list-style-type: none"> Both audits showed that the service was of benefit to the patients. The service has now become a permanent feature at NCH
Joint Gastro-Intestinal Directorate	1 year project funded by NHA to develop an across town colorectal care pathway. Patient input gained via interviews (home and telephone) and focus groups.	<ul style="list-style-type: none"> Patients views used to change the way care is planned and delivered Patient views and quotes used in staff training and awareness sessions
Genetics	Service evaluation – measures against NHA service spec – annual patient survey since 1997	<ul style="list-style-type: none"> Action plan to reduce delays in processing referrals Staff made aware of need to avoid late starts and over-running sessions

Directorate/Dept.	Detail	Example of action
Genetics	Cancer family history audit. Patient involvement in development of new bowel cancer assessment form sent to patient prior to clinic appointment	<ul style="list-style-type: none"> ● New form developed – good feedback from patients (therefore more patients fill in the form which saves time in clinic)
GU Medicine	Service evaluation to obtain views of sex industry workers to ascertain if they would use a satellite GU service in their area.	<ul style="list-style-type: none"> ● Data collection in progress
GU Medicine	Audit of privacy and dignity within the GU unit via patient questionnaires	<ul style="list-style-type: none"> ● Replacement of curtains with doors in exam rooms. Project ongoing to re-audit now doors fitted
Neonatology	Audit of named nurse policy – patients are being asked about their named nurse and perceptions of how the policy works	<ul style="list-style-type: none"> ● Data collection in progress
Paediatrics Children's diabetic service	Audit of children and their parents views of the service. The audit was suggested by parent of a child attending clinic	<ul style="list-style-type: none"> ● Improved facilities in waiting rooms (eg magazines provided) ● 2 additional PCs allowing children access to health information ● Reminder letters sent to all patients who miss appointments ● Looking at feasibility of making available a drinks machine containing diabetic drinks and volunteer trolley selling specialist items (sweets etc)
Paediatrics	Lambley ward information review consultation with patients	<ul style="list-style-type: none"> ● Leaflets updated

Directorate/Dept.	Detail	Example of action
Paediatrics	Patient satisfaction survey in cleft clinic to explore changing of consultations so that patients have time for consultation with all professionals.	<ul style="list-style-type: none"> ● Dependant on changes now that clinic is a regional centre
Gynaecology	Audit of service user views on waiting times and information provision Chandos erectile dysfunction clinic.	<ul style="list-style-type: none"> ● Patients satisfied with the service – no further action taken.
Gynaecology	Views of patients on patient information received (Gynaecology/Oncology patients)	<ul style="list-style-type: none"> ● New information booklet introduced ● Information booklet to be audited with patients in future.
Gynaecology	Audit of patients views on nurse led clinics for sterilisation and Mirena IUD	<ul style="list-style-type: none"> ● Data collection in progress
Gynaecology	Patient focus group to ascertain views of patients on early pregnancy assessment unit nurse led clinic	<ul style="list-style-type: none"> ● Focus groups planned for November 2000
Maternity	Audit of ward standards. This is a re-audit on aspects of antenatal intrapartum and post natal care	<ul style="list-style-type: none"> ● To provide continuity, staff involved in delivery give wherever possible opportunity to discuss labour and delivery with mother. ● Head of midwifery to make improvements in system re getting results of antenatal screening to mothers with adequate explanations ● Further training for staff in new advances in antenatal screening tests

Directorate/Dept.	Detail	Example of action
Maternity	Wound infection audit. Telephone interviews contacting patients at home 14 days post-op to ask about the wound and for comments about the service	<ul style="list-style-type: none"> ● Ongoing in process
Maternity	Interviews about perceptions and experiences – de-briefing of women following complications during child birth.	<ul style="list-style-type: none"> ● To be re-audited during 2000 ● Development of guidelines for Nottingham following joint NCH/QMC working party
Medicine	Patient survey – Fleming ward. Nurses introduced bedside hand over for routine information – patients asked their opinion	<ul style="list-style-type: none"> ● Patients happy with procedure – felt included and informed ● Additional information gained during survey which enabled further changes in practice
Medicine	Discharge audit and practice to be presented to and discussed with the CHC	<ul style="list-style-type: none"> ● In process – may result in a patient representative on the directorate discharge audit team
Radiology	Directorate wide patient survey of the service involving the CHC, covering privacy and dignity, the service generally and including any other issues important to patients.	<ul style="list-style-type: none"> ● Patients indicated a general satisfaction ● Changes made to working practices ● Findings have initiated further detailed audit on some issues raised
Radiology	DNA rates in ultrasound. Patient survey followed by telephone interviews to non responders. Undertaken as DNA rates were high and waiting lists long.	<ul style="list-style-type: none"> ● Findings indicated that main factors were within hospital's control (eg emergency US overtaking routine appointments and failure of appointment letters to arrive in time if at all)

Directorate/Dept.	Detail	Example of action
Gastro-Enterology	Information review with patients	<ul style="list-style-type: none"> ● New information leaflet produced by patients (members of the National Association for Colitis and Crohns disease)
Gastro-Enterology	<p>Audit of patient perceptions of:</p> <p>a) a new set of IBD leaflets</p> <p>b) the, then new role of the specialist nurse</p>	<ul style="list-style-type: none"> ● Information found informative and easily understood ● Comments about the new role – favourable
Renal	Patients involved in developing patient held record	<ul style="list-style-type: none"> ● Patient held record introduced
Dialysis Unit	Questionnaire survey of diet needs of dialysis patients	<ul style="list-style-type: none"> ● Information service and advice given
Cardiac – Rehab	Focus groups and questionnaires to ascertain patients views of the cardiac rehab programme	<ul style="list-style-type: none"> ● Findings of both focus groups and questionnaires gave support to the programme
Outpatients	Edward Unit. Audit of patient satisfaction with the service including, environment, information provision (verbal and written)	<ul style="list-style-type: none"> ● Results fed back to staff – changes- particular attention then given to importance of verbal information to back up the written material
Outpatients	Main outpatients. Review of appointment letters with patients regarding content and layout.	<ul style="list-style-type: none"> ● Comments used to change content and layout of letters
Outpatients	Main outpatients. Patient questionnaire to ascertain views about verbal information given to patients by staff and around privacy and dignity when the information was given	<ul style="list-style-type: none"> ● Staff trained on importance of giving full explanations and importance of privacy and dignity when giving information

Directorate/Dept.	Detail	Example of action
Surgery	Audit of wound infections for colorectal and hernia surgery and general satisfaction survey of the service as a whole. Telephone interviews to patients 2 weeks after surgery.	<ul style="list-style-type: none"> ● Patient comments have been used to change information leaflets. ● Ongoing for past 3 years – rates meet national standards
Anaesthetics	Patient satisfaction survey to obtain patients views on administration, environment, consultation and treatment	<ul style="list-style-type: none"> ● Ongoing
Thoracic Surgery	Patients instigated the setting up of a self help group for patients having oesophageal surgery, ward nurse facilitated.	<ul style="list-style-type: none"> ● Self help group set up and running by patients with input from ward staff
Thoracic Surgery	Post-op patient audit on their perception of pain control where epidurals used as route to administer analgesia – where was the problem with pain and if addressed quickly	<ul style="list-style-type: none"> ● Majority of patients happy with pain control ● To be re-audited 2000
Thoracic Surgery	Patient complaints reviewed regularly by ward manager	<ul style="list-style-type: none"> ● Changes made for example – patients complained that toilet doors on ward were too heavy, adjustments were made by estates dept
Thoracic Surgery	Information provision to patients	<ul style="list-style-type: none"> ● Discharge talks are being introduced for patients, relatives and carers to answer all questions and allow feedback about the service

Directorate/Dept.	Detail	Example of action
Pharmacy	Planned audit of patient views of information leaflets within drug packs dispensed	<ul style="list-style-type: none"> Planned for 2000
Plastic Surgery	Patients involved in production of leaflets on all plastic surgery procedures to be given out pre-op clinics etc	<ul style="list-style-type: none"> Patients involved in producing leaflets
Burns Unit	<ul style="list-style-type: none"> Patients involved in the setting up of a monthly toddler and parent group on the burns unit, nurse led and providing opportunity for exchange of experiences with professionals and other parents Self help group (BUSH) meets regularly on the unit 	<ul style="list-style-type: none"> Patient groups
Paediatric Surgery	Involving patients in provision of relevant patient information regarding babies with cleft palate	<ul style="list-style-type: none"> Breast feeding video for mothers of babies with cleft palate produced by NCH and parents of affected children. Book for use in counselling parents containing before and after pictures of babies who have had repair surgery developed with parents
Nottingham Back Team	Consultation with patients re new service development and to develop patient information	<ul style="list-style-type: none"> Ongoing – awaiting info

Directorate/Dept.	Detail	Example of action
Nursing and Corporate Affairs Pan-Hospital Project	Joint clinical governance project with CHC. Focus groups and interviews (home, NCH and via telephone) to establish what clinical governance means from the patients perspective. This very extensive project obtained a wealth of information about all aspects of the services.	<ul style="list-style-type: none"> ● Report issued to all participants including various 'patient representative' bodies ● Report shared widely with both local and national health bodies ● Development of an action plan to address findings in process over next 2 months ● Catering services have a already provided improved advertising for the various catering outlets on site (clear signs of what is available and where). ● Operational services have invited all patient/carer participants in the project to evaluate the draft Estates consultation document to make improvements to the campus. To date six patients have expressed a desire to be involved in a proposed workshop at the end of October 2000. ● The QMC is carrying out an identical project adopting the methodology developed at NCH Joint NCH/CHC project contd
Nursing and Corporate Affairs Pan-Hospital	Disability Discrimination Act Focus groups, interviews with patients from all disability groups to inform all work required to meet all access requirements of the DDA and best practice generally. All relevant self help and specialist also involved.	<ul style="list-style-type: none"> ● Specific project on wayfinding and signage has led to changes (induction loops, textphones, road naming, accessible toilets) ● Work is informing various pan hospital projects

Directorate/Dept.	Detail	Example of action
Nursing and Corporate Affairs Pan-Hospital	Forming robust links with patient representative groups. Self Help Nottingham and NCH working in partnership.	<ul style="list-style-type: none"> ● Ongoing – Objectives developed to ensure closer working in all aspects and to support patient partnership strategy work
Nursing and Corporate Affairs Pan-Hospital	User involvement in staff training	<ul style="list-style-type: none"> ● Notts Deaf Society delivering training to staff in areas highlighted as a problem by the Deaf Society – training delivered by profoundly deaf trainer
Operational Services Pan-Hospital	Involvement of local ethnic/cultural groups in provision of meals to meet religious/cultural needs	<ul style="list-style-type: none"> ● Meetings with Hindu Council and the African Caribbean Asian Forum ● Menus and advertising designed ● Appropriate and acceptable catering suppliers identified and contracted

The patient and public involvement strategy

The patient and public involvement strategy

Developing a strategy for patient and public involvement

All strategies, regardless of their subject, should provide a clear ‘vision’ – an aspirational statement, or picture – of what they aim to achieve in terms of outcomes and processes. A patient and public involvement strategy will help to determine what needs to be done to realise the vision outlined in Chapter 10 of the NHS Plan. NHS trusts and PCTs need to put this into their own context and link it with their own, their partners’ and the wider aims and goals. There should be a **shared vision** for patient and public involvement and internal and external stakeholders should contribute, support and endorse it.

Practice guidance 4

The strategy

The strategy should provide the long-term (3 year) development plan for the PCT or trust in respect of its patient and public involvement work and draw upon and incorporate the work carried out as part of the baseline assessment. It should set out the future direction for the development of the PCT’s/trust’s intended work in terms of:

- **Vision and set of core principles** that outline the organisation’s aspirations for patient and public involvement. This might be a template for good practice, the values and beliefs that underpin this work and how it relates to the vision and mission of the organisation. It could include a set of standards and expected commitments for the work.
- **Assessment of current performance**, identification of the main strengths and weaknesses of current practice and main development objectives for the future. This section will be informed by the findings from the baseline assessment.

Practice guidance 1

- **Key priorities for development.** Decisions about priorities should incorporate resource factors and potential benefits, but take account of the wider organisational and social care context within the local health economy. Decisions made about priorities should be linked to the reports from, and discussions with, the local patients' forums (when set up), PALS and OSCs and take account of the needs and interests of external stakeholders.
- **Objectives.** The areas of activity to be developed, how it links into the PCT's/trust's Local Delivery Plan and the mechanisms and processes for influencing decision making at a strategic and operational level.
- **Resources and support.** How the organisation will provide support for the implementation of the strategy.

You should focus on the following **framework** when developing your PPI strategy and undertaking the planning process.

Practice guidance 3

The context: In any health economy patient and public involvement should be integral to the values and activity of the organisation concerned.

The overarching standard: In any given context, patient and public involvement is defined, specified and understood by all those involved.

Timescales

Effective patient and public involvement is about involving people from the beginning of a process so their contribution can have a real influence on service planning and development. It can be a lengthy process, which means that forward planning is crucial to allow sufficient time for people to participate in a meaningful way, and for the NHS organisation to provide feedback on the decisions it has taken.

Work with marginalised, discriminated and excluded communities may require a longer and more sustained timetable in order to create trust and break down barriers – sustainable investment in capacity building is important.

Practice guidance 9

Choosing a method

Careful consideration needs to be given to the choice of methods used to involve patients and the public. These need to include methods to capture the widest views and those groups of patients or local communities that are likely to be affected by the proposed changes. Thought needs to be given to how the views of marginalised and less vocal groups will be reached. Good practice entails employing a variety of methods, carefully selected for their appropriateness and sensitivity to different communities.

Practice guidance 10

Building the capacity of people to be equal partners

Patient and public involvement is about building relationships with people. This takes time, effort and commitment, as does sustaining them.

Successful involvement entails a power shift where people are engaged as equal partners alongside health care managers and clinicians. On the one hand, this means building people's capacity to participate in a meaningful way, and on the other, for health care professionals to demonstrate that they can listen and respond.

The PCT patients' forum (when set up) will be a local resource to help build capacity for engagement and involvement within communities and will help existing networks and community groups to maximise their effectiveness.

Partners

To develop patient centred services PCTs and trusts need to create an involvement culture. This will only happen when engagement with patients and the public is an inter-linked on-going body of work rather than a series of one-off events and where patients and the public are considered to be equal partners around the table.

Provision of information

To 'provide open access to information about services, treatment and performance' is one of the core principles of the NHS. The provision of accurate, accessible and relevant information should lead to:

- clarity and understanding about an individual's rights and responsibilities
- transparency of service provision
- better understanding and confidence in the NHS.

Training

Training should be offered to patients and the public who wish to get involved in the new PPI systems. One of the functions of the Commission for Patient and Public Involvement in Health will be to develop and license training and induction material for patients and the public who wish to become involved.

Practice guidance 12

Public accountability

It is important the NHS demonstrates its accountability to patients and the public. One way it can do this is by ensuring that there is openness in all activities where confidentiality is not required.

There must be a clear feedback loop for all patient and public involvement work. You should explain to people the decisions that have been taken and how they have been arrived at.

In summary the **strategy** should:

- provide a sense of purpose and direction (vision statement)
- identify clear lines of accountability and responsibility for the work
- link the work to the organisation's wider aims and goals
- be integrated with the Local Delivery Plan
- 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 effectively
- identify clear objectives, measurable targets and realistic actions to pursue
- confirm that due regard has been given to the involvement of a wide-ranging audience in the development of the strategy.

Example – East Devon PCT actively engaged local people in preparing the Trust's future plans for patient and public involvement. A conference attended by people from a range of organisations, support groups and user and carer groups was an important step in the process of involving local people in setting the direction for patient and public involvement in East Devon. The information gathered at the conference will inform an updated Patient and Public Involvement Strategy.

The planning process

The planning process

The planning process for patient and public involvement should identify the priorities for the work. These should be arrived at from reports from PALS, the patient surveys, complaints, the patients' forums (when set up) and the OSCs and build on other involvement work undertaken by the PCT/trust. The process should run alongside your existing planning and updating mechanisms, in particular for your Local Delivery Plan.

The planning process should focus on the 'big picture' and lead to an on-going body of work which embraces and links together many types of activity rather than be a series of stand-alone events.

You may wish to involve and consult the patients' forums (when set up) and the local OSC in your priorities for involving and consulting patients and the public. The planning process should be an iterative process, building on and developing the work programme.

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 time scale
- *who* will be responsible for undertaking and managing its execution.

The **planning** process should:

- translate broad aims and plans in the strategy into specific activities and a work programme
- target service areas and stakeholder groups
- seek input from a broad range of interests including staff, patients, and the public, particularly groups the NHS has traditionally found hard to reach

Practice guidance 9

- consider communication needs
- have a strong focus on joint working, cross agency collaboration and staff involvement
- clarify:
 - how and where the results of patient and public involvement work will affect decisions and impact on services, in particular the intended outcomes that will lead to improved services/patient experience
 - resource input (investment in activity, staff input, who does what, lead responsibility)
 - arrangements for providing feedback
 - links with other relevant involvement work by other agencies and where and how collaboration will be pursued and information shared, including work undertaken by the Coronary Heart Disease Collaborative, Cancer Networks etc.
- identify training and development activities to support the work (with staff and patients and the public)

A suggested approach to the planning process

The process suggested below incorporates the narrative content and substance of what may go into your work programme.

If you wish to use a written format, Figure 2 on page 23 may be helpful. Planned activities could be listed under each of the main strategy objectives for patient and public involvement and against the outputs from the PALS, patient's forums (when set up) etc. This would be useful for internal monitoring and evaluation purposes as well as enabling efficient reporting on the work.

At the start

1. Purpose and vision
 - clarity of where and how patient and public involvement fits into corporate priorities.
 - vision of patient and public involvement for the organisation (include the PALS)

2. Baseline assessment
 - clarify process and those involved
 - key findings from assessment of work done in the past – main strengths and weaknesses identified
 - main conclusions
3. Future development priorities
 - strategic objectives for the next three years
 - how these are linked with, and take account of, reports from PALS, the inpatient survey, complaints, patients' forums (when set up) and the OSC
 - capacity building (internally and externally) and long-term resourcing and support
4. The next year's priorities and plans
 - key activities and initiatives planned
 - capacity building (internally and externally) and resourcing and support
5. Impact of the work
 - main achievements so far
 - expected impact in coming year
 - process for monitoring and evaluating the work

Subsequent years' planning

1. Strategy outline and priorities
 - review of key long-term priorities
 - how strategy guided last year's work
 - any refinement of development priorities in the light of new circumstances
2. Impact and evaluation of past work
 - assessment of work completed
 - impact and outcomes of the work

3. The next year's priorities and plans
 - activities and initiatives planned
 - capacity building (internally and externally), resourcing and support
4. Impact and evaluation of the work
 - expected impact and outcomes
 - process for monitoring and evaluating the work.

Example – Southend PCT, Castle Point PCT and Southend District CHC worked together to promote active participation in the development of the local action plan. Following a conference attended by more than 700 local people, 100 people expressed an interest in becoming more involved. The project is promoting 'expert patients' and public and patient involvement in healthcare. It is empowering citizens through training and practical exercises.

Figure 2 Suggested written format for planning patient and public involvement work

Organisation Key strategy objective:						
Action planned (including how it builds on past work)	How it relates to outputs from PALS, inpatient surveys, complaints, patients' forums (when set up), OSCs and other PPI work	Timescale	Target groups/ areas	Resources	To be actioned by	Expected outcomes (what and for whom?)

Working in partnership

Working in partnership

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

- maximise the potential gains of undertaking involvement in a more coherent, co-ordinated and integrated way
- minimise the prospect of ignorance, misunderstanding and confusion on all sides which may waste resources as well as missed opportunities.

A partnership approach

As with other partnership work, organisations need to work collaboratively with key stakeholders to develop their patient and public involvement strategies. You need to be driven by the same approaches, disciplines and protocols that guide other aspects of joint working. Some NHS organisations already have effective structures and processes to build on and for others this is an opportunity to implement good practice. This cannot happen overnight, and needs to be developed gradually and sustained by an ongoing commitment in terms of time, energy and commitment on all sides.

Good communication requires sharing information in a climate of 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 staff with recognised expertise in patient and public involvement may provide a useful way to promote close working and a partnership approach.

Partnership approach

Shared:

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

Benefits of joint working

Organisations in health and social care need to be aware of what each other are doing in the area of patient and public involvement and how their individual activities connect and inter-relate.

Patients and the public are not usually aware of the boundaries and distinctions between different agencies – they are interested in the delivery of ‘seamless’ quality care.

Delivering quality services requires a joint agency approach both towards delivering patient-centred services and involving patients and the public in planning. Patient and public involvement can be the glue that binds organisations and agencies together. Having a common task can promote:

- mutual understanding between agencies
- legitimacy for the work
- dialogue between different agencies
- shared agendas.

Through working in partnership organisations will:

- get a picture of the whole
- be able to identify and work to fill the gaps
- make more imaginative use of resources.

One of the reasons some people – staff and patients and the public, may feel disillusioned about partnership working is that they feel they put a lot in to make progress on other people’s agenda but get little back. It is important to consider:

- if everyone involved is getting what they want from the process
- if there is an agreed programme for dealing with a range of issues so that people know that their issue will be raised
- having an agreed protocol for dealing with an issue that is not on the agenda but is important to one partner.

The local compact

The local compact is a valuable tool for both the voluntary and community sectors and NHS organisations to work with to involve local people in improving the delivery of NHS services at a local level. They provide opportunities for negotiating new ways of working to monitor, review and implement service changes.

Experience shows that the process of producing a local compact is as important and influential as the final document itself. It involves local councillors and officials, NHS staff and local voluntary and community organisations working together to clarify roles and functions as well as expectations and ways of working. Through this:

- understanding and trust can develop
- there should be a recognition of shared objectives, areas of difference and complementary roles.

Community and voluntary groups play an important role in health – they support service users, act as advocates and lobbyists, provide a range of health and support services and are a conduit for information, particularly on health promotion. Local community groups with an interest or role in health and/or social care are a vital source of expertise in their specialist areas e.g. sickle cell, Parkinson’s, care for the elderly, HIV/AIDS, improving physical access, mental health and testicular cancer.

Local Strategic Partnership (LSP) are being established across England as the basis of partnership working in each local authority area, bringing together the public sector with the voluntary, community and private sectors. LSPs are intended to provide a forum for strategic planning and decision making, and an umbrella under which local partnerships can operate. Engaging with local communities is one of the key aims for LSPs.

LSPs or partnership arrangements that will develop into LSPs, have been established in almost all local authority areas and health is represented, mainly through PCTs, on each LSP.

LSPs are the key element in developing integrated approaches to local service delivery, and to tackling policy priorities in a joined-up way. They bring together service providers, communities, the voluntary sector and business to identify local priorities and to devise and implement strategies to meet them. LSPs have a role to:

- develop community and neighbourhood renewal strategies
- rationalise strategic partnership working
- co-ordinate local plans, partnerships and initiatives and
- develop local Public Service Agreements.

PCTs are expected to engage fully with LSPs.

What should NHS organisations do if they have not already signed up to their local compact?

- Contact your local authority to see if a local compact has been established. If there is one your organisation should become a partner and sign up to it
- If a local compact has not yet been established, make sure that your organisation is one of the statutory partners working with local community and voluntary organisations to develop one.
- Initiate periodic joint reviews to measure the current and potential health role and the contribution of local community groups
- Consider budgets and programmes that can fund and or support community involvement to help achieve your organisational goals.

- Consider identifying specific posts within the NHS organisation to monitor, facilitate and support community involvement and volunteering within and across it, for example community development, public involvement and volunteer service manager posts.

Local compacts around the country will take different forms depending on which organisations takes the lead in establishing them. They will normally be configured around local government boundaries. NHS organisations without obvious local compacts to join should be flexible in their thinking. For instance rather than signing up to a number of local authority compacts, a group of strategic health authorities might look at jointly signing a local government regional compact.

Practice guidance 14

Managing patient and public involvement and consultation

Managing patient and public involvement and consultation

Questions to ask before you start

Patient and public involvement requires careful planning. It should not be an afterthought or an add-on. PCTs and trusts need to consider how it fits in with the national and local priorities and be clear about what they want to achieve.

The following is a checklist of questions for you to consider at the planning stage. If the answers to any of the questions are not clear, then it may be appropriate to hold off the involvement work until there is clarity, or advice has been sought. By ensuring that work is really focused there is a greater chance of it achieving its purpose i.e. engaging with appropriate people and communities in the right way, with clear routes into the decision making process.

What does the PCT/trust want to know from patients and the public?

Be clear about the area or subject that you are inviting patients and/or the public to be involved in. For example, the views of patients about primary care services are very wide, but the information needs of women with breast cancer are narrower and more manageable. Is the work aimed to give and/or receive information or do you intend to get people more involved?

Why does the PCT/trust want to know this information?

What is the point of doing the public involvement work? For example, is the focus to feed into a community regeneration project or commissioning decision? Is a service review being conducted? Is this an information giving exercise only or is the intention to enable patients to have a greater say in decisions and work as partners with health professionals?

What does the PCT/trust want to influence and how?

It is important to be focused from the very start. This may mean being persistent with those who will be using the findings of the involvement work to inform their decisions. You must be clear about how exactly you intend to use the results and when you will use them. This is important when planning the work and is vital if you are to be accountable to the people you are involving. Patients and the public should be made aware of:

- why they are being involved
- in what capacity they are being involved
- how they will be given information
- when and how they can expect to get feedback on how their views were used; and
- the decisions made and the rationale for them.

What is the PCT/trust going to do with the findings it has obtained?

Think about how the information obtained is going to be used. Patient and public involvement will fail if there is nowhere for the findings to 'go', as changes will never happen. Is the timing right to feed outcomes into commissioning or joint planning processes?

NHS organisations have a set agenda – what will happen to the issues and concerns raised by the public?

The results of involvement and consultation must be properly considered before any decisions are made.

What scope is there to make changes or influence decisions?

Be very clear about what is feasible. If there are constraints say so at the beginning. Are people being asked to be involved in joint decision making or is this information gathering where people are asked for their views alone?

Point to note: under the NHS Code of Openness¹ (This will be superseded by the requirements of the Freedom of Information Act. The Act will be partially

¹ NHS Code of Openness, DoH 1995

effective for the NHS from October 2003 and fully effective from January 2005.) PCTs/trusts must provide accurate information to patients and the public about the services they provide and their decision-making processes.

Link www.foi.nhs.uk

Most public involvement work is long term. Be careful not to raise people's expectations if you are unable to deliver in a short time. Be honest and realistic. Remember that involvement is ongoing and that you may need to consult again if plans change.

Why work with other organisations?

There are a number of reasons why it is beneficial to work with other statutory and voluntary sector organisations within the local health economy:

Practice guidance 4

- Overview and scrutiny committees have the power to review and scrutinise all the health services provided in its area – services must be planned across a local health economy

Practice guidance 12

- Working across a local health economy, for example on Priorities and Planning Framework targets develops a consistent approach
- Patients and the public do not recognise organisational boundaries and will give views to organisations/groups they know
- Patient and public involvement work is resource intensive, resources can be shared, and knowledge and experience pooled if more than one organisation is involved
- Working with other organisations facilitates learning and shared best practice
- Some groups in the community may have 'involvement fatigue' because their involvement is sought by a number of different organisations on a range of issues. There may be opportunities to involve some groups through the Local Strategic Partnership (LSP) and the local compact.

Practice guidance 4, 9

- Working through the local compact arrangements with the voluntary sector, you may be able to access certain groups within the community they have traditionally found difficult to reach.

Practice guidance 4, 9

Who else should be involved and what methods to use?

Practice guidance 7, 8, 9, 10

Who else should be involved depends on what you are asking people to be involved in and why.

You must involve:

- those people who use the service and those who potentially may at some point use the service, as well as those waiting
- people who do not access the service despite a need e.g. young people and sexual health services, adults and alcohol services and those people for whom a service may be specifically targeted e.g. health promotion and smokers.

You might also involve any of the following people or groups as appropriate:

- local people
- pressure groups
- gender/disability/ethnicity specific groups e.g. pensioner's forums
- community groups and community activists
- friends and families of patients
- harder to reach groups
- people who have identified issues e.g. complainants, PALS clients
- staff

What methods to use depends on what level of involvement is required – this is explained in practice guidance 10

Practice guidance 10

Will the patients who get involved need to be supported?

- Will the questions asked or the discussions you have had be likely to evoke strong emotions in the patient, for example by asking them to relive their treatment experience?
- What support might patients need if this happens?
- How might this be provided both at the end and afterwards?
- How will patients anonymity be protected (unless waived)?

Once all this has been thought through, it is important to give patients/carers all the information they need to help them decide whether or not they want to be involved in giving you their views.

How will the PCT/trust use the views of patients and the public?

- What are the implications and the reasons for not meeting the patients' and public's preferred option?
- What flexibility does the PCT/trust have to respond to different ideas put forward by patients and the public?
- What flexibility is there in the PCT's/trust's Local Delivery Plan for doing things differently?
- Have decisions already been made which have implications for the ability of this work to influence change?

How will feedback be given to patients and the public?

For an NHS organisation to be accountable to patients and the public it must not only involve them, but must also be prepared to explain how the views collected have been responded to.

There are very good reasons why it is important to give feedback to those who have been involved:

- as people have given their time and their personal views it is courteous to respond
- feedback promotes openness and accountability and develops confidence and trust, which is the basis of a sustainable relationship of any sort.

Where patients and the public have worked closely with the PCT/trust to make decisions, it may be appropriate to make a written record of the decisions taken and give it to the people who were involved. The wider public will also need to be told of the decision.

Where a PCT/trust has sought the views of patients and the public and a decision has been taken by the organisation alone, feedback should be given to all those involved.

The following may help as a guide to information that might be given in feedback. Summarise:

- the patients' and public's views and highlight where there are differences
- key factors that the PCT/trust has had to take into consideration.
e.g. financial constraints, clinical governance issues
- the final decision and why it was made
- how patients' and public's views influenced the decision

Having determined what needs to be fed back to the public and those who have been involved, consider the following options:

- produce a press release
- produce an advert in the local paper or on local radio
- report in own or local authority newsletter
- place reports and findings on websites
- place material in local libraries, leisure centres
- distribute printed information through schools, GP surgeries, art centres, housing offices, one-stop-shops
- use the local newspapers to feature regular articles
- inform representatives of relevant committees, advisory bodies, user groups, campaigning bodies, special interest groups, advice agencies
- write to specific individuals and groups.

When to monitor and/or evaluate?

Monitoring and evaluation serve different purposes and PCTs/trusts need to be clear about which is appropriate.

Monitoring is used to assess progress while a process is going on. The purpose is to support project management and accountability.

Evaluation is an assessment of the impact of patient and public involvement. It is generally undertaken at the end of a piece of work or at a point in the lifetime of a project that is agreed at the start. Evaluation focuses on whether involvement has achieved its aims and objectives as set out in the organisation's PPI strategy. The purpose is to determine what has worked and what hasn't and to develop an iterative process that builds on past experiences.

Are you clear about what you are evaluating?

Evaluation should be carried out for involvement and consultation processes and for the PPI strategy as a whole. In all cases the focus should be the aims and objectives defined for the work before or during the planning stages of the process. 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 the work is underway.

To measure how things have changed as a result of involving and consulting patients and the public, it is important to have a clear view of how things were before the process began. The baseline assessment, which is required as a preliminary step to developing the PPI strategy, will provide a good basis for assessing the progress and the impact of involvement.

Practice guidance 1

Was it successful?

How do you measure success? For example how good was the process? The process matters – how did the dialogue happen, how did people feel at the end of it? Did they feel they had had an opportunity to express their views, to contribute and influence thinking?

For most people – staff, patients and the public, it is the outcome of the discussions that are most important, the changes that happen as a result of their involvement. Even if it is the most inclusive process, if nothing changes as a result of patients and the community talking to the NHS they will have their doubts about whether it is worth doing again.

What did we learn on the way?

It is important that NHS organisations learn more about what makes a difference for people. Do you want to have a process that has more skilled people with more confidence at the end of it – so that they can help lead the next round of discussions?

Are you more interested in getting new ideas and new perspectives at a particular stage than checking how many people agree with your ideas?

It is important to check out what the agenda is, whether everyone is talking about the right questions.

The best way of checking is to ask patients and the public for their views on the process.

Planning consultation

Planning consultation

NHS organisations should see **consultation as an on-going involvement process and a way to seek formally the views of patients and the public.**

For many NHS organisations consultation has meant little more than holding a public meeting to discuss a proposal drawn up by the HA /trust for a change in service.

“We’ve consulted with patients in the past, but they were not in favour of the changes we suggested, so now we’re reluctant to consult them....they don’t have the full information required to make a good decision”¹

Section 11 means you must involve and consult patients, the public at the beginning and throughout all stages of a process to:

- plan services;
- develop and consider proposals for changes in the way services are provided;
- make decisions affecting the operation of services.

What to consult about – what to ask?

Consultation usually takes the form of asking people for their views about services or a proposal to change services and what services they would like. These are important, but there are other things PCTs and trusts may want to find out, including staff, patients’ and the public’s:

- knowledge
- experience of providing/using services
- behaviour
- wants
- information needs
- attitudes
- considered and informed opinions.

1 NHS Trust, CHI report March 2002

The role of consultation in planning

The consultation process is a legal requirement and should be part of an on-going process to involve patients and the public. The experience of many NHS organisations and local authorities, which have successfully undertaken involvement and consultation over a number of years, is that it is possible to develop a dialogue with the community (or at least part of it) over time. The whole becomes more than the sum of the individual consultation exercises. It is ongoing and becomes integral to other systems and processes.

If consultation were to take place only as a one off exercise that is not part of an on-going involvement process and is then put to one side, it will not be possible:

- to build up a true or useful picture of what patients and the public think
- to involve patients and the public in the development of the service that is being consulted on
- to develop an ongoing dialogue or relationship with the community
- for patients and the public to gain more confidence in the NHS.

Planning consultation

There are some things it is important to think about right at the start, because they will impact on decisions to be taken at various stages throughout the consultation process. They include:

- What is the respective responsibility of each of the local NHS organisations?
- Have any local NHS organisations already carried out a consultation on the same or a similar issue?
- Who should be consulted, on what and how?
- What resources are available and needed?
- How will conflict/complaints be dealt with?

Practice guidance 11

- How will the outcome feed into the decision making process?
- When and how will decisions be made?

- How will the results be fed back to the patients and the public who have been involved, either directly or indirectly?
- What evaluation is going to be done of the consultation, and how?
- What is the timetable for both the involvement and consultation processes?

Remember:

1. Patients and the public (and others' including staff, as appropriate) should be involved in the development of proposals to change services and developments of plans for new services from the start of the planning process.
2. If it is agreed with stakeholders that a formal consultation should be held the Cabinet Office Code of Practice should be followed (see framework at the end of this section). This means you must build in sufficient time to do this from the outset.

Co-ordinating consultation

There are a number of important reasons why it may be beneficial to co-ordinate consultations across the local health economy:

- To set high and consistent standards of consultation geared towards meeting overall organisational objectives.
- To share best practice and expertise on approaches to consultation so that strategic health authorities, PCTs and trusts can learn from each other.
- To share common data between services and organisations. The discussions one organisation is having with patients and the public may spread to other service areas (patients and the public do not work within our service pigeonholes) and it is important that the information is not lost.
- To share the cost of a consultation
- To ensure that the views of all relevant groups and communities have been taken into account in drawing up and consulting on plans for change
- To ensure that the consultation is as effective as possible and that particular groups and individuals do not get 'consultation fatigue'

- To ensure a co-ordinated approach on issues that cut across more than one PCT/trust.

Many of the same reasons apply to why it is important to co-ordinate with different agencies – for instance, joint working with the local authority for more cost-effective consultation. The aim is for the NHS to work with its partners to achieve a consistently high standard of consultation across all service and issue areas.

Practice guidance 4

To promote consistency, efficiency and common standards it is recommended that PCTs/trusts develop a mechanism for co-ordinating and recording plans of patient and public involvement work and statutory consultations – those being proposed and those that have been undertaken. e.g. it may be useful to establish a public involvement and consultation diary – a database which will provide an up-to-date account of patient/public involvement work being undertaken within a local health economy. Over time this will build an accurate record of work undertaken, the communities/patient groups involved, the outcomes and the evaluation reports.

Evaluating consultation

Consultation should be efficient, effective and equitable and, more importantly, it should be adequate both in terms of time and content so that all parties with an interest are given a proper opportunity to make their views known. The focus of an evaluation should be on how well the process was undertaken and what changes it has led to. This may be difficult to specify because a range of factors influence decision-making. The following checklist will be used by the IRP to assess the rigour of a process and the impact it has had.

Practice guidance 5

Framework for consultation

(Adapted from the Cabinet Office Code of Practice on written consultation)

1 – Timing

Time must be set aside so that a written consultation document can be properly designed and disseminated where appropriate.

Early involvement is often the key to the success of a consultation, and to securing co-operation in it: omitting it may cause delay and expense later.

Let interested parties know about the timing of the events that will form part of the consultation.

Set aside sufficient resources for the consultation. Effective consultation may involve significant expenditure of time and money.

Allow a reasonable time for receiving the responses and for analysing them.

2 – Clarity

You should:

- explain which people and groups the consultation is particularly aimed at
- identify who has been involved in developing the issues that are being consulted on
- include an assessment of the impact of the issues on groups likely to be particularly affected and particular impact by gender, age, ethnicity or disability
- be clear about any aspects of an issue on which decisions have been taken, or are inevitable
- indicate where the PCT/trust provisionally favours a particular course of action. NB the agenda should not be so rigidly defined as to deter respondents on related questions of interest to them
- set out the deadline for responses and the timetable envisaged
- make it clear that representative groups must provide a summary of the people and organisations they represent when they respond
- specify that responses may be made public unless confidentiality is requested.

3 – The documents

Any document should:

- be simple and concise
- have numbered paragraphs
- include a two-page summary
- include the membership of the steering group so that people can see that patients and the public have been involved in the drafting
- be drafted in plain language and not too glossy or elaborate
- set out the main information and competing arguments relevant to a decision
- include a set of key questions
- give email as well as postal address for responses
- provide contact details of someone who will respond to questions and someone independent to the consultation process, who will pursue complaints or comments about the consultation process
- be available in paper format, free of charge and on a website from the start of the consultation.

4 – Communication

Make every effort to communicate effectively with all those who are, or potentially are, interested. This may involve contact with representatives of voluntary or other interest groups as well as narrowly defined groups. Patients, the public and front-line staff should be included.

Make any document widely available both in paper form and electronically. Send it to all interested parties and make it available, free of charge, to the general public and front line staff.

Consider how to effectively reach socially excluded groups and people the NHS has traditionally found hard to reach:

- does the issue impact on other linguistic groups, or particular minority ethnic groups?
- does any document need to be reproduced in different languages or formats? E.g. be made available in a format for people with a visual impairment (braille, large print, tape)

Prepare a press release or make a similar announcement about the consultation.

Use different methods of publicity e.g. flyers, advertisements, word of mouth, letters, email and websites and in an accessible form for people with learning disabilities.

Make face-to-face visits, do presentations and discuss the issues with interested organisations, stakeholder groups, user groups etc.

Make sure feedback that is given orally is properly recorded.

Consider funding independent facilitators to undertake outreach work with socially excluded groups and groups the NHS has traditionally found hard to reach that may have little central organisation.

5 – The consultation and considering the responses

Ensure you allow adequate time for obtaining the responses – avoid consultation periods being limited in order to meet deadlines. The consultation period should never be shortened for reasons of convenience.

Twelve weeks should be the standard minimum period for a consultation, any variation to this must be agreed at the planning stage with main stakeholders.

Where consultation takes place on the basis of amendments made in the light of earlier consultation, a shorter period may be acceptable but would need to be agreed.

The set up of organisations should always be taken into account when agreeing the consultation period. The issues may be complex and organisations that may not have many staff members, or that need to consult members through a structure of committees to draft responses, may require longer.

Consider when the consultation period falls – it may be less effective if it falls within a substantial holiday period.

In order to ensure consistency between respondents, a provisional view should be taken at the planning stage about how to deal with requests for deadlines to be extended.

6 – Analysing the responses

Responses should be carefully and open-mindedly analysed, and the results made widely available. An account of the views expressed and the rationale for the decisions finally taken should be given.

Responses to consultations should be acknowledged.

Responses should be carefully analysed for:

- Possible new approaches to the issue consulted on
- Further evidence of the impact of the proposals
- Levels of support among particular groups.

Look out for single-issue groups monopolising the debate, pay particular attention to the views of representative bodies, voluntary organisations user groups and other organisations representing groups that are especially affected by the issues.

Keep as full an account as possible of both formal and informal responses. Ensure that everyone's view is considered fairly.

Decisions should be made public promptly with a summary of the views expressed and clear reasons for rejecting options that were not adopted. This information should be made available to everyone who responded and made available on the website.

Respondents who ask why individual issues have been rejected should receive an explanation. Individual responses should be made available to anyone else who asks for them.

It may be necessary to keep confidential responses that may affect third parties' interests or privacy.

If new and significant options emerge from the consultation, it may be right to consult on them again (though a shorter consultation period may be justified)

7 – Monitoring and evaluating consultations

A consultation lead/co-ordinator should be designated to ensure:

- Consultations are, where possible, co-ordinated across the organisation/s
- the progress of the consultation is monitored
- dissemination of the lessons learnt

When completed the consultation should be evaluated with independent involvement to find out:

- which techniques were particularly effective in securing a range of useful responses, and which were not
- which represented value for money (taking into account staff time, as well as direct expenditure)
- how far service provision changed as a result of the consultation. If it did not, the reasons should be explored
- respondents' feedback. This may emerge from response rates, an analysis of the comments or by surveying users after major consultations.

There is no one recipe for successful consultation. It is inevitable that local circumstances will influence how a consultation is carried out. Factors such as the quality of ongoing relationships with partners, the local political context, the urgency of the service change being consulted upon, the relationship with the local media and the skills and interests of the NHS staff involved, will impact upon the consultation. Nevertheless if any of the elements of good practice outlined here are not practised, the consulting body should be ready to respond to the question “why not?” with robust and plausible reasons.

Link <http://www.cabinet-office.gov.uk/servicefirst/2000/consult/code/ConsultationCode.htm>

Overcoming barriers to involvement

Overcoming barriers to involvement

There are many powerful reasons for involving and consulting patients and the public but objections are still often raised against it. It is helpful to recognise these issues so that the PCT/trust can deal with them when they arise.

There follows a list of arguments that are commonly used and some responses to them.

It isn't fair to burden people who may be disadvantaged or in difficulties.

Recognise that sometimes people will not want to be involved and that it should always be a choice. However, the evidence suggests that most people, whatever circumstances they are in, would like a greater say in their lives and the services they receive.

What people really want are decent services rather than having a say in them.

PCTs and trusts need to enable people to get involved if they are to know what people want and what will best meet their needs

We don't want to raise people's expectations unrealistically.

Tell people clearly and simply what involvement is possible, what is on offer, what resources are available and what difference they can make. People are quite capable of understanding practical problems and constraints as long as the organisation is open and honest about them.

There just aren't the resources.

Involving people doesn't have to mean more money has to be spent on delivering services but it will certainly result in using what resources there are more appropriately. Attitude change is free!

People are too apathetic or disinterested to get involved.

It is easy to mistake people's exclusion and powerlessness for apathy. It is more important to remember that being on the receiving end of a service can inhibit people's expectations and lead them into dependent roles and relations.

So if people do not respond to invitations to get involved the PCT/trust should look more closely at its approach – it is up to the organisation to demonstrate that the involvement it is offering is not 'just another token effort'.

Patients and members of the public who do get involved are often unrepresentative.

Unrepresentative of who or what? Patients and members of the public usually bring their own experiences to the debate. Unless they are speaking on behalf of a patient's group or an established forum they are rarely able to represent the collective views of others. Questioning people's right to be involved can serve as an excuse for continuing to exclude them (representativeness is a double standard that is usually only applied to patients and carers).

Patient and public involvement means criticising and checking up on staff.

Giving power to patients and the public does not have to mean taking it away from staff, involvement is concerned with changing the nature of the relationship between participants which can have benefits for everyone.

Practice guidance 8

Involving people creates delays and inefficiencies.

Making the wrong decision quickly makes less sense than taking time to involve patients and the public in making the right one. The more time you spend with people trying to get things right, the less you will have to waste trying to sort out mistakes.

It is not really possible to involve children and young people.

Children can express their preferences about how they are treated and what they want from a very early age and they should be listened to. Different Children of different ages may be involved in different ways and to different degrees – but then the same is true of adults.

The vulnerability of children's rights is an added reason for involving them and making sure this is done with sensitivity and support.

How can you involve people when their rights have to be restricted?

People's rights are sometimes restricted for the benefit of their health and the health of others. When people's rights are in question, it is important that they are involved and consulted. This will ensure they are kept fully informed, given opportunities to put their case properly, and be involved in decision making processes.

Involving Staff (paid and non-paid)

Involving Staff (paid and non-paid)

The NHS is the biggest employer in Europe, employing 1.2 million staff. This large staff group are also citizens, members of the public and may at some time in their lives be patients.

Developing different ways of working

It is important that staff, as well as patients and the public, are given opportunities to be involved in service planning and development and to engage with patients and the public in this process. Staff who involve patients come to understand that people have worthwhile comments to make; that their views cannot be second-guessed and that involvement could lead to significant changes in professional behaviour.

On occasions staff see themselves as representing patients' views, they believe they know what patients want and need. It is important that they understand:

- why they cannot represent patients' views – it is important to hear 'where patients are coming from'
- why their views (as staff) are being sought
- that their views are as important as the views of patients' and/or the public.

It is important that staff recognise the different authority and responsibility they have as a member of staff and how these differ when they are a patient, relative and/or member of a community.

Involving staff in their paid capacity

As a member of staff their authority might be:

- as a formal representative of the board/local authority
- to commit resources and make decisions
- extensive knowledge of research and/or practice relating to a condition
- experience of planning and managing change

- experience of a particular service or speciality.

The responsibilities that go with this role might be:

- being accountable to the board/senior managers
- having to explain the reason for decisions and recommendations
- basing decisions on information available
- balancing their interests with the interests of current patients and those of future patients
- making best use of public resources
- keeping colleagues and other organisations informed
- taking account of the interests of other staff and the wider public
- using the perspective of patients and the public to reflect on their practice.

Involving staff when they are a patient, relative or member of a community

As a patient, relative or member of the community their authority will be different. It might be:

- personal experience of living with an illness
- being a friend, relative or carer of someone who lives with a condition
- knowing other people and families in similar situations
- knowledge of research and practice relating to their condition
- knowing many people in the local community and being widely trusted
- experience as an activist
- a formal representative of a consumer group or community organisation.

The responsibilities that go with this role might include:

- reflecting the experience of other people as well as your own
- checking back with people in their network or who they are representing
- informing their networks.

Building capacity

In the past there has been hesitancy amongst some doctors, nurses and other health professionals to involve patients and the public in planning and developing health services. In order to ensure that services are designed around the needs of patients, staff need to understand what involvement is, why it is important to involve and consult patients and the public and how to do it well.

They need:

- training and support to carry out patient and public involvement
- to know the results of national and local patients' surveys
- to seek the views of excluded groups who receive health services and health visiting services
- for the lead PCT nurse to be visible and readily accessible to the public
- to ask patients and the public to get involved from an early stage when planning service changes
- to develop skills and confidence to involve children and young people, learning disabled people, people with mental health problems, and people from minority ethnic communities
- to support people who lack confidence to voice their opinions
- access to up to date information and sources of information and advice for the public, such as through NHS Direct, interactive web sites and email consultations
- to work closely with PALS, Volunteer Service managers and patients' forums (when set up)
- to have close links with lay members of PCT/trust boards
- feedback on what action has taken place as a result of their involvement.

Example: A series of locally based projects and city-wide learning networks run by Leeds Health Authority and Leeds Health Action Zone identified key areas about which staff on the ground, and their managers would value information and support in order to make change happen. To meet this need they have developed a series of toolkits as practical guides for staff working in health and social care in Leeds. One of these is a Service User and Carer Involvement Toolkit that provides guidance to staff on how and why to involve people who use the services that they provide and help with how to do it.

**Involving specific
groups that the NHS
has traditionally
found hard to reach**

Involving specific groups that the NHS has traditionally found hard to reach

It is often much simpler to make contact with individuals, voluntary or community groups and organisations you already know. Investing time and effort to engage specific groups within a particular locality is often seen as too time consuming, cost precious and they get ring fenced as 'hard to reach' groups, a term that reinforces negative stereotypes.

There are ways of reaching most groups in the community, but some of them may require additional support to engage on a level playing field. There is no easy answer as to how it should be done. The single most important piece of advice is to talk to the target group about the best way to consult and involve them. This could be done on a small scale, with individual groups or as part of a larger involvement or consultation exercise including all potential audiences.

Practice guidance 10

Another suggestion is to make use of those people who have existing expertise of working in any capacity – paid or unpaid with particular groups. Some groups have little or no trust in local health services, the local authority or other agencies. In some cases trusted parties have acted as intermediaries. It may be possible to work with community leaders, local Councillors and the community press. In the longer term there are issues to be addressed about how to build a relationship with such groups.

It is important to remember to meet the needs of those being approached. This might mean:

- holding events during the day, during the evening and/or at weekends or both
- providing crèche facilities
- providing transport
- ensuring venues are accessible by all disabled people (transport, wheelchair access etc.)

- providing facilities such as induction loop systems for use with hearing aids, signers and interpreters
- providing information in different ways, such as large print sizes, accessible language, on tape and translated into the languages spoken locally
- finding out whether people have special dietary requirements.

Word of mouth advertising through a particular community can be very effective. This applies to all sorts of communities, patients' groups etc.

The following pointers may assist in involving specific groups (this is not an exhaustive list and should be used as the starting point for consideration):

Children and young people

Children

- Work with paediatric units and parents groups to identify the most appropriate ways of involving children
- Provide information in an appropriate style and format
- Talk to children, not just their parents or carers.
- Develop partnerships with local schools and pre-schools to develop involvement mechanisms that can compliment the curriculum.
- Consider using video and interactive material and the internet

Example – Walsall Healthy Schools Scheme run by Walsall Health Authority, set up an initiative to directly consult young children in school. Art workers in schools used a variety of approaches to lead creative arts consultation sessions with children aged 5 – 10 to find out their health and well being needs.

Young people

- Develop links with the local youth service and other external agencies that work with young people
- Target publicity in appropriate places
- Provide information in an appropriate style and format
- Involve young people, not just their parents or carers

- Organise events that will be attractive to young people
- Consider using video, interactive mechanisms and the internet
- Develop partnerships with local schools and colleges to develop involvement mechanisms that can compliment the curriculum.

Example 1 – Rotherham PCG commissioned the Youth Service to carry out a consultation to obtain the views of young people on sexual health services and to look at ways of making the services more ‘young people friendly’.

Example 2 – Wakefield West PCT has a jointly run project (with a youth worker). The project recruited and trained 15 young people aged between 15 and 20 to become peer researchers.

Following a recruitment process, training was given in communication skills, IT, planning and analysing research. The young people devised a questionnaire and structured interview and conducted the interviews through schools, youth service provision, the youth offending team and colleges.

The project has equipped and empowered young people in the PCT area with useful skills and fired young people’s interest in health matters – those involved are keen to participate in another project.

Gay and lesbian communities

- Consider targeting through the gay press and leaflets rather than relying on local meetings
- Use local gay venues
- Contact local gay organisations
- Use local gay and lesbian switchboards
- Involve lesbian and gay health workers organisations, networks and conferences
- Avoid alienating lesbians and gays from general approaches by ensuring all materials and approaches avoid heterosexual assumptions, stereotypes, images and language.

Homeless people and travellers

- Work with the relevant voluntary agencies, council departments and utilise health visitors

Example – Hull & East Riding Community Health NHS Trust identified that the gypsy and traveller community living on settled sites in Kingston upon Hull was experiencing inequalities and social exclusion. The community said,

“Suspicion, fear and pride make us reluctant to ask for the help we need. We need support for our community so that we can, with help overcome our problems.”

A photo-documentary project was carried out to talk to the community and capture their life, heritage and culture. This was launched at a Whole Systems Event, organised by Hull & East Riding Gypsy & Traveller Participation Group which includes education providers, health providers, the voluntary and community sectors and the Council, to establish the community’s priorities to improve their living conditions and quality of life.

Learning disabled people

- Involve the relevant support groups and independent agencies
- Ask if the person has a health facilitator, family member or carer who they would like to be present
- Talk to, and look at, the person not the advocate or supporter who may be present
- Speak more slowly and be prepared to be interrupted and go over things again
- Have information available in an accessible format (e.g. straight forward, jargon free language, short sentences, large print, pictures)
- Link with Learning Disability services in the community
- Work with advocacy and self-advocacy groups
- Ensure people with learning disabilities are involved, not just advocates
- Check out the ‘Valuing People’ consultation and implementation work for effective ways of working

Link www.doh.gov.uk/learningdisabilities

Example: “Speaking up” in public to doctors and nurses at a Primary Care Group Board was a new experience for self-advocates from Toxteth and Cranby Resource Centre, Liverpool. Some of the things they said were: ‘We would like the same checks as everyone else’; ‘We want you to explain and listen to us and not just talk to our carers’; ‘We want leaflets about health with pictures and for you to get to know us as people and ask our point of view.’ The result was an agreement to review primary care provision across the area.

(From Valuing People)

Older people

- Develop links with external agencies that work with older people and carers
- Have information available in large print and on audio tape
- Involve older people in their own homes or community group setting if this is their preference

Example – Cheltenham & Tewkesbury PCG conducted a survey of older people using trained older people to undertake the interviews.

The PCG advertised for older people to undertake the interviews through older people’s groups and the media. It trained seven volunteers who undertook the interviews in people’s homes. This allowed the PCG to reach ‘the hard reach’ people in the borough, use the skills of older people to build a comprehensive picture of the needs of the local people and obtain a frank and realistic view of the issues.

People from minority ethnic communities and other people whose first language is not English

- Evidence clearly shows that people from black and ethnic minority communities tend to have poor take up of health services so it is important to consider potential service users and carers
- Map out a range of formal and informal places where users and potential service users can be reached e.g. shops, schools, colleges, faith organisations, English language classes, mother and baby clinics, local festival celebrations
- Avoid holding events on days that are celebrated by particular groups in the community
- Select appropriate community venues where people feel comfortable and times (checked with the community) when they can attend meetings or can be contacted
- Provide refreshments that are appropriate to people's religious and cultural needs
- Avoid making stereotypical assumptions about individuals or groups (ask them to identify processes to overcome barriers to involvement and for solutions)
- Provide information, in 'plain English' (jargon and acronym free) that is appropriate to people's culture and language. Remember that some people may not read or write their first language. In addition to translated material, consider the use of audio/video tapes as well as word of mouth
- To assist people to gain a better understanding of the issues under consideration think about sending out briefing information, in appropriate languages, in advance of any meeting
- Offer trained interpreters. Do not rely on family members to interpret as this can place an unnecessary burden on them and will be inappropriate when dealing with sensitive or personal issues
- Provide specific support for people from black and ethnic communities to develop their own initiatives to increase the involvement of their members
- Tackle issues that particularly affect people from minority ethnic communities

- Respect each other's differences
- Challenge discrimination such as racist language and behaviour, from whatever source
- Establish links with the relevant community group leads

Example – Walsall South East PCG used a venue in a local community setting that is used by the Asian community for their events and meetings for a diabetes event. They took fliers and posters out into the community rather than post them and used local networks, community leaders and link workers to advertise the event at group meetings and spread invitations by word of mouth. The event:

- was a 'walk in – walk out' event so that people could attend when they were able
- was 'fun' and interesting; offering health information and checks to those attending
- had refreshments provided by the local Asian cookery club and provided opportunities for people to learn about healthy eating using their own ingredients
- had stands staffed, where possible, by people who were able to communicate in other languages

People with disabilities

- Consider the barriers to disabled people – remember that access is not only about physical access but includes attitude, use of appropriate language, information and confidence
- Ensure that any information provided informs people of full access details and invites them to notify their requirements e.g. personal assistant, special parking space. All Information should be in accessible formats
- Ask disabled people for advice. Do not make assumptions about people's abilities or needs and remember that some impairments 'are hidden'

People with hearing impairment

- Offer British Sign Language (BSL) interpreters for BSL speakers
- Provide a loop system at the venue (this allows people with suitably equipped hearing aids to have the background noise eliminated)
- Have a minicom available to enable telephone contact
- Consider using faxes and the internet, have a text phone number or email

People with mobility needs

- Provide disabled access and allow space for people who use wheelchairs when planning seating
- Make sure the transport provided is accessible
- Consider involving people in their own home or community group setting

Link www.radar.org.uk

People with sight impairment

- Have information available on audio tapes
- Make sure that sign posts and information are put in large print and that all written signs are in dark lettering on a pale background
- Involve people in their home or community group setting
- Offer Braille transcriptions for Braille users
- Ensure venue is accessible for Guide Dogs

People who use mental health services

- Involve people who use mental health services, not just their advocates
- Involve link workers and carers
- Understand the implications of the Mental Health Act

Refugees and asylum seekers

- Work with specialist voluntary agencies
- Involve link workers and independent advocacy services
- Provide interpreters

Methods and Approaches

Methods and Approaches

What level of involvement is required?

Involvement can be viewed as a continuum ranging from minimum to maximum involvement. The level of involvement should be matched to the circumstances and context in which it is to take place. For example, working at a minimum level by giving information about a health development might be the most appropriate level of involvement at a particular time and in specific circumstances. Certainly without being well informed, patients and the public can never be properly involved.

The diagram (Figure 3, page 69) sets out a continuum and provides ideas about involvement at a range of levels. These come with a warning: It is possible to carry out each method or approach in a more or less involving manner. Good practice is to consider a range of approaches, determining how they fit together to establish a pattern of ongoing involvement and dialogue.

PCTs and trusts should think about how they will use the outcomes arising from the different approaches as they are identified on the continuum. Generally, as you move along the continuum towards maximum involvement there will be more in depth involvement in the organisation's decision-making processes. Who makes decisions and how they are made will affect the way feedback is given to those who have been involved.

The methods and approaches set out in the diagram are illustrative examples; they are by no means exhaustive. Those undertaking patient and public involvement are encouraged to be creative in designing hybrids and innovations that really suit the needs of those being involved. The purpose of the involvement should also determine who is being involved.

There is not a simple 'route map' that you can work through to pick the most appropriate consultation methods and approaches. This is for a number of reasons. There are big differences between service areas, different NHS organisations, different areas and local circumstances.

Key messages are:

- **Make the best of what you have**

Check what information the trust/PCT and neighbouring NHS organisations have already obtained from patients and the public before consulting. Establish an involvement and consultation diary.

- **Plan well and in advance**

It may be tempting to leap in and get on with it, but time spent carefully planning at the beginning is likely to be time well spent. Remember patients and the public should be involved in the ongoing planning of services and the development of proposals not just in the consideration of a proposed major change.

- **Be honest**

Involvement can go badly wrong if people believe they are being invited to explore a wide range of possibilities when in reality only very limited options are open to them.

- **Use the results**

Just doing involvement/consultation is not enough. Genuine and serious thought needs to be given to what has been said. How this will be done needs to be considered at the planning stage.

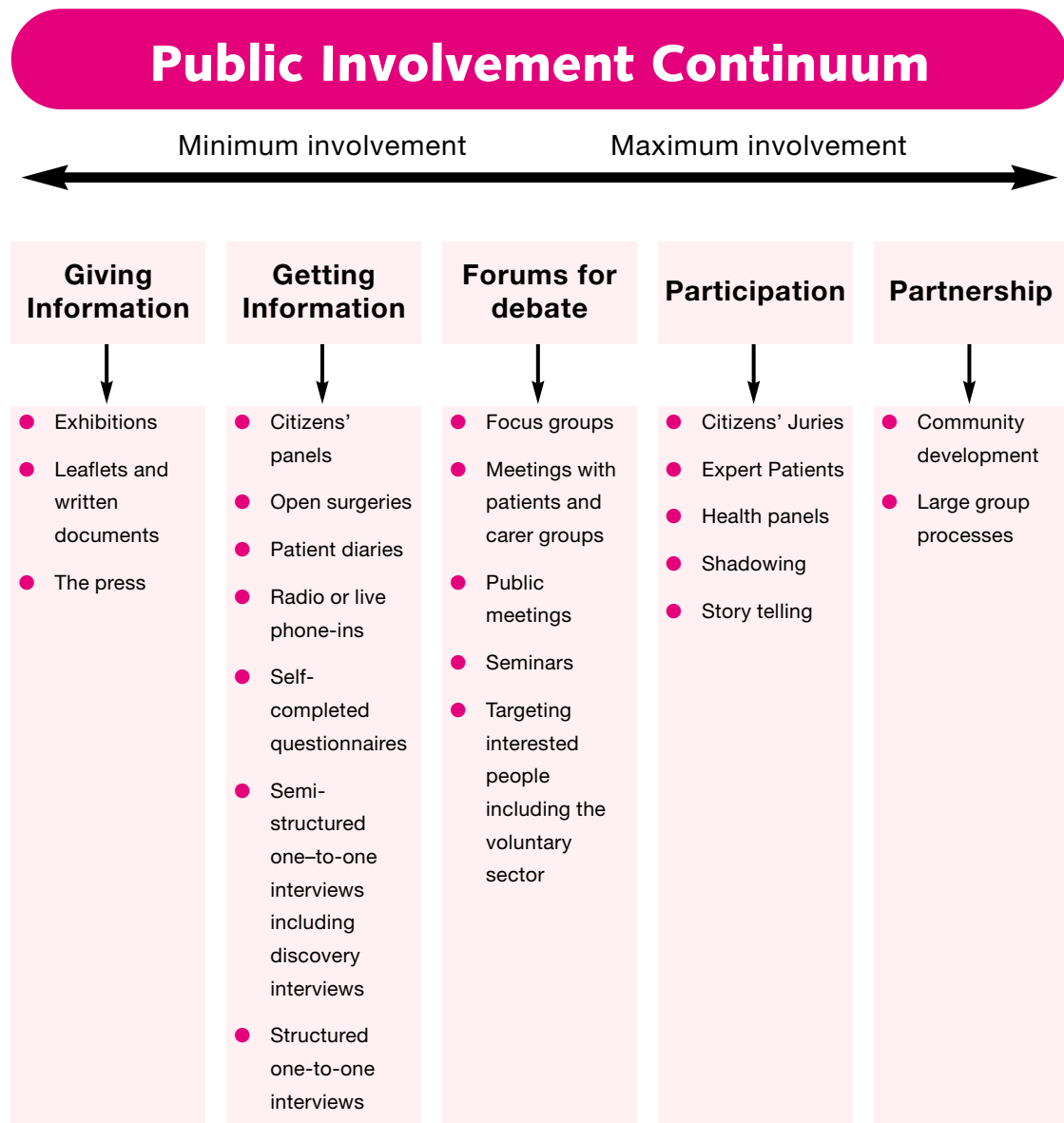
- **Take it seriously**

It is not difficult to ‘do involvement/consultation’ so that the necessary boxes can be ticked, but if it is not done in the genuine spirit of wanting to listen and take note of what is being said, it will probably be a waste of time for all concerned. Indeed, it may be worse than that: it may actually be harmful.

People developing and using methods to involve patients and the public may wish to seek the advice of others about how best to do this. In some circumstances e.g. if there is lack of clarity as to whether the work could be seen as research, it may be helpful to seek advice from the local research ethics committee.

Figure 3 Continuum of Involvement

Based on a diagram produced by Bedfordshire Health Authority



Contents

This section offers a range of methods that can be viewed as an à la carte menu enabling the most suitable approaches for the work in hand to be selected. They are arranged in sections that relate to the Continuum of Involvement on page 69. Each method deals with the pros and cons and provides a checklist of hints and pointers.

Giving information

Exhibitions

Exhibitions aim to convey information in a visual form. Audiences may be specifically targeted, e.g. in the work place, schools, shopping centres, high streets, community centres, outpatients, GP practices, clinics.

Leaflets and written documents for dissemination to the public

The objective is to convey information to the public about a specific issue or a range of issues. The style of the document will depend on the target audience. It should be honest and open.

The press

Newspapers and magazines may carry your message either as an advertisement – which you pay for and control – or as editorial – which is free, but is not within your control.

Getting information

Citizens' panels

Citizens' panels can be used to build a picture of a community's priorities. They are used to get a measure of public opinion on a specific issue a health organisation is working on. They can be conducted through telephone interviews and written or electronic surveys. Panel members are usually recruited via the telephone, advertising in the local press or writing to a random selection of the population. Panel member's names, addresses and numbers are held, with their permission, on a database. They are informed of the results of each survey through a newsletter.

Topics and questions generated must come from the organisation and feed directly back into decision-making processes.

Many local authorities have citizen's panels that may be able to be used by NHS organisations

Open surgeries

An opportunity for members of the public to discuss health care issues with a representative of the NHS organisation(s) or partner organisation(s).

Patient diaries

Patients or carers follow a set of guide questions to keep a personal written record of their treatment and care over a period of time. It is important to brief the patients well before they start – best results are obtained explaining face to face how the diary should be completed. This method can be used as an alternative to in-depth, face to face interviews.

Radio or live phone-ins

Radio stations cover local stories in news bulletins. They may send a reporter or conduct an interview over the phone about an issue if they see it as important. They may also offer you the opportunity to answer questions, phoned in by members of the public, live on the air. Some stations have community programmes where issues can be debated.

Self-completed questionnaires

Set of questions on a form to hand or mail out to a number of people in order to collect statistical information. See also structured interviews.

Semi-structured one-to-one interviews including discovery interviews

An interview which aims to obtain feedback or explore an issue or service. It enables the interviewee to bring to light and consider their own feelings and concerns. Can be face-to-face or on the telephone. The interviewer aims to cover a range of pre-set topics, without asking the interviewee to answer specific questions from a limited range of possible answers. They produce qualitative rather than quantitative data.

Structured one-to-one interviews

This may be a face-to-face or telephone interview. A one-to-one interview during which the interviewer asks a number of pre-determined questions and allocates the answers to one of a pre-determined set of possible responses. The analysis of the results of structured interviews is relatively straightforward.

Forums for debate

Focus groups

These are in-depth discussion groups of between six to twelve people that are focused around a specific set of issues or topics. A 'researcher' facilitates the discussion and ideally, a note taker will be present.

Meetings with patient and carer groups

Organised groups of people focusing around a common illness or condition, service or geographical location. These may be local community based groups or branches of national patient/carer organisations, for example the Kidney Patient's Association. They may be support groups, for example coronary heart disease support groups or groups set up to give a 'user view', for example cancer user groups, mental health groups or maternity services liaison committees.

Public meetings

A meeting for which there has been an open invitation. There may be a set agenda or discussion may focus on issues raised at the meeting. In the past, public meetings have tended to be the 'default position' for formal public consultation activities. However more recently, they have been used more creatively and there has been more interaction and engagement with the public e.g. market place events.

Seminars

A seminar is a discussion group that aims to impart, exchange and receive information. There is much greater input from the facilitator than in a focus group.

Targeting interested people including the voluntary sector

This is a method that focuses on engaging with people where they come together for another specific purpose. For example, parents outside schools, older people at social events such as luncheon clubs. People using primary care services may form an **advisory or reference group**. Such groups of people may be convened by the PCT/trust. A group may come together briefly (for example, talking with young people who are waiting in a cinema queue).

Participation

Citizens' Juries

A Citizens' Jury is a model of public participation that is particularly appropriate for involving the wider public in decision making; specifically decisions about strategic planning choices or service prioritising. The jury consists of 12 – 16 members of the public selected as a cross section of the community. They meet for several days to hear 'witness' evidence and examine the issue in depth before making recommendations (usually non-binding) to the NHS organisation. An independent moderator assists the smooth running of the process.

Expert Patients

'Expert Patient' is a term used in the White Paper Saving Lives: Our Healthier Nation, to refer to people who have an experience of a condition or illness and who are prepared to share it to convey knowledge about living with it to others. It is mainly used to refer to people taking part in self-management programmes, for example the Expert Patients Programme which enables people with a condition to train others with a similar long term condition to develop skills in managing their own illness.

Health panels

Health panels have primarily been used to explore local people's views on policy issues and the allocation of health service resources. Panels are usually made up of between eight to twelve people who are recruited using a quota sampling technique to reflect the socio-economic make-up of the area. To ensure a regular supply of new voices each panel member has a fixed term and is then replaced by a new person. Panels usually discuss topics which are 'live' i.e. of genuine concern to the organisation running the panels. Panels can raise issues that are of concern to its members.

Another type of panel is a postal panel or internet panel. These are generally of a larger representative group of people who may be sent questionnaires or telephoned on particular issues. This type of panel can be useful to obtain views from a particular group who may not come to a session or may be otherwise difficult to reach: such as carers, young men, people with disabilities or minority ethnic groups.

Shadowing

Shadowing allows staff to gain a new and different perspective of the patient's experience by accompanying a patient or user as they use services. An agreed period of time is spent shadowing an individual and lessons learnt are used to improve future services.

Story telling

Story telling is a patient-centred approach that allows patients to tell their story to a member of staff from a different clinical area. The interview is taped and a 'mind map' extracted. The patient is then asked to confirm what was heard. From this an action plan is drawn up and shared back with the patient.

Partnership

Community development

Community development is an approach that involves the community in identifying their own health and social care needs and finding ways to address them. This might be through influencing and informing commissioners and providers and other key agencies of the communities right to help shape service provision. It is likely to involve supporting the community to set up and sustain support systems and projects.

Large group processes

Large group processes are models of public involvement developed to work with a large number of stakeholders in sharing vision and change management. These models are appropriate for involving a range of stakeholders, including local people and those who have access to resources to enable change to take place. These processes are most effective on issues that affect a large number of people across organisations and communities.

The advantage of using these processes is the speed of implementation of outcomes and it is possible to involve people who are closest to the issue or problem being discussed to exchange information with other stakeholders. Three processes are discussed here: search conference, open space and team synteegrity. Each of these processes involves between 30 and 120 people. They are highly participative, fundamentally assume that people want to be engaged and have a voice, and assume that people are capable of taking some control and organising themselves for the task at hand.

Giving information

Exhibitions

Exhibitions aim to convey information in a visual form. Audiences may be specifically targeted, e.g. in the work place, schools, shopping centres, high streets, community centres, outpatients, GP practices, clinics.

PROS	CONS
You may reach members of the public you may not normally reach	You will provide the public with an opportunity to give you their wide ranging agendas. You may not be able to respond
If the exhibition is staffed it is an opportunity for representatives of NHS organisation(s) and partners to exchange information with members of the public	If you choose the wrong site you will waste your time and money
A good opportunity to raise the profile of the NHS organisation and publicise what it does	Resource intensive if the exhibition is staffed at all times
A comments book encourages people to respond there and then	An unconstructive or unrelated response can set the tone for future contributions and doesn't allow an opportunity to discuss the reason for the response
An opportunity to give the public other relevant information to take away or to point them in the right direction	

So you think you want to mount an exhibition...

The exhibition will need:

- careful advanced planning
- to be held somewhere it can be easily accessed by the public, preferably picking up on passing trade: for example a supermarket, street market or station
- preferably to be staffed at all times, by the **right** people
- to be actively promoted by advertising via local newspapers and/or radio and by circulating posters and flyers

- to look good – be professionally designed
- to be interactive – ask questions of visitors – get their views and opinions
- to provide the right amount of information to enable people to make informed comments on issues affecting them or at least to be directed to where further information can be obtained
- to be presented in plain English, free of jargon,
- have information available in different languages if appropriate
- to include photographs, maps, diagrams and models, use computers, TV monitors and videos if appropriate, to communicate effectively

If you still think mounting an exhibition is the best approach consider the following checklist...

- ✓ Is the exhibition site relevant to the locality of the services that are being consulted on, and where local people go?
- ✓ Has someone been given responsibility for preparing and coordinating the information for the display?
- ✓ Do you need to have a leaflet or other handouts?
- ✓ Do you need to offer interpreting services?
- ✓ How will you ensure that the exhibition looks attractive and welcoming?
- ✓ What times will you open? What will happen during other times?
- ✓ Are staff prepared to work at these times?
- ✓ Could you leave the exhibition unattended?
- ✓ How are you going to record comments?
- ✓ Are the staff well briefed to answer a range of questions and/or to act as messengers for the NHS organisation(s)/partner organisations?
- ✓ Do you need to feedback to the people who have been involved? If so, how will you do it?
- ✓ Are there providers whose expertise you could use e.g. health promotion?
- ✓ How will messages from the public be taken into the NHS and partner organisation and how will they be acted on?
- ✓ How will the exhibition be formally evaluated?
- ✓ Is the purpose of the exhibition clear to everyone involved at the outset?

Giving information

Leaflets and written documents for dissemination to the public

The objective is to convey information to the public about a specific issue or a range of issues. The style of the leaflet/document will depend on the target audience. It should be honest and open.

PROS	CONS
A document may be seen as a starting point in a consultation	A document becomes outdated quickly
It outlines the organisation's position	May be seen as a 'fait accompli'
It is an accepted way of disseminating information	There is no guarantee the document will be read
An opportunity for the NHS organisation to make a statement	The language may be inappropriate
Public relations value	Will a document really lead to action/change?
Keeps the public informed and aware of the issues	Sometimes there may be too many around at one time – overload!
It is a record of the NHS organisations' position at that point in time	Can be perceived as expensive
You can publish documents electronically on the Web and update them	Labour intensive – administration, distribution

So you think you are going to prepare documents for the public...

- Is this the best way to give information to people?
- The proposal outlined in the document should not be written in isolation and should be followed up with an action plan
- Ideally a document should be tested with a range of people from the target audience before it is published
- A consultation document should be followed by a strategic document outlining the changes that have been made as a result of the involvement and consultation and the next steps in the process
- Information has to be accurate, understandable and targeted

- What other information do people need to put the document or issues it contains in context?
- Are you clear about who the audience is and how to target information to them appropriately?
- You need to provide the right amount of information – sufficient, not too much, or too little
- The document should be viewed as part of the process, not the process
- The production of clear, readable documents is a specialised task and resource intensive

If you still think a document for the public is the best approach consider the following checklist...

- ✓ It needs to look attractive. Use desk top publishing packages and designers where appropriate.
- ✓ The text must be written in plain English. Is it free of jargon? Do you need to buy in editorial skills?
- ✓ Are you going to produce a summary of the document which highlights the key points for local people?
- ✓ Do you need to have either the main document or the summary translated into local community languages?
- ✓ Do you need to consider any other media, i.e. audio tapes in community languages, video, braille, internet, CD Rom?
- ✓ How is it going to be distributed – mail house/in-house?
- ✓ Do you need posters to let more people know of its existence?
- ✓ Will you use the local media to advertise the document?
- ✓ Would built-in response forms be a useful way of obtaining feedback?
- ✓ A draft document should say 'draft' on every page.
- ✓ Consider the format and length of the document – is it right for your target audience?
- ✓ Do you need to include a glossary of definitions and acronyms?

Giving information

The press

Newspapers and magazines may carry your message either as an advertisement – which you pay for and control – or as editorial – which is free, but is not within your control. We advocate making use of the Communication Manager and Press Officer's skills.

PROS	CONS
It is a fast and very effective way of bringing issues to people's attention	You can only get very simple messages across
You will reach a wide audience in local papers and can target specialist press e.g. minority ethnic newspapers	Despite your efforts you may not appear in print
You can build up a relationship with reporters for future initiatives	You cannot control what happens – you can only try to influence
	You may be misquoted if you don't use the advertisement approach
	Can be expensive

So you think you want to use the press...

- Will you pay for editorial/advertorial space or will you send a press release and hope your news will appear? A follow up phone call to a press release may help.
- Would holding a press conference be a more effective approach?

If you still think using the press is the best approach, consider the following check list...

- ✓ Consider whether you should hold a press launch or a press conference.
- ✓ If you are not sure, learn how to set out a press release or set up a press conference. You might want to ask the experts to do it for you – most PCTs and trusts have a Communications Manager.
- ✓ Consider sending relevant photographs to the press with your press release – this may enhance your chance of success. Photographs need to be of a professional standard.
- ✓ Make sure key people are willing and able to talk to the press for follow-up interviews.
- ✓ You need to have a protocol for dealing with any complaints that arise via the press.

Getting information

Citizens' panels

Citizens' panels can be used to build a picture of a community's priorities. They are used to get a measure of public opinion on a specific issue a health organisation is working on. They can be conducted through telephone interviews and written or electronic surveys. Panel members are usually recruited via the telephone, advertising in the local press or by writing to a random selection of the population. Panel member's names, addresses and numbers are held, with their permission, on a database. They are informed of the results of each survey through a newsletter.

Topics and questions generated must come from the organisation and feed directly back into decision-making processes.

Many local authorities have citizen's panels which may be able to be used by NHS organisations.

PROS	CONS
A panel is made up of about 1,000 to 3,000 people depending on the size of the population it represents	Can be resource intensive in terms of time and money. They are expensive to administer
Panel members are recruited to reflect the socio-economic make-up of a community and can therefore be seen as representative. There may be specialist panels e.g. elderly, young people or black and ethnic panels	Language can be a problem and translation/interpreting may be needed
People must give their consent and be prepared to be a panel member	As panel members become more experienced they may want to debate issues, which is time consuming and adds to the expense as questions take longer to answer
If they are managed by an external facilitator it gives independence and credibility	People move house and lose interest which means new panel members need to be recruited

PROS	CONS
A steering group usually agrees the questions and links the panel with the organisation's decision making forums	As panels do not encourage debate, answers received may be superficial
Panel members may be sent information about a topic in advance either through the post, electronically, or they may have it read to them over the phone	
Panels provide a quick measure of public opinion on a specific issue that can be defined and measured fairly objectively	

So you think you want to use a citizens' panel...

- Is there an established local authority panel that you could buy into or use?
- Can you obtain reports from existing panels as background information before you start?
- Do you have sufficient resources?

If you still think a citizens' panel is the best approach consider the following checklist....

- ✓ Have you considered how you will use the findings obtained from the panel?
- ✓ Are you prepared to spend more resources/time to obtain more in depth information to supplement the panel's findings?
- ✓ How will ongoing recruitment to the panel be managed? Will you use an independent organisation to recruit or have you bought into another organisation's panel?
- ✓ How long will the term of a panel member be? Often panel members serve for three terms and are then replaced.
- ✓ Who should be members of the steering group that agrees the questions for the panel and links into the organisation's decision making forums?
- ✓ Will you pilot the questions for the panel?
- ✓ Is there a way to give feedback to panel members, e.g. a newsletter?

Getting information

Open surgeries

An opportunity for members of the public to discuss health care issues with a representative of a NHS organisation(s) or partner organisation(s).

PROS	CONS
Can be linked with councillors, MPs, social services, Council for Voluntary Services, GPs surgeries and/or education	Political angle
Can build healthy partnerships with other organisations	Could be a waste of time for all involved if no commitment from the decision makers to listen
On-going dialogue may be established	May be perceived only for complaints or enquiries about individuals' treatment
Aids accountability and gives a channel for people to challenge and question	May get the same people attending all the time, or very few attending
Non-executive directors could hold the surgeries.	Takes a senior member of staff's time (need a good working knowledge of the NHS locally) on a regular basis
	Generates work to feed back to planners/developers/operational managers particularly if the surgery is designed to problem solve

So you think you want to set up an open surgery...

- Are you clear what this surgery will offer e.g. is it problem solving or an information exchange?
- Might technology offer another approach for a weekly "chat room" session/surgery on a web site?

If you still think open surgeries are the best approach consider the following checklist...

- ✓ What venue will you use – e.g. a market stall, library, local school, supermarket? Could you provide a virtual surgery through use of email on your organisation's website?
- ✓ How will you market and publicise the service?

- ✓ How will you set the standards so people know what they can expect?
- ✓ How will the surgery relate to the formal complaints system and PALS?
- ✓ Who will attend from the NHS organisation?
- ✓ Do you need an appointment system or a 'sit and wait' system?
How can the chosen system be made flexible? How will you find out what people want?
- ✓ If you use the internet, will you have a dedicated resource for responding to enquiries?
- ✓ How will comments obtained be fed back into the planning process?
- ✓ How will you provide feed back to the panel members/public?
- ✓ Who will be responsible for the work?

Getting information

Patient diaries

Patients or carers follow a set of guide questions to keep a personal written record of their treatment and care over a period of time. It is important to brief the patients well before they start – best results are obtained explaining face to face how the diary should be completed. This method can be used as an alternative to in-depth, face to face interviews.

PROS	CONS
Gives the patients and carers a feeling of being listened to and is an acknowledgement that their own issues are being taken seriously	The patient completing the diary will usually feel they have invested a lot of time and input and will want to see some clear actions result from it
Allows patients and carers to reflect, explain, expand and suggest ideas and new solutions	Danger of getting off the point and not covering the subject areas in the guide questions
If appropriate, over time, they can be used to develop a relationship of trust	Unless part of an identified development plan, it could leave patients feeling unclear of where to go from here
Provides in-depth information of a qualitative nature, enables an understanding of different perspectives and provides a story of the patients experience	Diaries can be very time consuming to analyse and you may misinterpret a comment.
The use of guide questions enables you to probe further the issues the study is examining.	Unless the guide questions have been developed to reflect the concerns of the patients/carer (and not the professionals) and are couched in a language that the patient can personally relate to, the quality of the completed diaries may be compromised.
Can give an indication of how people feel about the way in which they are treated	When analysing the data the whole picture needs to be “read”, comments in the diary should not be read in isolation of the rest of the diary
Records events and feelings as and when they happen	Those who have difficulties with reading and writing or are not confident with their literacy skills may not be comfortable with this method

PROS	CONS
Working from the patients' perspective you may uncover issues that you were not aware of	

So you think you are going to use patient diaries...

- Are you clear whose agenda it is?
- It is essential to pilot the approach – have you time to do this?
- Is the organisation prepared to invest the amount of time needed to deal with any unresolved issues or risks that patients/carer may raise?

If you still think patient diaries would be the best approach, consider the following checklist...

- ✓ How will you recruit patients to complete diaries?
- ✓ Who will decide the guide questions?
- ✓ Can the questions be determined from earlier focus group work?
- ✓ What sample size will you use?
- ✓ How will you feedback the results?

Example – Derbyshire Royal Infirmary developed the use of patient diaries with teenagers to identify their needs whilst in hospital. The teenagers were given a diary to complete from the day of admission to 5 days past discharge. They were asked to record their fears, anxieties and 'the best part of the day'. The information was used to improve the planning of admissions from waiting lists, and facilities on the wards.

Getting information

Radio or live phone-ins

Radio stations cover local stories in news bulletins. They may send a reporter or conduct an interview over the phone about an issue, if they see it as important. They may also offer you the opportunity to answer questions, phoned in by members of the public, live on the air. Some stations have community programmes where issues can be debated.

There are many different techniques that can be used. Seek the advice of the Communications Manager or Press Officer.

PROS	CONS
A very fast and effective way of bringing things to people's attention	It can be risky – it may generate a negative response
An opportunity to come across as human rather than a bureaucrat	You may be put on the spot
An opportunity to educate/disseminate information	You may not give your 'best performance'!
You may reach people who are otherwise difficult to reach e.g. carers at home, young parents, older people	There may not be an appropriate radio station in the area
Not usually resource intensive	

So you think you are going to do a radio or live phone-in...

- Can you afford/are you prepared to take risks?
- Can you explain your project well and get your ideas over simply and clearly?
- Are you prepared to be put on the spot?

If you still think using a radio or live phone-in is the best approach consider the following checklist...

- ✓ Will it be live or recorded?
- ✓ Keep in your mind three key points that you want to get across on the radio – this is your opportunity.
- ✓ Identify and have an answer prepared for the worst possible questions.
- ✓ Be very clear about what you want to do – do you want to impart information, gain people's views or recruit people who are willing to get involved?

- ✓ If you are doing an interview over the telephone – from your office, make sure you are not going to be disturbed.
- ✓ If it can be avoided, do not do a telephone interview over a mobile telephone.

Getting information

Self-completed questionnaires

Set of questions on a form to hand or mail out to a number of people in order to collect statistical information. See structured interviews.

PROS	CONS
A way of gathering relevant, and usually quantifiable information	Not a good method to elicit qualitative information
Information obtained will be pertinent to the issue	Not in-depth as no opportunity to explore issues/ideas/experiences further
If well done can collect useful information from large numbers or representative samples	Possible low response rate or biased response
Can be done face-to-face, may increase response but will almost certainly increase cost. See one-to one interviews	Provides only a snapshot in time
Flexible and adaptable to a large number of issues	Administratively can be quite unwieldy
Can give baseline data on something to be measured or monitored against	Cost: professional help may be needed to design and undertake the survey
You could use a professional organisation to do the work which would give more independence	

So you think you want to do a questionnaire...

- Is the topic area you want to find out about appropriate for a questionnaire, e.g. is it a sensitive issue?
- Is the information you require quantifiable or able to be categorised?
- Are the people you need to collect information from likely to complete a questionnaire?
- Do you need to collect information from a large number of people?
- Do you have a 'sampling frame', a 'database' of names and addresses of people you want to collect information from?
- Do you wish to include some free text boxes for respondents to include additional information of their choice

If you still think a questionnaire is the best approach consider the following checklist...

- ✓ What do you want to find out about?
- ✓ Who is your target audience?
- ✓ Do you need help with sample sizes/representation?
- ✓ How are you going to distribute the questionnaire? Could you use email, or a website or, in future, digital TV? (consider if traditional distribution methods should be complimented with electronic methods to ensure wider opportunities for involvement)
- ✓ Have you the time and resources to collect the answers face-to-face, or will you post questionnaires out?
- ✓ Who will prepare the questions?
- ✓ Who will analyse the responses?
- ✓ Will you need expert help to do this?
- ✓ Will the returned information be of use if there is a low response rate?
- ✓ How could you improve the response rate – could you offer an incentive, prize etc.?
- ✓ Will you send a reminder if you do not receive a good response?
- ✓ How will you feedback the outcome of the questionnaire to those who have been involved?
- ✓ Will you offer interpreting services to non-English speaking people?

Example – As part of a regeneration programme Central Liverpool PCT sent out a survey to all household registered with four general practices and to local groups. Members of a sub-group, who were local residents designed the questionnaire, decided upon its distribution and return methods and organised meetings with residents associations. 2000 completed questionnaires were received. The PCT said, “it took about a year to work through the process – lots of hard work, but its more than worth it for us to be able to say that local people really want this new facility.”

Getting information

Semi-structured one-to-one interviews including discovery interviews

An interview which aims to obtain feedback or explore an issue or service. It enables the interviewee to bring to light and consider their own feelings and concerns. Can be face-to-face or on the telephone. The interviewer aims to cover a range of pre-set topics, without asking the interviewee to answer specific questions from a limited range of possible answers. They produce qualitative rather than quantitative data.

PROS	CONS
Obtains relevant information through a semi-structured approach	Interviewing skills are required
Target specific audiences – ensures good cross-section of population	Need to meet sufficient people for answers to be generalised to the group in question
Is structured enough to allow some comparisons	Expertise needed to prepare framework for interview – questions must not be prescriptive
Allows freedom to explore general views/perceptions in more detail	Data analysis skills needed for qualitative data
Provides a framework for the discussion	Can be difficult to organise interview times/dates
Can use external organisations to do the work which will add independence	Cost, time consuming and resource intensive
Can be a useful method for getting into sensitive topics	

So you think you want to conduct semi-structured interviews...

- Are you clear about what you want to find out?
- Do you want to collect data you can compare from the people you interview as well as explore their experiences and views in a less structured way? If so, this is an appropriate method to use.
- How much time and money do you have?

If you still think semi-structured interviews are the best approach consider the following checklist...

- ✓ Who will prepare a framework for the discussion?
- ✓ What are the key points the interview should cover?
- ✓ Will interviews be face-to-face or by telephone?
- ✓ Where will the interviews take place?
- ✓ Who will do the interviews?
- ✓ How will you recruit the interviewees?
- ✓ How many interviews do you want and do you have enough time?
- ✓ How will you analyse the data?
- ✓ How will you present and feedback the results of your findings?

Discovery interviews

Discovery interviews were developed by the Coronary Heart Disease Collaborative as a process for joint discovery by NHS staff, patients and carers. They are semi-structured interviews exploring patient and carer experience with the aim of giving services and NHS development programmes a better understanding of what is important to those who use services. Discovery interviews allow health workers to hear patients' stories in their own words, face to face, and better understand how they can help make a difference.

The findings of the discovery interviews are used to identify ideas for change that can then be tested using small pilots.

Getting information

Structured one-to-one interviews

This may be a face-to-face or telephone interview. A one-to-one interview during which the interviewer asks a number of pre-determined questions and allocates the answers to one of a pre-determined set of possible responses. The analysis of the results of structured interviews is relatively straightforward.

PROS	CONS
Approach lends itself to wide topic area	Not much use for exploring people's reasons for their views, values or feelings about an issue
Quick and less costly than semi-structured interviews	Prescriptive – may reflect your perceptions, agenda and prejudices
You could use a professional organisation to do the work, giving more independence	Only allows for minimum input from the respondent
Allows for tick box answers – easy data analysis, the data that comes in is quantifiable	The respondent's answers may be influenced by the gender, culture, ethnicity or age of the interviewer
The people being interviewed do not need training/provision of information	Needs expertise to design the questionnaire
	Can be costly but less so than semi-structured

So you think you want to hold structured one-to-one interviews...

- Are you very clear about what you want to find out and how you will word questions in order to do this? Consider piloting the questionnaire to ensure the focus is right to get the information you need.
- Can responses to these questions be quantified or at least categorised?
- Should you employ professional help with formulating the questionnaire?

If you still think one-to-one interviews are the best approach, consider the following checklist...

- ✓ Who will prepare the questions?
- ✓ Who are you targeting?
- ✓ How will you select your interviewees?
- ✓ Will interviews be face-to-face or by telephone?
- ✓ Where will the interviews take place?
- ✓ How will you analyse the data?
- ✓ How will you present and feedback the results?

Forums for debate

Focus groups

These are in-depth discussion groups of between six to twelve people that are focused around a specific set of issues or topics. A 'researcher' facilitates the discussion and ideally, a note taker will be present. More recently, the line between focus groups and discussion groups has blurred. Attention to the following points is still important though.

PROS	CONS
Interaction between participants may produce new ideas	The articulation of group norms may inhibit or silence individual voices of dissent. Needs experienced facilitation
Useful for providing an overview on issues little known about and for identifying issues to be explored in more depth later	Does not generate 'evidence' in terms of large numbers/statistics
Participants can be recruited based on specific criteria such as age/sex/geographical location/specific service user	Mixed groups of different age or sex may not work well depending on the topic
Allows you to identify a framework for the discussion but the content emerges from the interaction between participants The views of the 'silent voices' may be elicited – a skilled facilitator can manage the group dynamics and balance the contributions of the very vocal and very quiet and inhibited members of the group	Not a rigid approach therefore information you get back from each group may not be directly comparable. Employing a suitably qualified facilitator and professional recruiters and note takers can be costly
The facilitator can interact directly with the respondents, allowing for the clarification of responses; they can probe for further information and interpret non-verbal responses	It is more difficult to ensure confidentiality in a group than in an individual interview. Need to get group to agree ground rules
Can empower people by enabling them to have their views endorsed by others and move them from a negative to a positive role	Mixed groups of lay and professional people may need special handling

PROS	CONS
Can include people who do not read and write, as the focus group will be in the form of a discussion	May be difficult to find trained group facilitators in the range of languages that you may need
Can be a practical solution to obtaining the views of people who do not read or speak English if a facilitator with appropriate language skills can be found	May need to hold a number of groups to validate data/findings between groups
Can provide in-depth information on views and the feelings behind them	The gender, culture, ethnicity or age of the facilitator may influence the discussion
Can include and elicit the views of people who think they have nothing to say	Some people may not turn up. To work effectively a group ideally needs to have at least five or six people and no more than twelve. The optimum number is eight to ten
Can be a learning experience, enabling participants to reach a better understanding of a topic which may include information about available services	
Can bring similar people together which may result in the formation of a sustainable group	

So you think you want to run a focus group...

- Is it a 'why' question you want to answer or a 'how many' or 'what'?
For example, do you want to know why people hold a view or how many people hold a view or what are the issues/solutions?
- A focus group will help you to understand what views people hold and allows you to explore why they hold a view, not how many share this view.

If you still think a focus group is the best approach, consider the following checklist...

- ✓ What criteria will you use for selecting people for the group?
- ✓ How will you recruit/select people to take part in the focus group?
Do you need to employ professional recruiters?
- ✓ Is this method appropriate for the subject matter?

- ✓ Is your sample appropriate for the subject matter?
- ✓ How much money do you have to spend?
- ✓ How many people should be in the group? How many are you realistically likely to be able to attract?
- ✓ What incentives can/will you offer people to attend? Do you need to consider payment/expenses to get people to turn up?
- ✓ Are you prepared to pay people for travel, childcare expenses, their time etc.?
- ✓ Are you prepared to put time into developing the group – provide adequate information/training to enable them to participate effectively?
- ✓ Who should facilitate the meeting and are they trained?
- ✓ Should the facilitator be independent of the PCT/trust?
- ✓ Who should take notes and are they trained?
- ✓ Where should it be held?
- ✓ When would be the best time of day to hold it?
- ✓ Have you considered making a video or audiotape of the discussion? This is useful but you will need to have the group's consent to do this.
- ✓ What are the ground rules? e.g. no side conversations/respect confidences/everyone has opinions and is entitled to be heard.
- ✓ What questions should you ask?
- ✓ What level of information do participants need?
- ✓ How long should a group discussion last? As a rule of thumb, two hours is the maximum time, but your group might have special requirements
- ✓ How will you analyse the data?
- ✓ What will you do with it?
- ✓ How will you feed back the outcome?
- ✓ Will you provide refreshments? Some people, dependent on culture, may not consider sandwiches as an appropriate menu. You may wish to provide hot food. If you do decide to provide sandwiches remember to have separate trays for vegetarians and, if appropriate, one for Muslims (do not mix ham/pork related fillings with other fillings)

Notes on focus groups:

1. Participants in a group should, ideally, be broadly homogeneous in terms of age/sex/social class and other criteria relevant to the focus of discussion. For example, someone may be an unemployed or economically inactive (retired or full-time parent) nurse and someone else may be a lay expert in the subject of the focus group. Would you include them in a professional group or a lay group?
2. It may not be possible to recruit a homogeneous group within the time and money available, so the group may be a mix of people by age, sex, ethnicity etc. This will make the dynamics more difficult to manage and will require a very experienced facilitator. Data collected might need further validation amongst other groups. In such circumstances interviews may be more appropriate.
3. Groups which involve lay people and professionals (patients and staff, for example), or experts and non-experts, are more difficult and require ground rules to be agreed about jargon and sharing of expertise. These groups are not by definition focus groups and would be better called workshops or seminars.
4. Mixed groups or mixed workshops may not work. The disadvantages are that the non-expert may feel inhibited by the expert. Clearly opposing views may create unhelpful tensions. Lack of respect for the value of patients' experience or the knowledge of professionals may antagonise or create disillusionment in the group.
5. In such a group patients may feel inhibited in expressing their real feelings and staff may defend themselves and their colleagues and either further inhibit the patients or create an argument. If the staff refuse to acknowledge the reality of the patient's experience, the patient will become disillusioned and disinclined to express any opinion. This would not foster a suitable environment for a focus group.
6. The benefit of this approach may, however, be to open up the range of views and values of experts and non-experts, professionals and patients etc., in order to allow some recognition of differing perspectives and joint working to agree compromises.

Forums for debate

Meetings with patient and carer groups

Organised groups of people focusing around a common illness or condition, service or geographical location. These may be local community based groups or branches of national patient/carer organisations, for example the Kidney Patient's Association. They may be support groups, for example coronary heart disease support groups or groups set up to give a 'user view' for example cancer user groups, mental health groups or maternity services liaison committees.

Contact may be initiated by either party and may have a set agenda or be unstructured.

PROS	CONS
Captive audience which is: – knowledgeable – committed	Are only able to offer feedback on issues that relate to their particular experience.
Time – relatively easy and quick to make contact	They could be biased, or limited in their range of views
Can put you in touch with users and carers for future focus groups	Are you involving, consulting or lobbying?
Can build on-going partnership	Possible lack of objectivity – do you need to ask other users as well?
Collective knowledge which does not rely on views of one individual	

So you think you want a meeting with patient or carer groups...

- Do you know what groups exist in relation to this issue? How can you find out? NHS Direct or the local voluntary/community sector directories may be useful.
- Are you clear about why you want to meet with them or, if they have set up the meeting, what they want to talk to you about?
- Are you prepared to discuss the group's agenda as well as ask them for their views?
- What will you do about the issues the group might raise which are not on your agenda?

- How easily can you put across your agenda – is there a chance it could be misconstrued?
- Have you got resources/a suitable venue/time?
- Do you intend this to be the start of on-going partnership working or a one off initiative?
- Remember you are not the only expert here!

If you still think a meeting with a patient or carer group is the best approach consider the following checklist...

- ✓ Do you know if the group meets regularly, where and at what time?
- ✓ Have you arranged to meet the group at a venue and time to suit them?
- ✓ Have you given the group sufficient lead-time for it to mobilise its members?
- ✓ Have you given the group clear information about the purpose of meeting beforehand?
- ✓ Will you provide refreshments. Some people, dependent on culture, may not consider sandwiches as an appropriate menu. You may wish to provide hot food. If you do decide to provide sandwiches remember to have separate trays for vegetarians and, if appropriate, one for Muslims (do not mix ham/pork related fillings with other fillings)
- ✓ Will you provide a crèche, expenses, an interpreter?
- ✓ Have you made it clear whether this is a one-off initiative or on-going partnership?
- ✓ Have you agreed how you will feedback to the group?
- ✓ If this is an on-going partnership, you will need to agree how you are going to work together in the future.

Forums for debate

Public meetings

A meeting for which there has been an open invitation. There may be a set agenda or discussion may focus on issues raised at the meeting. In the past, public meetings have tended to be the 'default position' for formal public consultation activities. However more recently, they have been used more creatively and there has been more interaction and engagement with the public. e.g. market place events.

PROS	CONS
Opportunity for a wide range of people to comment or raise issues and, importantly, directly challenge issues	There may be a very low turn out
Opportunity for the PCTs/ trusts to put their side of the story	A risky approach – you have no control over who attends or what might happen
PR value – the only public debate on the issues may have been through the media	Often beyond your control – e.g. individuals claiming that they are the 'voice of the people'
Provides an opportunity for joint consultation e.g. working with PCTs/trusts, local authorities and social services on issues of common interest	May be a quick fix – tokenistic
Offers opportunity for public to challenge issues directly which increases accountability	Takes organisation which costs time and money e.g. <ul style="list-style-type: none"> – hall hire – advertising – PA systems – travel expenses – crèche – refreshments
Lay bodies and pressure groups often like public meetings – an opportunity to challenge statutory organisations	The voluntary sector needs advance warning – lots of it
Provides an indicator of problem areas and local issues that may not have emerged previously. May provide a good indicator of where to focus attention in future	The audience may be hostile – will you need to inform the police?

PROS	CONS
	In the past there has been a tendency to 'default' to having public meetings even though feedback from attendees is unlikely to be representative of the local community
	May only attract interested parties/lobby/pressure groups etc
	There is never a best time or place to hold these meetings
	May need to hold more than one

So you think you want a public meeting...

- Why do you really want or need to hold a public meeting? Is this really a default or fallback position and would other approaches be more appropriate?
- Are you willing/prepared to deal with conflict?
- Are you willing to deal with unconstructive excitement at the meeting?
- Will you have a structured presentation and/or provide supplementary written information to participants on the issue?
- Are NHS staff confident and competent to answer questions from the floor on a range of issues? Have you got the right people?
- Could you talk about the issues to key individuals more effectively?
- Remember public meetings are often win-lose situations.
- Could the PCT/trust, local GPs, voluntary groups etc. have information stands at the meeting? This could be a way of raising awareness of the wider issues.
- Why are you opting for a public meeting?

If you still think a public meeting is the best approach consider the following checklist.

- ✓ Where should it be held?
- ✓ Is there disabled access?
- ✓ Is there sufficient car parking?
- ✓ Is the venue well known, how many people will it hold?

- ✓ Is the venue easily and quickly accessible by public transport?
- ✓ If anticipating the need to deal with hostile groups do you need to have an alternative exit/mobile phone for emergencies? Should you inform the police?
- ✓ What is the best time to hold the meeting – day/evening?
- ✓ Are the schools on holiday – will this make a difference?
- ✓ Are you going to allow time to meet the audience informally before the meeting?
- ✓ Who will be on the ‘platform party’ representing the NHS?
- ✓ Will senior staff in the organisation attend and will they be prepared to answer questions?
- ✓ Will people who might be required to answer questions be in the audience or on the platform?
- ✓ How are you going to arrange the seating?
- ✓ Would it be helpful to have non-executive members or clinicians in the audience to bring a different perspective to the debate?
- ✓ Who should Chair the meeting – have they the required skills, how are they perceived by the audience? Make sure you have the right person and not just the most senior person.
- ✓ Would it be better if the Chair was not associated with the organisation holding the meeting?
- ✓ What basic information do you need to give in order to set the scene? For example, do you need to explain the role of the PCT and set out the issue for discussion?
- ✓ Will you have an agenda?
- ✓ PA systems – do you need one? Do you need a loop system or a signer for people who are hearing impaired?
- ✓ How should information be presented? Beware of using jargon and being patronising.
- ✓ Would it be helpful to have experts available to answer specific questions, e.g. clinicians?
- ✓ Will you need to prepare a presentation pack and provide training to speakers?

- ✓ Will you prepare an information pack to hand out to the public?
- ✓ How do you anticipate the public audience will receive your message/subject?
- ✓ Is the meeting intended to inform change or provide information?
- ✓ What can you change as a result of the meeting – where will the views and concerns raised go after the meeting?
- ✓ How will you feed back to the audience and the general public the outcome of the consultation?
- ✓ Refreshments – some people, dependant on culture, may not consider sandwiches as an appropriate menu. You may wish to provide hot food. If you do decide to provide sandwiches remember to have clearly marked trays for vegetarian selections and also give consideration to dietary requirements for people with religious beliefs for example, do not mix ham/ pork related fillings with other fillings or do not eat pork.
- ✓ Also bear in mind that providing a “good” standard of refreshments may sometimes attract adverse comments from some participants about the use of NHS money.

Forums for debate

Seminars

A seminar is a discussion group that aims to impart, exchange and receive information. There is much greater input from the facilitator than in a focus group.

PROS	CONS
An opportunity for NHS organisations to provide information and seek views	Could be extremely boring – someone talking at the public – unless a range of techniques are used e.g. presentations, group discussions, displays etc
A way of securing partnership and involvement	Needs careful planning to get the best results – think about ways to make it interactive
A way of creating a listening culture, and soliciting sympathetic views based on a better understanding of the relevant issues	You may attract individuals who are only interested in airing personal grievances
A means of promoting ‘partnership’ and equality between agencies, voluntary sector and the local population	Cost: reimbursement of expenses for child care, travel and refreshments
A way of identifying areas where information will help improve the quality of community participation	
Tenants/residents associations, disease or issue specific groups, individuals, voluntary and statutory sector organisations etc are likely to find this process rewarding	

So you think you are going to organise a seminar...

- What format will the seminar take e.g. presentations, workshops, and plenary sessions?
- Where will it be held?
- Who should be invited and by what means, i.e. personal invite, telephone call, letter?
- How many people do you want to attend?
- What do you want to achieve and is this the best way of doing it?

If you still think holding a seminar is the best approach consider the following checklist...

- ✓ Is there disabled access (parking, building access, toilet facilities for people who use wheelchairs etc)?
- ✓ Do you need to have a loop system and/or signer for people who have a hearing impairment?
- ✓ Is the venue well known?
- ✓ How many will it hold?
- ✓ What is the best time to hold the meeting – day/evening?
If daytime remember that senior citizens may not be able to use their travel pass between certain times. If in the evening you may need to provide transport for some groups of people e.g. older people, women, disabled people
- ✓ Will you need to provide interpreters?
- ✓ Do you know how to find/make contact with the people you want to invite, e.g. groups the NHS has traditionally found hard to reach?
- ✓ How will the event be advertised?
- ✓ Are your mailing lists up to date?
- ✓ Who is going to facilitate or chair the seminar? Would it be better to have someone not associated with the NHS organisation?
- ✓ Who is going to speak/present?
- ✓ What format should the programme take? The objectives should be made explicit and agreed at the start
- ✓ Have you enough trained staff to facilitate the workshops?
- ✓ How are you going to feedback to the participants the outcome of the event?
- ✓ Refreshments – some people, dependent on culture, may not consider sandwiches as an appropriate menu. You may wish to provide hot food. If you do decide to provide sandwiches remember to have separate trays for vegetarians and, if appropriate, one for Muslims (do not mix ham/pork related fillings with other fillings)

Forums for debate

Targeting interested people

This is a method that focuses on engaging with people where they come together for another specific purpose. For example, parents outside schools, older people at social events such as luncheon clubs. People using primary care services may form an **advisory or reference group**. Such groups of people may be convened by the PCT/trust. A group may come together briefly (for example, when talking with young people who are waiting in a cinema queue).

PROS	CONS
Potential to reach large mixed audience and identify trends and issues	People may not be interested and therefore not wish to participate
Obtain a wide, cross section of views	It may be difficult to use all the information obtained – you may lose credibility
An opportunity to <ul style="list-style-type: none"> ■ obtain positive and negative feedback on a range of services; ■ give information (education) about NHS services and systems; ■ target existing activities/meetings; ■ form a group which will act in the longer term as an advisory or reference group; ■ have wider ranging discussion 	May be viewed as anecdotal and therefore seen as too subjective What about the views of the wider public? Should these be considered as well?
	Time consuming – are the staff who need to listen prepared to go out to engage with people at a time that suits the group?

So you think you should target interested people...

- Are you clear about your main objective:
 - education?
 - giving information?
 - gaining views on specific issues?
 - forming a reference/advisory group?
- Don't assume people will be interested
- Are you prepared to do the background research to identify where to locate the people who will be most interested in the issues?

If you still think targeting interested people is the best approach consider the following checklist...

- ✓ How will you actually target people? Could you use websites or email?
- ✓ Where do the people you want to target meet/come together?
- ✓ What would be the most appropriate venue and time to meet with people? Are you governed by when and where they meet?
- ✓ If you want to convene a group, are you prepared to pay for travel, childminding, care etc., to allow people to participate?
- ✓ Have you considered how you will use anecdotal data?
- ✓ How will you feed back the outcome of the consultation to the groups you have targeted?
- ✓ Will you provide refreshments? Some people, dependent on culture, may not consider sandwiches as an appropriate menu. You may wish to provide hot food. If you do decide to provide sandwiches remember to have separate trays for vegetarians and, if appropriate, one for Muslims (do not mix ham/pork related fillings with other fillings)

Example – To establish a cultural and religious circumcision service for infant boys in Leeds the Health Authority established a project group that was led by a Specialist Registrar in Public Health and included South Asian, African and Caribbean voluntary groups, representatives from the Community Trust, PCG and local authority. Voluntary groups working with the Health Authority organised five events for the Pakistani, Bangladeshi, Arabic, and African and Caribbean communities.

The service specification from the project group reflected the communities' priorities for a culturally sensitive service.

Participation

Citizens' Juries

A Citizens' Jury is a model of public participation that is particularly appropriate for involving the wider public in decision making; specifically decisions about strategic planning choices or service prioritising. The jury consists of 12 – 16 members of the public selected as a cross section of the community. They meet for several days to hear 'witness' evidence and examine the issue in depth before making recommendations (usually non-binding) to the NHS organisation. An independent moderator assists the smooth running of the process.

PROS	CONS
People reflect broadly the characteristics of the wider population	Although the jurors are drawn from the local population. Their different views and values may not necessarily reflect those of the wider population
People participate as citizens not as patients, users or carers. So, in theory, they are not direct stakeholders	You may attract jurors who find it difficult to articulate their views, concerns, experiences
Jurors are given detailed information about the issue they are asked to decide on	It may be difficult to clarify and focus on the exact question to be put to the jury
NHS organisations can pose difficult issues to the jury around prioritisation of services. These issues may be very subjective involving value judgements in reaching decisions	There may be a range of issues requiring decisions, and it may be difficult to decide which to open up to a Citizens' Jury
Jurors can call in other people: professionals, patients etc. to give 'evidence' to them so they are able to get a rounded understanding	The jury takes an enormous amount of planning in order to make it a success. This may take one person all their time for a few months
The process is not rushed and jurors are able to rationalise and discuss their decision as a group	It is costly at around £25,000, this is just the jury costs, and does not include hidden internal planning costs such as staff time
If the NHS organisation makes a decision different from the juries decision, it has committed itself to justify the reason why and make clear the basis on which the decision was made	The NHS organisation is not obliged to act on the jury's decision and may choose not to but should explain its reasons for this

PROS	CONS
Aids openness in decision making as proceedings should take place in public	A legal jury works together to reach a majority consensus. The Citizens' Jury splits into cells (small groups) so more difficult to reach a consensus. A consensus may not be reached

So you think you are going to use a Citizens' Jury approach...

- Do you have a specific and focused issue on which a decision needs to be made?

If you still think a Citizens' Jury would be the best approach, consider the following checklist...

- ✓ Is the NHS organisations' board fully committed to this idea?
- ✓ Do you have the necessary time to dedicate to the planning of this exercise?
- ✓ Who is in support of this exercise?
- ✓ Is it possible to provide the jurors with the kind of information they need?
- ✓ Are there witnesses willing and able to attend as required?
- ✓ Is the decision one that can be influenced by the Citizens' Jury?
Or are there other factors at play, which have the ultimate influence?
- ✓ Do you have the funding to do it properly?
- ✓ How will you recruit jurors?
- ✓ Where will it be held?
- ✓ Will you be able to access experienced support to run this exercise?

Participation

Expert Patients

'Expert Patient' is a term used in the White Paper Saving Lives, to refer to people who have experience of a condition or illness and who are prepared to share it to convey knowledge about living with it to others. It is mainly used to refer to people taking part in self-management programmes for example the Expert Patients Programme which enables people with a condition to train others with a similar long term condition to develop skills in managing their own illness.

PROS	CONS
Easy to access	Danger that the 'professional patient' may lose touch with their original experience
Expert patients are a skilled and knowledgeable resource	Some Expert Patients could hold views that are limited or biased
Expert Patients can work independently to empower others	Could restrict access to broader and more diverse range of patients

So you think you want to work with Expert Patients...

- Are you clear about the issues you would like to engage Expert Patients in?
- Have you considered the resources they might need to get involved?
e.g. training, expenses, support
- Are you prepared not to be the expert!

If you still think working with Expert Patients is the best approach consider the following checklist...

- ✓ Do you know how to identify and access Expert Patients?
- ✓ Are you clear about the issue you are involving them in?
- ✓ Have you agreed what support and or resources they will require?
- ✓ How will you evaluate their participation?
- ✓ How will the information be used?

Participation

Health panels

Health panels have primarily been used to explore local people's views on policy issues and the allocation of health service resources. Panels are usually made up of between eight to twelve people who are recruited using a quota sampling technique to reflect the socio-economic make-up of the area. e.g. the Asian community is diverse, the panel should relate closely to local demography – proportional balance. To ensure a regular supply of new voices each panel member has a fixed term and is then replaced by a new person. Panels usually discuss topics which are 'live' i.e. of genuine concern to the organisation running the panels. Panels can raise issues that are of concern to its members.

Another type of panel is a postal panel or internet panel. These are generally of a larger representative group of people who may be sent questionnaires or telephoned on particular issues. This type of panel can be useful to obtain views from a particular group who may not come to a session or may be otherwise difficult to reach: such as carers, young men, people with disabilities or minority ethnic groups.

PROS	CONS
Health panels offer the opportunity for complex issues to be discussed and deliberated by people in an informed way	If too many issues are discussed there will be discussion and little time to allow debate or panel members may end up just giving their views rather than the reasoning behind them
Panels are useful for views on resource allocation and priorities between set treatments	Professionals draw up the information given to panel members before the panel meets. They anticipate what type of information panel members may need to rationalise their view. It may be unknowingly selective or inadequate. Some panels employ an independent facilitator to balance perspectives
People on panels gain information about a wide range of issues	At panel sessions additional information requested by panel members may not be available, particularly if the facilitator is not from an NHS organisation

PROS	CONS
People on the panel receive some information on the issues being discussed before they meet as a panel. They are asked to get the views of their family and friends on issues and bring them to the panel	The NHS organisation does not have to base its decision on the panel's view. However, the credibility of both may suffer if the responses of the panel are dealt with in a patronising or tokenistic way
Panels reflect a cross section of the population and therefore provide an opportunity for minority ethnic communities and others to give their views	Panels do not provide quantitative information because the number of panel members taking part is too small
Panels can be externally facilitated which gives them independence and increased credibility. All members of the panel should be encouraged to have their say	The success of a panel discussion is heavily dependent on the skill of the facilitator
Panel discussions are usually recorded and can be analysed and presented back to the NHS organisation in a meaningful way. This analysis and recording can be done independently so as to reduce charges of bias	The results of the discussion may be less credible if the facilitator is not independent
Panels can meet at regular intervals. This helps to develop a dialogue with local communities	Panels may be costly to maintain.
People often enjoy taking part in health panels. They find they have a voice and can have a meaningful debate. Panels can move towards consensus as a group	Although panels do discuss the members' views they may not have time to find the reasons for them. Often views are collected at the end of discussion using voting and scoring slips
The views of panel members can be used effectively to contribute to the professional debate	

So you think you are going to use a health panel approach...

- Do you want well-deliberated public views on complex issues?
- Are you prepared to spend time and resources on informing the panel so that it can give a reasoned view?
- Do you have sufficient resources to sustain a panel?

- Is the NHS organisation really committed to taking panel views into account in decision making?

If you still think a health panel would be the best approach, consider the following checklist...

- ✓ How will you recruit your panel? Make recruitment criteria open and transparent
- ✓ How much money do you have?
- ✓ Who will do the recruitment?
- ✓ Who will facilitate the panels?
- ✓ Who will decide what issues go to the panels?
- ✓ Are you prepared to consider proposals that the panel initiates and you have not previously considered?
- ✓ Who will prepare the information and decide what's relevant and what isn't?
- ✓ Who will be responsible for planning and co-ordinating the health panels?
- ✓ How will you analyse the data from the panels?

Example – The Somerset Health Panels are an on-going consultation project. Local people in each PCT area meet twice a year to discuss important health and social care issues.

The objective is to give maximum voice and influence to local people with regard their own care and decisions about reconfiguration and the delivery of health services locally.

The project consists of twelve panels, each made up of a broad cross spectrum of twelve local people, who sit on the panel for three meetings (eighteen months) and then retire, ensuring continuous rotation of new members. Panel members are randomly recruited, door to door, to a quota on age, sex, educational status and dependent children under 15. The panels normally discuss two issues over an approximate two hour period. The topics for discussion are submitted from the health and social care community. A maximum of two observers may attend per meeting.

Participation

Shadowing

Shadowing allows staff to gain a new and different perspective of the patient's experience by accompanying a patient or user as they use services. An agreed period of time is spent shadowing an individual and lessons learnt are used to improve future services.

PROS	CONS
Allows first hand experience of a service from the patient's perspective	Can be time consuming
Allows a chance to see the culture and climate within which other individuals work	Needs a lot of preparation around issues like confidentiality, health and safety etc.
Strongly supports understanding and rapport between staff and patients	Needs commitment to be flexible and non-judgemental
It is suitable for all levels of staff, including executive and non executive board members, as shadowing is effective at bridging cultures	

So you think you want to set up an opportunity for shadowing

- Are you sure that your NHS organisation and the individuals involved are prepared to invest the amount of time needed? For example, will the person shadowing be prepared to shadow a patient using public transport to access an outpatient clinic and then experience waiting with them to be seen by a consultant?
- Think about how you will use the insights gained from shadowing and how you might involve the person being shadowed in developing improvements for the future.

If you still think shadowing is the best approach consider the following checklist...

- ✓ Plan in advance – make sure that key people in the department concerned know what is going on, but make sure that the result is not 'red carpet treatment'.
- ✓ How will you gain the patient or users informed agreement to be shadowed?

- ✓ Prepare the patient and shadower to spend non-judgmental time together at the end to reflect on their experience.
- ✓ Think of health and safety and confidentiality requirements.
- ✓ Organise a meeting or telephone conversation for the patient and shadower to discuss ground rules. For example, make it clear that the patient or user can terminate the shadowing at any time or may exclude the shadowing partner from any part of the experience.
- ✓ For security reasons, ensure appropriate departmental staff are informed that shadowing is being undertaken.
- ✓ Ensure that the shadower is prepared to spend as much time as it takes to experience the service with the patient.
- ✓ Ensure that the person shadowed receives feedback on the event and that they have an opportunity to make suggestions about how things could be changed for the better.
- ✓ Consider whether you might want to hold follow-up sessions for patients and their shadowers, perhaps as a focus group or forum.

Participation

Story telling

Story telling is a patient-centred approach that allows patients to tell their story to a member of staff from a different clinical area. The interview is taped and a 'mind map' extracted. The patient is then asked to confirm what was heard. From this an action plan is drawn up and shared back with the patient.

PROS	CONS
You follow the patient's agenda and listen to whatever they want to say	Sometimes the patient does not say anything about the health care they are receiving from the relevant department
The interview is undertaken by a colleague from a different department and therefore should not be biased in any way	It is very time consuming both to organise and undertake
It is taped so you are able to take direct quotes for the 'mind map'	It requires the assistance of staff from other departments
Often things you may think are problems are not high on the patient's agenda	The things that patients are worried about may need work which may require resources
It is patient focused	You set the criteria for choosing a patient and select the patients that fit the criteria
A useful training tool and for local changes	Without a mechanism for feeding up wider issues some of the benefits will be lost

So you think you want to use story telling....

- Before you start – are you clear about how you will use the information given to you by the patients?
- Have you considered what the expectations may be of patients who tell their story and of the member of staff who listens to the stories?

If you still think story telling would be the best approach, consider the following checklist...

- ✓ What criteria will you set for selecting patients?
- ✓ How will you set this?
- ✓ Is your department committed to this idea and clear how it will respond to issues raised by the patients and/or the member of staff who undertook the interview?
- ✓ Has the department considered how it would respond to difficult personnel issues?
- ✓ What procedures exist within the department/trust/PCT for agreeing processes that will bring about sustainable change to the way services are delivered?
- ✓ Have you considered how you will feedback to individual patients how their interviews have been used by the department/trust/PCT.

Example – Patients from A&E, Outpatients, General Surgery and General Medicine at East Somerset NHS Trust were invited by participants on the RCN Clinical Leadership programme to “tell their story” of the care they had received. The stories were tape-recorded by a colleague and peer reviewed by the lead nurse.

The Trust is finding out what the patient’s perspective is of what was good or bad about the care and their experience of the service provided.

Partnership

Community development

Community development is an approach that involves the community in identifying its own health and social care needs and finding ways to address them. This might be through influencing and informing commissioners and providers and other key agencies of the communities right to help shape service provision. It is likely to involve supporting the community to set up and sustain support systems and projects.

PROS	CONS
It strengthens local community infrastructure and is a basis for leveraging in other resources. Local feelings are taken into account	Very local: can be centred around a housing estate, GP practice or community centre – this may not be a problem
It can establish links with traditionally harder to reach groups, people who are not registered with a GP and those who are not in touch with statutory services	Community development is not about representativeness – this may not be a problem
It provides an opportunity for local people to examine what they feel they need to improve their health and well being. It focuses on lay rather than professional views	Costs are incurred in addition to the worker's salary: – pump priming to start project work – practical support to evaluate work
It develops confidence and self-esteem in local people and offers the opportunity to develop new skills and knowledge. This leads to people taking more control over their own lives and environment	The results are unpredictable. By contrast with a consultation exercise, where the community can be focused, community development outputs may lead to new directions
It provides assessments in areas where the health and social care needs are often directly poverty related and cannot be tackled in isolation of other agencies and the community	Needs identified locally cannot automatically be implemented as they often involve other agencies, factors or dynamics
It facilitates collaboration between sectors and brings statutory and voluntary agencies together with local people	The nature of the work involves developing open and honest relationships with partner agencies and the community. This takes time, commitment and experience

PROS	CONS
It is long-term, thus allowing in-depth understanding and commitment. It highlights broader health concerns or related determinants such as transport, employment, housing, leisure facilities etc.	It is time consuming to get it right initially. It requires long-term commitment and (preferably joint) funding
It can be a starting point to attract more and bigger funding packages to a specific place or area. A small investment can bring enormous benefits	The outputs might be costly to implement
	There may not be an outcome for a long time

So you think you are going to use a community development approach...

- Are you prepared to make a long-term commitment – minimum of three years?
- Have you got the funding?
- Are you able to support the community to develop their own projects and support networks?
- Lay people's views about medical care may be different from those of professionals at all levels, including GPs.
- How will the organisation use and respond to community development?
- Do not make promises that you may not be able to respond to.

If you are still think community development would be the best approach, consider the following checklist...

- ✓ Will you be able to respond to the needs identified?
- ✓ Do you have an agreed mechanism for change?
- ✓ What are the joint commissioning or formalised partnership structures which you will feed into?
- ✓ Will there be a budget available for small projects to be set up for training lay people in research skills, committee skills, assertiveness etc.
- ✓ Have you considered how you will feedback how the lay view compares to those of professionals – neither is paramount?

- ✓ What support and resources can you actually put in to show that you are committed?
- ✓ Are people at all levels of the organisation(s) aware and committed to what community development is and what it can do?
- ✓ Can you operate and influence at the different levels required?

Partnership

Large group processes

Large group processes are models of public involvement developed to work with a large number of stakeholders in sharing vision and change management. These models are appropriate for involving a range of stakeholders, including local people and those who have access to resources to enable change to take place. These processes are most effective on issues that affect a large number of people across organisations and communities.

The advantage of using these processes is the speed of implementation of outcomes, it is possible to involve people who are closest to the issue or problem being discussed, exchange information with other stakeholders. Three processes are discussed here: search conference, open space and team syntegrity. Each of these processes involves between 30 and 120 people. They are highly participative, fundamentally assume that people want to be engaged and have a voice, and assume that people are capable of taking some control and organising themselves for the task at hand.

PROS	CONS
Emphasis on self-management in small group work	Processes are time-consuming
Openness	Processes take an enormous amount of planning and organising
Practitioners claim that the processes are designed to empower participants	Can be costly
Everyone is equal and an expert	
The method upholds the idea that individuals are experts in their own lives	
There are facilitators but no other experts	
Processes are consensual	
Processes can bring together key stakeholder groups who are often opposed to each other	

Future search conference

Future search conference is a way for a community or organisation to create a shared vision for its future. It brings those with power to make decisions together with those affected by a decision, to try to agree on a plan of action. It enrolls a large group of stakeholders, selected because they have power or information on the topic at hand or are affected by outcomes. Ideally the process involves 64 people, who form eight stakeholder groups. They take part in a highly-structured two to three day process covering five stages: reviewing the past, exploring the present, creating ideal future scenarios, and identifying shared vision. The conference ends with the development of action plans. Self-selected action groups develop projects and commit themselves to action towards their vision.

The process is designed to empower participants and works on the principle that people are experts in their own lives.

Search conference requires at least one facilitator, and a large room.

Open space

Open space is a democratic framework that enables an unlimited number of participants to create their own programme of discussions around a central theme. It is particularly effective in generating participation, learning and commitment. It works well if there is an urgent issue needing quick action and when a large and diverse group is involved. The process starts with everyone arranged in a circle, and people are invited to identify issues that they are passionate about. These are written on a sheet. Groups may naturally form across more formal boundaries, and may wish to continue working together after the open space event.

Team synteegrity

Team synteegrity is a process for enabling large groups to work together in a democratic and non-hierarchical fashion to capture their best thinking. It is particularly appropriate to use when groups are characterised by high levels of diversity – either because they come from different professional backgrounds or because they come from different cultural, political or social perspectives. The process engages 30+ people for three to five days in an intense mix of facilitated thinking and dialogue. The groups and themes for discussion are organised around a geometric structure. The structure provides the schedule for interaction and discussion.

Dealing with conflict and handling complaints and in the public arena

Dealing with conflict and handling complaints and in the public arena

Dealing with conflict

The purpose of this section is to highlight some of the issues around handling conflict. However it is recommended that specialised training is provided for staff.

‘Conflict is a process which begins when one party perceives that another party has frustrated, or is about to frustrate, some concern of his’¹

Conflict can stimulate new ideas and solutions but it can also result in gridlock. Gridlock occurs when one or more parties continue to behave as if they are independent of everyone and everything else. In order to unlock the situation it is necessary to connect the parties with what is important to all concerned.

Conflict resolution is a process that has as its objective the ending of the conflict between the disagreeing parties. 5 stages of conflict have been identified as:²

1. **latent** – where the conditions for conflict exist
2. **perceived** – where the individuals or groups concerned know that there is a conflict but nothing has been publicly declared
3. **felt** – where one or more parties feel tense and anxious
4. **manifest** – where there is observable behaviour designated to frustrate others’ attempts to achieve their goals
5. **aftermath** – which is the relationship between the parties after the conflict has been resolved or suppressed.

1 K.W. Thomas, 1976

2 L. Pondy 1967

There are different approaches that can be taken to resolving conflict – each has two dimensions:

- how assertive or unassertive each party is in pursuing its own concerns
- how cooperative or uncooperative each is in satisfying the concerns of the other

For example there might be conflict over the proposed siting of a new service. In this case the parties concerned could be asked what is important to them. When common criteria can be found there is an opportunity to open up and move with the debate.

It is important that NHS staff are aware of the stages of conflict and have a plan for how they will handle it in the public arena.

Handling complaints

This section deals specifically with complaints that arise when involving or consulting patients and the public. For detailed information consult the current NHS complaints procedures.

When using any method for engaging patients and the public individuals or groups may take the opportunity of being at a public forum to complain about services, either something that may have happened to them or a member of their family or a friend or neighbour.

If a person makes a complaint about their health care during a public involvement event you should:

- ✓ listen, acknowledge but do not get involved in detail. Do not try to justify an NHS action but do acknowledge the complainant's feelings in a sensitive way
- ✓ have copies of the NHS Complaints leaflet with you to hand out
- ✓ give the name and contact information of the relevant, designated Complaints Manager and the PALS if appropriate
- ✓ make sure you know where to refer people who wish to complain, e.g. the complaints section at the PCT or trust. You may wish to provide information about the ICAS
- ✓ explain the complaints procedures – make sure you know the outline and time-related standards contained in the current NHS complaints procedure
- ✓ if you think the person complaining may have difficulty in articulating or pursuing a complaint you may wish to take his or her name and contact details and pass it on to the PALS to follow up.

The new patient and public involvement systems

The new patient and public involvement systems

For over 25 years Community Health Councils (CHCs) have undertaken the role of representing the interests of the public in local health services. The NHS Reform and Health Care Professions Act 2002 abolishes CHCs and puts in place the Commission for Patient and Public Involvement in Health and patients' forums. At the time of publication of this guidance it is not finalised when all the new systems will come into place. For example whilst the roles and responsibilities of the Commission and patients' forums are set, the timetable for implementation of the patients' forums is still under review. This guidance makes it clear what the roles are but recognises that they will develop over time.

Patients' forums

Patients' forums will be made up of local people and will represent the views of communities about the quality and configuration of health services to PCTs and trusts. This representation will be actively finding out what patients, carers and families think about their health services, and whether those services are meeting their needs.

They will:

- monitor and review NHS services of their trust from the patient's perspective, using information from a number of sources, including PALS and the formal complaints system and make reports and recommendations to the trust
- be able to inspect premises used by NHS patients from the perspective of the patient's experience of services. This will include new powers to inspect premises where primary care and NHS care are provided by the independent sector
- produce an annual report of their work and make their findings and reports available. These reports may be published as part of an annual Patient Prospectus that all NHS trusts will be expected to issue
- be able to make referrals to OSCs, the CPPIH and any other body they think appropriate

- collect information on the range and operation of services, identify trends and make reports to decision makers
- monitor the quality of the PALS in the area, and bring any shortcomings in the service to the attention of the relevant trust and if necessary to the Commission for Patient and Public Involvement in Health.

Forum members will be included as candidates for appointment to trust boards.

PCT patients' forum

In addition to the above, PCT patients' forums will:

- promote the involvement of the public in decisions and consultations on matters affecting their health
- provide independent complaints advocacy, commissioning the more specialist services
- put forward the views of the public to key local decision-makers
- provide a 'virtual' one stop shop service by providing advice and information to the public about public involvement, and complaints processes
- monitor how well the local NHS is meeting its duty to involve and consult the public
- advise the relevant health bodies and other decision makers about how to encourage the public to be involved in the decision making processes and in particular to meet their duties under section 11 of the HSCA (where applicable).

Patient Advice and Liaison Service

In every NHS trust and PCT there will be a **Patient Advice and Liaison Service (PALS)** that will:

- resolve problems on the spot
- provide information to patients, carers and their families about local health services and put people in contact with local support groups

- help people to access the NHS complaints procedure and direct people to the independent complaints advocacy service (ICAS)
- act as an early warning system for trusts and patients' forums (when set up) by monitoring trends and highlighting gaps in services and making reports for action to trust management.

Overview and Scrutiny Committees

Every local authority has an overview and scrutiny committee. The Health and Social Care Act 2012 provides new powers to overview and scrutiny committees of those local authorities with social services responsibilities (county councils, London Borough Councils, unitary authorities, Common Council of the City of London and the Council for the Isles of Scilly).

They can:

- review and scrutinise all matters relating to the planning, provision and operation of health services in the area of the local authority (as stated in the regulations)
- make reports and recommendations to local NHS bodies and their local authority on any matter reviewed or scrutinised and must be consulted by NHS bodies on any proposal for a substantial development or variation in health services
- have matter referred to them by patients' forums (when set up)
- require NHS bodies to provide information to them and
- require officers to attend to answer questions.

The regulations for overview and scrutiny of health do not define 'substantial'. It is the responsibility of NHS organisations to reach a local understanding or definition with their overview and scrutiny committee(s) on any key proposals. This process should be informed by discussions with other key stakeholders including patients' forums (when set up).

[Link OSC Guidance](#)

Commission for Patient and Public Involvement in Health (CPPIH)

Nationally there is a **Commission for Patient and Public Involvement in Health**. It is a non-departmental public body, which was established early in January 2003. Its three core functions are:

- advising and assisting patients' forums (when set up) and providers of independent complaints advocacy services
- representing to the Secretary of State and certain other bodies the views, as regards the arrangements on PPI, consultation and independent complaints advocacy services, of patients' forums and voluntary organisations representing patients and
- promoting at a national level the involvement of the public in consultations and processes leading to decisions by key health decision makers.

It:

- sets standards for patients' forums and providers of independent complaints advocacy
- monitors and make recommendations about their performance to patients' forums and providers of independent complaints advocacy support (ICAS)
- submits reports to the Secretary of State and other bodies on how the whole system of patient and public involvement and independent complaints advocacy services are working and advise him about them
- makes reports as it sees fit to other national bodies such as CHI, the National Care Standards Commission and the National Patient Safety Agency on patient and public involvement issues and issues that in its opinion give rise to concern about the safety or welfare of patients that have not or are not being dealt with properly
- carries out national reviews of services from the patients' perspective – collating data from forums and making recommendations to the Secretary of State, and to other bodies and persons it considers appropriate
- assists and facilitates forums in co-ordinating their activities

- takes account of forums' views on the arrangements for PPI, consultation and independent complaints advocacy services
- has powers to require information be provided to it from health service bodies.

Link Regulation 9 CPPIH Functions Regulations and OSC Regulations

Independent Complaints Advocacy Services (ICAS)

It is the duty of the Secretary of State under section 12 of the HSCA to make provision for ICAS. PCT patients' forums will be able to provide or commission. ICAS will:

- focus on helping individuals to pursue a complaint about a particular NHS service
- aim to ensure complainants have access to the support they need
- provide complainants with information and advice
- be an advocate for the patient e.g. write letters, attend meetings and speak on their behalf
- ensure that patients have a clear understanding of what to expect and a realistic expectation of the possible outcome
- advise patients of the options open to them once a response has been received.

Patients will be able to access ICAS through many avenues. PALS will provide a valuable gateway both in terms of raising patients' awareness of the service and referring patients to it. Complaints managers at trust level will also promote the service and signpost patients to it.

The Commission for Patient and Public Involvement in Health will identify and disseminate quality standards, set criteria and provide a national assessment for the service.

Glossary

Glossary

CHI	Commission for Health Improvement
CHC	Community Health Council
Compact	See practice guidance 4
Consult	Have deliberations (<i>with</i> person, or abs). 2. v.t. Seek information or advice from (person, book, one's watch, etc); take into consideration (feelings, interests) ¹
DH	Department of Health
DNA	Did not attend
HSCA	Health and Social Care Act 2001
ICAS	Independent Complaints Advocacy Service
Involve	Include (<i>in</i>) ²
LSP	Local Strategic Partnership
IRP	Independent Reconfiguration Panel
PALS	Patient Advice and Liaison Service
Patients	People who are currently using health services
Patients and the public	The term patients and the public is used in this Guidance to include patients, users and carers as well as the public
PCG	Primary Care Group
PCT	Primary Care Trust
PEC	Professional Executive Committee
PFI	Private Finance Initiative
PPF	Planning and Priorities Framework 2003 – 2006
PPI	Patient and public Involvement
Public	The general public/citizens
NSF	National Service Framework
OSC	Overview and scrutiny committee
SoS	Secretary of State
Staff	People who work in the NHS in all capacities

1 Concise Oxford Dictionary Definition

2 Concise Oxford Dictionary Definition

Further reading and useful websites

Further reading and useful websites

Choosing what approach to use

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Methods and approaches

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Compacts (with voluntary organisations)

Copies of Compact publications (including the codes of good practice and guidance for establishing a Local compact) can be obtained from:

Home Office
Active Community Unit
Horseferry House
Dean Ryle Street
London SW1P 2AW

Tel: 0207 217 8400
e-mail: public_enquiry.acu@homeoffice.gsi.gov.uk
internet: <http://www.homeoffice.gov.uk/acu/acu.htm>

Download Compact publications from:
<http://www.ncvo-vol.org.uk/main/gateway/compact.html>

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<http://www.doh.gov.uk/research/rd3/nhsrandd/consumers.htm>

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Public and Patient Involvement in London: a practical guide

<http://www.london.nhs.uk/modernising/london-p&pi.htm>

Well Connected a self assessment tool on community involvement designed to help organisations assess their progress, identify strengths and weakness, and highlight area for action. www.haznet.org.uk – choose the HAZs – view by HAZ and it is the first in the Bradford list

www.childrens-heart-fed.org.uk

www.collegeofhealth.org.uk

www.idea.gov.uk/knowledge

www.kingsfund.org.uk

www.natpact.nhs.uk

www.nel-involve.org.uk

www.nhsestates.gov.uk/patient_environment/index.asp

Policy makers guide to public involvement www.policyhub.gov.uk click on new policy making reports

www.princes-foundation.org/foundation/buidingdesign.html

Care trusts

The Care Trust website: www.doh.gov.uk/caretrusts

DH guidance on the governance of Care Trusts:

www.doh.gov.uk/caretrusts/governance.pdf

DH guidance on applications for Care Trust Status:

www.doh.gov.uk/caretrusts/application.pdf

Application for a PCT to Care Trust

Link <http://www.hms.gov.uk/si/si2001/20013787.htm>

Supporting policy documents

Building a safer NHS for Patients

Disability Discrimination Act

Learning to Listen

Quality protects www.doh.gov.gov.uk/qualityprotects

Race Relations Amendment Act

Reforming the NHS Complaints Procedure: a listening document

Shifting the Balance of Power within the NHS

Shifting the Balance of Power within the NHS: Communications, Feb 2002

Valuing people: a New Strategy for Learning Disability for the 21st Century

www.doh.gov.uk/learning_disabilities

Vital Connections

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