



## **User and Public Involvement in Health Services: a Literature Review**

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This report is dedicated to the memory of David Brandon. David's life's work was about user empowerment and involvement. David was working on this review shortly before he died in November 2001. We hope that the material here will encourage many other people to put into effect the values that David believed were so important.

## Executive summary

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### Background

Scottish Human Services commissioned this literature review as part of its work for the Scottish Executive funded Partners in Change project. Together with the toolkit Building Strong Foundations, it forms a resource for helping to build an NHS that “listens better to patients and responds more effectively to their needs” (Our National Health, 2000).

The review is of literature published primarily in the UK during the past 5 years, examining theories and involvement initiatives across the health and illness spectrum, and reflecting on the effectiveness of different approaches. It was carried out by Scottish Health Feedback over three months between January to March 2002. The main focus has been on literature documenting the experience of health services attempting to involve patients and the public more, identifying where possible what has worked and any barriers. It had three main aims:

- To provide evidence to persuade sceptics in health and other services that partnership projects and other involvement initiatives are indeed worthwhile and productive enterprises with positive and concrete outcomes.
- To seek out empirical evidence of “how to do it” and “what works” wherever this existed.
- To provide a firm foundation for improving and generating more involvement initiatives in the future.

The review sought to cover the literature in respect of three main interfaces with health services:

1. In respect of individuals own direct care;
2. Involvement in monitoring and improving the quality of services.
3. Involvement in strategic planning and developments.

### General Issues

The review discovered that 'involvement' is not an homogenous term and has a variety of meanings attached to it. There were two broad approaches identified from the literature - consumerist and democratic approaches. However, involvement was about more than consumerism, and in some sense, this notion contradicted the growing desire to make health services more 'person-centred'.

It is often helpful to distinguish between involving people as individual users/patients and carers, and involving them as groups, for example, users'/patients' groups or as citizens. Further, a distinction is made in the literature between 'reactive' and 'pro-active' approaches to involvement, which not only affect the purpose but the way involvement activities are carried out. Being clear about why, who and how involvement will take place is essential. Involvement is a multi dimensional concept, for example, levels of involvement vary considerably from merely sharing information through to user participation and direct user-control. The review examined four main types of involvement: the direct involvement of individuals and carers in their own health care; user and public involvement in service quality; in policy and planning; and involvement through community development approaches.

### Involvement in Health Services

The literature identifies a range of benefits from involvement including improved clinical outcomes, more appropriate and relevant services, and improved user/patient satisfaction. The barriers identified include staff's negative perceptions of involvement, a lack of understanding of the nature of user and public involvement, skill and knowledge deficits, resource issues, and a lack of joint working. The history of public involvement in health services is somewhat disappointing but there has never been such a promising time as now to promote better user and public involvement for a variety of reasons. It has been historically weak because it has developed in an ad hoc and isolated way. Despite an increase in 'involvement' activity, there is little evidence of any real shift in power or that local people can hold health services to account.

As Bell (2000) points out, public involvement should be the “bread and butter to a responsive, equitable and efficient health service” and the literature is replete with references as to the theoretical benefits of involvement. Similarly, Hogg (1999) and Barnes (1997) argue that wider participation requires long term investment of resources to encourage and support users and the public, thus giving them the confidence and means with which to participate in meaningful ways.

## Involving Individuals in their Own Care

There are strong arguments for involving people in their own care and research has consistently found that users/patients want more ‘person-centred’ consultations with health care professionals. The quality of relationship with health professionals is a key factor in the quality of care identified by users/patients. Research has demonstrated close links between person centred values and approach and effective involvement, and a shift in thinking to acknowledging the expertise of users about what it is like to live with their illness or disability.

Reasons for involving users/patients in their own care include that it results in better health and treatment outcomes, and increased user/patient satisfaction. Studies consistently emphasise that person-centred approaches require time, information and training, better interpersonal communication, mutual understanding and trust. The main barriers to increasing the level of partnership are time pressures, the lack of training, skills and experience, and lack of information.

The three most commonly discussed models in relation to involving users/patients in decision-making are - paternalistic, informed decision-making and ‘professional-as-agent’ models. While there is knowledge about what shared decision-making is, there is less evidence of it happening in practice. Consequently, researchers have described shared decision-making as the “neglected half of the consultation”. There is evidence that users/patients want more information, and positive results have been obtained from involving users/patients and their carers in producing information. Although patient held records offer

potential for meeting some of the criticisms of poor communication and coordination in health, there is still a need for further research evaluating practice.

## Involvement in Monitoring and Improving the Quality of Services

In addition to involving users in their own care, it is important to consider ways of involving users/patients in defining what quality is as well as measuring quality in services. Involving users/patients in the quality of services is based on the principle that users are best placed to say what they want out of services and whether the services are doing a good job. To date, the scope of user/patient involvement in clinical audits has been largely limited to one-off satisfaction surveys. Nevertheless, there are strong arguments in the research for user/patient involvement in medical audits.

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While there is some evidence of user involvement in setting service standards in other public services, there is little evidence of this happening in health services and there are still few good examples of user involvement in the whole process of evaluation and service audit. Involving users and carers in all stages of the development of standards, including clinical practice guidelines, purchasing and commissioning of services and research is an important element of quality assurance. However, genuine involvement takes time and resources.

## Involvement in Planning and Development

The principle that people as users and carers, potential users and interested citizens should be involved in the planning of health and social care services has become more widely accepted since the advent of community care. User involvement can also take place at a national strategic level. However, the reality often falls short of the ideal and there is less 'real' involvement in planning in the longer term than might be expected. User involvement in planning is essential so that it is informed by real needs, aspirations, personal experience and direct evaluation. Ideally,

users should be involved from the earliest stages of planning as this offers the best chance that more responsive and user-led services will be developed.

Important power differentials need to be acknowledged though, and the need for acceptance of the unique contributions of individual stakeholders in the planning process. However, it is only through involving local communities that agencies can arrive at a better understanding of how local services need to change and develop. In addition, it is important to tap into the expertise of local user groups as well as being aware of national research presenting users' views. Research evidence on involving users/patients in rationing and prioritising services is contradictory, but this depends on the level of information shared and how the issues are presented. Effective involvement depends upon allocating sufficient time to discuss options and issues.

## **Repertoire of Involvement Methods**

There are many different ways of listening to people both as individuals and as collectives or groups. One of the difficulties is that "involvement" is, or should be, something that occurs in every facet of health care and in every encounter between user and health care services - for example, a consultant or GP who listens attentively to his/her patient and is prepared to alter their views of the treatment plan etc because of this interaction. This can hardly be labelled as a "method" or still less a "technique" of involvement. This is an exceedingly important general point. The most significant forms of involvement are those that become part of the day-to-day practice of health care delivery and planning, whether at the level of the individual encounter or at a more collective level, yet these are often the least visible.

There is a danger that focusing on methods through published materials creates an impression that promoting involvement is only a matter of adopting and applying some identifiable "techniques". A repertoire of methods should not be mistaken for the whole project of achieving greater involvement. The different ways and methods by which the public are asked their views and opinions are "not neutral techniques" (Jones and Jones, 2002).

Some require people to respond as consumers or users of services, while others support people to participate as citizens. Many methods have been categorised as research, consultative or deliberative, and the literature evaluating these is discussed. A broad array of methods/ways of involving users and the public has been tried. No one method constitutes 'involvement', and there are no 'recipes or fixed formulae'. There is no 'one right method' and it is possible to use one method to develop another.

### Involvement through Community Development Approaches

Community development approaches have been discussed as an example of both a democratic and truly proactive approach to empowering individuals and communities to be involved in identifying needs and gaps in services and developing new service responses. It is essentially a long-term process of involving individuals and communities in their own health. Community development uses a variety of participatory research methods and activities that address four dimensions: personal empowerment, positive discrimination, community organisation, and participation and influence. These have grown out of dissatisfaction with the traditional power relationships in the production of research. The main purpose of participatory research approaches is to raise awareness and ensure that those affected by the research retain control from the outset.

Community development recognises that access to health care services is a less significant determinant of health than many economic, social and environmental factors. Such approaches challenge the definition of health as an individual problem for which there are individual solutions and health care systems that treat symptoms and not the root causes of ill health. Community development is still at a relatively early stage of development within mainstream agencies and there are few written accounts within the field of statutory health care.

## Discussion and recommendations

One of the conclusions from the review is that it is possible to be engaged in numerous involvement activities without really involving people if professionals continue to drive the agenda and make decisions about treatments and services without taking users' views into account. In the review, a number of recommendations are identified that constituted 'good' user and public involvement. These are:

- There is an 'ethic of involvement', it is not an add on or a 'top down' approach.
- A strategic approach is adopted across the whole organisation with strong leadership.
- There is both community and organisational development.
- Partnerships are formed with other local agencies, e.g. local authorities.
- No single approach or technique is taken to constitute user and public involvement.
- Various techniques can be used, chosen according to the purpose of the initiative.
- The resource implications of involvement are acknowledged.
- There are tangible gains from participating and these are communicated.
- Communication mechanisms are set up to ensure regular feedback in accessible formats.
- Involvement strategies are evaluated and the process is one of continuous learning.



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# Acknowledgements

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Julie Ridley carried out a literature search on involvement in health services and wrote this report with Lyn Jones.

Scottish Health Feedback

# 1. Introduction

## Key points - section 1

- 'Involvement' is not an homogenous term and has a variety of meanings attached to it.
- The terms 'involvement', 'participation' and 'consultation' are sometimes used interchangeably, and at others to mean different things.
- Two broad approaches to involvement were identified within the literature - consumerist and democratic approaches.
- It is often helpful to distinguish between involving people as individual users/patients and carers, and involving them as groups, for example, users'/patients' groups or as citizens.
- A distinction is made in the literature between 'reactive' and 'pro-active' involvement, which not only affects the purpose, but the way involvement activities are carried out.
- Being clear about why, who and how involvement will take place is essential.
- Involvement is a multi dimensional concept - for example, levels of involvement vary considerably from merely sharing information through to user participation and direct user-control.
- This review has examined four main types of involvement: the direct involvement of individuals and carers in their own health care; user and public involvement in service quality; in policy and planning; and involvement through community development approaches.

### 1.1. Background

Scottish Human Services as part of its work for the Scottish Executive funded Partners in Change initiative, commissioned a review of the literature on involvement in health services. Partners in Change is a capacity building initiative whose purpose is to promote involvement throughout the NHS in Scotland. In *Our National Health - A plan for action, a plan for change*, (2000), central government stated its vision for an NHS that “listens better to patients and responds more effectively to their needs”. Ensuring patients have a stronger voice and involving people and communities in the design and delivery of health services was central to “a truly modern, responsive health service.” This policy commitment to involvement was further strengthened by the publication of the guidance, *Patient Focus and Public Involvement* (Scottish Executive, 2001a).

Although involving people in health services has become a widely familiar concept, now firmly embedded within national health services policy, as Ritchie observed:

*“While no-one would say they were against partnership, not everyone is completely convinced it can work. There are some people who are sceptics, and who see partnership as an extra something you have to fit in on top of all the other meetings. There are also a lot of other people who are trying hard but doubt if the level of change they are seeing is worth the effort”.*  
(Partners in Change, 2001, page 4)

It was in the context of this concern that this literature review was commissioned and carried out over three months between January-end of March 2002. The work was intended to complement the development of a ‘Toolkit for Involvement’ as mentioned in *Patient Focus and Public Involvement*. It aimed to set the discourse within the experience of involvement in the NHS, as well as the theory. At the same time as this literature review was being undertaken, academics at Edinburgh University were completing a research study exploring different perceptions of participation for the Department of Health in England and this included an extensive literature review of patient and public involvement in health care (McCrae et al, 2002). While there is an inevitable overlap of some material, it is envisaged that the reviews will prove complementary.

## 1.2. Aims and purpose of the review

This brief literature review had three rather ambitious aims specified at the outset. As stated, one was to provide evidence to present to sceptics in health and other services to help them judge whether partnership projects and other involvement initiatives are indeed worthwhile and productive enterprises with positive and concrete outcomes. The motivation behind the review is therefore undoubtedly associated with an agenda, one that is broadly in favour of more and better involvement. However, we have sought to be neutral and even-handed in our searches and in our choice of material to present, looking both for literature presenting the benefits of involvement in health services and that presenting any barriers to it and problems it might raise.

The second aim was to seek out empirical evidence of “how to do it” and “what works” wherever this existed. And the third was to provide a firm foundation for improving and generating more involvement initiatives in the future. In short, the review was intended to build the argument for better involvement in health services and wherever possible, to identify elements of good practice. If involvement is to be perceived as more than a series of techniques, those working in the health services require more than mere descriptions of different processes and methods. This literature review, therefore, has attempted to discuss both general themes in relation to involvement and specific experiences of the practice of involving users/patients and the public.

Involvement in the health services covers a vast range of activities from information provision about health problems and services, to the active involvement of users and communities in decision-making and the design of future health provision. This review has sought to cover the literature in respect of three main interfaces with health services:

1. In respect of individuals' own direct care;
2. Involvement in auditing, monitoring and evaluating services and their quality;
- and
3. Involvement in strategic planning and developments.

In addition, it has covered some of the literature on community development approaches to health.

In doing so, it has concentrated mainly on policy documents pertaining to Scotland. While the searches performed and literature retrieved were broad based using general keywords such as 'involvement' and 'participation' in all these areas, this review cannot claim to have included all of the literature on all aspects of health and involvement: limited as it is to what could be searched, accessed and read within a three-month period. The emphasis is therefore on the inclusion of empirical studies wherever these existed, and a more detailed bibliography appears at the end of the report for the more inquisitive reader to follow up.

### 1.3. Definitions and conceptual framework

*To be involved means to be implicated, be bound up with, to be emotionally concerned, to be engaged with, or to comprehend. (Chambers Dictionary, 1993)*

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Involvement is a generic or umbrella term to which a plethora of meanings have been attached. When it is used in a loose way, it can be rather uninformative (Readers Digest Association, 1985). Simply saying that people are 'involved' in health services for instance, tells us nothing about the way they are involved, the intensity, what it is they are involved in, the range of people taking part and so on. The Latin roots are to be found in 'involvere' meaning 'to enwrap', from 'volvere', 'to roll or turn'. The Chambers Dictionary definition and its Latin roots imply close interconnection and engagement.

There is considerable diversity over definition to be found in the literature and different conventions are in widespread use. While some authors have used 'consultation' as a term to convey a range of approaches to involving the public and communities (e.g. Laird et al, 2000), for others, 'consultation' implies a passive or even tokenistic attempt to engage with the public (McCrae et al, 2002; Scottish Association of Health Councils, 1999; Arnstein, 1969). There are a great many meanings associated with the

concept of involvement in state services and this is reflected in the following quotation cited in Lupton et al (1998):

*“The ambiguity attached to participation has helped to foster its own cause. Because so many different hopes have been linked with it, so many different expectations about what it will achieve, it has been embraced by spokesmen of highly varying political hues. Consumers have advocated participation in order to achieve their particular ends and the service providers have similarly welcomed it in order to serve theirs. The very uncertainty of its impact has enabled a common rallying call.”*  
(Richardson, 1983, p99)

Shifts in political ideology have influenced how ‘involvement’ is portrayed. Hogg (1999) reflects on the changes in thinking in the following four distinct models of operation:

1. Traditional model of paternalism - This model assumes ‘professionals know best’, requiring patients to trust in the skills, knowledge and ability of clinicians.
2. Consumerist model - This model assumes that individuals are in charge of getting the ‘best buy’ and that with internal competition, consumers can decide to take their custom elsewhere if they do not like what they receive.
3. Partnership model - This model views the giving and receiving of health care as a negotiation agreed between the patient and professionals and is more in line with the current emphasis on user and public involvement.  
and
4. Autonomy model - This model places respect for the individual first and recognises the different perspectives of patients and professionals.

It is likely that elements of all of these ‘ideal’ models could be found to be operating somewhere within current services. The value of such models is in providing a theoretical framework for better understanding and discussing experience.

### 1.3.1. Consumerist and democratic approaches

Two broad approaches to involvement can be identified within the literature, although there are variations on the theme (Mullen and Spurgeon, 2000; Lupton et al, 1998). These are consumerist approaches and democratic approaches. Many commentators for instance, have located the growth of interest in involvement within a general increase in 'consumerism' in the late 1960s and 1970s (Mullen and Spurgeon, 2000). The consumerist approach is based upon the private sector notion of 'markets' as in Hogg's model 2 above. It emphasises the importance of 'market research' to identify the preferences of individual customers and to enhance the organisation's market competitiveness. It also places emphasis on the rights of consumers to information, access, choice and redress in relation to specific products or services. Some have argued however that this notion of health service users as 'consumers' contradicts the growing desire to make health services more 'person centred', and that while the act of getting closer to users of services might involve consumerism, it goes beyond it. Williams and Grant (1998) for instance commented:

*"People are more than consumers. To be people-centred and to value individuals requires an appreciation of the totality of the individual and not concentration on a specific role. This is surely the same criticism which has been laid at the door of the medical profession: in treating people as patients they have reduced the individual and thus devalued them." (Page 86)*

The second main approach, the democratic approach, relates to people in their capacity as ordinary citizens and taxpayers with rights to access to services and to contribute or participate with others collectively in the society in which they live. This approach emphasises equity and empowerment with participation as a key concept (Lupton et al, 1998). There are two main principles underpinning this approach: that public participation is beneficial to maintaining a healthy democracy and in allowing people to become full citizens, and second, that the diversity of interests in society should be fully represented in the political process.

A further refinement of this analysis is Barnes' (1997) thesis that in order to understand involvement in health services, it is first

necessary to establish the motivation behind it. Barnes identified four broad purposes. The first purpose was to meet the needs of the organisation, and to learn how users perceive services, to measure quality, effectiveness, and equity. A second purpose was to achieve individual empowerment, enabling people to become effective consumers of health services and to take action to improve their own health status. Third, public involvement can enable the expression of aspirations and become “an agent of change at a system level” and lastly, involving people in health services can help to enhance democratic accountability and citizenship.

### **1.3.2. Reactive and pro-active involvement**

Another important distinction that has been made by some authors is in describing involvement as either ‘reactive’ or ‘pro-active/initiator’ involvement (Mullen and Spurgeon, 2000). This distinction concerns not only the approach taken to involvement and the methods used, but also the view taken of the purpose and the very nature of involvement. Where involvement is ‘reactive’, the health care system asks people to react to activities, services, plans, proposals and priorities. In contrast, ‘pro-active’ or ‘initiator’ involvement means people as service users and citizens becoming involved in initiating and formulating definitions of need and making proposals for new or improved services. In making this distinction, it would appear that many activities currently falling under the umbrella of involvement are of a reactive nature compared to those which have involved people through community development approaches, which set out to ensure people’s participation in agenda setting, needs definition and problems solution. By way of differentiating between reactive and proactive approaches in this review, Section 7 focuses specifically on involving people through community development approaches.

### **1.3.3. Types of involvement**

It is possible within the literature to identify different types and levels of involvement. In short, three main types can be distinguished: involvement of individuals in making decisions about their own treatment and care; involvement in examining and improving the quality of services; and as taxpayers and

citizens in policy and planning (McCrae, 2002; McIver and Brocklehurst, 1999; Charles and De Maio, 1993). While it is usually agreed as helpful to differentiate between individual and collective involvement, this does not necessarily equate with 'how' or 'what' each can be involved in. For instance, both individuals and groups can be involved in assessing and evaluating service quality and in strategic planning and service development.

The Government White Paper, *Our National Health* (2000) identified four main types:

1. Individual patients (or carers) in their own care.
2. Patients in monitoring and improving the quality of care in an existing service.
3. Patients and the public at an organisational level.
4. Patients and the public in planning changes in service provision.

Additionally, some authors distinguish between involvement at a national level, as well as involvement in locality commissioning and in defining health needs (McCrae et al, 2002; Barnes, 1997).

#### 1.3.4. Level of involvement

As well as examining types of involvement, qualitative distinctions can be made between different levels or degree of interaction. For example, Charles and DeMaio (1993) as cited in McCrae (2002) identified three main levels: consultation, partnership and ultimately control. The Scottish Association of Health Councils et al (1999) differentiate between communication (establishing meaningful dialogue), consultation (asking users' views) and partnership (equal relationship between users and professionals). The 'ladder of participation' developed by (Arnstein, 1969), is an expression of this idea of different degrees of interaction, making it clear that relatively few 'rungs' can be described as real 'citizen power, and setting it within the context of wider power relations. For instance, Arnstein argued that consultation was nothing more than tokenism and that partnership would be a better route to citizen empowerment. Arnstein preferred the notion of

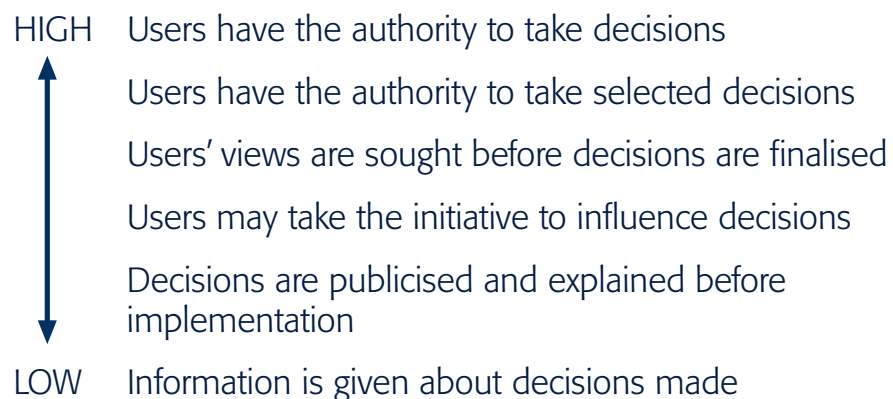
'participation' to 'involvement' because of its emphasis on interaction. The 'ladder of participation' is described in the Figure below.

Figure 1: Arnstein's ladder of citizen participation, (1969)

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

Arnstein had suggested that most activities taking place under the umbrella of participation were hollow, and that only the top three rungs (partnerships, delegated power and citizen control) involved genuine participation or dialogue with people. A number of studies since Arnstein's 'ladder of participation', have adapted this conceptualisation including Hoyes et al (1993), cited in Small and Rhodes (2000), who developed the following 'ladder of empowerment':

Figure 2: Hoyes et al (1993) 'ladder of participation'



While widely acknowledged as a useful model, there are criticisms of the 'ladder of participation' concept in its presentation of a linear process, and its failure to taken account of the range and complexities of modern day relationships between users and service providers (Small and Rhodes, 2000; Laird et al, 2000). Nevertheless, it is helpful to have ways to distinguish between involving users/patients or the public through merely giving information or gathering information about people's views of services through one-off focus groups or surveys and longer-term initiatives offering community or user control (SAHC et al, 1999; Taylor, 1996).

### 1.4. Method and scope of the review

The literature on the subject of information for patients in itself is vast (Olszewski and Jones, 1998). There is also an increasing body of literature on involvement in planning, albeit mainly in relation to local government and the implementation of Community Care policy. Additionally, from the late 1980s, there is published work on community development and more recently, the new public health agenda (Jones, 1998). This review does not make any claims for comprehensiveness in tackling the subject of involvement in the health services but attempts to identify the main themes running through the literature. While it is predominantly about involvement in health services, it has inevitably reviewed some literature about involving people in health generally when discussing community development approaches for example.

Sources for the literature review built on the reading lists and web searches initially carried out by David and Toby Brandon, as well as by Paula Ribeiro and Sylvia Cox at the Dementia Services Development Centre's 'Communication for Change' project (which is also linked to the Partners in Change project and funded by the Scottish Executive). Keywords including participation, public, patient, user, involvement, planning, consultation, consumer, and combinations of these, were used to search online databases through the Scottish Health Services Centre. These included the Centre's Health Management Library; Health Management Information Consortium or HMIC (including the King's Fund library database); the Applied Social Science Index or ASSI; Joseph Rowntree Foundation; and the Cochrane

Library. In addition, reference and bibliography lists of books and journal articles obtained were scanned for useful material.

Websites such as the Designed to Involve website, the Scottish Development Centre for Mental Health and other specialist websites were searched for references. Books and journal articles were accessed through the SHSC Health Management Library, Universities of Edinburgh and Dundee, and the British Medical Journal online. The Dementia Centre also provided specialist references. In addition, the Scottish Consumer Council and the Scottish Association of Health Councils were contacted directly.

In common with other researchers, it was soon discovered that the size of the literature base on this topic was potentially infinite, particularly given the growing political and academic interest in involvement and participation in public services over the last 25 years (McCrae et al, 2002). It was essential to limit the scope of the literature review so that the task became manageable within the short time available. This meant focusing the review as far as possible on:

- theories and involvement initiatives across the health and illness spectrum over the United Kingdom , primarily using literature published in the past 5 years;
- research findings and outcomes, emphasising partnerships or initiatives that worked but also outlining barriers to change;
- different approaches, and identifying the achievements made so far and providing evidence to build on them;
- drawing upon existing literature reviews;
- reflecting the range of involvement activities including one-off consultation, audits, assessment of services, setting quality standards, training/supporting people to have more say, community development approaches etc.

While we have not specifically left out any material relating to particular groups of users or communities, the review tends to reflect where the balance lies within the literature, and there may therefore be inequitable treatment of some areas.

Where the review touches on matters of NHS structure and policy, there is a particular focus on the position in Scotland.

### 1.5. Report structure

A number of key areas have been addressed in this report, including in Section 2, a brief historical overview of involvement and how far it has evolved in the NHS, the forms involvement might take, the benefits that have been identified for individuals, the public and the NHS itself, as well as the challenges. Section 3 examines the literature concerning the involvement of individuals and carers in their own treatment and care. Section 4 then looks at what has been written about user and public involvement in auditing, reviewing and monitoring the quality of services. Section 5 then focuses on user and public involvement in policy, strategic planning and service development. Section 6 explores the repertoire of methods that exist as helpful tools to involve people in different ways and for different purposes, while Section 7 briefly looks at the literature on longer-term approaches to involving communities in their own health, collectively referred to as community development approaches. Section 8 then discusses the 'findings' of the review more generally and tries to draw together the characteristics of effective involvement. Section 9 provides a detailed reference and bibliography on involvement in health services.

## 2. General Overview

### Key points - section 2

- Involvement is far from a new concept. In recent decades, user and community movements, policy developments, increased demands on services and resource prioritisation, and growing user litigation have contributed to moving involvement up the policy agenda.
- In Health, the focus on involvement has historically tended to be at the individual level, while at a strategic level, involvement is generally underdeveloped.
- Despite growing interest in promoting involvement, most commentators agree its development in health services has been slow and patchy.
- There are several reasons for this: two key ones are, confusion about just what it is; and the uncoordinated nature of many projects.
- Despite an increase in 'involvement' activity, there is little evidence of any real shift in power or that local people can hold health services to account.
- The literature identifies a range of benefits from involvement including improved clinical outcomes, more appropriate and relevant services, and improved user/patient satisfaction.
- The barriers identified include negative perceptions of health service staff, a lack of understanding of the nature of user and public involvement, skill and knowledge deficits, resource issues, and a lack of joint working.
- Further research is needed to evaluate the involvement approaches being adopted by health services.

### 2.1. Introduction

This Section briefly examines literature that has traced the historical development of involvement in the NHS suggesting a variety of reasons for the current focus on involvement, and then looks at the evidence about its implementation. There is a compelling case for user and public involvement and the review highlights literature showing the benefits as well as barriers or challenges.

### 2.2. Brief historical outline

Involvement is currently (early 2002) high on the policy agenda and there is, arguably, an unparalleled window of opportunity for advancing effective involvement in the health services (Scottish Executive 2001a, 2000a). Indeed, how the NHS engages with its various publics has been dubbed "the greatest challenge for health services at the beginning of the twenty-first century" (Brooks, 2001), and one that is "critical to its future development" (Barnes, 1997). Several authors argue, especially in relation to new primary care structures, that in the present there is unique potential to develop a more integrated approach to partnership with users and the public (Hopton and Hill, 2001; Scottish Association of Health Councils et al, 1999). Even the briefest scan of the literature shows a mushrooming of interest in involvement over the past 25 years. The range of multi-disciplinary literature concerned with both theoretical and ideological discourse, as well as more practical issues, is now "diverse" and "something of a minefield" (Gillam and Brooks, 2001).

The context of this growth is one of increasing demands on health services, resource prioritisation, and growing user litigation resulting in low professional morale (Brooks, 2001). Central to current policy and organisational change is the concept of democratic accountability and citizenship and the desire to make services more responsive to users' definitions of need (McCrae et al, 2002; Scottish Executive 2001a, 2000a; Brooks, 2001). One of the most significant changes in the NHS has been the shift in political rhetoric from the 'market' model and the notion of users/patients as consumers, to the ideology of citizenship and democratic accountability (McCrae et al, 2002; Barnes, 1997). From the beginning, Lupton et al (1998) argued, the relationship

of the NHS to the public has been characterised by a focus on the individual user/patient. The inherent tensions between medical power, managerial accountability and public participation have remained a constant theme in subsequent reviews of the NHS. This historical legacy has emphasised clinical freedom over the interests of users and the public and has meant managerial accountability of doctors was virtually non-existent except through professional organisations. Public involvement in health care has been characterised by fragmentation. User/patient or community groups lobbying around specific issues, for example, breast cancer, have led to uneven service developments. Strong and Robinson (1990) (cited in Lupton et al, 1998) maintain that NHS reforms overall have militated against increasing user and public involvement as health authorities have focused attention on implementing national agendas.

While user and public involvement is not an original concept, the extent to which this has been a reality is debatable. According to Dick and Cunningham (2000), several user and community movements, together with policy developments have converged over recent decades to make user involvement a necessity in the planning, management and delivery of health social care. The main contributory trends they identified were:

- The emergence and activism of assertive organisations of people who use services and take action as campaigning and collective advocacy groups.
- The development of a 'social model' of disability which emphasises the need to tackle discriminatory attitudes, economic, social and environmental barriers.
- The growth of philosophies of care such as normalisation and social role valorisation which emphasise social integration and a valued life for people who have traditionally been excluded.
- The translation of the market and consumerism into public services bringing the concept of the service user as consumer.
- An emphasis on responsive services, quality assurance, charters and users and carers as experts.

(Dick and Cunningham, 2000, p2)

Other reasons identified in the literature explaining the surge of interest in user and public involvement in health services can be summarised as:

- A shift in the political philosophy and perception of the role of the state (McCrae et al, 2002; Williams and Grant, 1998; Barnes and Evans, 1998).
- Rejection of professional dominance or that the views of 'experts' should go unquestioned (Hogg, 1999).
- An increase in lay knowledge and a general move towards more forms of self-help (McCrae et al, 2002; Olzsewski and Jones, 1999; Barnes and Evans, 1998).
- An increased awareness of patients' rights and of medical uncertainty (McCrae et al, 2002; NHS Executive et al, 1998).
- A shift from acute to chronic health problems (McCrae et al, 2002; Brearley, 1990).
- Acceleration of healthcare costs and the focus on rationing and targeting resources (McCrae et al, 2002; Barnes and Evans, 1998).
- Developments in health technologies and scientific knowledge raising ethical, moral and political issues that require broad debate (Barnes and Evans, 1998; NHS Executive et al, 1998).

Table 1 summarises key landmarks in the development of involvement in health services identified from the literature. It shows a scene set for involvement to grow, nourished by explicit policy statements and central government initiatives including Partners in Change (Scottish Executive, 2001; 2000). But the historic legacy of the NHS also presents difficult challenges and highlights areas that might need attention. It was not until 1974 that reforms of local government and health services introduced Health Councils (Local Health Councils in Scotland) as local watchdogs with a wide remit of "representing the interests of the local community". This was the first time that consultation with patients and the public was introduced formally into the NHS, over two decades since its inception. It has been suggested that

involving the public mainly through this channel has established an “unhelpful”, and “somewhat limited”, style of public consultation (Hogg, 1999). The introduction of the Patients’ Charter in 1991 arguably afforded users/patients the right to have any proposed treatment, including any risks involved and any alternatives explained to them before agreeing consent. In practice, although the Charter played some part in bringing about a change in outlook within health services (SHF, 2000), it has a “contentious public reputation” due to lack of clarity about its aims and inadequate user and staff involvement in its creation (Farrell et al, 1998).

It is clear to several commentators that involvement requires much more than cosmetic changes within the health services and further that there are implications for the overall culture of the NHS. Inevitably, parts of the health care system will be more familiar with involvement both as a concept and a practical reality. The 1997 White Paper *Designed to Care* underlined governmental interest in promoting better partnership between those who use health services and the professionals who delivered them to bring about a “patient focused service”. Within the context of ‘clinical governance’, NHS Trusts were now obliged to ensure patients and the public become fully involved in determining the quality of services. More recently, *Our National Health - A plan for action, a plan for change*, (Scottish Executive, 2000) included a commitment to strengthen users/patients and the public influence in the NHS, and to create opportunities for ‘real partnerships’ to bring about ‘real change’ across Scotland. Its two core aims were to ensure users/patients had a stronger voice and that people and communities were involved in the design and delivery of health services. A significant development in the past decade has been such formal recognition of wider, non-service based influences on health and the promotion of a public health agenda (Scottish Office, 1999).

### Development of Involvement in Scottish Health Services

1948	The NHS is born but focuses on individual patients while local authorities retain responsibility for public health matters. Limited involvement of individuals.
1960s	Series of public scandals regarding older people, people with mental health problems and people with learning difficulties raises public awareness of malpractice and poor quality services.
1968	Medicines Act give patients right to know names of prescribed drugs.
1974	Health services reform establishes the Health Councils and the post of Health Service Commissioner to deal with non-clinical complaints.
1980s	Sees development of community health and public health movements, and growth of user and advocacy movements. User-led campaigns, for example re breast cancer, mean user involvement becomes more developed in certain areas.
1983	'Griffiths Report' is critical of the consensus management approach and insularity of NHS managers, and urges greater sensitivity to customers. Introduction of competition, contracts, and the 'market model'.
1990s	Growing interest in consumerism and quality within NHS. The NHS and Community Care Act (Scotland), 1990, emphasises joint working and user and carer involvement in health and social care.
1991	The Patients' Charter introduced new procedural rights for patients.
1997	Designed to Care White Paper - vision of "a patient focused service built on partnership" (p2). Also launched idea of Healthy Living Centre acknowledging wider influences on health and a new public health agenda.
1999	Towards a Healthier Scotland White Paper - recognises need to tackle inequalities through action on 3 levels: life circumstances, lifestyles and health topics.
2000	Our National Health - a plan for action , a plan for change included commitment to strengthen the influence of patients and the public.
2001	Patient Focus and Public Involvement - guidance to better involve users and citizens.

Table 1: Summary of key landmarks in the development of involvement in health services

### 2.3. Extent of 'involvement' in the NHS

The exploration of the meaning and the history of involvement or participation highlights that its development in the health services is a complex one. Bell (2000) comments that the NHS has no history of involving the public in "any meaningful way", and McFadyen and Farrington (1997), in common with other writers, deduced that user participation in the NHS "appears slow to date". A review of arrangements for consulting users/patients and the public found them restricted:

*"Although health authorities have increased local consultation, its quality remains dubious, with greatest emphasis on one-off consultation exercises." (Jordan et al, 1998)*

As Barnes and Evans (1998) claim, the development of involvement is "historically weak" for two main reasons: there is a general lack of focus and confusion about what it is; and second that many innovations have been one-off projects and involvement is not perceived as integral to the way the service works. Our National Health (2000) identified the need for radical change to bring about a "patient-centred NHS", concluding "there is a clear view that the NHS still does things to people rather than with them". Taken overall, the existing literature indicates that despite a rash of involvement activity in many different health settings, the "reality does not fully live up to the ideal" (McCrae et al, 2002). A more cynical view of involvement of patients and citizens concludes:

*"The public, as citizens or as users, have rarely been directly involved, except where their views coincide with those of the more powerful." (Hogg, 1999, page 2)*

Despite substantial evidence of involvement activity therefore, there is less evidence of a real shift in power within health services or that local people are able to hold health purchasers or providers to account (Barnes, 1997). The dominance of the traditional, professionally driven approach to clinical care over person-centredness in health services is arguably the main obstacle to change (Williams and Grant, 1998). A recent study carried out by the Greater Glasgow Health Council attempted to

assess whether changes within the NHS had resulted in more patient and public involvement and what role the Health Councils had played. The findings of this survey found practice wanting and suggested, "more is required to be done" (Crawford, 2000). While there were certainly isolated examples of involvement methods such as health panels being carried out, the issue was "proving hard for Trusts and Boards to address" according to some local Health Council Convenors and Health Council Chief Officers, who commented that there was a long way to go to "change professional 'mind sets'".

The Audit Commission (1996) similarly found users had little involvement in decisions made by GP practices about commissioning services. That involving the public is complex was demonstrated by Peck (1998), who undertook a retrospective case study of the process and outcome of public consultation on the proposal of a mental health unit to become a first wave NHS Trust. The overriding conclusion Peck reached was that the legacy of involvement in the health services was at best one of "ambiguity", while at worst, one of "duplicity" in its approach. Taken overall, this would suggest that there are powerful cultural barriers to achieving the desired changes within the health services. Further empirical research is needed to monitor the approaches adopted by health services to the public and the responses they elicit from the public (Peck, 1998).

That such a reality is changing however slowly can be gleaned from the research of Hopton and Hill (2001) in relation to the relatively new Local Health Care Cooperatives. These researchers found evidence that embryonic participatory processes set up through LHCCs working in partnership with social inclusion partnerships or community health projects were influencing and informing LHCC culture. The locality structure of LHCCs meant they were "well placed to lead this function on behalf of the whole system" (Hopton and Hill, 2001, p11). The "Designed to Involve" project funded by the Scottish Executive for two years from 1999 to 2001 concentrated on encouraging and supporting initiatives in Primary Care, and worked extensively through contacts with LHCCs. This project has now been succeeded by an initiative with a wider focus, on encouraging involvement across the board in the NHS in Scotland. This is the "Involving People"

Team, located within the Health Gain and Quality Division of the Health Department of the Scottish Executive.

Other developments at Primary Care level include work commissioned to develop an action plan for involvement within a Primary Care NHS Trust (Scottish Health Feedback, 2001a), and the Patients Influencing Health Care project set up to promote patient centred health planning within Highland Health Board (von Reuser, undated; Courcha and James, 1999). Clearly, the Partners in Change initiative itself is concerned with bringing about changes in the landscape of involvement in health services.

## 2.4. Benefits of involvement

The argument that public services should become more responsive and accountable to the needs of the people who use them has thus been won - in theory, at least. While it is generally acknowledged as not that easy to achieve in practice, there is evidence for a number of benefits for the users, as well as the commissioners and providers, of health services (Department of Health, 1999a).

Proponents of user and public involvement have identified a variety of benefits to individuals, organisations, communities and society, some of which it must be said, will be easier to substantiate than others. These benefits have included:

- Better outcomes of treatment and care.
- Services become more appropriate, responsive and more effective as they become more tailored to people's real needs.
- Increased accountability of public services leading to increased confidence of the public in health services, thus reducing the 'democratic deficit'.
- Improvements in staff and patient morale.
- Development of alternatives - involvement as an 'agent for change'.
- Empowering individuals and communities and increasing their sense of ownership of health services.

- Improved health and a reduction in inequalities.
- For organisations, greater understanding of the links between health and the circumstances in which people live their lives.
- More attention given to cross cutting issues and close cooperation between agencies with a role to play in health improvement.

(E.g. SAHC et al, 1999; Doyal, 1998; NHS Executive et al, 1998)

There are many examples within the literature of positive claims for user and public involvement in health services. Wilson (1999) highlights the validity of involving users in health services:

*“People who use services can be the best judges of the service’s strengths and weaknesses.”*

McIver and Brocklehurst (1999) cite Horder and Moore (1990) who asserted that there is sufficient evidence to make claims for positive correlations between aspects of communication and patient satisfaction, recall and better understanding of treatment. Others have suggested more general health improvements:

*“Health policies that are open to public accountability, in which citizens and users have a strong voice, are likely to lead to a healthier society where health is put before health care and commercial interests.” (Hogg, 1999, page 187)*

The Department of Health (1999) claimed that involving people in influencing decisions that affect them had a positive impact on self-esteem and self-confidence. The success of the latest healthcare policies will be highly dependent upon radical changes in the interaction between users and professionals (Foote and Plsek, 2001). The challenge to the core concepts of service and entitlement that have so far been the bedrock of the health service, should however not be underestimated:

*“This culture of charity in the NHS has often resulted in a take-it-or-leave-it philosophy in our delivery of care. The provision of service further tends to imply that the recipient is a passive receiver of a fixed product. As a result, there are unequal degrees*

*of obligation on the part of the provider and recipient, which may be a barrier to development of the mature healing relationship that is needed in healthcare.” (p32)*

Foote and Plsek (2001) asserted the time was right to move from a 'service ethos' to considering the processes of healthcare as a system. Systems thinking they argue would encourage the active, "equal-partners relationship" needed. Sang and O'Neill (2001) envisaged user/patient involvement in clinical governance as enriching the delivery of clinical services and the long-term development of services. Continuous improvement, they state, begins with learning about users/patients' experiences. As Fisher and Gilbert (2001) conclude, the 'value-added benefit' of user involvement is that it provides a practical perspective on problems and their solutions.

## 2.5. Challenges/barriers

Notwithstanding the above benefits, several obstacles stand in the way of developing effective involvement of users and the public. A major challenge that has been identified by the literature concerns the perceptions of health services staff. The NHS Executive, (1998) state that because of their professional training and background, health services professionals can feel threatened by the notion of user and public involvement. The Scottish Association of Health Councils et al (1999) allege that:

*“The NHS has a fine record of working for people, providing expert services and care: moving towards working with the public will need changes in organisational culture and new skills for managers and staff.” (page 19)*

Moving towards more democratic forms of health care implies a shift in the traditional 'professional model' of accountability that has operated in the health services, where doctors accountability was through professional organisations, and moving away from an 'economic' or 'market model' towards one of partnership (McCrae et al, 2002). It is often suggested that a radical shift in attitudes as well as organisational structure is required. In fact, some have suggested that the implications seem likely "to prove far more radical than first envisaged" and even that as a policy "it

may come back to haunt those who argued for its adoption as a health care goal", (Williams and Grant, 1998). As Small and Rhodes (2000) comment, an interest in user involvement does not mean that "traditional conflicts between service providers and users go away". Indeed, these authors suggest that professional support for involvement might be limited if it impinges on their sense of expertise and judgement:

*"User involvement is only welcome when it conforms with what the professional wants to hear." (Pearson, 1995 cited in Small and Rhodes, 2000)*

Confusion about the nature of user and public involvement can act as a significant barrier. The NHS Executive (1998) writes about the "myth of perfectibility" or a perception that if first attempts do not succeed then the whole involvement agenda is abandoned. When there is poor understanding of what user and public involvement is, involvement activities will be uncoordinated, there will be a lack of clarity about what is being asked of people, and this will result in a lack of ownership across the organisation. There are limitations as to what can be achieved by user and public involvement, and as argued in the previous section it is critical for the organisation to be clear from the outset about the purpose of the exercise, who should be involved and how they are to be involved.

Voluntary organisations, users/patients, the public and health services staff may all have different, if equally legitimate, perspectives on the outcomes of partnerships (Lewthwaite and Haffenden, 1997). While it cannot simplify decision-making nor provide a straightforward route to conflict resolution, involving users and the public can make the process more visible and ensure that voices once excluded are heard so that decisions are taken within a more democratic framework (Barnes, 1997). It is further underlined by Summers and McKeown (1996), that enthusiasm for the general idea of involvement needs to be matched with "realism and honesty about what can be achieved".

Many health service staff are not trained to be good at working in partnership with patients, users, communities or citizens and this deficit has to be recognised and addressed at both pre and post

qualifying training levels. Senior health managers in a survey of Primary Care Groups, identified the problems in implementing the participation agenda as shortages of expertise, time and money (Shepherd, 2001). This research found that most had produced information leaflets about their practice, but few had used other mechanisms such as focus groups or community involvement initiatives. It was concluded that the NHS needed to develop "significant capacity" in order to implement this agenda. Another major issue, given that other public agencies have been charged with the involvement agenda, is the possibility of 'consultation fatigue' among citizens and communities when agencies do not work in partnership.

Difficulties with the concept of representative participation are often at the core of concerns about involving people (Hopton and Hill, 2001). Concerns about how to avoid tokenism, finding representatives who are able to focus on broad rather than single issues, involving 'hard to reach' groups, and ensuring that forums for public involvement are not dominated by specific interest groups, are frequently at the heart of the hesitation to involve people.

Finally, the obstacle of cost in terms of time and money has to be acknowledged (Cole, 2000). For many health services staff, involvement feels like an added burden onto an already overwhelming workload. For organisations decisions to incur the extra costs of prioritising involvement also weigh heavily on the managerial conscience, when they have to be taken alongside decisions about spending money on direct services. However, as Cole (2000) and others have observed, such investment in the present could save both time and money later on.



### 3. Involvement of Individuals in their Own Health Care

#### Key points - section 3

- Research has consistently identified that users/patients want more 'person-centred' consultations with health care professionals.
- The quality of relationship with health professionals is a key factor in the quality of care identified by users/patients.
- Reasons for involving users/patients in their own care include that it results in better health and treatment outcomes, and increased user/patient satisfaction.
- There is a growing acceptance of the view of users as experts in their own right.
- Research has demonstrated close links between person centred values and approach and effective involvement.
- The three most commonly discussed models in relation to involving users/patients in decision-making are - paternalistic, informed decision-making and 'professional-as-agent' models.
- While there is knowledge about what shared decision-making is, there is less evidence of it happening in practice.
- Evidence is that users/patients would like more information.
- Positive results have been obtained from involving users/patients and their carers in producing information.
- Although patient held records offer potential for meeting some of the criticisms of poor communication and coordination in health, there is still a need for further research.
- The main barriers to increasing the level of partnership are time pressures, the lack of training, skills and experience, and lack of information.
- Shared decision making has been described by researchers as the "neglected half of the consultation".
- Studies emphasise that person-centred approaches require time, information and training, better interpersonal communication, mutual understanding and trust.

### 3.1. Introduction

In Section 1, a distinction was drawn between the 'involvement' of individuals (and their carers) as users/patients or in user/patient groups with the 'involvement' of the wider public and communities. In this Section, the literature concerned with involving people as users/ patients is discussed. To reflect the fact that the majority of writers use the terms 'patient involvement', this review has adopted the terminology 'users/patients' when referring to the involvement of those who receive health services.

While it is acknowledged that 'users/patients' are not a homogenous group, there has not been the time to consider in any depth, specific issues pertaining to for example, people with dementia, or people with learning disabilities or mental health problems despite a wealth of literature in these areas. The issue of the involvement of people with dementia has however been the focus of a separate project by the Dementia Centre. Within the disability movement itself there is in fact strong antipathy towards single interest or disease group approaches because this leads to fragmentation and focuses on differences rather than common issues. Overall, therefore, this review has concentrated on broad general issues of involvement and makes only passing reference to specific groups.

### 3.2. User/patient participation as a concept

*"Today's patients live in a brave new world in which they have their own Charter, actively encouraging them to ask questions, demand their rights and what's more, to expect to have them granted. While they still can not exercise the ultimate in patient choice, euthanasia, they live in an era in which...ever greater efforts can be made to involve them in decisions about their own health care." (Greenwood, 1996, p15)*

The above quotation suggests that users/patients receive more opportunities for greater involvement in their own care than in the past, but in reality it might still depend upon where they live, their race, disability, gender, and other socio-economic variables, as well as whether the health professionals treating them pursue

user involvement through their practice. 'Patient participation' is now a widely accepted concept in health, "heralded as a means of enhancing decision-making and human dignity and enriching quality of life" (Cahill, 1996). It is widely recognised as a 'good thing', resulting in increased satisfaction and benefits to users/patients. Over two decades ago, the World Health Organisation (WHO, 1978) promoted the right of users/patients to be involved in their health care. However, according to Cahill (1996) the concept remains "elusive" and a "modern day icon in need of closer examination". In defining user/patient participation in relation to nursing, Cahill suggested the following attributes:

- A relationship must exist.
- There must be a narrowing of the appropriate information, knowledge and/or competence gap between practitioner and user/patient.
- There must be a surrendering of a degree of power or control.
- There must be engagement in selective intellectual and/or physical activities during some of the phases of the health care process.
- There must be a positive benefit associated with the activity.

Further, Sang and O'Neill (2001) suggest there needs to be a "much more robust and less rhetorical analysis" of user/patient involvement and that users/patients themselves had a lot to say on the subject. Research that has examined users'/patients' preferences for a 'patient-centred approach' to consultation in primary care has showed that most users/patients want the approach to be 'patient centred' (Little et al, 2001). Three important domains of such an approach have been identified as communication, partnership and health promotion:

*"We have shown that most patients waiting to see a doctor strongly want a patient centred approach, not only a friendly approachable doctor who communicates well but health promotion and a partnership approach to both the problem and treatment. Furthermore, most patients probably want patient centredness rather more than they want a prescription or an examination" (Little et al, 2001)*

These authors argued that doctors should be sensitive to those

individuals who are likely to have a particularly strong preference for 'patient-centredness', as well as those who do not. Other surveys have consistently suggested that a significant minority do not want the ultimate responsibility for making choices, even though they would like more health information (Olszewski and Jones, 1998; Entwistle et al, 1997). The Consultation and Involvement Trust Scotland at the end of their first year of operation concluded that less emphasis was being placed on involving people in decisions about their own care than on involving users collectively in strategic planning, and the experience of many of the services users they met suggested that services took little account of what users wanted (CITS, 2000). Research exploring involvement of users and carers in the care programme approach in mental health (Joseph Rowntree Foundation, 1997), found that few users had been asked their views about their admission to hospital or knew about complaints procedures. Those involved in the care programme approach felt more involved in planning their own care and treatment, had more choice and were better informed about rights and services.

In spite of this, with the traditional somewhat paternalistic relationship between doctor and user/patient buckling under pressure both from within the consultation and externally, through changing societal norms, the 'patient centred' approach appears to be gaining increasing support (Toop, 1998). The defining features of this model have been identified as a focus on the whole person; the doctor's knowledge of the patient; caring and empathy; trust; the choice of appropriately adapted care; and the user's/patient's participation in decision-making (Leopold et al, 1996 cited in Toop, 1998).

Research into patient-doctor interactions or consultations has identified a range of different models as operating at present. The three most currently discussed models of treatment decision-making are 'paternalistic', 'informed', and the 'professional as agent' model (Coulter, 1997). In the paternalistic model, it is assumed 'doctor knows best' and the patient adopts a passive role. The second model is informed decision-making where there is an exchange of information between doctor and patient and a degree of user/patient involvement in arriving at a decision. The most empowering relationship is one described as the

'professional-as-agent' model, where the doctor acts more like a broker and presents the options and discusses possible outcomes of each. As already acknowledged however, few users/patients desire to carry the ultimate responsibility for treatment decisions.

Reality of course is usually more complex than such ideal models would suggest, and some researchers have observed elements of all three within a single consultation between a doctor and patient or over the course of consultations in the case of people with chronic ill health (Charles et al, 2000). The implication of this is that assessing users'/patients' preferences for participating in decision making will need to be assessed on an ongoing basis rather than a one-off task.

In the paragraphs that follow, reasons for involving users/patients, perceiving users as experts, effective involvement and advocacy, shared decision making, access to information, patient or client held records and the impact of professionals' attitudes on the degree of involvement are discussed.

### **3.3. Why involve users/patients?**

A number of reasons have been proposed in favour of directly involving users/patients in their own care, which have included:

- It can empower users/patients, giving people a greater sense of dignity and worth.
- Users/patients have demanded more information about their health conditions, treatments and care.
- It is central to the notion of "informed consent".
- There is some evidence of improved health outcomes and increased user/patient satisfaction.
- Reduction in 'inappropriate' use of services as people become better informed.
- Greater likelihood that users/patients will act in accordance with the treatment plan if it has been explained and they understand it.

These reasons will be discussed throughout this Section in relation to concepts such as 'shared decision-making', for which there is less empirical evidence than for example, about user preferences for 'patient centred' styles of consultation. A study by Greenhow et al (1998) demonstrated patient satisfaction to be positively correlated with involvement. This study in a large urban general practice in England explored the effects of consulting style on patient satisfaction, and provides support for patient-centred styles of consulting in which patients are actively involved in the decision-making about their own treatment and care, while overall levels of involvement in individual care planning remain.

Keeping involvement top of the agenda was a major conclusion from another study, involving six health authorities in England (Haffenden, 1998). This joint study between the health authorities, the Long Term Medical Conditions Alliance and 15 national voluntary organisations to devise a model for working in partnership to commission quality services, found similarities of experience across a range of patients with long term or chronic illnesses. All highlighted problems with diagnosis, a lack of information about their condition and the options, the need to have someone to talk to who understood, delays in referrals for outpatient appointments with specialists, a lack of respect from professionals and a lack of continuity of care.

Having direct involvement in services has been linked with reducing the 'inappropriate' use of services as people become more confident about when it is appropriate to seek professional help and when self care is sufficient (NHS Executive et al, 1998). It is also claimed that users/patients are less likely to miss appointments and to be more likely to carry through treatments because they understand and agree with it and were a part of the decision-making process.

### 3.4. Users' expert knowledge

The Department of Health (1999) highlighted a growing acceptance that users/patients and carers are the 'experts' in how they feel and what it is like to live with a particular condition or disability. As Greatly (2001) points out, it is generally now agreed as 'good practice' to involve users in determining their treatment

and care. The direct involvement of users/patients is based on valuing the credibility and authority of their perspectives and giving this an equal footing with that of professionals' perspectives. Evans (1999), writing about the developing pattern of good practice in user involvement through the implementation of community care policies, emphasised the importance of professionals learning to value users' expertise:

*"That user expertise is gained not from colleges and formal learning, but from the 24 hour day, day in, day out, experiences of needing to use services for personal support." (pg)*

Wilson (1999) pointed out that people living with a long-term illness develop expertise and wisdom about their condition and want to play a part in making decisions about their own health care. The implication of this is that a shift is needed in the relationship of power/knowledge (Small and Rhodes, 2000). The key to successful doctor-patient partnership according to Coulter (1999) is to recognise that "patients are experts too". Such partnerships require both doctors to be well-informed about diagnostic techniques, causes of disease, prognosis, treatment options and preventive strategies, and users/patients to have first-hand experience about what it is like to live with a medical condition or disability, their social circumstances, individual values and preferences. The terms 'person-centred' and 'person-centred planning approaches' that often appear in this literature will now be explored in more detail below.

### **3.4.1. 'Person centred planning'**

Research has demonstrated a close link between person centred values and approach and effective involvement (Dick and Cunningham, 2000). To be effectively involved in their care, the users in a study by Dick and Cunningham (2000) demonstrated the need to be comfortable with all aspects of the arrangements for reviews, to be free to express their views, and to be able to communicate in a way that was easy for them. 'Person-centred planning' has evolved over the past twenty years mainly in North America, and latterly in the UK. It represents a paradigm shift in working with people in ways that focus centrally on the individual (Sanderson et al, 1997). Essentially, it is a way of organising

around one person, which focuses on the person's whole life and not just a particular illness or treatment episode to define and create a better future for that person. It has been described as:

*"Person-centred planning is a philosophy and an approach, not just a set of tools and techniques. However, the family of tools which are used in person-centred planning provide a practical demonstration of philosophy in action." (Ritchie, 2002)*

Person centred planning is associated with the 'exchange model' of assessment as described by Smale et al (1993), which assumes that all people are expert in their own problems and there is no reason to assume that professionals will or should ever know more about people and their problems than they do themselves. Person-centred planning approaches cover a variety of ways of working with people, all of which focus positively on the individual and what is going on in his/her life, ensure that the person is in control of the process and that the medical needs of the person do not supercede their universal needs (Jeffrey, 2001).

Person-centred planning developed from a commitment to social inclusion and the experience of disabled people who lacked control over their lives and felt 'managed' by the service system and that what happens to people who are labelled as disabled is powerfully shaped by medical models (Ritchie, 2002). 'Person-centred planning' is not a procedure of the service system, but the use of 'person centred planning' tools ensures that all those involved with the person focus on the whole person, their capacity and what they want to happen in their lives. It offers a more individualised approach to assessment and an empowering way of involving individuals in deciding for themselves what they want for the future and the support they need to be in that future. In the mental health field, methods of centrally involving users in assessing their own needs and developing their own care plans were developed in Bristol during the 1990s (Le Grand et al, 1996).

### 3.5. Shared decision making

The notion of 'shared decision making' has been well exercised in the medical journals recently. An increasing amount of literature is available, which attempts to define, discuss and measure 'shared decision-making'. It is the case that increased participation in clinical decision-making is often presented as an end in itself on humanistic grounds but also in response to the growing criticism around poor communication (Elwyn et al, 1999a). While there is extensive evidence that users/patients want more information and involvement, there is a paucity of knowledge about the circumstances in which shared decision-making should be encouraged and the effects of doing so (Entwistle et al, 1998; Coulter, 1997).

The NHS Executive et al (1998) assert that when patients are well-informed and active participants in decision making about their own care and treatment, clinical outcomes are improved. Conversely, there is evidence to show that poor communication between doctors and patients can have a negative effect on therapy, treatments, and the long-term management of an illness (Elwyn et al, 1999a; Olszewski and Jones, 1998). In spite of this, McCrae et al's (2002) recent review of the literature concluded that the concept of shared decision making has been poorly defined, and further that in reality it does not happen regularly. As Elwyn et al (1999a) assert, shared decision-making in primary care is the "neglected second half of the consultation".

There is some evidence to show that treatments are more successful where a patient-centred approach is taken in consultations (Kaplan et al 1989 cited in Hogg, 1999). Research which has examined the impact of shared decision-making through randomised trials found that some aspects were improved such as users/patients' knowledge of their medical condition, satisfaction with the decision-making process, general health perceptions and physical functioning (Barry et al, 1997). However, Florin and Coulter (2001) suggested that shared decision-making required specific skills that were not yet widely taught.

Three main precursors to shared decision-making have been identified by Elwyn et al (1999b) in a study of newly qualified doctors: the availability of information, that the timing of the decision-making process is appropriate, and the readiness of users/patients to accept an active role. These researchers found the concept of shared decision was “novel” to general practice registrars. A subsequent study of experienced GPs by some of the same researchers, showed positive attitudes among GPs towards involving users/patients in decisions, providing this was what users/patients wanted (Elwyn et al, 2000). The study concluded that the benefits of user/patient involvement and the skills required to achieve this approach needed to receive higher priority at all levels of policy and practice.

### 3.6. Accessing information

Direct involvement of individuals in their own care requires access to information that is both comprehensive and accessible to the individual user/patient (NHS Executive et al, 1998). The NHS Centre for Reviews and Dissemination (1997) argued that offering cancer patients full verbal and written information about their condition and its management would “make a major contribution to improving quality of care”. Studies consistently report that many people would like more information from health professionals about specific conditions and treatments, but that generally they do not seek this to help them make decisions about treatments (Olszewski and Jones, 1998). Having more choice and having more information about medical conditions and the treatments available are not necessarily the same thing.

Some studies report positive relationships between the communication practices of doctors and health outcomes (Simpson et al, 1991). Many studies demonstrate that users/patients appreciated getting information and conversely that poor communication is the number one dissatisfaction with hospital care (Olszewski and Jones, 1998). In a survey of users of mental health services, access to good information was significantly associated with how satisfied users said they were with community care services as a whole (Rose, 2001).

The provision of information has been found to improve people's understanding of drug treatments and the likelihood that these will be taken as intended. Research also suggests it contributes to quicker and better recovery after surgery, and leads to less depression and anxiety (Olszewski and Jones, 1998). The Nuffield Institute for Health and NHS Centre for Reviews and Dissemination (1996) in presenting studies of consultations with cancer patients showed that patients and their doctors may disagree on the adequacy of the information given. While patients were often dissatisfied with information they received, doctors tended to over-estimate the amount of information given and might even disagree with the emphasis on the need to provide more information. The same authors found women with breast cancer were less anxious when given full verbal and written information, as well as opportunities to discuss options with clinical staff. Similarly, the NHS Centre for Reviews and Dissemination (1998) found that patients with lung cancer who were given sufficient information were less anxious and expressed higher satisfaction. Bell et al (1996) for the National Cancer Alliance found the provision of information to be a significant issue for cancer patients, and at times became a pressing need.

Information appears to be sought to help people manage the social, psychological and financial constraints that illness imposes. The desire for more information includes wanting information on diagnosis, prognosis, risks, results of tests and investigations, therapeutic procedures, drug information, aetiology, care and treatment following discharge from hospital. Olszewski and Jones (1998) highlight that the majority of evidence about information needs comes from professionals' perspectives while there is a "paucity" of research specifically investigating lay perspectives on clinical information.

Rather than demanding major involvement in treatment decisions, Olszewski and Jones (1998) review of the literature on information concluded that users/patients wanted to have more information about why the doctor recommends one treatment over another (Olszewski and Jones, 1998). In this sense, these authors suggest, information can be seen as a "means of establishing trust" between user/patient and healthcare

professional. Although providing more and better information is widely accepted as a priority in health services, Entwistle et al (1997) argued that it is not always straightforward to implement and it requires substantial resources if it is to be done well. Involving users/patients in the development of information resources has been shown to be a means of improving their quality (Coulter et al, 1998).

Involving users and families in the production of 'patient information literature' was found by Willock and Grogan (1998) to be essential if such literature is to be relevant to their needs and truly "client-centred". Similarly, Kennedy et al (1999) found the development of a guidebook for people with ulcerative colitis by involving patients and self-help groups from the start, was equally well received. The aim was to produce information in a format that allowed patients to manage their condition better and to keep records of test results, treatment and symptoms. Its development was part of the national 'Promoting Patient Choice Programme' funded by the King's Fund. The researchers concluded that the principles of user involvement in the collation of this guidebook could be extended to other groups.

### 3.7. Patient or client held records

Several reports have proposed patient held records (PHRs) as a way of addressing the problems of poor communication reported between healthcare professionals and patients. Whether or not such rights are exercised, users/patients have the right to access medical records following from the 1984 Data Protection Act, and subsequent legislation including the Access to Health Records Act in 1990. However, as Wright and Young (1994) point out, a key issue in empowering individuals to exercise such rights is the lack of awareness of this right. It is generally claimed that PHR have the potential to give increased control and autonomy to patients, although this has yet to be tested in many areas of health care.

The idea of patient held records (PHR) is not a new one, it has been around since the 1970s though not widely adopted except for antenatal records and parent-held child development records. User/Patient enthusiasm for the idea has been shown by research, for example, Wright and Young, (1994) demonstrated

enthusiasm from older people for the idea of a 'health record' containing information useful in an emergency, although they also highlight complex issues around access to social and health records. Stafford and Hannigan (1997) demonstrated some of the ways that use of a client held record was able to promote user empowerment with users of mental health services and facilitate greater collaboration and communication with health care professionals. As a clinical tool, these authors explain the benefits for specific interventions.

At a conference in 1998 (Scottish Partnership Agency for Palliative Cancer Care and National Council for Hospice and Specialist Palliative Care Services, 1998), professionals reported mixed findings on the use of PHRs. While many found the PHRs "valuable", the main barrier to the use of PHRs was the lack of participation of professionals. Similarly, Hayward (1998) found that although most cancer patients in a pilot study had been positive about PHR, there was resistance from some professionals to filling it in. However, overall, this writer suggests that having established the use of PHR in the medical unit, communication was improving. Further research in this area would be helpful to illuminate the many areas of uncertainty about the use of such records (Scottish Partnership Agency for Palliative Cancer Care and National Council for Hospice and Specialist Palliative Care Services, 1998).

### **3.8. Effective involvement and independent advocacy**

Any discussion of involving people in their own care would not be complete without reference to the role of advocacy. Where service users are unused to being asked their opinions or making decisions, and/or there are communication or other barriers to involvement, how involved they are might depend upon the support of an independent advocate or user self-advocacy group (Dick and Cunningham, 2000). Many service users are vulnerable, or find it difficult to communicate their needs, partly because of the very difficulty that led them to be users of services in the first place and partly because systems sometimes disempower people.

Independent advocacy services are often thin on the ground. There is widespread consensus that there is a pressing need to develop advocacy support. A recent Scottish Health Feedback study (2001a) within a Primary Care NHS Trust area in Scotland, found only small-scale advocacy projects with limited resources available to sustain their activities and the need for major improvement in advocacy provision. The principles for commissioning good advocacy services were set out in Scottish Executive guidance (2000d). Some of the key features that advocacy services should have are:

- They should be firmly rooted in, supported by and accountable to a community - either geographical or a community of interest.
- They must be independent of all service providers.
- They should be able to advocate for service users across a range of services, whether provided by health services, the local authority or voluntary organisations.
- They should be properly funded.
- They should be given ongoing assistance and support - but not controlled.
- They should be regularly evaluated, and funded for this.

There are different ways of implementing these and the other key features laid out in that guidance: there is no "one best way". Developing independent advocacy is not seen as the sole responsibility of NHS Trusts, but rather a joint responsibility between local authorities and health services. Standards for independent advocacy have since been developed by Advocacy 2000 (Advocacy 2000, 2002).

### 3.9. Organisational and professional implications

The literature suggests doctors' attitudes can present a formidable barrier to greater involvement of users/patients in decision-making. Brown's (2001) study of organisational values in general practice and public involvement, found marked differences between general practices linked to service providers' beliefs and

attitudes about the purpose of the organisation and the types of relationship that were appropriate with users and local people. Leadership models emphasising the medical model or a narrow business approach accorded low value to user involvement, while those emphasising teamwork and a broader social role appeared more compatible with the development of involvement.

An exploratory study by Elwyn et al (1999b) found that registrars in general practice were not trained in the skills required to involve users/patients in clinical decisions. They admitted that 'friendly persuasion' was their usual practice:

*"Sharing decisions entails sharing the uncertainties about the outcomes of medical processes and involves exposing the fact that data are often unavailable or not known; this can cause anxiety to both patient and clinician. Movement towards further patient involvement will depend on both the skills and the attitudes of professionals..."*

While most general practice registrars participating in the research acknowledged potential benefits from greater involvement, discussions in the focus groups centred on the difficulties of achieving this. Much medical information was uncertain, and according to research participants, there were only a few consultations where the problem lent itself to providing a range of options. Factors such as the user's/patient's "age and educational achievement" also had to be taken into consideration.

Other researchers have highlighted difficulties caused by the imbalance in power in the interaction between doctors and users/patients:

*"Typically, doctors have more power than patients to structure the nature of the interaction between them. As a consequence, patients may feel that their voice is overridden, silenced, or stripped of personal meaning and social context. To improve communications between doctors and patients we need also to understand the nature of the decision making that is taking place in the consultation." (Charles et al, 2000)*

In a study of what users/patients said about “patient-centred cancer services”, Bell et al (1996) identified the quality of relationship with health professionals as a key issue. Vital attributes from doctors were “humanity, sensitivity and approachability”. Creating such relationships would enable better exchange of information and views.

### 3.10. Health consumer groups/patient groups

A growth of user/patient groups has happened alongside initiatives to promote user involvement, and therefore deserves mention at this juncture. Some of the more recent groups tend to be a direct response to particular medical scandals or blunders. The strength of such groups is in raising the collective voice of users/patients such as in the case of parents affected by the Alder Hey organ scandal (Cole, 2000). Those involved in such groups have learnt how the health service operates through painful experiences and have used this knowledge to further the advancement of user/patient involvement in health services more generally. For example, a member of the parent support group PITY II - Parents Interring Their Young Twice - comments:

*“We’d like to see health professionals being more honest and open in giving information, and not treating people as though they are incapable of understanding anything. A lot of people are frightened of asking questions and accept everything the doctor tells them. But all this has made us aware that we should ask more and more questions.” (Cole, 2000, p25)*

An increasing number of lay people have been appointed to health service bodies either as patients or prospective patients to represent user/patient interests. One of the main lessons from the inquiry into the baby deaths at Bristol Royal Infirmary was that users’/patients’ - including families’ - needs must be at the centre of the NHS. Some have raised questions about the selection and contribution of representatives (Williamson, 1998). Members should be appointed as representative on the basis of their having the appropriate knowledge for the group’s task, and the validity of users’/patients’ and professionals’ views should be judged by the same criteria.

## 4. Involvement in Monitoring and Improving the Quality of Services

### Key points - section 4

- It is important to consider ways of involving users/patients in defining what quality is as well as measuring quality in services.
- Involving users/patients in the quality of services is based on the principle that users are best placed to say what they want out of services and whether the services are doing a good job.
- The scope of user/patient involvement in clinical audits has been largely limited to one-off satisfaction surveys.
- There are still few good examples of user involvement in the whole process of evaluation and service audit.
- There are strong arguments in the research for user/patient involvement in medical audits.
- While there is some evidence of user involvement in setting service standards in other public services, there is little evidence of this happening in health services.
- There are strong arguments in favour of user involvement in all stages of the development of clinical practice guidelines.
- There is also an argument for user involvement in purchasing and commissioning services, although there is limited literature in health on this subject.
- The experience of involving users in research has been positive, although genuine involvement takes time and resources.

## 4.1. Introduction

In addition to involving users/patients in their own care, organisations can involve users/patients and their carers in finding out how services are perceived and how satisfied users are with them. It is important to measure the quality, effectiveness and equity of public services (Barnes, 1997). The Department of Health (1999) stated that involving users/patients and carers was an important part of improving service quality. In this Section, literature about the involvement of users/patients in determining the quality of services, in service audit and evaluation, in setting standards, purchasing services and research has been reviewed. The searches carried out for this review did not highlight a great deal of literature specifically in the area of involvement in service quality, at least in the field of health services. There may be more reports of this kind of activity within sociologically-oriented journals and other sources, but time did not allow the search to be extended this far.

## 4.2. Involvement in the quality of services

As the literature reviewed earlier has argued, there are strong political, moral, social and clinical arguments for user involvement and these are as valid when considering involvement in the quality of services as in involving individuals in their own care. As Dickens (1995) states, no matter how service quality is defined and measured, the consistent finding from research is that quality derives from users' expectations and experiences and the satisfaction or dissatisfaction that those experiences provide. It is therefore imperative that users/patients are involved in defining what quality is and measuring quality in services.

Bradford's Home Treatment Service, a community-based service for people with mental health problems, has directly involved users in defining quality in services through an innovatory appointment of a service user within the clinical team with powers to decide how clients are treated (James, 2000). As a member of the clinical team, the service user has "equal say on all matters" and has helped shape the nature of service provision:

*“As a user, Peter knows what it is like to be talked about by professionals. He has helped shape the team’s culture away from a feeling of them, the patients, and us, the professionals. He can also communicate with patients in a way the rest of us cannot.” (p6)*

There are other innovative examples of how users have been involved both in defining and measuring quality, for instance, at the core of the ‘Quality Network’ a joint initiative between National Development Team, British Institute of Learning Disabilities, People First Scotland and Speaking Up!, is the belief that people with learning disabilities are the experts on their own lives and therefore, best placed to say what they want out of services and whether services are doing a good job. It is firmly rooted in the social model of disability and the principle of social inclusion. Although the authors of this review were aware that several health services as well as voluntary organisations in Scotland had participated in the Quality Network programme, the literature search failed to uncover any written accounts of this experience at this time.

Another related example, is the quality assurance framework for hospital services devised by the Royal Edinburgh Hospital Patients Council which defines aspects of quality for hospital services for people with mental health problems, and how to measure them from the users’ perspective (Royal Edinburgh Hospital Patients Council, 1998).

In terms of involving people in defining and measuring quality, a workshop held with local community groups alongside health care professionals and managers as part of a project to devise an action plan for involvement in one Scottish NHS Trust, identified the following factors that should be taken into account when involving people in the quality of services:

- Inform people what to expect when they come for treatment and the possible outcomes of the treatment itself.
- Involve people in their treatment plans.
- Treat people as people, not a condition.

- Regularly ask people what they think of the services.
- Ensure complaints are dealt with quickly and in person.
- Train staff in “good customer relations” - that is, to respond to people, sensitively and positively.
- Organise regular events/opportunities for Trust staff and users/patients to meet together to discuss experiences of services.

(Scottish Health Feedback, 2001c, p10)

### 4.3. Involvement in looking at how services are performing

The ways in which health care systems in the past have attempted to gather users/patients views on the evaluation of services have generally been limited to one-off surveys. These have typically concentrated on determining “user/patient satisfaction”, a concept whose meaning and usefulness in the context of health services have been contested. It is now widely argued that the limited focus on satisfaction as an evaluative measure of health services has “trivialised” the concerns of users/patients by focusing mainly on the ‘hotel’ aspects of care and issues regarding the interpersonal and communication skills of professionals, while neglecting more fundamental aspects such as outcomes, appropriateness and effectiveness of health services (Fitzpatrick and White, 1997). These authors highlighted that less is known about whether users/patients found treatments helpful in relation to their problems than about any other dimension of quality of health care. The proposed solution has ranged from addressing the validity of such measures to proposing that users/patients devise and carry out service evaluations independently. Further, if users/patients can help to define quality, they can contribute to judgements about the extent to which those definitions have been delivered (Newton, 1996).

The involvement of users/patients and carers within clinical audits needs to be set within the context of the wider debate about user and public involvement as discussed earlier. A project to identify the extent of user and carer involvement in clinical audit was carried out in the South West of England (Barnard,

1998). The study found that despite the fact that nearly all NHS Trusts were involving users and carers in clinical audits in some way, the scope of involvement was limited: the majority had carried out patient satisfaction surveys (67%) and only 13% of Trusts had involved users and their representative in setting standards, and even fewer (3%) had involved users and carers in devising or deciding outcome measures.

Obtaining user/patient feedback when measuring how effective a service is performing is now a fundamental principle of 'good practice' (Morris, 1995; Knox and McAlister, 1995). Notions of consumerism, a public service orientation and the pursuit of quality have enhanced this emphasis on service users' perspectives (Knox and McAlister, 1995; Dickens, 1994). The importance of involving users/patients in evaluations leads not only to addressing the issues and concerns of those directly affected by the service, but also builds ownership of suggestions or recommendations arising from the evaluation.

There is an increasing body of research documenting different approaches to enabling the inclusion of user perspectives in evaluation, including those of older people with dementia (Murphy et al, 2001). Bamford (2001) concludes from their work that while involving people with dementia in examining the outcomes of health and community care proved "challenging", the ability of users to contribute valuable and unique insights could not be contested. These insights often revealed discrepancies between users' views and those of their carers (both formal and informal), which further supports the need to consult people with dementia directly.

While researchers have done much valuable work on how to make the views of services users central to creating service quality, there are still few good examples in the literature of the involvement of users throughout the whole evaluation process. One such example is a service evaluation carried out by People First, an organisation for people with learning disabilities (Whittaker et al, 1990). People First along with a Social Services Department and researchers explored the views of people with learning disabilities about moving from institutions into ordinary houses as part of a hospital closure programme. Additionally, in

looking at 'what makes a good health service', the Scottish Health Advisory Service (SHAS) reviews of learning disability services now gather views of service users as part of their assessment and include a 'service user version' of their standard assessment forms sent out prior to SHAS Reviewers visiting the services.

In a review of the literature, Newton (1996) found no shortage of recommendations that users/patients should be involved in medical audits, even though it has become established as a "doctor-led process". User involvement should be viewed as complementary to the clinical expertise of doctors. It was envisaged that the best potential strategy for helping this to happen was to locate initiatives within practices, and to involve users/patients speaking on their own behalf or of closely related users/patients.

In terms of ongoing audits and evaluating service quality, there is great potential for closer partnership between health services and local authorities in terms of drawing upon their well-established networks of accountability. For example, in some local authorities there are established Panels of local people who are regularly consulted about aspects of services as well as about new proposals (COSLA, 1998). Evidence from research in relation to housing has shown that such participation is critical to sustained improvements (Taylor, 1995). An NHS Trust in Cambridge (Wilson, 1999) demonstrated the benefits of setting up user/patient Panels to actively consult users on an ongoing basis. The experience of Addenbrookes NHS Trust showed how such a Panel served to improve the Trust's understanding of users' needs, concerns and the effects of services on their lives.

#### 4.4. Involvement in setting standards

There is a growing tradition of involving users and carers in compiling standards in Social Work but this is not so well established in Health. For example, Harding and Beresford (1996) described the involvement of different groups of service users and carers from a wide range of voluntary and user controlled organisations in compiling standards for social services staff. The authors commented that the consistency of what users said about the meaning of quality services was "remarkable". Their

findings are discussed under three main themes: the quality of relationships, the quality of skills and the quality of services. The evidence from the study showed that people valued this involvement in setting standards of practice and had relevant and valuable contributions to make to this process:

*“When it comes to quality and standards, we should have our views taken into account as service users and carers. Service users’ and carers’ voices need to be heard at all levels of the process of setting standards and improving quality.” (Harding and Beresford, 1996, p3)*

For several authors, the first step towards community participation in setting health care standards is to ensure user involvement in all stages of ‘clinical practice guidelines’ or as they are sometimes referred to ‘evidence based clinical guidelines’ (Wersch and Eccles, 2001; Bastian, 1996; Duff et al, 1996). These guidelines affect not only the quality of care, but access to care and the availability of choices. It has been argued therefore that users have a “considerable stake” in being involved in these guidelines. Involvement in clinical guidelines is suggested as one way of “bridging the knowledge gap between health care professionals and patients” so that joint decision-making becomes more of a reality (Duff et al, 1996).

Researchers advocate the use of different strategies in combination to ensure users’ views are incorporated into standards: for example, the involvement of accountable user representatives in group decision making, user and community consultation, and the use of research literature describing people’s experiences (Wersch and Eccles, 2001; Bastian, 1996). However, Wersch and Eccles also found, while involvement was desirable, it was not always “straightforward”, especially when users were included in guideline development groups that also included professionals. The researchers’ investigation in the North of England concluded that there was no “one right way” to involve users in this process and that further work was needed on how to achieve it.

### 4.5. Involvement in commissioning and purchasing services

If users/patients have been involved in evaluating the quality of services and in identifying service gaps, it seems reasonable to suggest there is a place for user involvement in purchasing services. Indeed, some authors have specifically advocated this approach in relation to people with disabilities (Simons, 1999; Herd and Stalker, 1996). However, there is a general paucity of literature on this subject. A seminar held in 1996 to discuss issues around purchasing services for people with learning disabilities, challenging behaviour and mental health needs, recommended involving users and carers in service specifications and agreements to help ensure services remain relevant to life experiences and wants (Harris, 1996).

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The National User Involvement Project was a four-site development project carried out by user consultants working with joint commissioners, local organisations of disabled people and users of community services (Joseph Rowntree Foundation, 1999). It found many commissioners still unaware of key aspects of facilitating user involvement, and difficulties in involving service users in making commissioning decisions. Dedicating resources to outreach work was an effective way of contacting service users from more marginalized groups. Service users needed a range of support and training in order to be fully involved and disabled people themselves often believed that commissioners needed specific training in how to involve them effectively.

### 4.6. Involvement in research

Experience from setting up research advisory groups of users suggests there is strong argument for involving users in research from the outset when drawing up the scope and design of the research (Rhodes et al, 2001). Lessons from this study were that genuine user involvement in research takes time and resources, careful consideration must be given to ensuring 'hard to reach' groups and researchers need to be open minded in their approach and be prepared to listen. More is said about 'participatory research' approaches in Section 7.

An approach known as User-Focused Monitoring (UFM) has been developed and implemented by the Sainsbury Centre for Mental Health (Rose, 2001). This innovative approach empowers service users by giving them real work as interviewers - some 61 user interviewers were deployed and interviewed over 500 service users living both in the community and in hospital settings. This approach has enabled the voices of the most disabled users to be heard and for the research agenda to be set by users themselves. Further, the approach has allowed the collection of "more accurate and sensitive information about users' experiences of mental health services than traditional, professional approaches".



## 5. Involvement in Planning and Development

### Key points - section 5

- Since the implementation of community care, user and public involvement in planning health and social care services is widely accepted.
- However, the reality often falls short of the ideal - there is less 'real' involvement in planning in the longer term than might be expected.
- User involvement in planning is essential so that it is informed by real needs, aspirations, personal experience and direct evaluation.
- Ideally, users should be involved from the earliest stages of planning as this offers the best chance that more responsive and user-led services will be developed.
- Power differentials need to be acknowledged, and the need for acceptance of the unique contributions of individual stakeholders in the planning process.
- Only through involving local communities, can agencies arrive at a better understanding of how local services need to change and develop.
- It is important to tap into the expertise of local user groups and to be aware of national research presenting users' views.
- Research evidence on involvement in rationing and prioritising is contradictory. Effective involvement depends upon allocating sufficient time to discuss options and issues.
- User involvement can also take place at a national strategic level.

### 5.1. Introduction

The third dimension of involvement in health services is in respect of involvement in the planning and development of services. In this Section, involvement in planning is explored and attention is drawn to the experience of community care planning, ideas about including the 'informed views of citizens' in planning, involvement in deciding priorities and rationing, and involvement at national level.

### 5.2. Involvement in planning

The principle or notion that people as users/patients, carers, potential users and interested citizens should be involved in the planning of health and social care services has become more widely accepted since the advent of community care policy. Reality, however, often falls short of the ideal, and it remains challenging to public authorities to find effective ways of involving people in planning in the longer term rather than in one-off consultations. Bringing the experience and expertise of those who use services to the activity of planning is essential for achieving quality. The task of planning can then be informed by people's needs, aspirations, personal experience and direct evaluation (Herd and Stalker, 1996). As these authors state, "there can be no substitute for the real world knowledge of service users." Fisher (2001) argued that by asking local people about health issues that mattered to them, health planners could arrive at clearer recommendations and that by pursuing these ideas collectively, implementation was more likely.

The NHS Executive et al (1998) commented:

*"The expertise and knowledge of those who use health services can make an important contribution to needs assessment and service planning and delivery at an individual level. The involvement of users organised into advocacy groups, voluntary organisations and self help groups can enable the collective, accumulated knowledge of services users to play a role in overall service planning and development." (p8).*

An early exploration of the issue of user involvement by the National Institute for Social Work, concluded that users should be involved from the earliest stages of planning services or arrangements related to them (NISW, 1993). This offers the best chance that more responsive and user-led services would develop (Department of Health, 1999a; Herd and Stalker, 1996). It has been suggested by Evans (1999) that the knowledge and experience gained since the implementation of community care is leading to the development of good practice models, and that there is much to learn about involvement in planning from this.

A study during 1993 and 1994 by the Social Services Inspectorate with the National Health Service Executive exploring the implementation of community care however showed that if users and carers were involved, it was more likely at day-to-day level than at a strategic planning level (Department of Health, 1994). Styles of meetings, the language used, and the complexity of the organisational systems all contributed to hindering real involvement. Nearly a decade on, one would hope that this situation is improving. A study of involving service users in mental health services showed similar findings (Bowl, 1996). Despite the emphasis in community care planning on user and carer involvement, none of the service users interviewed had seen their community care plan or been consulted on its content. Many were confused as to the purpose of various planning committees and it was not unusual for the role to change midstream. The research demonstrated the critical role of professionals in encouraging action and providing the practical support needed to facilitate involvement.

Research, which has focused on service planning within primary health care, has found that public involvement in health service planning presents many challenges in terms of cultural change and how best to engage local people (Kirk et al, 1997). The researchers found that despite high recognition for the principle of involvement, there were no clear models developed or evaluation to implement this objective.

Herd and Stalker (1996) emphasised the importance of acknowledging power differentials in planning - that is, the imbalances between the different planning participants in terms

of their funding, power and obligations within the process. Further, individual service users have had least power in the past. Such imbalances should be recognised and addressed in the planning process. That different stakeholders will make “different but legitimate contributions” should be perceived as a strength. Service users in particular will be able to contribute knowledge and opinions on the experience of receiving services, what is missing, challenging conventional wisdom and developing new ideas and service standards.

### 5.3. The informed views of citizens

The second strand of the strategic approach to involvement advocated by the NHS Executive et al (1998) aimed to empower people as citizens to become more informed about both health and health service issues and to contribute to decision-making on this basis. The Department of Health (1999) argues that it is only through involving local communities that a better understanding of how local services need to change and develop will happen. There is a range of methods suitable for achieving this purpose and what they have in common is that they set out to increase the knowledge of citizens and ask them to reflect on priorities, usually with the support of an independent skilled facilitator. The issues and questions to be considered are likely to be characterised by:

- A requirement for value based judgements, choices and assessments of equity and social justice
- Complexity
- Controversy.

(NHS Executive et al, 1998)

Examples include the Age Concern Panels of Older People in Fife, and the recent work commissioned by the Scottish Executive, including Focus Groups with older people, carried out to tap into the public perspectives about providing free personal care for older people (Scottish Executive, 2001). Through Community Planning, there is now an onus on local councils to provide ‘community leadership’ by setting up partnerships with other agencies and having responsibility for community consultation and involvement. It was envisaged that this would bring about more participatory forms of government.

A paper on commissioning health and social services with disabled people emphasised the importance of using the expertise and experience amongst disabled people themselves in planning and commissioning services (Morris, 1995). It was suggested that designated planning officers should establish close contact with local organisations of disabled people and that disabled people should always be involved when trying to improve access to services. A number of national bodies such as the Sainsbury Centre for Mental Health (Rose, 2001) and the National Cancer Alliance (Bell et al, 1996), have carried out extensive research and consultation with and by service users, which provides a rich seam of information about what users/patients say about services and what they want that could be mined by those involved in planning.

#### **5.4. Involvement in deciding priorities and rationing**

There are concerns about involving the public in making decisions about healthcare rationing. Some would argue that it is “morally wrong” (Doyal, 1996). The principle of equity and fairness argues Doyal, “must be protected from collective and individual arbitrariness”. The argument for taking the public’s views on rationing in the health services into account is founded on the aim to make health services more democratically accountable, acknowledging that such decisions are essentially political in nature (Combe, 1999; Coote and Lenaghan, 1997).

After reviewing 20 deliberative public involvement exercises, Combe (1999) concluded that what the public think about rationing is unclear. Survey data is not often comparable due to variance of method and wording of questions. Other conclusions reached were that the amount of time and money currently being spent on involving the public in rationing decisions is potentially wasteful because experience is not being shared and lessons are not being learned. It is suggested that it should be possible to identify how not to involve the public in such decisions and to develop a guide to better practice.

The research evidence on involvement in rationing and prioritising is contradictory. Some studies have found public

reticence at becoming involved in setting priorities, except when these are at a very high level of generality (Bowling, 1993). From this research it would appear that citizens do not want to take responsibility for collective decision-making. The more specific the levels of enquiry, the more 'ill-equipped' people feel overall. On the other hand, Lenaghan et al (1996) concluded from their evaluation of pilot citizens' juries to consider priorities for health care, that given enough time and information, members of the public were willing and able to contribute to this debate. Dolan et al (1999) showed that the public's views on setting priorities differed systematically when they were given more opportunities to discuss and deliberate. There was greater recognition of the complexities of choices and rationing decisions and more sympathy for the managers' role with increased understanding of the issues.

### 5.5. Involvement at national level

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By involvement at a national level is meant involvement or participation that is "concerned with strategic direction, rather than with detailed service issues" (Barnes, 1997). It is concerned with user and public input to training, research and policy development. While it is important to focus on increased strategies for user and public involvement at local level, Barnes (1997) highlights the limitations of this approach in isolation from tackling involvement at a national level. Capacity for change is constrained and shaped by policy and resource decisions taken at national policy level, over which local health services have no direct control. This will demand a variety of methods including involving representatives of user groups in policy making, for instance People First were involved in the national strategic review of learning disability services in Scotland (Scottish Executive, 2000). Other methods might include commissioning national citizens' juries to engage the public in issues that are nationally relevant, or developing new ways of involving the public in this way.

It should also mean working with national colleges and universities delivering professional and management training to ensure that user perspectives and how to involve users and the

public are covered in professional training. Barnes (1997) also suggests that people should be involved in supporting the evaluation and dissemination of models of good practice in user and public participation. Earlier work by NISW (1993) drawing together findings from different studies exploring users' and service providers' experiences, identified the importance of user organisations in helping to identify the barriers to effective involvement and in advising how these might be overcome. As part of the Allies in Change programme the Scottish Development Centre for Mental Health has recently published a guide or 'Route Map' for people who use mental health services to review how organisations and services involve people effectively (SDC, 2001).



## 6. 'Repertoire' of Involvement Methods

### Key points - section 6

- A broad array of methods/ways of involving users and the public has been tried. No one method constitutes 'involvement'.
- The different ways and methods by which users and the public are asked their opinions are not 'neutral' techniques - some consult people as users of services while others support people to participate as citizens.
- Methods are often classified as qualitative and quantitative research techniques but also as consultation techniques and deliberative approaches.
- The purpose of involvement has a major bearing on the methods adopted: there are no 'recipes or fixed formulae'.
- There is no 'one right method' and it is possible to use one method to develop another.

## 6.1. Introduction

There are many different ways of listening to people both as individuals and as collectives or groups. This Section reviews some of the main methods or techniques to be found in the literature but does not claim to cover every method: it should not be taken as the ONLY ways to involve people. Some methods are difficult to categorise, and others are still to be invented! One of the difficulties is that “involvement” is, or should be, something that occurs in every facet of health care and in every encounter between user and health care services - for example, a consultant or GP who listens attentively to his/her patient and is prepared to alter their views of the treatment plan etc because of this interaction. This can hardly be labelled as a “method” or still less a “technique” of involvement, and cannot be usefully discussed within a Section on “methods”. This is an exceedingly important general point. The most significant forms of involvement are those that become part of the day-to-day practice of health care delivery and planning, whether at the level of the individual encounter or at a more collective level, yet these are often the least visible.

An inevitable limitation of a review such as this is that it draws on published accounts, which often describe initiatives where some new way of drawing on inputs from patients or the public has been tried, or some identifiable method has been tried in a new context. There is a danger that this creates the impression that promoting involvement is only a matter of adopting and applying some identifiable “techniques”. A Section on “Methods” is particularly prone to intensify such an impression. However, there are undoubtedly many ideas and techniques that are valuable, and that it would be helpful for those wishing to look for new ways to extend involvement to know about. The warning we wish to give here is not to mistake a repertoire of methods for the whole project of achieving greater involvement.

The overview given in this Section is a general one: we do not attempt to be comprehensive or to give detailed accounts of all the methods people have used. A wider range of methods and more detailed descriptions of them are given in a companion publication to this one, *Building Strong Foundations* (Scottish Executive, 2002).

One further point to bear in mind is that the different ways and methods by which the public are asked their views and opinions are “not neutral techniques” (Jones and Jones, 2002). Some require people to respond as consumers or users of services, while others support people to participate as citizens. In Section 7, community development approaches are explored in more depth as a more proactive way of developing partnerships with individuals and communities along the lines suggested by Arnstein’s (1969) model of participation (See Section 1). In this Section, a range of methods more akin to ‘research’, alongside some defined as ‘citizen participation’ and ‘participative democracy’ are discussed below.

## 6.2. Classifying methods

If services are to be shaped by users/patients and the public’s views, McCrae et al (2002) argued that methods of engaging people that are “both methodologically sound and appropriate to the purpose as well as the people who are being involved” have to be found. The purpose of involvement has a major bearing on the methods adopted: There are no recipes or fixed formulae. As Barnes and Evans (1998) assert, involvement is “not something for which menus can be provided and tasks ticked off”. There is no “one right method”, and it is possible to use one method to develop another, as in using a focus group to help identify important aspects of particular issues to ask about in a survey (Laird et al, 2000; Cabinet Office, 1998).

A key message from this literature is that no single method will suffice (SAHC et al, 1999; NHS Executive et al, 1998; Barnes, 1997). Methods chosen will depend for example, on whether the intention is to involve a cross-section or representative group, or to involve specific groups who have been historically excluded from decision-making (Barnes, 1999; Cabinet Office, 1998). It will also depend on whether the aim is to draw on the direct experiences of users and carers or the public, to inform the public and then ask their opinions, to explore uninformed views, or to empower local people or groups to define the problem and propose solutions.

It is not the intention to replicate what can easily be found in the existing literature, examples of which appear in the Bibliography

at the end of this report. What follows is a discussion of the research literature about how some of the main methods have been used to involve users/patients, the public and communities to provide the reader with a flavour of what is available. This Section should be read in conjunction with the Toolbox Building Strong Foundations that has been developed by the Involving People Team with Partners in Change (Scottish Executive, 2002).

Much involvement activity has been loosely described as 'research' because it draws upon the methods of academic and market researchers. Traditionally therefore, involvement methods have been listed according to whether they are quantitative or qualitative. McIver and Brocklehurst (1999) further differentiated between three main categories of methods and techniques: research methods, involvement or consultation techniques and 'new' or deliberative approaches. Others have rejected any classification scheme (Laird et al, 2000). These authors argue that each approach can be developed and used in innovative ways according to the particular purpose, and a strong participative element can be built into most approaches. In this review, methods have been discussed under the following four main headings to reflect the nature of the literature: qualitative research methods, quantitative research methods, consultation techniques, and deliberative approaches. Community development approaches have been discussed separately in Section 7.

### 6.2.1. Qualitative methods

Qualitative research approaches offer the best opportunity for exploring people's perceptions, attitudes, ideas etc in some depth and to respond to participants' own agendas. Being less concerned with quantifying an issue or problem, qualitative methods allow for an exploration of why? and how? Qualitative methods offer scope for flexibility in design to suit participants' and encourage as active participation as possible. These methods aim to capture information about people's understanding and perceptions, the meanings they attach to things and what is important to them. Qualitative approaches allow the researcher to adjust according to the responses of participants and to follow ideas and themes not previously identified. Such methods, while providing a rich seam of information, tend however to be both time-consuming and expensive.

## Focus Groups

Focus groups tend to be made up of 6-10 individuals invited to participate in a group interview process, led by a trained facilitator. This technique allows for exploration of a topic in depth and can be useful to find out what particular sections of the community think about an issue or service. In exploration of user/patient satisfaction, focus groups have provided "rich and meaningful feedback on standards of care" (Evason and Whittington, 1997). Morgan and Krueger (1993) point out that focus groups are especially useful when there is a perceived power differential between the participants and decision-makers.

Participants are usually selected for their expert knowledge or experience on the topic under discussion, and because of their experiences can "point up inconsistencies and discontinuities and can reflect on how the whole package works for them" (Evason and Whittington, 1997). Although important to have a flexible structure, the process aims to cover pre-determined areas, which is especially important if there is more than one group and is why skilled facilitation is important (Laird et al, 2000; von Reusner, 1999).

The patient and purchaser partnership project described by Lewthwaite and Haffenden (1997), found focus groups to be a powerful method for identifying problems affecting the quality of existing services. Similarly, von Reusner (1999) found focus groups to be an effective way of channelling potentially destructive criticism into constructive recommendations for change and to be applicable across a wide range of services. Focus groups were found by Laird et al (2000) to be a popular consultation technique with the majority of organisations in their survey, including health agencies. Raynes et al (2000) concluded that focus groups were a practical way of collecting information about dying patients, alongside other sources of information in planning and auditing the provision of care.

Skilled and independent facilitation has been shown to be essential for successful focus groups in terms of achieving credibility and giving weight to participants as the 'experts' (von Reusner, 1999; Morgan (1993) cited in Lewthwaite and Haffenden, 1997). In focus groups with breast cancer sufferers, facilitators highlighted the need to create "an atmosphere which was safe

and non judgemental”, thus enabling participants to feel confident that their views were being taken seriously by the Health Board commissioners (Courcha and James, 1999, p16). These researchers recognised advantages of two facilitators for focus groups in terms of differentiating between the tasks of active listening and interacting with the group and accurately recording what participants said. Raynes et al (2000) also recognised the need for “skilful facilitation” and “accurate recording” in focus groups:

*“Inexperienced facilitation and poor recording may give rise to bias and misrepresentation of views. One or two individuals may either disrupt the group or influence adversely views expressed by other members. In-depth interviews may be more likely to elicit the subject’s true views that may not be fully expressed in a focus group setting.” (p174)*

COSLA (1998) provides examples of how focus groups have been adapted to facilitate a group discussion of an issue and arrive at an agreed position, for example, using ‘nominal group’ techniques. This technique has been useful for agenda setting and prioritising listings by users or citizens but cannot be used to explore issues in-depth. While identifying a number of benefits of using focus groups, Chambers (2000) and von Reusner (1999) suggested the drawbacks of focus groups include the narrow focus on perceptions, that groups may be ‘typical’ but not necessarily representative, participants may not be ‘informed’ about the issues being discussed, marginalized groups may not participate and they are time consuming and relatively costly.

### User or Health Panels

A User Panel can be a small sample of up to 12 randomly selected users and managers brought together to discuss specific concerns. Unlike a focus group that usually only meets once, the User Panel will meet regularly over a longer period (Service First, 1998). This method can be used to highlight problem areas as well as to test opinion or reaction to changes and proposals. A related concept is the Health Panel, which draw upon the public’s views on matters related to health and health services. The principle is to gather 12 randomly selected individuals representative of the population as a whole, to discuss broad

health issues. Health Panels were first set up in the UK by Somerset Health Authority in 1993 to focus on difficult rationing decisions (Richardson, 1998). Participants receive briefing papers before meetings and are encouraged to reflect on the issues with relatives and friends. An experienced facilitator ensures there are opportunities for all members of the Panel to listen to each member, and they are asked to vote to reflect their decision at the end of the meeting. Membership of Panels changes over time to ensure a steady stream of new voices (Bowie et al, 1995).

An evaluation of pilot Health Panels facilitated in Argyll and Clyde by Scottish Health Feedback concluded that the running of the Health Panels could be seen as an overall success (Macdonald and Scott, 1999). However, the evaluation also uncovered a self-selection bias in members of the Panel, the majority of whom had either been employed by the NHS, had or cared for someone with chronic illness or disabilities or had been involved in a community organisation. There were difficulties with facilitating a group as big as 12 with certain members dominating the discussions, despite skilled facilitation. Voting at the end of the meeting afforded an opportunity to register minority views that had been lost within the discussion. The briefing system was largely successful in allowing members to explore topics in depth, although both the facilitators, Scottish Health Feedback, and Panel members felt it would have been useful to have an 'expert' opinion at times to clarify some issues and that the production of the briefings by the Health Board meant this did not always "present a balanced argument".

### **Citizens' Juries**

Citizens' Juries were first developed in Germany as 'planning cells' and later dubbed 'citizens' juries' in the USA during the early 1990s. They grew out of a perceived need to give ordinary citizens a stronger voice in decision-making or to "develop a habit of active citizenship" (Stewart et al, 1994). They are perceived both as an efficient way of obtaining the public's views and as participatory democracy. Juries are felt to offer a structured method of obtaining detailed, considered views from a range of citizens on specific topics. They usually comprise 12-16 lay people who hear evidence from a variety of specialist witnesses over

several days and are then asked to draw conclusions. They are however, time consuming and require clarity of topic and the role of the jury. Members may be representative of particular sections of the population or chosen at random from the electoral register.

The Local Government Management Board (LGMB) sponsored five pilot projects using Citizens' Juries and found that juries produced new ideas for the Councils and well thought out and better informed recommendations than expected (Service First, 1998). Others claim that juries are "socially inclusive", that they access views of people who would not otherwise engage in dialogue on issues of public policy, an opportunity for "informed deliberation", and encourage "creative cooperative action" (Barnes, 1999). Experience from the King's Fund pilots showed that "ordinary wisdom works", that ordinary people can get to grips with complex health policy issues and produce useful recommendations.

A number of lessons were learned from the King's Fund pilot juries during 1997 (Davies et al, 1998). There were three key areas of difficulty: how the decisions of the jury can have legitimacy; concerns about the cost-effectiveness of juries; and concerns around the implementation of jury recommendations. In light of this, the King's Fund suggested the following would indicate when it would be appropriate for a health authority to hold a citizens' jury:

- There is lack of consensus in the host organisation about the answer to a particular contentious question.
- Existing mechanisms to reach consensus have proved unsatisfactory.
- The organisation genuinely wants to answer the question.
- The organisation acknowledges that the public has a genuine and legitimate interest in the question.
- The question that needs to be addressed is at a strategic level and has significant operational implications.
- The organisation supports innovation and significant investment in local provision.

(Davies et al, 1998, p4)

Evaluations of this method have found that while participants have enjoyed participating in a jury, they were frustrated by not having enough time to deliberate further, not being sure about the impact of their deliberations and in wanting to continue (Woodward 2000; Barnes 1999b). That juries were accountable to the sponsors or commissioners rather than the wider public was identified by Stewart et al (1994) as a potential limitation when these were first introduced into the UK in the early 1990s. Mullen and Spurgeon (2000) similarly comment that despite broadly positive outcomes, the role of juries was to “influence rather than determine priorities”.

Some of the drawbacks that have been identified were the degree of planning and expense, and that only a fraction of the local community were involved (McIver, 1998). In the context of other involvement methods however, McIver (1998) found citizens' juries had the following strengths: there was clarity about the role and the juror's task was well defined; the method had in-built mechanisms to ensure that citizens' views had an influence on services; and they introduced new elements which served to strengthen the public involvement process.

The concept of juries has since been expanded to People's Juries and Stakeholder Juries in Social Inclusion Partnerships (SIPs). An evaluation of pilot People's and Stakeholder Juries in area-based SIPs in Scotland was broadly positive (Clarke et al, 2001). The main output from this research by the Institute for Public Policy Research (IPPR) and the Office for Public Management (OPM), was a Guidance Manual for SIPs on running the jury process.

### Rapid Appraisal

*“...seeks to gain community perspectives of local health and social needs and to translate these findings into action. Such methods have been designed to draw inferences, conclusions, hypotheses, or assessments in a limited period of time and are thus relevant to health service research.” (Murray, 1999)*

Increasingly popular since the late 1980s, 'rapid appraisal' is where a multi-disciplinary research team gathers information from as many different sources as possible about the needs of a local population and interviews key informants (Mullen and Spurgeon,

2000; Chambers, 2000; Murray, 1999). It is 'rapid' because it is usually carried out over a short period. Pioneered in developing countries, this approach is based on the idea that key people in any community can be interviewed in-depth to arrive at a representative picture of the views, priorities and needs of that community. Participants are sometimes selected from broader meetings called to discuss health issues. Those who are interviewed might typically represent three main subgroups: professionals, community leaders, and members of the public. This method has been used to identify discrepancies between sub-groups and has improved communication between the public and local health and government bodies (Ong et al 1991 cited in Mullen and Spurgeon, 2000).

Rapid appraisal has been used with specific groups of users/patients and to gain broad perspectives on accident and emergency services (Murray, 1999). Rapid appraisal was found by Murray to have the potential to "give substance and effect to the rhetoric of community participation" by offering practical ways of involving communities in assessing and meeting needs, and had potential to bring about change. Chambers (2000) identified potential bias in the selection of informants and from researchers if they are unskilled or they allow their own view to influence the interviewees, and issues around the time taken to do project work, especially if local professionals carry out the appraisal alongside their other roles.

### Study Circles

While there is little literature on this method, it is mentioned by COSLA (1998) in their guide to approaches and methods to focusing on citizens. These appear to be groups of between 5-20 people brought together on at least three occasions to discuss a specific issue(s). Their main purpose is to involve local citizens in setting goals for the area in which they live, considering options, choices and scenarios. The approach has been used predominantly in the USA, but there is now similar work in Bristol.

#### 6.2.2. Quantitative methods

Quantitative methods are concerned with measuring the incidence and significance of for instance, particular views or opinions as well as behaviours. It is concerned with the question

of how many and what proportion of the population? Surveys can be designed so that they are statistically representative of the target population. Responses can be statistically analysed and tested for significance, correlations, causal explanations, and so on. Questioning is pre-determined or structured reflecting the current knowledge of the askers/researchers and therefore may not truly reflect the concerns of respondents. Outputs from quantitative research reflect this.

### Surveys

The most commonly used method of data collection in all areas of health care has been the patient or user satisfaction and other surveys (McIver, 1999). Questionnaires can be used in face-to-face interviews or self completed by respondents as in a postal survey. Surveys can be a useful method for obtaining reliable statistical information but if poorly designed, or if only responded to by a minority, can give misleading results. This method is also limited in reaching minority ethnic groups and those with communication difficulties.

Research on consulting the public about funding of local services carried out by Spencer et al (2000), found that some were positive about the survey approach highlighting a number of advantages. However, local authorities highlighted low response rates and problems with self-selection skewing the balance of respondents. Other disadvantages were inability to allow sufficient exploration of issues.

Williams (1994) (cited in Drewett, 1997), asserted that in health services, patient participation has been translated as synonymous with measuring satisfaction. This arises from a belief that surveys are relatively inexpensive, a distrust of qualitative methods and a demand for quantitative data. Drewett (1997) argues that this has resulted in a lack of innovation and imagination to involve patients and carers in ways that are more meaningful. Furthermore, the findings of a study by Williams et al (1998) questioned the meaning of 'patient satisfaction', suggesting the high levels of satisfaction commonly found by surveys were unreliable. They found that the process by which users/patients

evaluated services was complex and that many expressions of positive 'satisfaction' masked a variety of negative experiences.

Surveys have been criticised for their "blandness and tendency to produce undifferentiated positive responses", their failure to take account of variables such as age, gender and ethnic origin, and mainly for their "concentration on the organisational and 'hotel' aspects of care (Evason and Whittington, 1997). Used in conjunction with other methods however, questionnaire surveys and focus groups for example, have been found by Conning et al (1997) to complement each other and enrich and enhance the audit process.

### **Citizens' Survey or Standing Panels**

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Panels are a well-established market research technique. Citizens' Panels were promoted as part of extending local democracy by involving people as citizens in the planning and design of services and other policy options. Such Panels have predominantly been used by local authorities and typically comprise 1,000 or more citizens who have been statistically selected as representative of the local population, area or group (COSLA, 1999). Once selected and recruited, they can be used for a large number of consultation exercises and research programmes subject to the limits of 'consultation fatigue' (Hatter, 1999). It can be costly to recruit and maintain Citizens' Survey Panels but there is potential for sharing resources across different agencies such as health services, SIPs and local authorities. The topics addressed by Citizens' Panels are predetermined by the consulting organisation and any options are usually decided beforehand.

Research by Spencer et al (2000) found that local authorities valued the continuity of Panels and the fact that Panel members had a chance to develop a greater understanding of issues and were able to give a more considered response. Having a Panel can raise the profile of user research and lead to the development of further involvement activities (Service First, 1998). Many Panels operated by local authorities are intended to form a closer relationship with a large sample of local citizens (Worcester, 1999 cited in McCrae et al, 2002).

### 6.2.3. Consultation techniques

#### Written consultation

This is the formal means by which people have traditionally been invited by health authorities and other organisations to comment on policies and proposals. The aim is to reach a range of key stakeholders and to determine their views on a particular issue, policy or proposal. Written consultation on planning and policy documents produced by NHS bodies became synonymous with involvement or consultation during the life of the Community Health Councils (Hogg, 1999).

#### Public meetings

Public or open meetings are those that are arranged to enable members of the public to express their views on a particular topic, policy or proposal. Such meetings are the traditional and "anachronistic" method of health authorities offering plans and proposals up for public scrutiny (Mullen and Spurgeon, 2000). Experience has shown that public meetings often have low attendance and are not representative of the community as a whole. In fact, Phillips (1995) suggests those who attend public meetings to be "a pretty unrepresentative bunch!": participants tend to be well educated, well spoken and well off (Jewkes and Murcott, 1998). The cost, weak attendance, and vulnerability of public meetings to lobby groups have been well documented in the literature (Edwards, 1995 cited in Mullen and Spurgeon, 2000).

#### Conferences

Conferences such as Community Conferences and Stakeholder Conferences have been used particularly by local authorities and SIPs to raise public awareness and understanding of certain issues as well as to allow the public to raise their own concerns, debate issues and convey their preferences or possible solutions (COSLA, 1999). Conferences, if not planned well, can suffer many of the disadvantages of public meetings, that is, poor attendance, those attending being unrepresentative of the population overall, and professionally dominated agendas. Some areas have established successful annual Community Conferences, including some LHCCs and SIP areas. Green (1999) describes the

Community Action on Health Initiative (CAHI) in Newcastle Upon Tyne, which established an annual Community Conference to involve local people in discussions with health service staff and managers about particular issues, concerns and developments. The agenda for the Conference was shaped by the concerns expressed by the community during a preceding round of visits to local community groups. It was used to set a collective health agenda and the issues raised direct the work of the CAHI for the following year.

#### 6.2.4. Deliberative approaches

##### Deliberative Polling

A representative sample of the target population is provided with background information on an issue and then invited to participate in a discussion about that issue or topic. Polls can be carried out before and after the discussion to test changes in opinion as a result of debate. Deliberative polls develop the conventional idea of opinion polls (Park, 1998). They are able to demonstrate what a more engaged and better informed public might think about an issue (McCrae et al, 2002). With large enough samples that are representative random samples, statistical analyses can be carried out and the results used to generalise (Park, 1998). However, Laird et al (2000) highlight problems identified by organisations responding to their survey as poor attendance or low response rates, and therefore results were not representative.

##### Referenda

Referenda can be a useful means of finding out about public opinion on a major issue or concern of great public interest and with a high turnout, the results can be used as a "strong indication" of local opinion (McCrae et al, 2002). They are rare at a national level but have been used locally (Laird et al, 2000; Service First, 1998). Experience suggests that a well-conducted referendum should be preceded by public debates and information on the issues concerned (COSLA, 1998). Participants are asked to vote either for or against particular options or range of options. From their research, Spencer et al (2000) suggest that the public appreciated the fact that referenda were short and simple and liked the idea of a vote, but there was little room to agree or disagree with the details of the proposed choices.

### 6.3. Other 'methods'

There will be many other ways in which public organisations are currently consulting service users and the public, which do not easily fit into any of the categories above or have not received much attention from researchers. These include reaching the public through open days or roadshows, exhibitions, campaigns and presentations, using new technology, and through ongoing partnerships with voluntary organisations, having users/patients/members of the public in service advisory groups, users/patients councils and so on. Providing a mechanism for people to comment or complain about services in a range of ways (written, by telephone, face-to-face) can be viewed as a useful way of getting feedback from service users (Cabinet Office, 1998). In addition to dealing with individual problems, analysis of complaints for instance offers the chance to monitor trends, problem areas and so on.

Many voluntary organisations or interest groups may consider themselves to have a 'watchdog' role. Such organisations provide a "ready made source of information" (Service First, 1998). This includes Local/Community Health Councils, Race Equality Councils, Self or Citizen Advocacy Groups and many specialist groups such as Alzheimer Scotland Action on Dementia. As well as having a view, such groups can tap into a wider representative view such as that of disabled people or carers.



## 7. Involvement Through Community Development Approaches

### Key points - section 7

- Community development is a long-term process of involving individuals and communities in their own health.
- Community development uses a variety of participatory research methods and activities that address four dimensions: personal empowerment, positive discrimination, community organisation, and participation and influence.
- Participatory research approaches have grown out of dissatisfaction with the traditional power relationships in the production of research.
- The main purpose of participatory research approaches is to raise awareness and ensure that those affected by the research retain control from the outset.
- Community development recognises that access to health care services is a less significant determinant of health than many economic, social and environmental factors.
- Such approaches challenge the definition of health as an individual problem for which there are individual solutions and health care systems that treat symptoms and not the root causes of ill health.
- Community development is still at a relatively early stage of development within mainstream agencies. There are few written accounts within the field of statutory health care.

### 7.1. Introduction

The previous Section identified a 'repertoire' of some of the ways or methods of listening to and involving people in decision-making and determining the quality of services. Using such techniques of themselves should not however be confused with promoting participatory democracy. Many of these techniques provide effective ways of gathering opinions, deliberating on an issue, consulting a wider public and so on but they do not necessarily provide ongoing opportunities for people as citizens to have a say in local health services. In this respect, community development approaches differ significantly from other involvement techniques.

The types and levels of involvement discussed in Section 1 differentiated between 'reactive' and 'pro-active' involvement approaches and between the two broad approaches of consumerist and democratic. In this Section, community development approaches will be discussed briefly as an example of both a democratic and a truly pro-active approach to empowering individuals and communities to be involved in identifying gaps in health service responses and developing new services. There are few written accounts of the adoption of community development approaches within the fields of statutory health care, while there is a thriving literature about the community development approach to health (Jones, 1998). This picture is bound to change as the emphasis on adopting community development approaches increases.

### 7.2. Defining features

"The community development approach...embraces certain principles, goals and methods of work. Its values and methods include: empowerment, user and community involvement and participation, joint working or partnerships between professionals and service users, accessible, user-friendly services, a clear structure of accountability and an inclusive approach which works with, not for, people." (McShane and O'Neill, 1999, p2)

Community development describes a long-term approach to involving communities in their own health. The explicit focus of community development is on reducing inequalities and

discrimination and empowering the most marginalized communities (NHS Executive et al, 1998). Hiebert and Swan (1999) argued that community development today challenges professionals to ensure that the community that is being 'developed' includes marginalized groups as equals to professionals. Community development uses a variety of methods and activities such as self help work, outreach, local action groups, lobbying, peer work, festivals and events, information, advocacy, group work, network building and pump priming community initiatives with small grants. However, for these to be considered community development, Barr and Hashagen argue that they would need to address the four dimensions of personal empowerment, positive discrimination, community organisation and participation and influence (Barr and Hashagen 2000).

This approach requires skills that are not common in the health services, except perhaps among Health Visitors and Health Promotion staff, and so often requires to be imported usually from the voluntary sector. Johnstone (1993) describes such an initiative, involving Public Health Nurses working alongside mothers in the community to empower less experienced mothers. The key characteristic of community development is that it starts from the experiences and perspectives of communities. In terms of health, local people need to be enabled or supported to identify the factors that impinge on their health and the solutions. It is argued that genuine participation is only possible when there is involvement in decision-making and evaluation (Jones and Macdonald, 1993).

In the course of work with communities in the USA, McKnight identified that of all the factors that determine health, including individual behaviour, social relationships, physical environment, economic status and access to health care, the latter, was the least significant (McKnight, 2001). McKnight concluded that to influence people's health status, "we need to get beyond medicine". Similarly Watt (1987) cited in Jones (1998), in the context of a community development conference stated:

*"General characteristics of community development health projects constitute...an understanding that a health service*

*cannot provide effective health care in isolation from its most needy users...Projects engage head-on with the medical profession, highlighting its centrality and pervasiveness in determining the nature of health and the health service."*

Community development approaches challenge the definition of health as an individual problem for which there are individual solutions, and health care systems that treat the symptoms and not the root causes of ill health (McCormack, 1993). Instead, such approaches emphasise the knowledge and expertise of individuals and communities living through an experience and the centrality of drawing on this source of expertise to define problems and solutions and ultimately to design more effective services.

The main benefits of community development approaches have been summarised as:

- Improving networks in a community, which has been shown to have a protective effect on health.
- Identifying health needs from users' point of view, in particular disadvantaged and socially excluded groups.
- Change and influence, as it enhances local planning and delivery of services.
- Developing local services and structures that act as a resource.
- Improving self-esteem and learning new skills that can aid employment.
- Widening the boundaries of the health care debate by involving people in defining their views on health and local services.
- Tackling underlying causes of ill health and disadvantage.

(Fisher, 2001, p134)

### 7.3. Community development and health

The community development approach in health began to emerge during the late 1970s and early 1980s with the development of community health projects in several parts of the UK, many emerging from grassroots action. Since the 1980s, community development has been perceived as offering some solutions to the welfare crisis (Jones, 1998). Essentially, community development work acknowledged that health was as affected by the social conditions of people's lives such as damp housing, unemployment, or poor access to facilities, as it was by lifestyle choices. Major policy documents including *Towards a Healthier Scotland* (1999) and *Our National Health* (2000) highlight the importance of considering life circumstances alongside lifestyle choices and disease in promoting health and wellbeing.

A World Health Organisation (WHO) position paper (1991) directly linked community participation to empowerment as a means in itself of promoting healthier individuals and environments. Furthermore, research has recognised the significance of powerlessness and empowerment to the health of individuals and communities (Wallerstein, 1993). The concept of healthy communities as developed by the WHO regards active community participation as essential to creating healthy communities:

*"The formation of local social capital can thus lead to the promotion of shared values and a common vision, integrated planning and resource utilization, and ultimately to systemic change."* (Murray, 2000, p101)

There is a growing body of literature showing that being part of a social network of contacts is protective for health (Fisher, 2001). The effects derive from improved self-esteem, trust and increased feelings of being in control.

### 7.4. Participatory research approaches

With many of the methods discussed in the previous Section, control of the process is still invested in the authority or organisation. 'Participatory research' approaches grew out of dissatisfaction with traditional power relationships between 'researcher' and 'researched' and a demand from disabled people in particular, for more empowering models (Oliver 1996). Community development workers in countries in South America, Africa and Asia pioneered participatory approaches in the early 1980s (Jones and Jones, 2002). In contrast to traditional research, 'participatory research' approaches sought to address the gap between the concepts and models as perceived by professionals or academics and the ways in which individuals and groups in the community perceive reality. The philosophy underlying such approaches is that in order to provide anti-oppressive research fulfilling a social justice agenda, it is fundamental that the views, perceptions, direct experiences and definitions of knowledge held by people on the receiving end of services are taken account of, valued and acted upon (Brandon, 2001).

The main purpose of participatory approaches was to raise awareness and ensure that those affected by the research retained control over the whole process from the start. As Oliver (1992) argued in relation to disability research, research should not be understood as a set of technical objective procedures carried out by professionals but "part of the struggle by disabled people to challenge the oppression they currently experience in their lives". The research question or problem, decisions about who should be involved and who the information was for, were to be decided by community groups as part of a longer term process of investigation, reflection and community action.

The degree of user involvement could be affected by a number of barriers including discriminatory attitudes, access barriers, issues around resources and representativeness (Brandon, 2001). Nevertheless, there is now evidence of research and evaluation being carried out by users and user organisations (Beresford, 2000). People with learning disabilities for example, have been involved as originators of research ideas, advisers and consultants to research projects as well as interviewers and analysers of

research findings (Ward, 1997; Whittaker et al, 1991). Examples such as the experience of the Pilton Health Project serve to confirm that the way issues are defined, articulated and tackled have a direct bearing upon the levels and quality of participation and the importance of this approach (Jones, 1998).

## **7.5. Community development at strategic level**

In the next few paragraphs, actual examples of the adoption of a community development approach in relation to health are documented.

### **7.5.1. Craigavon and Banbridge Community Health and Social Services Trust**

At strategic level, there is increasing evidence that community development is seen to be an important part of any participatory strategy and more resources are gradually being diverted to this end. However, although the rhetoric is spreading, the change in attitudes and organisational re-arrangements are slower to gain ground. The Craigavon and Banbridge Community Health and Social Services Trust in Northern Ireland is an exceptional example of a Health Service Trust which has accepted that community development has to inform its whole approach. (SHF, 2001c; McShane and O'Neill, 1999)

The Trust accepted the contribution of community development to the core business of Health and Social Services by mainstreaming this approach across all its programmes of care. The importance of increasing community development awareness and skills for other managers and staff was also recognised and the Trust was actively committed to a training strategy. It viewed this as a core feature of implementing the Government's strategy on social inclusion, social justice and partnerships for health and wellbeing.

The Trust's Community Development Unit has actively worked with different community groups, ensuring that broader aspects of health are highlighted. For instance, a Rapid Participatory Appraisal was conducted bringing together various parties such as

nursing, community work, social work staff and local people. This enabled issues to do with housing, the local economy and community infrastructure to be included and worked at to improve the wellbeing of the community.

#### 7.5.2. The Addiewell Project

One example of local communities becoming involved in setting the agenda around health was that of the Addiewell Task Group (Addiewell Research Project, 2000). In a joint initiative between local residents, West Lothian Council and the University of Edinburgh, the Addiewell Task Group developed indicators and measures to do with health and wellbeing that were seen as important by the community. The Health Unit based within the local Council worked alongside local people to ensure their participation in the identification, definition and proposals for measuring health indicators. The work was founded on the principle that the best people to decide what issues and indicators were important were local people themselves.

#### 7.5.3. Working together: Learning together

A two year training programme, Working Together: Learning Together, was set up as part of the Scottish Executive's 'Listening to Communities' programme, to provide training in understanding social exclusion, partnerships and Working for Communities Pathfinders in Scotland. The programme aims to ensure that communities are involved in "genuine, meaningful partnership where they can exert real influence" (Working Together: Learning Together website - [www.wtltnet.org.uk](http://www.wtltnet.org.uk)). There are 60 partnerships and 900 people participating in training from agencies and communities led by a consortium of organisations including the Scottish Community Development Centre, Community Learning Scotland, the Scottish Council for Voluntary Organisations, the Poverty Alliance, and the University of Dundee.

### 7.6. Challenges of community development

The community development approach encounters particular challenges in the context of health care (Jones and Macdonald, 1993). While support for the idea of extending community

development approaches into mainstream health services and other public services has grown, in reality organisations are not always receptive to the idea of a longer term ongoing dialogue which might lead to major changes within the organisation or into areas that the organisation had not previously considered (Jones and Jones, 2002). The conclusion of a DHSS (Northern Ireland) (1999) document was that community development is still at a relatively early stage of development within mainstream agencies. It found most NHS Trusts and Boards did not have a stated policy for a community development approach, and there was a lack of focus for this work and few instances of training for staff in this area.

The way of working with and not just on behalf of individuals and communities that is central to the community development approach, sits uneasily with traditional western medicine and the 'medical model' in which professionals know what the problem is as well as the solution. The challenge is not to the value of medical expertise per se, but rather to its dominance in respect of health knowledge and the allocation of resources. Few health service professionals are fluent with community development approaches and ways of working with, rather than on behalf of, people. In describing a public health programme set up to link new mothers with experienced mothers and Public Health Nurses in Ireland during the 1980s, Johnstone (1993) concluded:

*"Familiarisation of all health care workers with changes in policy and the background of research and development and aims of policy would eliminate some of the frustrations and create a more supportive environment...The community based approach has proved more effective in achieving change where this is indicated and is likely to be a more useful model for empowerment and self-care than the traditional type of health care approach." (p255)*

Subsequently, Johnstone (1993) advocated that the education and training of health care workers should include the possibility of working in partnership with people rather than for people. Community and user groups and health and social services professionals need to perceive each other interacting in different sets of roles and relationships (McShane and O'Neill, 1999).

McKnight (2001) also highlighted core differences between the shape and function of communities and service systems: communities were based around individuals and families, informal relationships, as well as formal groups, and relationships defined by choice. Service systems on the other hand, had hierarchical structures designed to ensure “a few people could control a lot of people” to produce goods or services. Such structures ensured uniformity and that goods and services met the same standards. Each kind of structure has its own (very different) rationale, ways of working and communicating, and the two kinds of system therefore often find it very difficult to engage constructively together. The central concern identified by McKnight (2001) was that of ensuring people were at the centre and influencing what happens.

## 8. Discussion and Recommendations

### Key points - section 8

'Good' user and public involvement has the following key elements:

- Involvement becomes a core activity, not an add on or a 'top down' approach.
- A strategic approach is adopted across the whole organisation with strong leadership from senior management.
- There is community and organisational development - citizens need to become more informed and experienced, but organisational systems and practices also need to change.
- Partnerships are formed with other local agencies, for example, Social Inclusion Partnerships and Local Authorities, to ensure coordination and cost efficiency.
- No single approach or technique constitutes involvement of users and public.
- Various techniques can be used, which must be chosen according to the purpose of the initiative.
- The resource implications of involvement are acknowledged - for example, training, venues, crèche facilities etc.
- Tangible gains from participating can be identified and these can be demonstrated and communicated.
- Communication mechanisms are set up to ensure regular feedback in accessible formats.
- Involvement strategies need to be evaluated and constantly reviewed as part of a dynamic process of continuous learning.

### 8.1. Introduction

Although 'how to do it' is generally the main question exercising the minds of those in health services when approaching the subject of involvement, as Lupton et al (1998) argued in order to develop a coherent strategy for public involvement, this question needs to be preceded by 'what for?' One of the conclusions from this review so far is that it is possible to be engaged in numerous 'involvement activities' including patient satisfaction surveys, without really involving people as citizens if priorities remain determined by professionals and the organisation. The historic overview identified that previous attempts have been weakened because involvement has often been 'one-off' or ad hoc projects rather than part of a strategic approach. Furthermore, such attempts have often suffered from isolation and marginalisation. Genuine attempts at involvement start from where people as users or citizens are, recognise the need for relevance, try to make the process accessible and act upon the findings.

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In this Section, we pull together the key issues that have emerged throughout this literature review, and which in our opinion, form critical success factors for 'good' involvement. Taken together the literature draws valuable lessons from a range of projects and initiatives that have promoted user/patient and public involvement in health services that can help shape future attempts to achieve better involvement.

### 8.2. An 'ethic' of involvement

SAHC et al (1999, p140) emphasised that involvement was not an "add on to existing work", and must be integral to the ethos of the organisation, built into the culture and responsive to both the public's needs and to those of the organisation." While recognising the competing priorities for the health services including pressures on front line services, the NHS Executive et al (1998) emphasised the need to ensure public participation becomes a "core purpose" and understood as a way of achieving health and health service objectives:

*"For consultation to become 'good consultation', it must be more than a top down approach. A truly participative consultative exercise will involve communities in all aspects of the process; say from identifying the issues affecting their communities and a*

*need for views to be sought...to the analysis of the outcomes of the consultation and development of appropriate strategies.” (Laird et al, 2000)*

Further, Small and Rhodes (2000) emphasise how involvement if effective can positively shape the lives of people receiving services but it must become an ‘ethic’:

*“...one has to look for user involvement in the minutiae of lives with illness, in the giving of information, in the way help is offered. An ethic of user involvement must frame all encounters the ill person has and inform the perspective of the care provider. It has to grow in and through structures, practices, expectations and responsibilities. It is a philosophy and not a procedure...It is about privileging the voice of those most effected by ill health and saying that it is just so to do.” (p221).*

A practice based study of approaches to effective user involvement in individual care carried out by Dick and Cunningham (2000) illustrated the value of a “whole organisation approach”. By this, the authors emphasised the importance of building involvement into systems and procedures, and for practitioners to be committed to finding solutions in partnership with users.

### 8.3. Strategic approach

The literature reviewed in Section 2 overwhelmingly concluded that despite numerous practical examples of involvement activity in the health services, it is rarely part of a coordinated strategy. The case for a consistent joined-up approach is a common theme in the literature (e.g. Scottish Health Feedback, 2001a; Coote, 2000; Department of Health, 1999a; NHS et al, 1998; Lewthwaite and Haffenden, 1997). One of the lessons learned from the Patients Influencing Purchasers Project in England, was that a clear strategy provided:

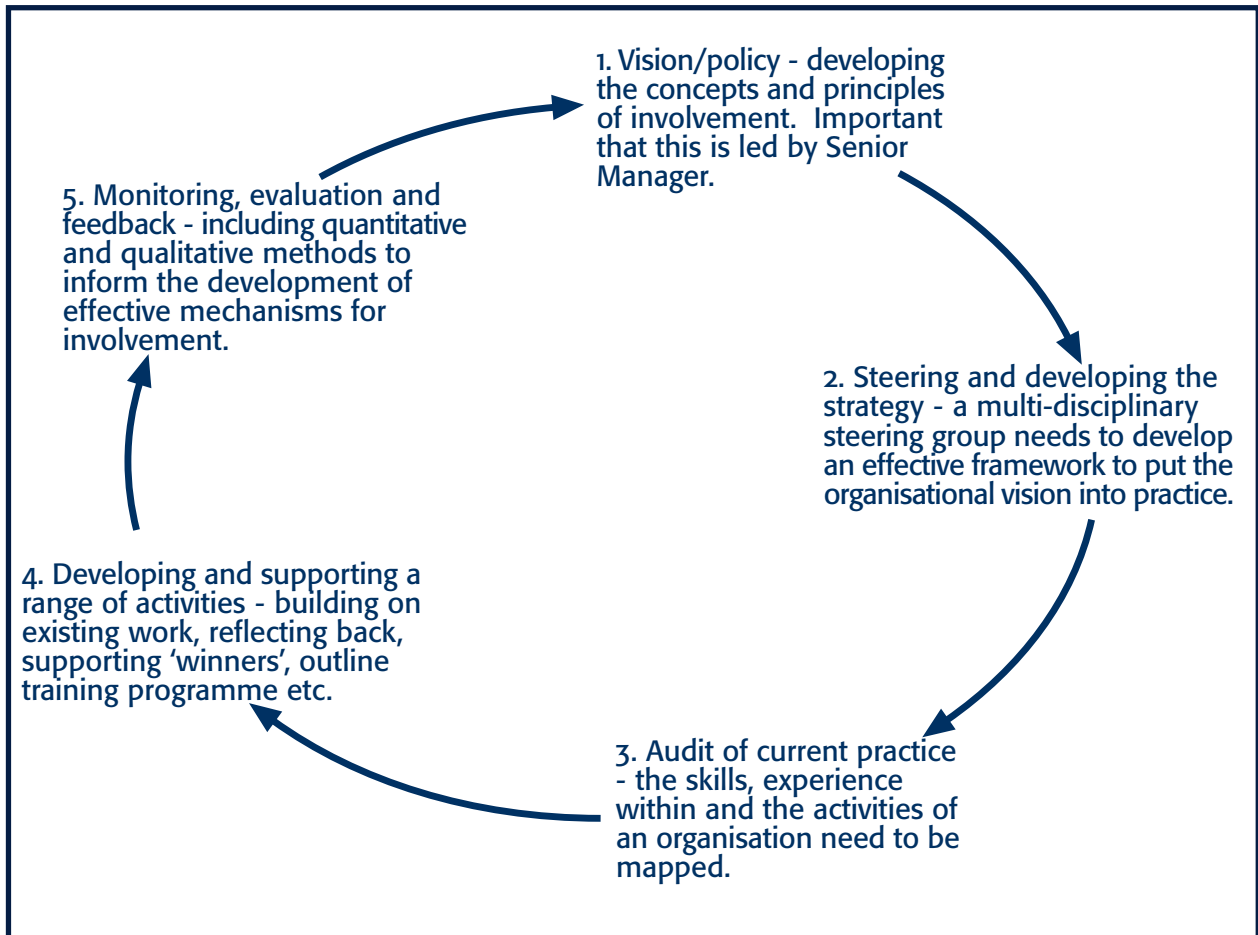
*“A signal that the health authority was prepared to take responsibility for the partnership, that there was a demonstrable process with resources to support it, and a commitment to evaluate the impact.” (Lewthwaite and Haffenden, 1997, page 25)*  
Effective and meaningful involvement requires a strategic

approach rather than a series of individual projects. Four different models have been identified from the experience of involvement in different contexts, which when taken together constitute the elements of an overall strategy. These were:

1. Direct participation of user and voluntary groups in decision making at local and national levels and individual partnerships between clinician and user/patient'
2. Informed views - by developing opportunities to engage with informal views and experiences of citizens about health and health services'
3. Community development - mobilising communities to become participants in defining problems and developing solutions to health and health service issues'
4. Local scrutiny and accountability - a process of democratic accountability bringing the NHS closer into the process of representative government at local and national level.

(NHS Executive et al, 1998; Barnes and Evans, 1998).

Building further on the experience to date, there are a number of discernible stages in working towards an effective involvement strategy. For example, SAHC et al (1999) identified the following five essential steps:



## 8.4. Community and organisational development

For involvement to be effective, it requires an infrastructure of user interests, for example, a network of user/patient organisations providing a strong representative lobby. Barnes (1997) and others (Lewthwaite and Haffenden, 1997) highlight that effective public participation will only come about with the development of both the community and the organisation. Citizens need to become more informed and experienced in engaging in a dialogue, but organisational systems and practices

also need to change to open them up to the involvement of local people, as well as developing staff better skilled to work with users and citizens.

The parameters of any partnership and the expected outcomes need to be defined and agreed with users/patients (Lewthwaite and Haffenden, 1997). Further, user, carer and voluntary organisations need to develop their capacity to involve a broader representation of users, and this has resource and training implications for development workers and other staff supporting these organisations. Local capacity for providing independent advocacy as well as collective advocacy will also need to be developed (SHF, 2001a; Scottish Executive, 2000).

Users/patients need the opportunity to have a real influence on their care and treatment. Many users/patients however, are vulnerable, or find it difficult to communicate their needs, partly because of the very difficulty that led them to be users of services in the first place and partly because systems sometimes disempower people. Advocacy services are one major source of support, potentially for any user/patient but particularly for people who are stigmatised and devalued in society and are not used to having their opinions sought. The principles for commissioning good advocacy services have been set out in recent Scottish Executive guidance (Scottish Executive, 2000c). Because the need for advocacy crosses agency boundaries, funding and support should be agreed jointly between local authorities and the health service.

### 8.5. Partnerships

Several authors point out the need for health services to work in partnership with other agencies such as local authorities that are also attempting to involve users and the public (NHS Executive et al, 1998). This is brought into sharp relief when involving those who are chronically or terminally ill:

*“Agencies’ failure to engage in a collaborative approach runs the twin risks of duplication of effort and the commandeering of the time and energy of people who may have little of both left in them.” (Small and Rhodes, 2000, p217)*

It is therefore essential that there is joint recognition that the issues that concern people with chronic and terminal illness in particular, straddle agency boundaries. Given that many people have complex needs that do not fit neatly into one 'service box' or other, the principle of partnership should equally apply across the board. Considerable experience and knowledge has been gained through the implementation of Community Care policy and planning, regeneration and community safety strategies and so on and there is much anecdotal evidence of joint working between SIPs, local authorities and LHCCs, although less evidence of the involvement of users in these exercises. Benefits of collaboration include sharing expertise, joint training, pooling resources, and joint action on cross cutting issues.

## 8.6. Matching methods to purpose

No single method will be sufficient to ensure involvement of different publics in a range of purposes (NHS Executive et al, 1998; Barnes, 1997). The SAHC et al (1999) emphasise the importance of choosing methods carefully to ensure their "appropriateness" both in terms of the purpose of the particular involvement exercise but also to suit the group of users or the public participating. In a chapter dedicated to 'choosing the right method for the right reasons', Chambers (2000) states:

*"Don't just do a survey or a focus group because it seems like a good idea or there is a requirement to do it or it will end up as a meaningless exercise at the expense of your time and needlessly raise other people's expectations about the possibility of change."*  
(p96)

A "vital piece of learning to date" is that there is not one but a range of ways of involving people and that the method(s) chosen should be matched to the purpose and particular circumstances (NHS Executive et al, 1998).

## 8.7. Resources

Wider participation involves a long-term investment of resources to support not only patients or users, but also staff (SHF, 2001a; Hogg, 1999; Lewthwaite and Haffenden, 1997). The costs should

include reimbursing users for contributing their expertise and skills, providing the necessary support, practical resources such as venues, crèches etc.

## 8.8. Tangible gains

While it is clear that involvement will not happen overnight, rather it is an “organic” process (Lewthwaite and Haffenden, 1997), this has to be balanced against the need for tangible outcomes to be demonstrated early on in the process. The NHS Executive et al (1998) emphasised the importance of planning for small and early successes to gain support both within the organisation and the participating groups.

The work carried out in one NHS Primary Care Trust (Scottish Health Feedback, 2001a), also highlighted the importance of being flexible enough to respond to ideas that emerged during the process from both users/patients and staff. In discussing involvement in relation to community care, Mills et al (1997) emphasised that aims and objectives of projects must:

*“...be part of a process of shaping decisions. And your project must carry some promise of change, or it will be merely a sham and the consumers involved with view it as such...Don't perpetuate the tokenism of the past by proceeding with a project that you believe will not bring about any change.” (pp63-64)*

Because involvement projects make significant demands on participants' time and energy, they want to see tangible outcomes for their investment (von Reusner, 1999). Participants generally want evidence of some measure of change as a result of their participation.

## 8.9. Regular feedback

Commonly, projects that have attempted to involve users/patients or the public, highlight the need to provide regular feedback about progress being made. A study to devise a model for engaging local people in identifying need in relation to early years services identified continual communication as a principal success factor (Watt et al, 2000). In this particular project, there needed to be communication between the commissioning body

and the research team, internally between sub-departments of the implementing body and between the research team and the participants.

This appears to be an issue that is much more significant than may generally be realised by those working within statutory agencies who genuinely seek to extend involvement and may feel they are already doing so. Work by Scottish Health Feedback (SHF, 2001a) with local patient and community groups found that many felt that their local Primary Care NHS Trust had made attempts to gather their views, but that they rarely, if ever, received any information about what decisions had been taken on the relevant matter, and what influence the views of the patients and the public had had. This made the effort to formulate and give opinions seem wasted, and reduced the motivation to engage in future. Similar reactions are widely, if anecdotally, reported elsewhere.

## **8.10. Long term commitment**

One Primary Care Trust Action Plan for Involvement (SHF, 2001a) stressed the importance of a long-term programme to build involvement, rather than a one-off action plan that would remain unchanged. Strategic action plans need to be flexible, to grow and adapt. In particular, they must respond to what users/patients and the public themselves feel about the way it works. A particularly strong message from the research carried out by SHF (2001a) was that there is no “one size fits all” with regard to involvement. It is more a matter of starting out and trying different strategies, monitoring and evaluating their effectiveness and finding out what works in each circumstance: a process of continuous learning.

## **8.11. Evaluation**

Building in evaluation of the involvement strategy is vital and needs to be in place at the start (Cabinet Office, 1998). This links with the point above, that involvement is a long-term process involving continuous learning and needs to be set within a strategic context. However, some commentators have found little evidence of any formal or systematic evaluation of involvement

and consultation carried out by Scottish organisations (Laird et al, 2000). The researchers found that evaluation if it happened at all, tended to be informal and anecdotal, relating to process rather than to outcome.

A project exploring user/patient and purchaser partnerships (Lewthwaite and Haffenden, 1997), also found that independent brokering of partnerships between users/patients, voluntary organisations and health authorities as purchasers was needed. This was at two levels: for the process as a whole when a model for collaborative work was emerging and, later to maintain the momentum of the partnerships towards agreed aims.

### 8.12. Shared principles and values

In conclusion, 'good' involvement is also built upon shared principles and values, arrived at in consultation with all stakeholders. An example of such principles and values is given in Appendix 1. The core values identified from the literature were those of transparency, openness and honesty in dealing with users and the public, ensuring that all communications are two-way and decision making is declared and explained (SHF, 2001a; UKCC 2000; SAHC et al, 1999). Additionally there must be an emphasis on equity and social inclusion in the sense of valuing diversity and promoting inclusiveness (UKCC, 2000). Finally, partnership and trust are key values in promoting understanding and respect for different roles.

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## Appendix 1

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### An example of aims and principles

The Trust commits itself to a long-term programme to continuously extend and deepen patient and public involvement in its work. The aims of this programme are:

- To engage patients of the Trust, and a wide range of members of the general public in Renfrewshire and Inverclyde, in helping to plan, monitor, shape and develop the services of the Trust;
- To ensure that the culture of the Trust and its staff becomes such as to encourage, support and promote such involvement, and to respond constructively to it;
- By means of such involvement to enable services to become progressively more responsive to patients and the public, and better adapted to provide for their needs;
- To nurture and develop a sense of ownership of the Trust's services among its patients and among the public of Renfrewshire and Inverclyde.

The programme will particularly seek to promote the active involvement of those patients and members of the public who are normally more disadvantaged than most in terms of their opportunity to voice their views and to influence services. It will do this through a strategic approach rather than developing initiatives in an ad hoc way.

The word "involvement" can mean different things to different people. It can range from passive involvement such as gathering information or opinions of service users or potential users about an existing service, through to consultation on strategies and plans, representation on planning or decision-making bodies, to the direct influence of users over the running of services.

All these forms of involvement are valuable, but if developments are confined to the parts of this spectrum that entail little or no change in the balance of power over services, the programme will have failed. The aim must be to achieve involvement across the spectrum so that patients and the public have, and feel that they have, a real degree of influence on the service.

This long-term programme to build involvement is not something that will be planned now and remain unchanged. It will need to be flexible, to grow and adapt. In particular, it must respond to what patients and the public themselves feel about the way it works. A particularly strong message from the interviewees was that there is no "one size fits all" with regard to involvement. It is a matter of trying and different strategies, monitoring and evaluating their effectiveness and finding out what works in each circumstance: a process of continuous learning.

The programme will also need to consist of many elements: it is not a matter of one good idea. There need to be many different things happening that reinforce each other.

(Taken from Scottish Health Feedback, (2001), "A Draft Action Plan for Patient and Public Involvement prepared for Renfrewshire and Inverclyde Primary Care NHS Trust")