Patient and Public Involvement in Health:

The Evidence for Policy Implementation

A summary of the results of the Health in Partnership research programme

Compiled by Christine Farrell
April 2004
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In the evidence driven culture of the modern NHS, patient and public involvement has often had to struggle for attention. Many believe that it improves health outcomes, service delivery and planning and patient experience and few would argue against it. Nevertheless, there has been a nagging sense that patient and public involvement is a nice idea with little real justification. How refreshing then to read the summaries of the research in this report.

Patient and Public Involvement in Health: the evidence for policy implementation reviews and summarises twelve pieces of research about patient and public involvement. The outcomes for patients, for staff, for communities, and for health delivery are almost universally positive. The report shows that patient involvement improves patient satisfaction and is rewarding for professionals. Public involvement influences planning and services, and increases confidence and understanding.

But we must not be complacent. The Commission for Health Improvement’s report Unpacking the Patients’ Experience: Variations in the NHS patient experience in England (Feb 2004) showed that involvement rarely changed things despite good intentions and this report shows that information, communication and skill in engaging with communities all need to improve.

The command paper Building on the Best (Dec 2003), which was based to a great extent on consultation with patients and the public, together with this report are a powerful convergence of evidence from both informal consultation and scientific enquiry. Each reinforces the other. In Patient and Public Involvement in Health, science confirms anecdote and objective scrutiny confirms subjective opinion. At last the evidence is here and I hope we can use it to extend and deepen patient and public involvement in the health service. Patient and public involvement is now, I am pleased to say, not only right but evidence based.

Harry Cayton
Director for Patients and the Public
Department of Health
Executive Summary

The involvement of patients, carers and the public in health decision-making is at the heart of the modernisation of the NHS. This policy drive is founded on good evidence. *Health in Partnership*, a Department of Health research programme, adds considerably to this evidence. This report is a synthesis of the findings from the 12 research projects in the programme.

The following are the key findings from the programme:

- **Patient involvement** increases patient satisfaction. Benefits also include greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust, better relationships with professionals and positive health effects.

- Patients feel involved in their care when they are treated as equal partners, listened to and properly informed. Privacy and time for discussion are both required to achieve this.

- Health professionals are generally positive about patient involvement, seeing it as a rewarding process for themselves as well as for patients. These positive attitudes are qualified by resistance to giving up control of the consultation.

- Communication skills contribute to increased patient satisfaction, participation and health care behaviours. Everyone who deals with users, including support staff, has an important communication role.

- The organisation of clinics and consultations plays a significant role in enabling and inhibiting patient involvement. Time remains a scarce resource for patient involvement and management of time a critical professional skill.

- High quality information enables both self-management and patient involvement, but identifying the right information at the right time is difficult. Information is used in many ways by patients and the professional consultation is not always the focus of information-seeking.
• **Public involvement** influences the policies, plans and services of NHS organisations and increases the confidence, understanding and skills of the people who participate.

• Leadership, board commitment and inclusion in strategic planning are all important for the success of public involvement, which should be a shared corporate responsibility.

• The diversity of values that inspire involvement work can be a source of strength, but little attention is paid to these values and the ways in which they influence the practice of involvement. Discussion and exploration of these values can help to achieve change.

• Public awareness of the opportunities for involvement in the NHS is low, but this does not reflect a lack of willingness to become involved. For those who do get involved, organisational failure to feedback the result of involvement is very discouraging.

• The importance of involving all local communities, including so-called ‘hard to reach’ groups such as ethnic groups, children and young people, is widely recognised. Collaboration and partnership with the voluntary and community sectors is an effective route to building community relationships. Partnerships enable learning, resources and expertise to be shared across health economies.

• For any member of staff, gaining confidence and skills in involvement work requires experience of the benefits of involvement and training and education in the methods of involvement. For any organisation, planning for public involvement should encompass planning specific initiatives and planning the broader cycle of learning, change and review.
1. Introduction

Effective patient and public involvement is fundamental to an NHS based on choice, responsiveness and equity. Delivering and designing health services around the needs of patients is key to the modernisation of the NHS and is integral to improving patients’ experiences of health services.

The involvement of patients and the public in health decision-making is now a central theme of national and local policy in the NHS. Involvement illuminates the patient experience and helps to shape a health service that is truly responsive to individual and community needs.

*Health in Partnership* is a programme of twelve research projects exploring different aspects of patient and public involvement in health. Commissioned by the Department of Health in 1999, the programme aims to inform policy and practice throughout the NHS. Its scope is broad, encompassing the subtleties of the interaction between professional and patient and the challenges faced by organisations seeking to build relationships with their local communities.

This report brings together key findings from all the projects in the *Health in Partnership* programme. These findings are a significant addition to the expanding body of evidence demonstrating the benefits of patient and public involvement. This report not only makes the case for greater involvement, it also offers insight into the practice of involvement at all levels.

There is a long history of patient and public involvement policy initiatives in health and social care. Key developments in this history include:

- the creation of community health councils, providing an early forum for public voices;
- the development of a needs-based approach to the planning of health and social services;
- the raising of expectations about patient rights and responsibilities through the Patients’ Charter;
Introduction

- the recognition of the skills of patients and carers in managing chronic conditions;
- the erosion of public trust in professionals following high profile inquiries into malpractice;
- the focus on the patient experience as the driver of NHS modernisation;
- the pursuit of closer partnerships between health services, local authorities and the voluntary sector;
- the establishment of public involvement as a statutory duty of NHS organisations.

Box 1.1 summarises key policy events since the beginning of the 1990s.

In England, a new national system of patient and public involvement has recently been established. This includes patient and public involvement forums and patient advice and liaison services (PALS) in every NHS trust, independent complaints advocacy services (ICAS) and local authority overview and scrutiny of health decision-making. These developments are supported by the new Commission for Patient and Public Involvement in Health and by a new Director for Patient and Public Involvement within the Department of Health.

The challenge for local stakeholders in health and social care – patients, clients, carers and local people; health and social care staff; voluntary and community organisations – is to grasp the opportunities offered by these new structures and the many other involvement initiatives in the NHS. They all offer the possibility of more fruitful personal and community relationships. This may be a long-term project requiring changes in culture as well as in organisation, but the findings of Health in Partnership demonstrate that the effort will be well worth making.
Box 1.1 Patient and public involvement in the NHS: policy timeline

2003 The national choice consultation, *Building on the Best-Choice, Responsiveness and Equity in the NHS* emphasises the links between individual patient choices, service responsiveness and equity of provision.

Patient and public involvement forums are established in all NHS trusts. The Commission for Patient and Public Involvement in Health begins work. Community health councils are abolished.

*Strengthening Accountability*, policy and practice guidance for implementation of Section 11 of the Health and Social Care Act, is published.

The Department of Health’s *Planning and priorities framework 2003-2006* includes the national priority of improving the overall experience of patients. The document stresses the role of primary care trusts in creating local plans that take account of patient and public knowledge as well as professional knowledge.

2002 Primary care trusts take full responsibility for the health of their local populations. Patient advice and liaison services (PALS) go live. Separate independent complaints advocacy services (ICAS) are also established.

2001 Section 11 of the Health and Social Care Act places a new duty on NHS institutions to make active arrangements to involve and consult patients and the public in a) planning services, b) developing and considering proposals for changes in the way those services are provided and c) decisions that affect how those services operate.

The Bristol Royal Infirmary Inquiry report emphasises the role of patient and public involvement in building a more open, responsive and safe health service. The government accepts the report including the principles that ‘patients and the public are entitled to be involved wherever decisions are taken about care in the NHS’ and ‘the involvement of patients and the public must be embedded in the structures of the NHS and permeate all aspects of healthcare’.

*Shifting the Balance of Power* defines a restructuring of the NHS that aims ‘to foster a new culture in the NHS at all levels which puts the patient first’.

*Improving Health in Wales*, the health strategy of the Welsh Assembly, seeks to ‘enter into a partnership with the people of Wales so that each citizen and each community is helped to play a role, directly or through bodies representing them, in the development of health policy, the setting of aims for the NHS, the improvement of health and well being and the narrowing of health and social inequalities’.
The **NHS Plan** defines a ten year programme of modernisation for the NHS. At the heart of the NHS Plan is a vision of a service ‘designed around the patient’. Chapter 10, *Changes for patients*, describes a range of initiatives to improve patient information, patient choice and patient and public involvement in the NHS. These include:

- expansion of the Expert Patient Programme;
- a requirement for letters between clinicians about the care of individual patients to be copied to their patients;
- better information about local services to inform patient choice;
- new patient advocacy and liaison services;
- a requirement for NHS trusts to seek patient views on their services and publish an annual prospectus;
- the creation of a patients forum in every NHS trust to provide input into how services are run;
- a new local authority duty to scrutinise the local NHS.

The Scottish Executive publishes *Our National Health: A plan for action, a plan for change* which aims to build a service ‘designed for and involving users’ where ‘people are respected, treated as individuals and involved in their own care; where individuals, groups and communities are involved in improving the quality of care, in influencing priorities and in planning services’.

1999 *A First Class Service* introduces a new approach to improving the quality of patient care in the NHS – clinical governance – that requires a shift towards a culture which is ‘truly patient-centred’.

1998 The **Voluntary Sector Compact** aims to strengthen partnerships between public services and the voluntary sector.

1997 *The new NHS: modern, dependable* seeks to ‘rebuild confidence in the NHS as a public service, accountable to patients, open to the public and shaped by their views’.

1992 *Local Voices* recommends community involvement to help the NHS ‘establish priorities, develop service specifications and monitor services’.


1990 The **Community Care Act** requires local authorities to consult with users and carers.
2. The research programme

2.1 Programme development

*Health in Partnership* was commissioned by the Department of Health’s Policy Research Programme as a programme of twelve studies on the common theme of patient and public involvement in health. This approach has several benefits: the evidence produced from a single project is reinforced by other projects within the initiative; learning from each stage of the individual research projects is shared between others during the research process; and the weight and range of the evidence produced is more extensive and so more effective in informing policy and practice in the NHS.

The programme was guided by an advisory group that included academics, representatives of voluntary organisations and patient groups, NHS managers, professional practitioners and Department of Health officials. The group agreed the following priorities for the programme:

- the comparison and evaluation of different ways of involving patients and their carers in decision making about their own treatment, care and support;
- exploration of ways of involving patients, carers and the public in the process of decision making related to service development;
- identification of the implications for the education, training and support of staff in health and related services.

These priorities were identified at the time, as key areas in need of evidence.

2.2 The twelve projects

Of the final twelve projects funded, six focussed on patient and carer involvement in decisions about their own treatment and care (nos. 1-6 in Box 2.1), four addressed public involvement in service planning and delivery (nos. 7-10) and two were principally concerned with education and training issues (nos. 11 and 12). One of the funding conditions was that projects should involve patients and the public in their design and execution.
Box 2.1 identifies each of the twelve projects. More details can be found in Chapter 8 and a full description of each project, a summary of findings and details of publications to date, can all be found on the Health in Partnership website (www.healthinpartnership.org).

The projects used a variety of research methods appropriate to the nature of the research questions being asked. These methods included a systematic review (1), a cluster randomised trial with crossover (11), consensus development techniques (12), in depth interviews (2,3,4,5,6,7,8,9,10,11), group interviews (6), focus groups (4,6,7,10), workshops (5,7,10,12), mapping techniques (12) and quantitative surveys (7,8,9,12). The use of such an extensive range of research methods both within and between the projects adds weight to the findings discussed in this report.

Numbered references throughout this report refer to the list of projects in Box 2.1.
### Box 2.1 The twelve Health in Partnership projects

#### Category A Individual treatment and care

<table>
<thead>
<tr>
<th>Project title</th>
<th>Researchers</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Interventions to promote a patient centred approach in clinical consultations</td>
<td>S Lewin, Z Skea, V Entwistle, M Zwarenstein, J Dick. The London School of Hygiene &amp; Tropical Medicine.</td>
<td>A systematic review under the auspices of the consumers &amp; communication group of the Cochrane Collaboration</td>
</tr>
<tr>
<td>4. How people use written health information in decisions about their treatment &amp; health care.</td>
<td>S Buckland, F Christopher, J Goode. The Help for Health Trust.</td>
<td>A qualitative study involving in-depth interviews and focus groups with callers to NHS Direct &amp; health professionals.</td>
</tr>
<tr>
<td>5. Decision-making in primary care: patients as partners in resource allocation</td>
<td>I Rees Jones, L Doyal, M Kelly, L Berney, S Curtis, S Hillier, G Feder, C Griffiths, P Rink, G Rowlands. Queen Mary College &amp; St. Georges Medical School.</td>
<td>A qualitative study using in-depth interviews with patients and GPs as well as workshops with GPs in two contrasting areas of London.</td>
</tr>
<tr>
<td>6. Having a say: promoting the participation of people with communication impairments, in health care decision-making.</td>
<td>S Byng, City University &amp; Connect. S Farrelly, Susie Parr, City University. L Fitzgerald, de Montfort University. Sara Ross, Communication Forum</td>
<td>A qualitative study using in-depth interviews with patients and with health &amp; social care staff.</td>
</tr>
</tbody>
</table>
Box 2.1 The twelve Health in Partnership projects continued

Category B. Public involvement in decisions about service development

<table>
<thead>
<tr>
<th>Project title</th>
<th>Researchers</th>
<th>Methods</th>
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</table>

Category C. Implications for training and development

<table>
<thead>
<tr>
<th>Project title</th>
<th>Researchers</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Shared decision making and risk communication in general practice.</td>
<td>A Edwards, G Elwyn, Christine Atwell. The University of Cardiff Department of General Practice.</td>
<td>Two GP training programmes were offered to GPs and subsequent primary care consultations were evaluated.</td>
</tr>
</tbody>
</table>
3. The value of patient involvement

3.1 The patient perspective

- Patients feel involved in their care when they are treated as equal partners, listened to and properly informed. Privacy and time for discussion are both required to achieve this\(^{3,4,5,6,11}\).

- Patients use information actively to meet their needs: communicating information about themselves with care and drawing on many different sources of information to manage their condition and their relationships with professionals\(^{3,4}\).

- Few patients have experienced shared decision-making, although the character of shared decisions is hard to pin down and patients have different expectations of the responsibility they want to accept\(^{3,4,11,12}\).

Good consultations

There is a clear consensus about the qualities of a good consultation. To feel involved in their own treatment and care, patients must feel that they are being listened to by the professional, being treated as an equal partner and being given appropriate information about procedures and the process of their care\(^{4,11,12}\). More generally, the characteristics of consultations that give people a sense of involvement are:

- an ethos of mutual respect and shared values;

- shared ownership and responsibility for treatment and care decisions;

- a supportive context in which privacy and adequate time are assured.

Different consultations involve different kinds of partnerships. When children are involved, the interaction is typically three-way, involving the child, the parent(s) and the professional\(^2\).
Information, communication and knowledge

Patients turn to health professionals for information and guidance, but the communication of information – and the power that goes with this – is not one way. Patients may communicate information with care in order to achieve specific outcomes. If they fear they will not get what they want by being completely open, patients may be selective in the information they convey.

There are many sources of information outside professional relationships that patients draw on to manage their conditions, a fact exploited by the Expert Patient Programme which has acknowledged that some patients may know more about their conditions than the professionals they consult.

For most patients, however, the limitations of personal knowledge about health problems or health care options compromise their ability to judge any decisions made about their health. They may also have a limited understanding of the differences between their own values and preferences and those of the health professionals they consult. Inescapably, high quality information and education remain integral to patient involvement.

Shared decision-making

Shared decision-making has been defined as: The process of involving patients in clinical decisions. The ethos is one where professionals (should) work to define problems with sufficient clarity and openness so that patients can comprehend the uncertainties that surround most decisions in medicine and therefore appreciate that choices have to be made between competing options.

In practice, shared decision-making in clinical consultations is still rare and its character is elusive. Different patients have different ideas about what constitutes the ‘main decision’ in a consultation and the perceived importance of such decisions may shift over time. There are many details of communication that can be indicative of shared decision-making but their significance varies in different contexts.

People also have different expectations of participation. For example, women consulting about family planning are more likely to want an active role in decision-making than people consulting about ENT cancers. Children are likely to rely on their parents and on family conventions about communication and decision-making but regarded decision-making as a shared responsibility.

Patients who are unfamiliar with shared decision-making may want to participate given the opportunity, but they are unlikely to want either to take sole responsibility for decisions taken or to leave this entirely to the GP.
Progress in shared decision-making is hampered by a lack of skills and experience on both sides of the relationship. GP training in shared decision-making does lead to greater patient involvement, but patients must also have the confidence to press for a more substantial role. Yet patients may not know what to demand if they have no prior experience of involvement. Shared decision-making should be promoted through a combination of professional training and patient empowerment.

### 3.2 The professional perspective

- Health professionals generally express positive views about patient involvement, seeing it as a rewarding process for themselves as well as for patients.

- The positive attitudes of health professionals towards patient involvement are qualified by resistance to giving up their own control of the consultation. Patient involvement may be used instrumentally to achieve clinically preferred goals.

- The importance of communication in the professional-patient relationship is accepted. In practice, however, different approaches to communication are adopted to both encourage and inhibit patient involvement.

- Everyone who deals with users, including support staff, has an important communication role.

- The possibilities of patient involvement are perceived to be very context dependent. Different groups of professionals perceive and approach involvement in different ways.

### Attitudes

In general, health professionals are positive about patient involvement, seeing it as a rewarding process for themselves as well as for their patients. These positive attitudes are, however, constrained by wider professional values and expectations.

Different professionals have different attitudes towards involvement. Nurses, for example, are supportive of the principles of involvement but their willingness to promote involvement can conflict with a professional ethic of protecting patients from negative or exploitative experiences.
GPs support the principle of patient involvement in decision-making but can find it difficult to translate this into practice. For example, in discussions with patients where resources are at issue, GPs’ apparent commitment to explicitness has little impact on interactions characterised by persuasion. In these circumstances, involvement serves an instrumental function in managing the attitudes and decision-making of patients.

In general, health professionals are less likely to encourage patient involvement in decision-making if they perceive there to be only one feasible or good option; if they think the decisions are about ‘technical details’ or practical issues; or if they are not willing to compromise, if this is what is required to accommodate patients’ views. Nonetheless, some practitioners are willing to compromise on what they think the best treatment is in order that the patient should influence the decision.

**Communication**

Health professionals are aware of the importance of good communication with patients but do not always think through what this means in practice.

The problems are most pronounced in interactions with patients who have communication difficulties where contextual constraints, such as lack of time, are often compounded by negative professional attitudes. Nonetheless, the insights of staff who are familiar with this client group have universal relevance. For them, patient involvement is an interactive process including ‘talking, listening and engaging in dialogue, understanding, checking, giving people time’ as well as explaining, giving information and providing options and choices.

The manner of professional-patient communication distinguishes one-sided (unilateral) approaches to decision-making from shared (bilateral) approaches. When professionals decide that a unilateral approach is appropriate, they are likely to present test results and state problems emphatically and point to the necessity of doing a particular thing. Within a genuinely bilateral approach, professionals will present results or develop statements about the problem more deliberatively, giving the explanations about how these may be interpreted.

The importance of the communication skills of clerical and other support staff in patient care is often underestimated. Their impact on patient experience can be very significant, especially for more vulnerable patients such as people with communication difficulties. There is considerable scope for increasing the provision of training in communication and disability/diversity awareness for these staff as well as for all clinical professionals.
Adapting to context

Different contexts are perceived by professionals to offer more or less scope for patient involvement. For example, life or death situations are perceived to offer little opportunity whereas chronic conditions have more potential. The range of these differences is perceived to inhibit the spontaneous promotion of involvement.\(^3\)

Shared decision-making remains the most difficult part of the involvement process. Although doctors value personal acquisition of shared decision-making skills, time constraints are still perceived to be a major obstacle to exercising them. Given the practical constraints of any consultation, doctors emphasize the need for selectivity, adaptation and respect for patient preferences when using approaches that enhance involvement in decision making.\(^11\)

Different groups of professionals perceive and approach involvement in different ways. Policy and practice initiatives should take account of the diversity of professional experiences and standpoints.\(^12\)

3.3 Outcomes of patient involvement

- Improvement in patient satisfaction is a clear outcome of patient involvement.\(^1,2,3,4,5,6,11\).

- Patients perceive a wide variety of benefits including greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust, better relationships with professionals and positive health effects.\(^1,3,4,5,6,11,12\).

- Professionals value the personal rewards of patient involvement but also see the process as a means of managing consultations more effectively.\(^3,5,11\).

Outcomes for patients

Patients support the idea of patient involvement in health care even if they do not themselves wish to be involved. Their satisfaction with consultations increases when health professionals involve them in the process.\(^1,2,3,4,5,6,11\). Other perceived benefits include: \(^1,3,4,5,6,11,12\):

- personal growth;
• increased confidence and self-perception;
• reduction in anxiety and fear;
• greater control over their own lives and conditions;
• greater knowledge and understanding of their condition(s) and health care needs;
• reinforcement of existing knowledge and acquisition of new information;
• increased trust in health providers;
• increased capacity to seek information from external sources and to make decisions about non-medical treatments;
• more appropriate use of health services;
• positive health effects;
• greater ability to discuss issues with doctors and other health professionals;
• more positive relationships with their own doctors.

Outcomes for health professionals

Professionals (particularly GPs) perceive a variety of benefits from patient involvement. These include both the outcomes of a more equal partnership between professional and patient and the outcomes of better management of the consultation process:

• personal reward;
• improved understanding of patients’ health problems;
• increased patient compliance;
• improved health outcomes through patient behaviour modification;
• greater trust with patients;
• patient satisfaction;
• better management of the consultation process.
**Partnership vs. management**

Although this evidence reveals some convergence between patient and professional views of the value of patient involvement, there is also a distinct tension. Patients see a range of benefits of involvement both to them and to the NHS. GPs, on the other hand, see benefits predominantly in terms of compliance, management and control of patients’ health behaviour.

This distinction can be described as a difference between involving patients and informing patients, or between shared decision-making and the careful management of consultation outcomes such as treatment choice, compliance and the length of the consultation itself. This management process involves selective bias in the presentation of facts in order to steer patients to the right decision. This may be viewed as ‘friendly persuasion’ and justified on the grounds that the responsibility of being involved in decisions would lead to increased anxiety in patients. Following professional training about shared decision-making, GPs do significantly increase their involvement of patients in decision-making but this does not necessarily lead to more shared decisions.

There is a broader tension between patient involvement and professional management of treatment and care. For example, the anxiety and fear which patients can feel at critical stages of their illness are not always reduced by shared decision-making. This fact can be used by professionals as a reason for not involving patients in decisions. On the other hand, user involvement can confirm that services are being provided in line with what patients want. This is reassuring for the professionals involved.
4. The value of public involvement

4.1 Diverse perspectives

- Members of the public have widely differing views about their own involvement in NHS organisations\textsuperscript{10,12}.

- Involvement is supported as a right, as a means to inform service development and as a means of public accountability through public communication. Involvement is opposed as an extra burden of bureaucracy and cost\textsuperscript{10,12}.

- Within voluntary organisations, involvement with the NHS is seen as integral to the goals of the sector\textsuperscript{8,9,12}.

- Professionals’ positive attitudes within the NHS are qualified by doubts about the representativeness and interests of members of the public who get involved\textsuperscript{8,12}.

Public perspectives

Public awareness of what ‘public involvement’ means is low. Nonetheless, people do have distinct views about whether and how members of the public should be involved in NHS decision-making. These differences can be categorised as\textsuperscript{10}:

- Those who think it is a right of the tax paying public to have a say in how the NHS develops. They are typically concerned about the politicisation of health care and feel that public participation helps to counterbalance the people’s interests against those of political parties.

- Those who think that the public should be involved to a limited extent. The involvement should focus on giving views about service delivery or service development but should not encompass decision-making about services.
• Those who would like to be kept informed about NHS policies and plans (local and national) because the NHS should be accountable to its citizens.

• Those who think that the public should not be involved in the NHS because they have nothing to offer and a wide range of opinions complicates matters, making the NHS more bureaucratic and costly.

Motivation for involvement in NHS planning and development is driven principally by altruism, personal and family experiences and the desire to improve services\textsuperscript{10,12}.

**Institutional perspectives**

The members and officers of voluntary organisations consider their involvement as representatives of the public and of their own organisations to be essential in fulfilling their organisational aims, gaining resources for these aims and developing relationships and services within the NHS\textsuperscript{8,12}.

Some professional primary care trust members are less certain about the value of public involvement, fearing that the people selected may not provide a representative viewpoint, or that they and their voluntary organisation representatives may push a self-interested agenda\textsuperscript{8}. This view is also expressed by some clinicians\textsuperscript{12}.

**4.2 Outcomes of public involvement**

• Public involvement increases the confidence, understanding and skills of the people who participate\textsuperscript{8,12}.

• Public involvement influences the policies, plans and services of primary care organisations\textsuperscript{8,12}.

• Partnerships enable learning, resources and expertise to be shared across health economies\textsuperscript{8,9,12}. 

The value of public involvement
Multiple outcomes

Public involvement benefits the people who get involved, the organisations they contribute to and the wider community.

Key outcomes for the people who get involved in NHS organisations are improvements in their confidence, understanding and skills. Lay people who pursue involvement in primary care trusts increase their confidence in dealing with professionals, their understanding of how the NHS works, their capacity to contribute to the local community’s interests and their personal skills in managing their own health. Members of voluntary organizations representing the public have more confidence and knowledge about health matters than ordinary citizens.

Although public members of primary care trusts identify their own personal development as a benefit of involvement, they put more emphasis on the benefits to local communities such as influencing developments in local services and improving communication and collaboration between the NHS and local community organizations.

For young people, these benefits are more balanced. They see involvement in service development as a chance to make a difference but also recognise the value of greater confidence and self-esteem, or of feeling valued and respected. Young people feel that involvement opportunities encourage them to take responsibility and prepare them for their future careers.

Public involvement influences the policies, plans and services of primary care trusts and partnership work enables learning, resources and expertise to be shared across local health economies. People involved in primary care service planning believe that public involvement leads to better understanding of health care needs, improved health services, less health inequality and health improvement. People outside primary care trusts see improvement in the health of local communities as a crucial long-term outcome.
5. Patient involvement in practice

5.1 The human element

• Personal values and beliefs play a crucial role in shaping patient and staff attitudes to involvement. Discussion and exploration of these values can help to achieve change but there is little evidence of such discussions taking place3,5,6,7,8,9,10,12.

• Health professionals working to agendas driven by different values are likely to encounter conflict, stress, inefficiency and division6.

• The attitudes and behaviour of patients and health professionals are at the heart of the experience of involvement. They can make the difference between enabling and inhibiting meaningful discussion and involvement3,5,6,11,12.

• Professionals may limit involvement by managing consultations and the discussions within them. Patients may inhibit involvement by accepting a deferential role5.

Values and beliefs

All health care is informed by personal and institutional values. Patient involvement is driven by values such as respect, responsibility and dignity, but may also be constrained by other values, particularly those associated with professional authority and control.

Beliefs are also important in shaping attitudes to involvement. Patient beliefs about health, illness, treatments, the role of health professionals and the character of health care systems can all affect personal attitudes to involvement. For example, the association of certain health problems with moral judgements or stigma may profoundly affect the approach to involvement of patients and professionals alike3.
Values that support patient involvement are also likely to have a positive effect on patient well-being in the day-to-day delivery of health care. The importance of these values is most evident when they are absent. For example, people with communication difficulties are especially dependent on the commitment of professionals to patient involvement. When this commitment is lacking, their experience of care can be stigmatising and excluding.

Even when professionals and patients share the same values of patient involvement, there may still be a gap between ideals and practice. This may be due to underlying conflicts of values within the institution. Unfortunately, staff rarely have the opportunity to discuss how their day to day practice reflects what they believe in, so these underlying value conflicts may not be addressed. If health professionals are working to agendas driven by different values, the conditions are created for conflict, stress, inefficiency and divisions between health care providers and between patients and providers.

Attitudes and behaviour

Professional and patient attitudes and behaviour play a central role in both enabling and discouraging involvement. Patients appreciate professionals who:

- appear helpful and take a positive, ‘patient-centred’ approach to the consultation;
- are well organized, sensitive, perceptive and courteous;
- remember and recognize them;
- speak to them by name;
- explain their behaviour and apologize for keeping them waiting.

‘Patient-centred’ consultation is a complex and contested concept. The definition used in our systematic review was: *shared control of the consultation, decisions about interventions or the management of health problems (made) with the patient and/or a focus in the consultation on the patient as a whole person who has individual preferences within social contexts* 1.

The experience of this kind of approach makes patients feel that they matter, that professionals are being honest with them, and that meaningful discussion is possible. In contrast, staff who are impatient, patronising or disrespectful, or who appear to be too busy, inhibit opportunities for involvement.

I do usually ask questions but I don’t always think that they answer me properly. They seem to kind of disregard what I’ve said. Sometimes I feel that they haven’t listened or they haven’t examined me properly or something. Sometimes it seems like they are writing a prescription out before you’ve finished talking to them.

patient 4
Professionals may inhibit involvement by seeking to manage consultations – and their relationships with their patients – in order to achieve the outcome they feel is most appropriate. Patients may also inhibit involvement, particularly if they feel deferential to professional opinion or guilty about ‘bothering’ busy professionals.

These findings reinforce the wealth of other evidence from research about the impact staff attitudes have on the patient experience. Changing the culture of the NHS, particularly where values and attitudes are concerned, is one of the greatest challenges facing the service.

### 5.2 Organisation

- The organisation of clinics and consultations plays a significant role in enabling and inhibiting patient involvement.

- The increasing standardisation of care through professional guidelines can conflict with the exercise of choice at the heart of the patient involvement process.

- Time remains a scarce resource for patient involvement and management of time a critical professional skill.

### Clinics and consultations

The immediate context of the professional-patient relationship has considerable influence on the nature of patient involvement. Factors affecting involvement include:

- the environment of the consultation;

- the organization of clinics, especially the time available for the consultation and the time between consultations;

- the privacy of the consultation;

- continuity of care;

- the nature and extent of policies, guidelines and protocols relevant to the health condition;

- the workload and morale of staff;
the ways in which professionals and other staff work together and communicate with each other.

As for many other issues, the organisational performance of clinics and consultations is rapidly exposed when it really matters. For example, the experience of people with communication difficulties includes unclear and inaccessible clinic signage; receptionists who do not know where disabled toilets are; GP surgeries that are not adapted for wheelchair users; background noise that inhibits communication; poor provision of communication aids; and slow referrals for rehabilitation, if they are offered at all.

Professional guidelines

There is potential for conflict between the promulgation of professional guidelines or protocols and the practice of patient involvement. The trend towards patient involvement is occurring at the same time as a shift towards greater standardisation of care, evident in the increasing prominence of guidelines for professional practice. If greater patient involvement means giving patients greater choice, this may not be compatible with the uptake of these guidelines.

Time

Time is a scarce resource in professional-patient consultations and the effective management of this time is a crucial skill.

Insufficient time is a barrier to the implementation of all aspects of patient involvement processes. If the interactive process at the heart of the experience of patient involvement is to flourish, this necessarily requires greater time for the discussion between the professional and the patient to develop. This is likely to remain a prominent problem, given the competing pressures on professional practice.
5.3 Communication and information

- Good communication and high quality information are essential ingredients of patient involvement. Poor communication between patients and professionals and across the NHS is a continuing problem.\(^3,5,6,7,9,10,12\).

- Good communication requires not only two-way exchange of information but also mutual willingness to listen and understand.\(^3\).

- Language barriers, lack of time and insufficient resources for translators and other communication aids, seriously inhibit the opportunities for involvement of people whose first language is not English, and other groups with communication impairments.\(^5,6\).

- High quality information enables both self-management and patient involvement, but identifying the right information at the right time is difficult.\(^3,4,5,6\).

- Information is used in many ways by patients and the professional consultation is not always the focus of information-seeking.\(^4\).

Good communication

Professional communication skills are critical to achieving effective patient involvement. Unfortunately, poor communication between patients and professionals and across the NHS is still a reality.\(^3,5,6,7,9,10,12\).

Patients are clear that good communication with a professional is at the heart of involvement. From the patient perspective, good communication requires that health professionals and patients both ask for and give information; and both seek to listen and understand.\(^3\). Unfortunately, even this most basic characterisation of communication rarely happens in practice.\(^3,4,6\).

A more detailed account of the qualities of good communication encompasses: ‘talking to the person, getting to know the person, giving time for the person to talk, looking at the person, listening, asking what the person thinks, waiting for the person to think, speaking a bit slowly, using simple language, no interruptions or shouting, not finishing sentences for people and backing up spoken information with written or diagrammatic material. Good communication is a shared achievement.’\(^6\).
Some health care professionals also recognise the importance of communication, and listening in particular, in encouraging patient involvement. To encourage a listening culture, staff must:

• be open to hearing patients’ constructive criticism;

• take patients’ concerns seriously by acting on them or referring them on to other appropriate staff;

• encourage patients to raise their concerns rather than assuming they are able to do this.

Language barriers are inevitably a major barrier to good communication and therefore patient involvement. Limited time during consultations and limited resources to employ interpreters means that people whose first language is not English stand much less chance of being involved in their treatment and care.

**High quality information**

High quality information helps to give patients the confidence to manage their own conditions and to enter into interactive discussions with health professionals. But there are no easy answers to the question of how much information to give and when to give it.

Information about health and illness is used in many ways by lay people, including:

• increasing personal knowledge about health conditions;

• reinforcing or confirmed existing knowledge;

• providing reassurance;

• increasing their confidence to discuss issues with health professionals.

Information can support self management and help people to make decisions about their treatment and care. From the perspective of the wider decision-making process about treatment and care, the professional consultation itself may not always stand out as the most important experience.
6. Public involvement in practice

6.1 Involvement is characterised by diversity

- There is no consensus about what ‘public involvement’ means or involves beyond its contribution to service improvement.

- There is still a fundamental difference within local health economies between those who value involvement work and those who remain sceptical about it.

- Professionals may consider public involvement to be too compromised by the lack of representation or knowledge of users, or too risky because of the vulnerability of users.

- The diversity of values that inspire those who are committed to involvement work can be a source of strength, but little attention is paid to these values and the ways in which they influence the practice of involvement.

- Public expectations of a lack of professional commitment to involvement increase public reluctance to participate in involvement work.

Different understandings

There is no general consensus about what ‘public involvement’ means or involves. When different people collaborate in the pursuit of public involvement, they may or may not have a shared understanding of the concept, even if they think they do.

One systematic attempt to develop a consensus among professional and user stakeholders only achieved a general agreement that users should be involved in decisions about their treatment and care and that the purpose of user involvement was to improve services. Although there was general agreement on specific aspects of user involvement, there was little agreement about who users were or how they should be involved.
Service users and members of the public are typically aware of what involvement in their own treatment and care means, but mostly unaware of what public involvement in NHS planning and development means\textsuperscript{10, 12}.

**Different values and attitudes**

Beyond differences in understanding are more wide-ranging differences in values and attitudes. This diversity is inevitable given the different backgrounds and experience of all the individuals who have any role in involvement work.

The most profound differences lie between those who do and do not value public involvement itself. This difference often lies across the divide between lay and professional stakeholders. For example, people within primary care organisations are more likely to be sceptical about the value of involving the public than their partners in the community, who may be driven more by altruism and service to the community\textsuperscript{8}. Hospice based palliative care consultants were more likely to support user involvement than their hospital colleagues \textsuperscript{12}.

Turning negative professional attitudes into positive approaches is one of the greatest challenges for the future of public involvement\textsuperscript{8}. Professional groups may be concerned that user voices are unrepresentative or uninformed, making them unfit for strategic decision-making (doctors); or that some users are too vulnerable to be involved (nurses); or that involvement might raise ‘unrealistic’ expectations of services. Users and voluntary organization members, on the other hand, put a higher value on inclusion \textit{per se}\textsuperscript{12}.

Differences in values and attitudes need not always be a problem. Among those who are committed to the principle of involvement, these differences can be fruitful if they are explored and exploited. Public involvement work may be underpinned by quite different ideas relating to altruism, democracy, community, partnerships and consumerism, but this diversity can bring a richness to the management of public involvement and be a source of value to local communities\textsuperscript{9}. Unfortunately, little attention is paid to these values and the ways in which they influence the practice of involvement\textsuperscript{8, 9, 10, 12}.

Sharing and understanding the values and perspectives of others is an important part of the long term culture shift towards public involvement. This will also require a greater appreciation of the importance of values such as openness and equality in achieving success in public involvement\textsuperscript{12}. 

Different expectations

The perceptions of members of the public of professional attitudes may adversely affect their own attitudes to involvement. Some members of the public feel that health service managers and professionals do not welcome public influence, seeing members of the public as ‘outsiders telling them what to do’ and so preferring to ‘make decisions behind closed doors’. Not surprisingly, this increases reluctance to get involved in health-care decision-making. The values of openness and especially equality were thought to be important to effective involvement. Voluntary organisations may also feel inhibited by the distinct power imbalance between patient groups and professionals.

People are also reluctant to participate in involvement activities because they feel they do not have the necessary personal expertise or time, or feel that the issues are not relevant to them at the current stage of their lives.

6.2 Collaboration and leadership

- Collaboration with local voluntary and community organizations is essential to successful public involvement.
- Partnerships enable experience, expertise, resources and learning from involvement to be shared.
- Leadership, board commitment and inclusion in strategic planning are all important for the success of public involvement, which should be a shared corporate responsibility.

Collaboration with the voluntary and community sector

The creation of working partnerships with local voluntary and community organizations is essential to successful public involvement. A history of multi-agency working and a willingness to learn from the experiences of others in the community is likely to lead to successful and relevant outcomes for local health services development.

The experience and expertise of local groups is a valuable resource. In tapping these resources, NHS organisations can save time and resources, gain opportunities to share learning about local public involvement work, and avoid duplication or reinvention of the wheel.
In practice, the development of local collaboration is patchy. Not all stakeholders see partnership with the voluntary sector as an essential ingredient of public involvement on the grounds that the voices of ordinary people are not represented by voluntary organizations.

Leadership and strategy

Leadership and commitment at board level are vital to the progress of public involvement, although they do not guarantee in themselves that anything will happen in practice. The commitment of primary care trust chairs is particularly important in presenting ‘an image of an organization willing to listen’. The association of the brief for public involvement with lay representation can lead to responsibility for developments in this area being given to lay members on trust boards, rather than being shared across board members and senior managers.

The inclusion of public involvement in strategic plans is also critical to the continuing practice of public involvement. In general, public involvement needs to be integrated into the responsibilities of senior officers and the internal trust processes of corporate planning and strategic development.

6.3 Communication and information

- Public awareness of the opportunities for involvement in the NHS is low, but this does not reflect a lack of willingness to become involved.

- Lack of information about the opportunities for involvement is common.

- Failure to feedback the result of involvement is very discouraging to those who get involved.

- The importance of involving all parts of local communities is widely recognised. The groups perceived to be the most difficult to involve are the general ‘healthy’ public, ethnic minorities, poorer people, young adults and patient groups without established local groups or campaigning bodies.
Recruitment and raising awareness

Very few people are aware of the opportunities that are open to them to get involved in health service planning and decision-making. Members of the public do, however, express a willingness to become involved and are often eager to offer their views and experiences\(^{10,12}\).

It is unrealistic to think that all members of local communities will be willing or able to participate in NHS planning and service development. Nonetheless, public involvement is held back by a lack of local information about the opportunities for involvement\(^{6,7,8,9,10,12}\). Information and feedback about public involvement opportunities in the NHS are essential if more members of the public are to become involved.

Information about involvement opportunities should be part of a broader educational process that enhances understanding within communities of health and health services. This is important given that the reticence of some people to get involved is due to their own sense of having insufficient knowledge to contribute to the NHS at local or national level\(^{10}\).

Public communication is itself at the heart of public involvement, so public involvement initiatives may be pursued in part to develop better communication between professional stakeholders, users and the public\(^{8,12}\).

Feeding back

When members of the public do participate in public involvement initiatives, they want to see that their efforts are useful. Feedback is vital to their continued commitment\(^{10,12}\).

The NHS has suffered both from a failure to communicate the opportunities for involvement and from a failure to communicate the results of involvement. For people who have participated in some way, this failure to receive any form of feedback about the results of their involvement is discouraging.

There are many methods of feedback including newsletters, websites, meetings, press releases and briefing notes\(^{12}\). Feedback needs to cover the actions taken in response to involvement, reasons why ideas are not taken forward and details of progress in implementing change\(^7\). The more long-term a process of involvement, the more central to the relationship on-going feedback and communication becomes.
Reaching all sections of the community

The importance of attempting to involve all sections of local communities is widely recognised. Even in the early stage of primary care group development (2000/2001), 44% of primary care groups reported that they had carried out an initiative to involve ‘marginalised’ groups. The groups perceived to be the most difficult to involve are members of the general ‘healthy’ public, ethnic minorities, poorer people, children and young adults and patient groups without established local groups or campaigning bodies. The recruitment of young men can be particularly difficult.

NHS organisations do not always have the necessary expertise in this field which makes it more important for them to work with other community groups. The difficulties of involving specific groups are compounded by a perceived shortage of funds for this kind of work.
7. Implementation: approaches and examples

7.1 Working on the staff-user interaction

- Patients and staff alike can improve their communication by paying greater attention to the detail of how they behave towards one another when in conversation.

- The content of a consultation defines the opportunities for patient involvement. Professionals can increase these opportunities by thinking through the stages of an effective consultation.

- Providing information in advance of a consultation increases the potential for involvement.

- Professionals who are worried that involvement will lead to conflict because of the constraints they face can benefit from thinking through difficult scenarios with their peers.

The dynamics of communication

The process of communication between staff and users is usually taken for granted. Yet if attention is paid to the subtleties of this process, improvements in the quality of communication are possible.

Box 7.1 offers a basic analysis of the components of good communication between a patient and member of staff. Although developed through work with people with communication difficulties, it has universal relevance. Many of the challenges for staff are also challenges for patients – good communication is a shared achievement. Attending to the experiences and ideas of people with communication impairment allows the processes involved in good and bad communication to be highlighted and scrutinised in detail.
All staff who have contact with patients need to be skilled in communication. The role of administrative and support staff in the experience of care, and patient involvement in care, can be very significant.6

### The content of the consultation

The quality of the interaction between a professional and patient during a consultation is crucial to patient satisfaction. As well as communicating with skill, professionals must also ask an appropriate range of questions to create the right opportunities for involvement. These can be divided into:

- recognition and clarification of a problem;
- identification and initial appraisal of potential solutions;
- appraisal of potential solutions and selection of a course of action.

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### 7.1 Enhancing communicating with patients who have communication difficulties

<table>
<thead>
<tr>
<th>patients’ suggestions</th>
<th>staff suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>use plain, non-technical language</td>
<td>listen</td>
</tr>
<tr>
<td>talk slowly</td>
<td>ask yes/no questions</td>
</tr>
<tr>
<td>use eye contact</td>
<td>keep eye contact</td>
</tr>
<tr>
<td>face the person</td>
<td>speak clearly</td>
</tr>
<tr>
<td>be patient, relaxed, wait</td>
<td>don’t shout</td>
</tr>
<tr>
<td>involve the carer/third party, if asked</td>
<td>check understanding</td>
</tr>
<tr>
<td>natural, respectful manner</td>
<td>if you don’t understand, say so</td>
</tr>
<tr>
<td>write down for later use</td>
<td>speak directly to the person</td>
</tr>
<tr>
<td>summarise recommended treatments</td>
<td>repeat/recap points</td>
</tr>
<tr>
<td>in clear language</td>
<td>use signs, symbols, writing, drawing</td>
</tr>
<tr>
<td>ask if written information is required</td>
<td>provide quiet places for reading</td>
</tr>
<tr>
<td>use an interpreter if required</td>
<td></td>
</tr>
<tr>
<td>provide information about contacts for queries</td>
<td></td>
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<tr>
<td>observe body language</td>
<td></td>
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<tr>
<td>get to know the person</td>
<td></td>
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</tbody>
</table>
Box 7.2 identifies typical questions that a health professional might pose in this three stage model.

**Box 7.2 Questions and comments to facilitate patient involvement**

**Recognition and clarification of a problem**

How do you think things have been? [in relation to a chronic health problem or previously discussed symptom]

Is there anything that particularly bothers or worries you about this symptom?

Have you any ideas about what might be causing this problem?

OK. Now I tend to think that the problem is basically caused by x. Does that seem to make sense?

We seem to have a couple of things to deal with here. I think the one that needs most urgent attention is this one because… What do you think?

**Identification and initial appraisal of potential solutions**

Now, for this kind of problem, we usually consider three main treatment options. I’ll run through them, and we can talk about which one will suit you best.

If we’re aiming to improve [this aspect of your health], we’ve got a couple of choices. One option is that we just leave it. Do nothing and just take the risk that there might be complications. It’s not an option I’d recommend, but it is an option.

Are there any other kinds of treatment you’ve wondered about and would like to discuss?

So I think any of those three – A, B or C – would be reasonable options.

**Appraisal of potential solutions and a selection of a course of action**

Options A and B would require you to do y each day, so we need to think how you feel about that.

A and B both have this impact, while C has slightly different effects and in specific ways is less likely to cause a problem…

Now for some people, A and B are equally good options. But because of your wish to avoid the identified side effects, I don’t think B is a good option in your case. The evidence suggests…
The potential for patient involvement during the consultation is also increased if information is provided in advance. Doing so:\(^3\):

- lets people know what to expect;
- encourages people to think about and adjust to a health status change;
- allows people time to develop an understanding of a recommendation and/or to adopt the selection of a course of action as their own;
- gives people time to reflect on their personal preferences and to decide whether they want to accept a particular health care option.

The clinical guideline that we usually follow recommends A because….

Does that make sense?

Given that you want to avoid this risk, you might want to put option C to the side for now, but it does remain an option.

So, as I say, I’d tend to recommend option A because … But you might have other reasons for thinking you might prefer B or C, and I’m happy to discuss those. A, B and C are all reasonable options. Does that make sense to you? Are there any other issues you think we should consider?

Have you considered these possibilities before? You might want to think about them, or talk them over with others

If you’d like a bit more time to think about it, you could take this information away and have a think about it. We don’t need to decide today. You could either ‘phone and let me know or we could book another appointment slot …

Do you have a preference for what we do?

Well it feels to me like we’re in agreement here… but can I just check? Which option do you think we should go with?

Good, we agreed then that we’ll do A. Let’s see how we get on with that then. If we could meet again in a couple of weeks to discuss how things are progressing, but do get in touch beforehand if you’re worried about something…

What I’ve learned is that it’s important to find out what it is that patients actually want. Much as you think that you’re a good doctor and a good communicator, often what is important to you is often the last thing that’s important to the patients.

consultant physician\(^3\)
Preparing for difficult scenarios

Patient involvement can be most challenging when choices are constrained by economic and other supply-side restrictions such as waiting lists. These constraints can deter professionals from engaging in patient involvement if they feel that this will lead to conflict.

**Box 7.3 Case study on patient involvement in resource allocation decision-making**

**Ethical principle**

Within areas of treatment, resources should be prioritised on the basis of extremity for need.

**Vignette**

A man in his early 50s needs a hip replacement. You make a referral and he is placed on a waiting list of approximately 6 months for his first outpatient appointment. 5 months later he is told that his appointment has been postponed and he will have to wait a further 12 months. During the 5 months since he was first referred, his condition has deteriorated and he is now on regular pain-killers. His hip problems are now seriously affecting his ability to do his job. You decide to start to make representations on his behalf in order to try and bring his appointment forward.

**Issues arising**

- How to determine extremity of need.
- Criteria used in priority setting.
- Choices between areas of treatment or within areas of treatment.
- Trade-offs between different groups of illnesses.
- Unmet need.
- Individual and practice strategies.
- Mechanisms for addressing matters at higher levels in the health service
In order to address these issues effectively, professionals need to think them through in detail and identify the range of problems to be addressed. This can be done as a workshop exercise using case studies drawn from life. Box 7.3 illustrates the use of a case study approach to explore an ethical principle that can be hard to sustain in practice. The material for this case study was developed through interviews with GPs about their experience of patient involvement.

### 7.2 Corporate concerns

- Gaining confidence and skills in patient and public involvement typically involves both experience of the benefits of involvement and training and education in the methods of involvement\(^1,7,11,12\).

- Organisations could invest in relationships with their local community to further public involvement, just as staff could build individual relationships to enable patient involvement.

- Collaboration with the voluntary and community sector is an effective route to building community relationships and achieving public involvement\(^12\).

- All relationships are based on trust, involving time, effort and openness\(^9\).

- Exploration of the differences in values and attitudes within organisations and between professionals is as crucial to involvement work as the discussions across communities or between professional and lay people\(^6,9\).

- An integrated corporate approach to involvement requires strategy, commitment, leadership and good working relationships between staff at all levels and local community voices \(^8,9\).

### Experience, education and training

Staff education and training will always be integral to any programme of change within the NHS. Initiatives to improve patient and public involvement must address the knowledge, attitudes and skills of professionals and staff at all levels of the service. Hands-on experience can be a powerful way to change attitudes as this opens people’s eyes to the real potential of involvement\(^7\) but formal training and education is also crucial.
At the level of the individual consultation, our systematic review has shown that training interventions can improve patient-centredness and the satisfaction of patients with these consultations\(^1\). Training for GPs that aims to improve their risk communication and shared decision-making skills is also effective\(^11\).

At the level of involvement in service development, training in the specific approaches and methods of involvement is particularly sought after\(^7\). Interprofessional training can also be an effective way of supporting staff who are afraid of coming face-to-face with users during involvement activities\(^12\).

### Building relationships

Relationships are at the heart of both patient and public involvement. Just as professionals are expected to develop relationships with their patients, so NHS organisations should invest in wider relationships with local communities.

Collaboration with the voluntary and community sector is an effective approach to public involvement\(^12\), principally because it is based on building and sustaining relationships that can be fruitful in many different ways over time. The illustration of collaboration in Box 7.4 begins with a specific focus but establishes a relationship that has on-going benefits.

#### Box 7.4 Local collaboration with the voluntary sector\(^12\)

A hospital trust paid for seven volunteers from a local cancer voluntary organisation to be trained as focus group facilitators. These facilitators ran a series of focus groups with people living with cancer and produced a report for the trust’s Cancer Services Review Group.

The aim of the process was to improve the service in line with user views. Although there were some difficulties initially, the experience gained by the trust and the voluntary organisation ensured that the programme changed and evolved over time.

This model has been extended to two other Trusts and is supported financially by the local cancer network.
Effective relationships are always based on trust. Building trust takes time, effort and genuine openness. Lots of seemingly small things can make a difference, such as:

- a willingness to meet community organisations on their own turf;
- a real effort to answer people’s questions fully, however tangential they may seem, rather than simply trying to fend them off;
- a board that tries to be open about how little it can actually do, as opposed to a board that always presents the most optimistic spin on its plans;
- a commitment to sustained communication across the whole health economy.

**Working together, sharing values**

The value of patient and public involvement work lies in the exploration of difference, particularly the differences between professional and patient views and between corporate and community views. But these simple descriptions disguise a much more complex reality in which very different perspectives also emerge between professionals or within communities. Involvement work is therefore best understood as a conversation between many stakeholders, each with their own values, attitudes, insight and knowledge.

If differences in professional attitudes are not explored, underlying value conflicts can hinder involvement work. Those who spend time exploring their beliefs and ideas are likely to gain a shared understanding of the value and purpose of involvement. Those who do not are likely to assume a common understanding exists when in fact it does not.

At the level of individual involvement in treatment and care, discussions within multi-disciplinary teams provide a good locus for sharing ideas and encouraging good practice. At the level of public and community involvement, a much wider conversation needs to take place, a conversation that is both about and part of the process of involvement. These conversations can take time and so may appear to inhibit change, but they help to secure the long term value of well-founded community relationships.
Aspects of an integrated approach

An integrated approach to patient and public involvement can take many forms. The following are key components of such an approach, designed to make involvement central to all the business of an NHS organisation:

- creating a strategy for public involvement with clear objectives;
- ensuring corporate commitment and leadership of public involvement strategies;
- involving all senior and junior officers in contacts with local community groups and initiatives;
- ensuring that board agendas always include items on public involvement;
- providing information to local communities about plans and developments together with clear indication of opportunities to become involved;
- providing feedback on the results of all involvement activity;
- learning from and building on local experience of public involvement, valuing the achievements of other NHS organisations, local government and the voluntary and community sector;
- establishing a sub-committee with representation from the public and other local agencies to maintain the profile of public involvement work and to prepare new developments;
- encouraging public involvement in general practice where there may well be a history of patient/public involvement;
- time, patience, effort and commitment.

7.3 Systematic approaches

- Investment in organisational development for patient and public involvement is better planned together with well designed involvement activities tailored to local circumstances.
- For any organisation, planning for involvement will include planning specific initiatives and planning the cycle of learning, change and review.
• Public involvement methods involve careful tailoring to local circumstances and client groups. However, every local experience always provides universal insights.

Culture and methods

The last section explored some of the issues that organisations and individuals can address in the pursuit of patient and public involvement. Its emphasis was cultural rather than methodological – focussing on relationships, values and commitment rather than prescribing a specific set of actions.

This section outlines two approaches to involvement that specify process or methods in more detail. The first is a model of a corporate cycle of involvement. The second is a set of practical guidelines for involving young people in service development. Both have universal relevance.

A cycle of user involvement

Much user involvement takes place within one-off projects or in response to very specific needs. Although such initiatives may be entirely appropriate for their immediate purpose, NHS organisations could also take a longer view of the place of user involvement in the organisation’s work.

Box 7.5 describes a cycle of user involvement in which the aims and methods of involvement are always subject to review and where feedback from users is fed regularly into service development. This model includes the vital tool of regular evaluation of user involvement and its impact on activities.

Box 7.5 A cycle of user involvement

Implementing and disseminating
(Re)defining the aims of user involvement
Mapping user involvement
Identifying service users
Developing and evaluating a user involvement system
Involving users in service evaluation and development
Documenting service user experiences
Guidelines for involving young people

The guidelines summarised in Box 7.6 were designed to enable NHS staff to involve children and young people - particularly those who have a chronic illness or physical disability - in local decisions about health services development. They are, however, relevant to all public involvement with a focus on improving services.

Box 7.6. Involving young people: summary of guidelines for a hospital setting

Understanding motivation

It is important for staff to think about how their project might appeal to patients. Young people say that they are motivated by:

- wanting to make things better for other young people;
- the opportunity to let staff know what needs to change;
- feeling confident that something will happen as a result;
- wanting to give something back to the staff;
- a challenge, a chance to do something different;
- feeling valued by having their opinions heard;
- something interesting to do in hospital - especially if it sounds like fun.

Approaching young patients

When approaching young patients to seek their involvement:

- get to know young people's interests and approach them individually;
- always check that the young person is willing to be involved;
- approach young patients when they are in hospital as later on it is harder to think about what needs to change;
- be sensitive about timing: do not approach someone who is undergoing treatment, in pain, has just had bad news, or just before examinations or results;
- explain what you want in a straightforward way;
• make it clear that the young person can opt in and out at any stage;
• make it clear (as appropriate) that it will be anonymous and confidential;
• provide reassurance that their opinions will be taken seriously.

Young people advise that if you want to offer money, do so after people have agreed to take part. Only if involvement is high and over a period of time – such as working in a group project – is payment needed. Treats such as trips and meals out make young people feel just as valued as cash.

Selecting topics

The focus of involvement should neither be too constrained nor too open-ended:

• a starter list of topics can be useful as it can be difficult for young people to pluck things out of the air;
• the list should comprise other young people’s ideas so they can pick from what has already happened elsewhere and add their own ideas;
• young patients need to know that they can add issues that are important to them;
• young patients need information about any topics which are ‘off-limits’ such as health and safety restrictions on bringing in food and using mobile phones.

Methods

There is no one right method to consult young patients. Written methods do not work for people who cannot read or write well. Shy people do not like group work. If staff offer a choice of methods, more patients may be happy to take part. Different methods suit different purposes. It is important to find methods which ‘feel right’ for young people.

Questionnaires

• Advantages: a quick and easy way to get information from lots of people; if anonymous, people can say what they think; can be used for routinely obtaining patients’ views.
• Disadvantages: the patient cannot ask for clarification; the response rate can be poor; can seem at odds with the aim of involving patients; unsuitable for finding out how people feel, what they want to change and why.
• Publicise the questionnaire, explaining what you want the information for.

• Give out questionnaires in hospital, where patients are a ‘captive audience’.

• Make it clear whether it is anonymous.

• Keep it short: should take no longer than 10 minutes to fill in.

• Involve young people in designing questionnaires (both content and style).

One to one interviews

• Advantages: the patient can ask the questioner for clarification; more personal than a piece of paper as you know someone is listening; can find out a lot (delve deeper/ask why/ find out feelings); easier than a questionnaire to say what you mean and get your views across; more reliable than groups for finding out an individual’s own view.

• Disadvantages: cannot develop own ideas via discussion (as in a group); whether or not the young person knows the questioner can be a problem with some topics (a reluctance to criticise someone you know/like or a reluctance to talk about personal matters with someone you do not know); time-consuming for staff.

• Consider a questioner from another department or from outside the organisation so that young people can criticise staff if they need to.

• A conversation is better than asking direct questions: no right or wrong answers, and young people can raise topics important to them.

• Keep clarifying what is being said so there are no misunderstandings.

Group work

• Advantages: different viewpoints are expressed and debated; not so ‘full on’ as one to one encounter so quieter people can ‘hide’ for a while; working together over time gives young people opportunities for deeper involvement and personal development through team-work, learning to compromise and sharing responsibility for action with adults.
• Disadvantages: a group is difficult for young people who are at risk of cross-infection, who lack confidence and who think their friends would see it a ‘geeky’ thing to do; groups can become too formal; groups can get stuck — at the beginning if the remit isn’t clear, during the project if people don’t come to meetings, or if the work gets very time-consuming; endings can be difficult (it can ‘fizzle out’, saying goodbye can be hard); it can be difficult to achieve a representative group.

• Small groups (six or even fewer) can be a productive way of working with young people since the most committed people are involved; contriving a larger ‘representative’ group may backfire; participants get to know one another and so can have good discussions yielding plenty of ideas.

• Time is needed for social activities: at the beginning for group members to get to know each other and feel relaxed; and later on for mixing hard work with some fun (this can help to counter the ‘geeky’ image too).

• Groups need a good facilitator, someone who: (a) will not seek to lead the group - but has strategies to help if the group gets ‘stuck’; (b) will stick with the group over time, to keep motivation going; and (c) will take care about endings.

• A relaxed atmosphere at meetings is important: avoid sitting in chairs in a semi-circle; have drinks and snacks, maybe even some music.

• Think about how to include people who cannot easily join a group: for example use an advocate or a video link.

• When an initial project comes to an end, consider the possibility of developing a standing group for consultation, such as a Hospital Youth Committee.

Developing a ‘listening culture’

Young people and staff urge the development of a ‘listening culture’, so that young patients can raise issues when the time is right for them, not just when they are asked by staff through a one-off involvement project.

• In a ‘listening culture’ staff hear young patients’ concerns and take them seriously by acting on them.
• Do not assume that young patients will know it is OK to bring concerns to staff. Always encourage patients to raise questions and concerns.

• Different patients feel comfortable with different staff, so encourage openness among all staff rather than designating one person with a ‘listening’ role.

Staff skills and personal qualities

Staff working with and involving young people must:

• be approachable, welcoming, and able to make the young person feel comfortable;

• be interested in the young patient as a person, i.e. someone a young person can have an ‘ordinary chat’ with;

• explain things in a straightforward way;

• take young people seriously, help them to express their views and not patronise or judge them;

• take forward issues raised with the relevant staff;

• mediate where there is conflict between patients and staff.

Staff development needs

Hands-on experience is a powerful way of changing attitudes but training and development needs must also be directly addressed:

• Formal training is important, for instance in participation techniques.

• Staff can feel isolated in this work and value support from peers in other organisations.

• Staff who resist the idea of involving patients can be encouraged by evidence of improved knowledge, such as through a post-project workshop explaining what was done and what was achieved. With support, young people can feed back at such an event.

• Commitment and support from senior staff is crucial.
Each of the individual research project reports contains many more examples of good practice in user and patient involvement. They also contain recommendations for change and for further research on specific aspects of involvement and areas where the good quality evidence for practice does not yet exist. These twelve reports and subsequent publications have much more to offer those who are involved in the implementation of patient and public involvement. This report, although it offers a convincing case for the implementation of user involvement, was not able to do justice to the wealth of detail contained in the individual research reports. We hope that the health in partnership website, where these studies can be found, provides an additional resource for those charged with the implementation of patient and public involvement in the NHS.

Feedback

Feedback is important to young patients:

• They want to know the views of other patients and find out what is planned to change and when.

• They also want to know the reasons why particular ideas are not taken up. Without explanation, young patients may become cynical about the value of consultation.

• Where changes are planned, give young patients an idea of the timescale and keep them informed about progress, including any delays.

• Tangible outcomes are very important for young patients as evidence that they have been listened to and their opinions taken seriously.
This section summarises the aims and methods of each of the studies in the Health in Partnership programme. For more detailed information on each study, including findings, implications for policy and practice and publications, see the Health in Partnership website: www.healthinpartnership.org.

1. A systematic review of the effects of interventions for providers to promote a patient-centred approach in clinical consultations

Simon Lewin, Department of Public Health and Policy, London School of Hygiene & Tropical Medicine. Vikki Entwistle and Zoe Skea, Health Services Research Unit, University of Aberdeen. Merrick Zwarenstein and Judy Dick, Medical Research Council of South Africa.

This systematic review aimed to assess the effects of interventions for health care providers that promote patient-centred approaches in clinical consultations. It considered the effects of these interventions on provider-patient interactions, health care behaviours (including health service utilisation), patients’ health and well-being, and patients’ satisfaction with care.

The review was conducted under the auspices of the Cochrane Consumers and Communication Group and adhered to their methodological guidelines.

Both consumers and health care professionals were involved in reviewing the protocol and draft report for this study.

Patient-centred care was defined as: a philosophy of care that encourages: (a) shared control of the consultation, decisions about interventions or management of health problems with the patient, and/or (b) a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts.

The review included randomised controlled trials, controlled clinical trials, controlled before and after studies and interrupted time series with at least 3 data points prior to and following the intervention. Studies were included if
The twelve studies they involved interventions directed at any type of health care provider, including those in training, with the aim of promoting patient-centred care within clinical consultations.

2. Participating in care: children and the NHS

Mike Bury, Jonathan Gabe and Gillian Olumide, Royal Holloway, University of London. Graham Clayden, St Thomas’s Hospital

The idea that children should involve themselves in their own health care has been promoted from above, by those planning for the perceived needs and desires of children, rather than by children themselves. How such partnership is enacted in particular health care settings is a complex process and has yet to be fully assessed.

This research project sought to focus on children’s, parents’ and professionals’ views of partnership, to provide an in-depth account of decision-making processes in paediatric consultations and to identify the factors that hinder or promote partnership in paediatric care.

Ninety consultations of children between the ages of 9 and 15 attending a paediatric clinic for chronic digestive disorders in a London teaching hospital were video-recorded. Half of these children were then interviewed in their homes and the contents tape-recorded. Members of the professional team (paediatric consultant, clinic link nurse, play specialist, psychiatrist, psychologist and surgeon) encountered by the children were also interviewed. In addition, a focus group involving 5 children was held to collect children’s views of the literature provided by the clinic.

Users were invited to become members of the Project Steering Group.

3. Exploring patient participation in decision-making: the views and experience of patients in diverse clinical contexts.

Vikki Entwistle, Health Services Research Unit, University of Aberdeen. Ian Watt, Department of Health Sciences, University of York

There is currently pressure to ‘measure’ and assess patients’ participation in health care, but the complexity of participation and decision-making may not be sufficiently reflected in existing measures of patient participation – particularly those that might feasibly be used in routine practice. This project sought to improve our ability to conceptualise, recognise and assess patient participation in decision-making, focussing on:
the various ways in which health professionals, patients and others interact in practice to reach decisions about the tests, treatments and care an individual will receive;

the range of ways in which patients might contribute to decisions about their health care, and the forms which patient participation in decision-making might take in diverse health care contexts;

the views that health professionals and patients hold about patient participation in health care decision-making; and

the strengths and limitations of current measures of patients’ and health professionals’ contributions to decision making.

Five areas of clinical practice were chosen: family planning, general practice, diabetes, homoeopathy, clinical cancer genetics and specialist care for cancers of the head and neck. Within each clinical area, purposive sampling techniques were used to ensure that a wide range of experiences of, and views about, the participation of individuals in decisions about their own health care were identified.

Methods included initial interviews with patients and health professionals, video-recording consultations, post-consultations questionnaires and follow-up interviews.

Consumers were involved as members of the project advisory groups that were convened for each of the five clinical areas studied.

4. **How people use written health information in decisions about their treatment and health care.**


The aim of this project was to explore, from the patient’s perspective, how written health information obtained from sources external to medical consultations is used by consumers, and how it affects decisions about treatments and health care.

The project was a longitudinal, qualitative study involving in-depth interviews with a sample of callers to two NHS Direct Services. Targeted advertising encouraged individuals to call NHS Direct for information on two issues: childhood asthma and menopause. NHS Direct staff recorded background
information about 342 callers for the menopause packs and 85 callers for the childhood asthma packs.

A sample of 60 participants was recruited for interview from among those calling for the packs (33 women calling for the menopause packs, and 27 parents of asthmatic children who had called in for an asthma pack). Fifteen follow-up interviews with a small sub-sample of those interviewed were undertaken approximately 6 to 12 months after the first interview. Finally, five workshops were run with both health care professionals and members of the public to discuss the implications of the findings. The information leaflets to be sent to callers were selected through discussions with parents of children with asthma, and women experiencing the menopause as well as by the project steering group. The steering group included representatives from the National Asthma Campaign and Women’s Health.

5. **Decision Making in Primary Care: patients as Partners in Resource Allocation**

Ian Rees Jones, Len Doyle, Lee Berney and Moira Kelly, St George’s Medical School and Queen Mary College, University of London.

The study addressed decision-making in primary care, focussing on patient involvement in decisions that involve scarcity. Its starting point was a hypothesis that if patients are to participate in decision-making then explicitness is a prerequisite for involvement. This means explicitness in the patient encounter but also explicitness on the part of the GP. The GP has to be clear both to themselves and to the patient about the criteria they draw upon when engaging with a patient in decision-making.

The aims of the study were:

- to describe the way in which the allocation of scarce resources is perceived and addressed implicitly and explicitly by GPs in consultations with patients.

- to explore patient perceptions and attitudes towards the allocation of scarce resources in the NHS with a focus on primary care, and their aspirations for involvement in GP decision-making.

- in the light of the findings from this research, to consider the ethical implications of rationing for primary health care policy and practice.

The study was qualitative, involving a series of interviews and workshops with a sample of 24 GPs and interviews with a sample of 18 patients.
6. Having a Say: involving people with communication impairments in decisions about their health care

Sally Byng, Connect - the communications disability network. Sharon Farrelly, City University, with Louise Fitzgerald, de Montfort University, Susie Parr, City University and Sara Ross, Communications Forum.

The drive to make information accessible and to support shared decision-making is welcomed by the majority of health care service users, but there is a group of people whose communication impairments compromise their ability to process spoken and/or written language and to use language in clarifying, negotiating and expressing their choices and decisions. These impairments can block access to information, partnership and influence in decisions regarding health care.

The overall aim of this study was to seek to promote the inclusion of people with communication impairments in health care decision-making. It involved:

- identification of the barriers and facilitators to involvement in decision-making from the perspectives of both people with communication disabilities and health care providers;
- exploration of the viability of addressing the issues faced in common by people with a wide variety of communication impairments;
- the development of practical ways for users and providers to promote involvement.

Qualitative methods were used including a review of the literature, in-depth interviews with 30 people who have communication disabilities and with 24 health & social care staff; a focus group of people with dyslexia and data analysis using the Framework method. An advisory group, including people with communication disabilities, met during the project to give advice to the project management team.

Four members of the advisory group had communications difficulties. They contributed extensively to the project design and delivery and help to publicise its findings widely.
7. **Involving children and young people with a chronic illness or physical disability in health services development**

Jane Lightfoot and Patricia Sloper, Social Policy Research Unit, University of York.

The study sought to investigate the involvement of children and young people with a chronic illness or physical disability in local health service development. The principal research questions were:

- what is the level of activity and methods by which this group of users is currently involved?

- what are the factors which can support and promote such involvement?

Using the research findings, the study aimed to produce practical Guidelines for NHS staff on involving young patients in health service development.

There were two stages to the study. The first stage was a national survey of health authorities and NHS Trusts in England, mapping current involvement work with young people with a chronic illness or physical disability. The second stage was qualitative, with six case studies of local involvement projects involving data collection from young people (through individual interview or focus group) and project staff in NHS Trusts (through an individual interview). Interviews were also undertaken with trust staff with responsibility for patient and public involvement. Following analysis of the data, young people and project staff took part in a workshop to prioritise the content and design of Guidelines for NHS staff.

Two young people from a local Youth Forum advised the researchers at key stages of project development.

8. **Patient and public involvement in NHS primary care**

Stephen Harrison and George Dowswell, Dept. of Applied Social Sciences, University of Manchester. Tim Milewa, Philip Heywood, Philip Tovey and Waqar Ahmad, Nuffield Institute, University of Leeds.

This study was conceived in the context of a major policy thrust towards patient and public ‘involvement’ in the NHS. It focused on factors such as the expectations and attitudes of key stakeholders within primary care groups/trusts, other relevant statutory sector organisations and voluntary, community and patient associations. The four research questions were:
• how is public and patient involvement conceptualised by key actors in PCG/Ts, relevant voluntary associations, community organisations and by other stakeholders?

• what motivations underlie decisions on the part of the different stakeholders to become involved in public and patient involvement initiatives and associated processes?

• what do the different stakeholders want or expect from public and patient involvement?

• to what extent do emergent processes of public and patient involvement modify established patterns of authority and control in the operation and planning of health services?

The investigation encompassed four broad phases: semi-structured telephone interviews with a sample of half the PCG/Ts outside London; 34 exploratory scoping discussions with informants from eleven PCG/Ts, other statutory sector organisations and voluntary and community organisations in three health authority districts; focused interviews with a further 68 stakeholders; and further in-depth and telephone interviews in relation to four PCG/Ts.

The project engaged users (Advocacy organisations, policy makers, and NHS personnel) through an Advisory Group and presentations/discussions at 10 external seminars and conferences oriented towards participants from diverse backgrounds. The Advisory Group included nominees from the Patients’ Association, the Association of Community Health Councils in England and Wales, Leeds Racial Equality Council and the Department of Health. Emerging findings were discussed at a meeting of the WHO European Partnership on Patients’ Rights and Citizens’ Empowerment, a seminar on public participation and a session on citizens’ involvement in planning health care at a European Health Forum conference.


Will Anderson, Dominique Florin, Lesley Mountford and Steve Gillam, The King’s Fund.

Primary care groups came into being in 1999, providing new opportunities for patient and public involvement in NHS decision-making. This study sought to describe and evaluate the approaches to public involvement of PCGs in London. Key questions at the heart of the evaluation were:
what were the contextual factors which shaped the choices that PCGs made in approaching their public involvement brief?

what approaches to public involvement did PCGs adopt?

what public involvement methods did PCGs employ?

how did PCGs seek to bring about change through public involvement work? A distinction was made between 'mechanisms of involvement' and 'mechanisms of change';

what were the outcomes of public involvement work in PCGs? What counts as an outcome was acknowledged to be a key, and often problematic, issue within PCGs.

A postal survey of lay members and chief executives of the initial 66 PCGs in London provided some basic indicators of the extent of commitment to public involvement work and the range of work being undertaken. Six case studies of PCGs were then selected as the focus for the in-depth research.

There was lay representation on the steering group and local lay representatives contributed to the definition and development of each case study.

10. Citizen involvement in health care: meanings, motivations and means


The aim of this research was to understand what citizens, lay carers, or members of voluntary groups, perceive to be the motivations and methods of influencing the NHS. The objectives were:

• to determine what is understood by involvement and participation;

• to determine what motivates citizens to seek influence in health care delivery, policy or planning;

• to understand which mechanisms are believed to be realistic and effective in exercising influence;
• to understand the perceived enablers and constraints on taking effective action.

This was a large-scale, exploratory, qualitative study based on a deliberative design. The same individuals were asked to discuss their views at more than one point in time over a staged process: in-depth home-based interviews with a sample of 44 citizens recruited from health centres, focus groups with a sample of 34 citizen groups, further workshops with the same sample of 34 groups and interviews with nine national health care voluntary organisations. The study was carried out in six areas, selected to present a mix of inner city, suburban and more rural locations in the north and south of England.

The project steering group included representatives of patient and professional groups. Over 200 users participated in the research as well as the determination of priorities and recommendations.

11. Shared decision making and risk communication in general practice

Adrian Edwards, Glyn Elwyn and Christine Atwell, University of Wales College of Medicine

Shared decision-making (SDM) between professionals and patients is increasingly advocated but the skills required of professionals to achieve SDM have not been evaluated in clinical practice. Similarly, few evaluations of decision aids to communicate risk and benefits of treatment in UK general practice have been undertaken.

The aims of the study were to evaluate the effects of training in shared decision-making and the use of simple decision aids on general practice consultations for chronic conditions.

The principal method was a cluster randomised trial with crossover in urban and rural general practices in Gwent. The participants were 20 recently qualified GP principals and 960 patients recruited from practice registers. After a baseline phase of ‘usual practice’, participating GPs were randomised to receive training first in shared decision-making skills or the use of simple decision aids, using simulated patients. The alternative training was then provided for final study phase. Patients were randomly allocated to consultations during the baseline or two intervention phases of the study.

Qualitative methods were also used: interviews in 40 purposively selected doctor-patient dyads and focus group interviews with participating doctors after they had completed the trial.
Users were actively involved in the research from start to finish. Their contributions included help with design of the research questions, protocol design, study implementation and monitoring. They were also active in the dissemination phase of the research.

12. Developing and Evaluating Good practice for user involvement in cancer services


This project aimed to document the range of existing mechanisms for involving users, to evaluate their effectiveness and utility from the perspective of users and health professionals, and to develop a consensus statement on the appropriate extent and role of users’ involvement in the evaluation and development of cancer services. The project also sought to identify the key forms of education, training and support that facilitated user involvement and to document the impact, both on health professionals and users, of user involvement training programmes where they occurred.

Initially, a mapping exercise was conducted of existing mechanisms within ASWCS for user involvement in cancer service, encompassing NHS organisations, the voluntary sector, hospices and local councils. This was followed by a consensus development exercise using nominal group techniques and a two-stage Delphi method. Interviews were conducted with 37 users of cancer services about their understanding, experience and satisfaction with user involvement. The results of these interviews were used to develop a questionnaire survey of users’ attitudes towards user involvement. Finally, three case studies were conducted in each of the health authorities covered by the Network.

A key aim of the project was the development of a practical guide to help support the creation of user involvement systems in cancer services by cancer health professionals. Users were involved in all stages of the research design, implementation and dissemination.
This section lists selected organisations and websites concerned with patient and public involvement. An up-to-date list of websites can be found on the Health in Partnership website itself.

**Health in Partnership**
www.healthinpartnership.org

Full details of all twelve studies in the Health in Partnership programme including methods, results and implications for policy, practice and research.

**Department of Health**
www.dh.gov.uk

All Department of Health policy relating to patients and the public is available to download from its website.

**The Bristol Royal Infirmary Inquiry**
www.bristol-inquiry.org.uk


**The Carnegie Young People’s Initiative**
www.carnegie-youth.org.uk

The Mezzanine, Elizabeth House, 39 York Road, London SE1 7NQ. Tel: 0845 456 1697

An international organisation seeking to increase the participation of young people in policy making.
Centre for Health Information Quality
www.hfht.org/chiq

The Help for Health Trust, Highcroft, Romsey Road, Winchester, Hampshire, SO22 5DH. Tel: 01962 872264.

Promotes standards for health information in the UK and offers consultancy and training in developing health information.

Commission for Patient & Public Involvement in Health
www.cppih.org

9th Floor Ladywood House, 45 Stephenson Street, Birmingham B2 4DY. Tel: 0845 120 7111

The national agency charged with supporting the development of patient and public involvement throughout the NHS.

Communities for Health
www.communitiesforhealth.net

A network of UK organisations that seeks to improve the health of communities by supporting people to play active roles in planning and action.

DIPEx: Database of Individual Patient Experiences
www.dipex.org

Combines information about specific conditions with audio and video accounts from patients who have experienced diagnosis and the reality of life with serious illness.

DISCERN
www.discern.org.uk

An online tool for assessing the quality of health information, including printed materials and web resources.

Developing Patient Partnerships
www.dpp.org.uk

Tavistock House, Tavistock Square, London WC1 9JP. Tel: 0207 383 6715

A charity seeking to encourage better communication between patients and primary healthcare professionals.
Expert Patient Programme
www.expertpatients.nhs.uk

The national programme promoting user-led training in self-management skills, particularly for people with chronic illnesses.

Health Voice Network
www.healthvoice-uk.net

A self-help network committed to enabling people to have more of a say in planning and improving services that affect their health.

Health of Wales Information Service
www.wales.gov.uk/subihealth

Includes the online guide, Signposts – A practical guide to public and patient involvement in Wales.

Improvement and Development Agency (IDeA)
www.idea-knowledge.gov.uk

Local government resources on partnerships and community.

Invol
www.invo.org.uk

Wessex House, Upper Market Street, Eastleigh, Hampshire SO50 9FD. Tel: 023 8065 1088.

Promotes public involvement in the NHS, public health and social care research, in order to improve the way research is prioritised, commissioned, undertaken, communicated and used.

Involving People
www.show.scot.nhs.uk/involvingpeople

The Scottish Executive’s principal website for patient and public involvement in health services.

Modernisation Agency
www.modern.nhs.uk

Publishes guidance on involving patients and carers.
**Further resources**

- **National Association for Patient Participation**
  www.napp.org.uk

  Voluntary network of primary care based patient participation groups.

- **Patient UK**
  www.patient.co.uk

  A database of patient information materials and contact information for patient organisations and support groups.

- **The Patients Forum**
  www.thepatientsforum.org.uk

  Riverbank House, 1 Putney Bridge Approach, London SW6 3JD.
  Tel: 020 7736 7903.

  A network of patient organisations, aiming to strengthen its members’ influence on decision-making, particularly in the NHS.
Case Studies. A detailed study of individuals or organizations. These can involve a wide range of methods including collating and analyzing documentary sources, undertaking observation, in-depth interviews, postal or interview questionnaires, and focus groups. The information collected from these sources is then analyzed in a systematic way to address the research questions being asked.

Commission for Patient and Public Involvement. The statutory national, non-departmental organisation established in 2003. It’s responsibilities include:

- establishing and supporting Patient and Public Involvement Forums for every NHS trust in England;
- representing the views of patients and the public about the arrangements for patient and public involvement, to the Secretary of State for Health;
- promoting the involvement of the public in consultations and processes leading to key health decisions, at local regional and national levels.

Cluster randomised trials with crossover. Studies of health care interventions that evaluate the impact of the interventions. The groups/places to be studied are selected and allocated to one of two interventions. The groups are subsequently changed over and experience the second (alternate) intervention.

Consensus development techniques. (a) nominal group techniques. Structured group discussions generate a list of items that are then prioritized using (b) a two-stage Delphi approach. The Delphi approach uses questionnaire/discussions to/ with ‘experts’ to confirm areas of consensus. These consensus statements are then circulated to allow participants to express agreement or disagreement with the statements.

Focus groups. Small group semi-structured discussions with 8 to 10 selected participants.
**Mapping techniques.** The main aim of mapping exercises is to collect data/information, using a variety of methods, to develop an overview of patterns in a particular ‘area’ e.g. types of issues amongst a range of stakeholders.

**Overview and Scrutiny Committees.** Local Authority Committees which have the power to:

- review and scrutinise all matters related to the planning, provision and operation of local health services including public health services, within their areas;

- report and recommend to local NHS bodies and their local authority, matters emerging from their reviews. Local health agencies must consult them about any major changes or variations planned;

- Patient and Public Involvement Forums can refer matters to the committee;

- NHS bodies can be required to provide information to them;

- officers can be required to attend to answer questions.

**Patient Advice and Liaison Service (PALS).** PALS offices are in every NHS Trust. The services they offer include:

- dealing with problems on the spot -providing information to patients, carers and their families about local health services and putting people in touch with local support groups;

- helping people to get in touch with NHS complaints procedures and directing people to the independent complaints advocacy services;

- acting as and early warning system for trusts by monitoring trends, highlighting gaps in services and providing action reports to trust management.

They have no formal role in relation to Patient and Public Involvement Forums.
**Patient and Public involvement Forums.** Local volunteers recruited to Forums linked to every NHS trust in England. They are supported by Forum Support Organisations and their responsibilities include reviewing the quality of health care provided by their trust, promoting the involvement of the public in decisions and consultations related to their health; putting forward the views of the public to key, local decision makers; providing advice and information to the public about public involvement and complaints processes.

**Patient-centred care.** A philosophy of care that encourages (a) shared control of the consultation, decisions about interventions or management of health problems with the patient and/or, (b) a focus in the consultation on the patient as a whole person who has individual preferences within social contexts.

**Patient involvement.** The full participation of patients and their carers in their own care and treatment. Patient involvement can also be at the level of service delivery and quality monitoring.

**Public Involvement.** The participation of members of the public or their representatives, in decisions about the planning, design and development of their local health services.

**Qualitative research.** Research that aims to understand the experience of individuals in context in order to explore why people and/or organisations act the way they do. Qualitative methods, including in-depth interviews and/or focus groups are used, to explore in detail, selected areas appropriate to the research questions being asked. The information collected from these sources is analysed in a systematic way to uncover patterns of behaviour or systems for a group of individuals or organisations.

**Quantitative surveys.** Large scale surveys, usually by questionnaire, of structured or random sample groups. The information gathered is then systematically analysed and subjected to statistical tests of significance. The results of the survey are then shown to be, or not to be, representative of similar populations.

**Shared (medical) decision-making.** Usually refers to clinical consultations where the ethos is one where health care professionals work with patients to define their problems. Patients are given full information about the range of treatment/management options available for a condition and any uncertainties about outcomes where they exist. Patients are encouraged to participate fully in the decision(s) made about which option(s) to pursue. See Patient-centred care above.
**Systematic reviews.** A review of existing research evidence/literature based on clearly defined rules regarding study identification, study quality appraisal and strict criteria for inclusion of studies in the review. The outcomes and methods of the selected studies are then analysed for comparability and the weight of the evidence assessed.

**The Expert Patient Programme.** A national Department of Health programme promoting user-led training in self-management skills, particularly for people with chronic illnesses.
This overview summarises a programme of research planned, commissioned and managed for the Department of Health by Carolyn Davies with support from Christine Farrell and Dione Hills. The contribution of the 12 research teams who produced the individual research reports and that of the patients, members of the public, NHS staff and members of voluntary organisations who participated in their research, was central. Without their work, there would have been no evidence to summarise.

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