Contents

Foreword

One of the key principles in the Health Strategy *Quality and Fairness: A Health System for You* is the provision of a people-centred health service that identifies and responds to the needs of individuals, is planned and delivered in a co-ordinated way and helps individuals to participate in decision-making to improve their health. To achieve this in a meaningful way we need to continuously adapt our services to meet the individual needs and preferences of those who access our services rather than expecting them to adapt to the way we do things.

We are pleased to publish this research-based discussion paper on public and patient participation in healthcare. It aims to contribute to the implementation of *Quality and Fairness* by raising awareness of the issues involved in delivering a people-centred health service. We believe it will be of interest to all healthcare staff in helping them understand the critical issues that can make a difference in delivering a people-centred health service in their organisations.

Putting the patient/client at the centre of everything we do and developing truly people-centred services will require a major cultural shift for us all. This is the real challenge and demands that we focus our efforts on the process as much as the outcome.   It is only by having healthcare staff participate in the process that the challenge of working in partnership with their patients/clients and the public in a wider partnership can be achieved.

So it involves new ways of working – more collaboration and better team working across the health services to promote and facilitate the provision of a seamless service that puts the patient/client right at the heart of what we do.

I would like to thank all those who contributed to this paper and particularly Professor Hannah McGee who led the research team. The greatest tribute that could be paid to all those involved is if the messages and principles of partnership set out in this paper were used by healthcare staff to guide, support and inform any new initiatives and service delivery in the future.

Denis Doherty
Director

Acknowledgements

Executive summary

Background

- The new National Health Strategy (*Quality and Fairness – A Health System for You*), launched by the Irish Government in November 2001, set out a vision for how the health system should develop over the next decade to deliver high quality care for all service users. The National Health Strategy set out a series of actions for achieving increased patient involvement on a number of different levels in healthcare. It will be the responsibility of named agencies to set up and oversee the implementation of each of these actions.

- In response to the proposals for people-centred care outlined in *Quality and Fairness*, the Office for Health Management commissioned the Health Services Research Centre at the Department of Psychology, Royal College of Surgeons in Ireland, to produce a research-based discussion paper on public and patient participation in healthcare.

Aim

- The aim of the discussion paper on public and patient participation in healthcare was to provide a description of international thinking on public and patient participation activities in order
  - to assist health managers to contextualise the proposals as set out in the National Health Strategy and
  - to provide them with examples of good practice models for doing so.

Objectives

- to identify models of best practice in public and patient partnership in healthcare from the international literature

- to outline current Irish examples of public and patient involvement in healthcare

- to identify principles of partnership to guide Irish service developments in the area.

Theoretical background to patient partnership

A review of the international literature on public and patient partnership revealed a number of key points.

- Public and patient partnership consists of four main themes: promoting active participation; enabling patients to become informed about treatment and healthcare; involving patients and carers in quality improvement; and involving the public in health service decision-making.

- Partnership operates on three main levels: 1) the individual, or one-to-one clinical encounter; 2) care planning, or care management, with a strong link to local services; and 3) the macro level of partnership, incorporating both community and policy arenas.

- A number of models which help to explain the dynamics of different approaches to partnership were identified. Most of these have focused on the extent of public or patient control over decision-making. However, there are other models based on factors such as consumerism, domains of action, change strategies, decision making and healthcare tasks.

- There is a danger that partnership initiatives will focus on medical aspects of care to the exclusion of other factors such as economic and educational status and the broader socio-cultural aspects of an individual's life. Inclusive and participatory approaches which have been developed in other sectors such as education and community development can provide valuable examples to the health sector.

Policy issues

- A range of different factors has driven policies for patient involvement in health service development. These factors include: crisis interventions; reform and restructuring of the health services; a developing quality in healthcare movement; patient safety and complaints systems; and a growing sophistication on the part of patients and their advocates.

- The objectives and scope of participation need to be clearly defined from a policy perspective.

- The extent to which policy-makers anticipate and allow for the consequences of participation needs to be considered at an early stage.

- Partnership is dynamic and should allow the full range of individual patient choice.

Public and patient partnership in other countries and in Ireland

- Among the most important centres for partnership in healthcare are the United States, Australia, Northern Europe and the United Kingdom.

- In the USA three main factors have contributed to the increase in popularity of participation initiatives: the development of increasingly complex medical technologies; a growing civil rights movement in the 1960s raising awareness of rights-sensitive issues in medicine; and the medical ethics movement which gave a new standing to the rights of individuals to learn about their illnesses and to help make decisions.

- In Australia consumer participation is linked to improvements in the quality of healthcare and improved health outcomes. A number of reports have promoted a national approach to consumer feedback.

- Across Northern Europe the issue of patient choice has become increasingly important in healthcare reform. Social and economic change has brought pressure for a high level of patient involvement in the practice of health professionals and health managers.

- In the United Kingdom various approaches to providing participation and partnership have been developed, in particular over the last decade. The essentials of participation and partnership are evident in the development of supportive structures at local and national level, in the development of training and resource information and in legislation for advocacy services and patient forums in the health and social services. The aim is to view patients and their representatives as insiders in the health system and to assimilate their expertise.

- Although a partnership approach has not been implemented on a national or strategic basis, several patient participation projects have been undertaken in Ireland which reflect different approaches and comprise different   levels of complexity. Examples of these are provided in this discussion paper.

Developing public and patient partnership in Ireland

- Public and patient partnership at all levels of operation abroad must be adapted to the particular context of the Irish healthcare system.

- Principles proposed to support and inform public and patient partnership initiatives include
    - A **rights-based approach** to public and patient partnership
    - A commitment to creating an atmosphere where **building trust** is supported and encouraged
    - A **flexible and accessible communication process** that is honest and open about the implications of healthcare decisions
    - **Motivation and commitment** to partnership on the part of both service users and service providers
    - **Flexibility** and willingness to adapt to changing circumstances
    - An ethos of **fairness and accountability** which includes in-built monitoring and evaluation systems
    - **Mutual co-operation and support** in times of difficulty
    - A concern for **process** as well as outcome – respecting how things are done as well as the end result
    - A commitment to **delegate power** equally across all parties in a partnership
    - A commitment to **embedding** partnership within the structure of the health system and across all sectors at all levels within the system.
    - A commitment to financial support

- Requirements for best practice in public and patient partnership can be viewed as comprising both interpersonal skills and concrete actions.

Inter-personal skills
Understanding the power relations at work in healthcare encounters at all levels and working to equalise these
Adopting comprehensive and holistic communication strategies
Developing good working relationships built on trust
Providing conflict resolution skills where necessary
Developing a culture of participation
Changing traditional professional and organisational cultures
Networking with community and voluntary groups
Respecting the service user's point of view

Concrete actions
Developing a clear statement of the respective roles of the actors involved in participation activities
Planning participation activities well in advance
Setting up an independent organisation to support and maintain patient participation initiatives
Agreeing clear aims and objectives
Adopting appropriate techniques depending on the situation
Displaying flexibility in the design of participation activities
Appropriately targeting service users/public
Delivering tangible results
Monitoring and evaluating agreed outcomes

Conclusion

The discussion paper identifies different levels of participation which have implications for individuals, health service providers and management throughout the health system in Ireland.

The paper serves as both a basis for discussion and a resource, directing the reader to helpful articles, books, websites and supports.

A common theme throughout the paper is the emphasis on process as much as outcome. Participation and partnership are not 'achieved' per se but are developed through time. By definition they are responsive processes and depend on engagement by individuals, community groups and health services staff and on their preferences, resources and abilities over time.

Irish initiatives on participation may well look to other existing structures – for example the 'quality in healthcare movement' in Ireland – with a view to sharing resources and expertise.

Explicit structures (legislative, administrative and educational) and co-ordinating centres were developed to support participation in the US, UK and Australia. The importance of such an approach is highlighted.

An important investigation remains – to identify the extent to which healthcare staff themselves recognise a need for change in the arena of patient participation, and to explore the needs of healthcare staff in a changing and more participative healthcare context. It is only by having staff fully participate in this process that the challenge of having them work as partners with patients and the public in a wider partnership can be achieved.

x

Chapter one

Introduction

Public and patient participation in healthcare has been on the Irish health system agenda for some time now. Pressures to provide more person-centred care and to involve patients and clients in decisions about their care led inevitably to more individualised forms of care. The health professional of the future will be expected to provide care in ways that respond to each individual patient's concerns, preferences and circumstances. Increasingly, the patient will come to have a greater voice in consultations with health professionals, which will reinforce the process of increasing individualised care. However, health professionals, like those in any 'people-processing' occupation, depend on the use of routine practices in history-taking, and on the use of investigative tests and treatments to manage the complexity of their responsibilities. The routinisation of health professional decision-making has been reinforced in recent years in both North America and Europe by external pressures in the direction of managed care. Here, clinical autonomy is controlled by protocols, guidelines and professional and external review. One can foresee substantial dilemmas for all health professionals as they attempt to meet the conflicting challenges of individually tailored services to meet patient or client needs while providing standardised services to meet professional norms of care in their clinical practice.

Public and patient participation in Ireland

The 1994 health strategy, *Shaping a Healthier Future* (Department of Health, 1994), challenged those providing health services to ensure that the views of patients/clients and of the wider public are taken into account in service planning and provision in Ireland. The 1994 strategy acknowledged that much work was required to achieve change in this area. Since then there has been significant growth in the use of patient indicators of service quality, for instance the use of patient satisfaction surveys. There has also been growth in the patient advocacy movement and in attempts to involve patients in establishing needs for services.

The new National Health Strategy, *Quality and Fairness: A Health System for You* (Department of Health and Children, 2001), set out a vision for how the health system should develop over the next decade in order to deliver high quality care for all service users. It was informed in the planning stages by a consultative process involving members of the public, support and advocacy groups, health boards and other health agencies, and staff at the Department of Health and Children. A number of basic principles underpin the strategy, including equity and fairness, quality of care, clear accountability and, most notably, a people-centred service.

The National Health Strategy has set out a series of actions for achieving increased involvement on a number of different levels in healthcare and has set time scales and responsible agents for these actions. It will be the responsibility of the named agents to set up and oversee the implementation of each of these actions. Table 1.1 outlines the national objective in relation to public and patient participation in healthcare. It clarifies the three levels of participation (from the individual through care management to the community), and describes actions and what it calls committed steps at each level.

Table 1.1: The National Health Strategy national goal No. 3: Responsive and appropriate care delivery.   Objective 1: The patient is at the centre in the delivery of care

Level of participation	Action	Committed steps
One-to-one	A national standardised approach to measurement of patient satisfaction will be introduced	• Agreed system published and implemented
	Best practice models of customer care including a statutory system of complaint handling will be introduced	• Customer care programme prepared and implemented in all boards • Legislation on statutory complaints procedure published
Care management	Individuals and families will be supported and encouraged to be involved in the management of their own healthcare	• Codes of practice for shared decision-making developed • Codes incorporated into professional training programmes • Training of existing staff
	An integrated approach to care planning will become a consistent feature of the system	• Training initiatives to promote inter-disciplinary working for existing staff delivered • Inter-disciplinary working incorporated into professional training programmes • Extension of key workers for older people and children with disabilities
Community involvement	Provision will be made for the participation of the community in decisions about the delivery of health and personal social services	• Public information/education campaign devised • Regional advisory panels/co-ordinating committees established • Establishment of consumer panels • Establishment of National Strategy Forum

This discussion paper aims to provide an overview of international thinking on public and patient participation activities in order to assist health managers to contextualise the proposals as set out in the National Health Strategy and to provide them with examples of good practice models from experiences elsewhere.

The context of health

Patient-centred care is first and foremost person-centred care. Moreover, participation in healthcare is underpinned by participation in health. While the main emphasis of this paper is on the interaction of individuals and collections of individuals with primary, secondary and tertiary healthcare systems it is useful briefly to examine the meaning of health and health services.

The World Health Organisation definition of health has been adopted to guide strategic policy development of health services in Ireland:

> a complete state of physical, mental and social well-being and not merely the absence of disease or infirmity; a resource for everyday life, not the objective of living; it is a positive concept emphasising social and physical resources as well as physical and mental capacity. (Department of Health and Children, 2001)

Defining health in this way allows for the broad context and meaning of health to be made explicit, it suggests an holistic approach and intimates that the attainment of health is a shared responsibility – shared by individuals, health professionals and the healthcare systems they work in, and governmental bodies.

Similarly the World Health Organisation takes a broad view of health services, as the following definition illustrates:

> Health service – any service which can contribute to improved health or the diagnosis, treatment and rehabilitation of sick people and not necessarily limited to medical or health care services. (World Health Organisation, 1998)

Consequently, those services aiming to support and maximise individual potential (for example home support, child and family services, disability services) come within the broad umbrella of health services. Health and social care together necessitate a multi-agency approach (O'Keefe and Hogg, 1999).

The discussion paper

The aim of the discussion paper is to inform and guide health managers in their efforts to promote a partnership approach between users and providers of the health services. The specific objectives are

- to identify models of best practice in public and patient/client partnership in healthcare from the international literature

- to summarise the current Irish situation concerning involvement in healthcare

- to identify principles of partnership to guide Irish service developments in the area.

This paper is organised to match these objectives and comprises: a review of international developments in public and patient/client participation in healthcare (Chapter 2); a review of participation initiatives abroad and in Ireland (Chapter 3); developing partnership in Ireland (Chapter 4); and conclusions (Chapter 5).

The terms patient, client and service user are adopted in the paper, reflecting the literature. Whatever the terms used, however, the focus is on participation and person-centred care.

Chapter two

A brief review of international perspectives

Forces promoting policy development in patient participation internationally

A number of influences have given rise to policies, both broad and specific, for patient involvement in health service development and evaluation in different countries. Amongst these are crisis interventions and inquiries (for example the inquiry into children's heart surgery at Bristol Royal Infirmary (Department of Health, 2001) and the Bovine Spongiform Encephalopathy (BSE) inquiry in the UK); reform and restructuring of health services (for example the purchaser provider split in the UK's National Health Service); a developing quality in healthcare movement; patient safety and complaints systems; and a growing sophistication on the part of patients/clients and their advocates. In more specific areas, such as health research itself, there is a growing impetus for the inclusion of participant and patient views in the design of research studies (Goodare and Lockwood, 1999).

This changing context of healthcare necessitates a view of the patient as an active participant rather than a passive recipient. Traditionally the patient/client has been viewed as an external entity. The most recent policy document from the NHS builds on the findings of the Bristol inquiry and identifies a crucial paradigm shift positioning the patient as an 'insider' in the health system.

> Our vision is to move away from an outdated system of patients being on the outside, towards a new model where the voices of patients, their carers and the public are heard through every level of the service, acting as a powerful lever for change and improvement. To give effect to this the patient must be at the centre of everything the NHS does (Department of Health, 2001)

The UK's most recent consultation exercise, *Shifting the balance of power: the next steps*, led to the development of its patient participation programme (Department of Health, 2002) and was firmly based on the recommendations of the comprehensive report, Learning from Bristol (Department of Health, 2001).

More generally, the 'quality in healthcare movement' has been steadily developing since the seminal paper by Donabedian (1988), which set out a model for describing the structure, process and outcome features of a quality health system. Also, the acknowledgement that health service provision is a complex process with a number of stakeholders highlights as centrally important the patient's own view of services. There are now international, European and Irish associations for quality in healthcare. Quality healthcare must take account of the outcomes which are important to people. Crucially, the very existence and publication of quality information assumes that the patient can and will exercise choice.

One model which explicitly links health and social context is the 'social model' developed through the physical disability movement (Oliver, 1996). This model focuses on enabling and empowering people with disabilities in order to facilitate their inclusion in all aspects of life.

The social model serves to focus on the person in the context of family, community and society. Participation frameworks informed by this model must focus on attitude and attitude change, access issues, formal and social support and responsiveness over time. Empowerment then is a product of both individual and societal change.

> The social model emphasises the re-casting of disability by disabled people and the importance of collective action. Calls are made for the individual and collective responsibility of all societal members to dismantle disablement and promote a socially aware, active and inclusive action (Chappell, 2001).

This context for disability and health has been adopted by the World Health Organisation in its classification system. A component of the International Classifications of Diseases and Related Health Problems (ICD-10) is 'The International Classification of Functioning, Disability and Health' (ICF). This system makes classifications from body, individual and societal perspectives and also includes environmental factors which impact on a person's experience of health.

Highlighting a social context for participation at this early stage of discussion is valuable in that it focuses attention on the attitudinal and social changes necessary to promote increased patient involvement, participation and empowerment. The views of individual citizens and of health service staff lie at the centre of participation and partnership. It would be naïve not to acknowledge the extent of paradigm shift necessary to achieve full participation.

> Partnerships require the medical profession to relinquish some of its independence and users some of their dependence. That is not an easy matter for either (Winkler, 1987).

Models such as the social model serve to emphasise the educational content of partnership, but also highlight partnership as a process occurring over time. Examples relating to disabilities or to chronic illness where relationships are built up over time, where multiple disciplines and carers may be involved, are particularly pertinent to understanding the time dimension. An example detailing integrated holistic support for children with physical disability will be described later.

The National Health Strategy reinforces the ideas outlined above.

> This Strategy is centred on a whole-system approach to tackling health in Ireland. It goes beyond the traditional concept of 'health services'. It is about developing a system in which best health and social well-being are valued and supported. At its widest limits this system does not just include the services provided under the auspices of the Minister for Health and Children. It includes both public and private providers of health services. It includes every person and institution with an influence on or a role to play in the health of individuals, groups, communities and society at large.
> (Department of Health and Children, 2001)

Developing policy for patient participation – what issues need to be taken into account?
From a policy perspective, the objectives and scope of participation need to be clearly defined. For example, policy documents such as the most recent strategic documents from the NHS (Department of Health, 2000; Department of Health, 2001) have distinguished between participation at the individual   level and participation at the 'citizen' level.   While the two are not necessarily discrete, their separation and definition are important at a policy level.   The implications for healthcare staff, for patients and clients themselves and for organisational and legislative structures need to be mapped out and may well vary from the individual to the community context.

The concepts of partnership, patient participation and empowerment are employed with the objectives of increasing informed decision-making and patient/client choice.   However, there may be unintended consequences of policies arising from these objectives, for example reduced uptake of immunisation programmes through the exercising of parental choice. The extent to which policy-makers anticipate and allow the consequences of participation needs to be considered at an early stage. The boundaries may need to be explicitly defined and the limits (if any) of participation clarified.

Partnership is dynamic.   Person-centredness should allow the full range of individual patient choice – including variation in an individual's preference at different points in time. In particular, the view of communication as a process (not a once-off event) taking place in a socio-political climate needs to be considered.   Failure to communicate was identified as a key problem in the Bristol children's heart surgery inquiry.   The report of the inquiry underlined the importance of including information and communication issues in policies aiming to enhance involvement.

> There are four fundamental principles which should in future underpin any policy aimed at meeting patients' needs for information.   First, trust can only be sustained by openness. Secondly, openness means that information be given freely, honestly and regularly. Thirdly, it is of fundamental importance to be honest about the twin concerns of risk and uncertainty.   Lastly, informing patients, and in the case of young children, their parents, must be regarded as a process and not a once-off event.
> (Department of Health, 2001)

Information *per se* does not necessarily foster participation. The Consumer Focus Collaboration in Australia uses the term 'purposeful reporting' to describe the process of information-gathering and feedback which should underpin true reporting to consumers (Consumer Focus Collaboration, 2001).   Some reviews have shown that the available information (for example UK league tables on hospital performance) is not always actually used by consumers (Shaw, 1997).   Consequently, purposeful reporting espouses a change in the systems for information preparation and feedback to consumers.   Six principles were identified in the Consumer Focus Collaboration and these reiterate the importance of process issues – effective information-sharing occurs over time:

- reporting on the quality of health services to consumers values open, honest and transparent dialogue between consumers and providers

- health agencies have a duty to comment on, interpret and share information on the quality of care with consumers and the wider community

- consumers need to be informed as to what they can expect of individual health agencies and the healthcare system

- the contribution of consumers to defining the measurement of quality is essential to improving the quality of health services

- consumers are entitled to information about how health resources are being allocated and whether the health system is delivering equitable outcomes

- reports to consumers on the quality of health services should integrate definitions of quality of value to consumers as well as those of value to providers.

Broadly, the principles which should guide policy development about participation were identified in the Bristol inquiry and are illustrated in table 2.1 .

Table 2.1 : Principles to guide policy development for patient participation (Learning from Bristol, 2001)

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

Public and patient partnership – what is it?

Public and patient partnership is viewed by Stuart (1999) as consisting of four main themes:

promoting patients' participation in their own care as active partners with professionals

enabling patients to become informed about their treatment and care and to make informed decisions and choices about it if they wish

involving patients and carers in improving service quality

involving the public as citizens in health and health service decision-making processes.

Consulting patients – how is it done?

The literature on patient/client partnership focuses on a range of aspects, including individual medical encounters or the doctor-patient relationship; patient satisfaction; shared decision-making, community participation and strategies for public participation in policy-making.

The focus of this discussion paper is on shared decision-making, community participation and participation in policy-making. The notion of patient satisfaction is considered briefly. It is often seen as a first step towards understanding the perspective of service users, but has limitations in a partnership approach to care per se.

Patient satisfaction

Hardy and West (1996) used the following definition of patient satisfaction '…patients' reactions to salient aspects of the context and process and results of their experience'. Many health service professionals and managers rely on patient satisfaction surveys as the only means of fostering patient involvement in the evaluation and ongoing development of their services. However, there are limitations to a patient satisfaction approach. Patients may be reluctant to criticise their healthcare, at least in part because they risk appearing ungrateful or unappreciative (Fitzpatrick and Hopkins, 1983), the construct is noted to be related to age and to illness and can demonstrate positive bias. Moreover, patient satisfaction as typically measured is essentially a passive concept, it acknowledges the legitimacy of a person's views on the process and outcomes of care, but says little about their role in decision-making and more proactive models of involvement.

Despite such limitations, patient satisfaction evaluation can be a major first step to take within healthcare systems unused to sharing decisions with patients and clients. It can also be a useful component of a wider consultation system on quality of care as part of a partnership approach (McGee, 1998) and as a mechanism to evaluate change.

Shared decision-making and patient-centred care

The traditional model in healthcare has assumed that professionals and patients share the same goals; that only the professional is sufficiently informed and experienced to decide what should

be done; and that a patient's involvement is limited to giving or withholding consent to treatment.   However, many studies now show that patients want an active role in decisions about their treatment (for example   McGee, 1993; Ruhnke, Wilson, Akamatsu et al, 2000; Bubela, Galloway and McCay, 1990).

There is thus an increasing impetus for shared decision-making and person-centred care. Person-centred care has become a central concept in healthcare as a response to

• a general trend towards increasing attention to customer needs

• the rapidly increasing cost of healthcare and the imperative for effectiveness

• the shift in focus to the improvement of processes and outcomes of care (Al-Assaf, 1993; Lehr and Strosberg, 1991)

• increased access of patients to information about healthcare treatments and options (Lutz and Bowers, 2000).

The dynamic of person-centred care may be seen in two ways: firstly person-centred care may be seen as relating to the reorganisation of healthcare delivery and secondly it may be seen as recognising individual needs (Lutz and Bowers, 2000).   From the reorganisation of service delivery perspective, patient/client needs are assumed to be understood by the healthcare system and healthcare providers. Consequently discussion centres on how services are organised for and delivered to patients.   From the perspective of focusing on understanding individual needs, a one-to-one dialogue between professional and patient on priorities, preferences and expectations for healthcare is required (Fraser, 1995; Gerteis, Edgman-Levitan, Daley and Delbanco, 1993a; Laine and Davidoff, 1996; Miller, 1997; Preston, 1994).   The best way of measuring person-centredness may be from an assessment made by the person himself or herself.   One study of preferences from a person-centred approach to consultation found that the key preferences were for care that

• explores the person's main reason for attending, their concerns and need for information

• seeks an integrated understanding of the person's world – their whole person, emotional needs and life issues

• finds common ground on what the problem is and mutually agrees on management

• enhances prevention and health promotion

• enhances the continuing relationship between the patient and the doctor. (Little et al, 2001)

'Personal Outcome Measures' is a system of accreditation designed to ensure person-centred care and individual involvement in all aspects of service provision. This system originates in the United States but has been adopted by a number of organisations working with people with learning disabilities in Ireland (See Table 3.1).

'Person-centred care' as defined here refers to the interaction between the individual patient/client and relevant health professionals. Moving from this individual perspective, there is the wider issue of the partnership between professionals and policy makers in the health system and the general public.

Public or community participation in health care

The concept of public or community involvement emphasises the value of citizens' knowledge and practices. It comprehends the active participation of local populations in service delivery and organisation. It also emphasises the need for health education and community organisation to empower communities to handle their responsibilities (Jewkes and Murcott 1998; Midgley, 1986). The community health movement arose mainly in developing countries and was promoted by professional community health organisers, often from developed countries, as a means of mobilising indigenous human resources and knowledge necessary to implement effective primary healthcare programmes on limited budgets (Zakus, 1998). When the community health movement was introduced in Western societies, the concerns with mobilising individual and community resources and implementing primary healthcare transformed themselves into the promotion of lifestyle changes, self-help, and health advocacy. The movement's experience with healthcare planning was applied to the rationalisation of increasingly costly Western healthcare systems (Rose, 1990; Watt and Rodmell, 1988).

Public or community involvement in determining the healthcare provision available to all is a generally agreed but difficult to deliver aspiration. Because certain groups in society are more likely than others to have their agendas prevail, the view of community participation as the democratic expression of the 'public will' is an overly abstract view that cannot capture the diversity of participants and the differences in participation across professionals and the public in many real world situations. For instance, a major effort to adopt a rational and democratic approach to allocating scarce health resources on a state level in Oregon, USA, during the late 1980s and early 1990s did not succeed (US Congress, 1992). The project involved wide consultation to determine a set of state-funded health services for all. While the process was rational and consultative, the outcome made clear that certain types of treatment would not be available free to state inhabitants. Many felt uncomfortable about the prospect of denying specific individuals a right to funded services. In addition, groups representing older and disabled people felt the health priority listings would disadvantage their constituencies. After much developmental work the scheme was abandoned. The project highlights the challenges inherent in developing partnerships and reveals the multiple constituencies who will have a stake in decisions taken concerning health matters.

One author has succinctly outlined the difficulties inherent in inviting public participation in health system planning:

> …consumer or community participation has been invited, if not invented by those very administrators who are now central to the system. This means that insiders determine the rules and structures through which outsiders can approach the decision-making arenas, as well as the resources to which they have access, once there.
> (White, 2000)

Models for participation

There is a diversity of approaches to partnership and patient participation and different conceptual models have been devised. Most have focused on the extent of public or patient control over decision-making. However, there are other models based on factors such as consumerism, domains of action, change strategies, decision-making and healthcare tasks to facilitate analysis. Some key models in the literature are summarised in table 2.2. The models do not share a single theoretical framework and their application or relevance depend to a large extent on the challenges of the situation, the context in which participation is being considered.

Table 2.2: Summary of published models of public and patient participation in healthcare

Model	Focus
1) Eight-rung ladder of participation (Arnstein, 1969)	Hierarchy of participation from patient satisfaction participation (low level) through partnership (middle level) to user control (high level)
2) Consumerism and empowerment (Webster, 1995)	Focus on who is the 'consumer' of the healthcare system, with cautions that (in the NHS) the consumers are still health professionals and administrators with little empowerment for patients or the public
3) Three-dimensional framework (Charles and De Maio, 1992)	Focus on level of user control; domain of action (treatment, planning or policy) and role perspectives (representing particular sub-groups or broader public good)
4) Competing models of involvement (Beresford, 1997)	Two types of involvement – 'consumerist' (service centred – consumer encouraged to provide feedback and ideas but organisation ultimately decides if or how information is used) and 'democratic' (power shifted from organisation to consumer so s/he is directly empowered and involved in decision-making and planning)

Model cont'd	Focus cont'd
5) Hierarchy of change strategies (Torre, 1986)	A continuum of change strategies from the 'micro' level (individuals can increase their own sense of control with no organisational change) through the 'macro level' (where structural or organisational change takes place because of collective 'political' power)
6) Models of decision-making (Charles, Whelan and Gafni, 1999)	Focus on treatment decision-making at different levels: information exchange (how, direction, type and amount); deliberation or discussion of treatment preferences; and deciding on treatment implementation (paternalistic, informed and shared models are outlined)
7) Consumer models of participation (Reiser, 1993)	Models of participation – consumer as consultant, instructor, assessor, or competent partner. These are considered concerning clinical practice, education, research and policy-making tasks.
8) Framework for evaluation of consumer participation strategies (Garavan, Winder and McGee, 2001)	Combination of model 4 (Beresford, 1997) and model 5 (Torre, 1986). Four change categories outlined – consumerist and democratic models by individual or group levels (see table 2.3)

The framework outlined by Garavan et al (2001) is proposed as an appropriate working model in considering participation activities in the Irish health setting.   The model is outlined in table 2.3.

Table 2.3: Framework for evaluating consumer participation strategies (Garavan et al, 2001)

	Consumerist Model	Democratic Model
Individual level	Dissemination of information Establishment of 'complaints' procedures Consumer surveys	Involving patients in their own care Consumer-purchaser schemes
Group level	Focus groups Active 'work' groups Patient participation groups	Inclusion of consumers on boards Citizen's juries Supporting user and advocacy groups Partnerships/stakeholder conferences

The least participative model in this framework is the individual level, consumerist model.   It assumes that patients are assertive and confident on the one hand, and depicts an organisation where participation is nominal at best on the other.   Strategies that can be viewed as working at the individual level are often entirely devised and directed by the organisation.   Patients take part at the behest of the organisation – their own motives for participation are unclear and likely to be varied.   They have neither individual nor collective control over the information provided or obtained by the organisation.

Democratic models are the most participative ones in the framework.   These involve the organisation yielding some of its power to patients so that they are more directly involved in their own care either on a one-to-one basis or at group or community level. Garavan et al (2001) point out that what is typically conceived of as active participation may not necessarily be the preference for all people in all circumstances.   For example, many people prefer a directed style of consultation with health professionals.   This has been shown in general practitioner interactions (McKinstry, 2000) and was more evident in older people (aged over 60 in McKinstry's study) than younger people.   There is, however, an important distinction to be made between a directed style of consultation which is pre-determined by the health professional and one which is the preference of the individual person, having been offered a choice, in a particular health setting.

Public participation in other sectors

Much of the literature on patient or service-user involvement in healthcare focuses on the interface with medical practitioners.   Little information is available concerning other health professional or policy-maker roles.   One exception to this is a study of participation in occupational therapy (Finlay, 1997).   Participatory approaches to planning and decision-making are evident in other public service sectors such as education (Webster, 1997), community development (Riseborough, 1997) and social work (Littell, 2001).

Methods of assessment

A range of methods is available to facilitate participatory initiatives in healthcare.   However, there are several issues to consider before selecting a method.   The level of interaction desired can influence the choice of method.   In addition, there are practical considerations to take into account.   For example, the availability of resources can often restrict the options available. Factors affecting cost include

•   the number and type of initiatives selected

•   costs of administration and support

- whether existing personnel, records and facilities can be used

- incentive fees and additional expenses (e.g. childcare).

Time is another major factor in success.   There are no exact specifications on how long an initiative can take.   Common problems that can occur with time include

- holding meetings at unsuitable times (for example during the working day or at holiday time)

- getting health professionals to attend meetings

- not allowing time for unforeseen events.

With these considerations in mind, nine methods are summarised in table 2.4.   The appropriate level of interaction, and advantages and disadvantages for each method are also provided.

Table 2.4: Public and patient participation in healthcare – major methods of promoting partnership

Method	Level of partnership	Advantages	Disadvantages
Postal questionnaires	One-to-one – useful for assessing service delivery Policy – useful for consultation on service changes	• Inexpensive • Accesses large numbers • Accesses those with mobility problems • Systematic • Allows for benchmarking • Widely used and recognised as social research tool	• Often low response rate • Self-selection (only those who wish to respond will do so and these may have extreme views) • Difficult for those with special needs • Some people resent receiving questionnaires • Need to allow time for completion • Predetermined questions
Focus groups	One-to-one – useful to share experiences of clinical encounters Case management – evaluation throughout the care process Policy-level – to assess acceptability of current or proposed policies	• Quite cost-effective • Can be used to consult discrete sections of the community • Useful for consulting specific target groups • Allows complex issues to be tackled • Possible to find out what is important to people • Groups allow ideas to be shared • Is not dependent on literacy	Small samples limit applicability of results • care is needed in analysis and interpretation • experienced facilitator required • Some participants may dominate the group • Group views can tend to the norm • Difficult to prioritise issues identified • Difficulties with confidentiality may prevent people from speaking out

Method	Level of partnership	Advantages	Disadvantages
Citizen panels	Case Management Policy	• Combines formal research methods with participatory approach • Provides representative sample of local residents and a cross-section of local population • Can be repeated to tackle different issues and/or track changes over time • Response rates tend to be higher than surveys • Feedback possible relatively quickly • Creates a continuing dialogue with participants • Provides a research resource that can be shared between local organisations • Special needs can be accommodated	• Setting up a panel can be time-consuming • Requires research skills; if badly sampled, can be unreliable • Not suitable for consultation about services used by small numbers of people • Requires language and literacy skills • Does not involve people actively in decision-making • Panel members can become too closely linked to the authority, losing objectivity and ceasing to be representative of the local population
Deliberative techniques	Policy	• Allows representation of a diverse range of views • Allows complex issues to be tackled • Develops an understanding of the issues • Allows prioritisation • Empowers communities • Involves citizens in considering policy and strategic decisions • Generates commitment and ownership of healthcare issues among participants	• Limited number of participants, therefore not representative • Less useful for taking decisions than contributing to the decision-making process • Less useful for day-to-day operations

Method	Level of partnership	Advantages	Disadvantages
Citizen juries	Policy	• Offers people an active role in the process • Helps to find out what people think at the same time as involving them in decision-making • Aids openness and accountability in decision-making • Outcomes are hard to ignore • Allows time to pursue issues in depth	• Requires time and effort from jurors. Can be expensive • Jurors need to know their views will count • Results are not binding • Jury process often meets with opposition from politicians and local media; accusations that juries are a waste of money • Organisations need to have made substantial progress in partnership before initiating juries • Expertise required to run juries • May be influenced by personal agendas
Health panels	Policy	• Enables people to reflect on an issue before indicating a position • Useful when discussing a matter not encountered before	• High level of advance briefing required • Small numbers mean it is not representative • More expensive than an ordinary focus group, but less expensive than a citizen jury
'Planning for real'	Community Policy	• Useful for planning and spending issues • Stimulating for participants • Can deal with complex issues	• Difficult to ensure that attendees represent the whole community • Highly structured approach • Expensive to set up initially

Method	Level of partnership	Advantages	Disadvantages
Simulations	One-to-One Case Management Community Policy	N/a	N/a
Community development	One-to-one Case Management Community Policy	• Empowers and informs participants • Promotes access to information and resources • Explicitly focuses on reducing inequalities • Starts from the perspective of the community • Assists collaboration between sectors and brings the local community and public, private and voluntary sectors together	• Many be difficult for health professionals to embrace the concept • Many problems cannot be solved within local communities • Requires skills that need to be developed • Requires significant resources • Difficult to involve hard-to-reach groups • Tensions may arise within communities when dealing with an emotive issue

Conclusion

Public participation is sometimes understood as being an end in itself, primarily concerned with democratic processes and empowerment, and sometimes as a means to substantive results in healthcare delivery. The issue of representation and of how the category of 'participant' is defined can cause tension. Public participants are seen by some to represent some amorphous, undifferentiated 'public' or aggregation of individuals, and by others to represent a collective, community or constituency of lay interests.

Chapter three

A brief review of international and Irish activities

The United States of America

Participation in healthcare has a long history in the USA. In the 1960s there was a focus on developing information and consent procedures for those members of the public and patients involved in medical research. In the 1970s, patient 'bills of rights' were issued in hospitals, describing hospitalised patient entitlements to information and actions. The 1980s witnessed many court cases, affirming the authority of patients or families acting on their behalf to decide issues of medical treatment. These events laid the foundation for patient rights and responsibilities in the United States. The 1980s also saw increasing concerns over variations in the provision of treatments by physicians. This, combined with concerns about the growing costs of healthcare, led to the development of the health outcomes movement. This movement's perspective was that the patient's view of events was pivotal. Interest in the patient perspective persisted through the 1990s (Johnston Roberts, 1999). As the healthcare environment became more competitive, healthcare corporations increasingly tried to attract and retain patients. These corporations regularly evaluated patient satisfaction and related outcomes. Patient responsibility in healthcare was also emphasised during the 1990s. For example, individuals were encouraged both by government agencies and health insurance companies to take care of themselves.

Among the US activities on participation is the input by the university sector. One such example is outlined as a case study.

> ### Case study: the Centre for Patient Partnerships at the University of Wisconsin
>
> The Centre for Patient Partnerships was officially launched in June, 2001, in response to calls for improved quality in healthcare. A report published by the Institute of Medicine (Kohn, Corrigan and Donaldson, 2000) had called for major changes in the healthcare system to improve quality of care and reduce errors. The report focused on 'system design' problems which rendered the system impenetrable for patients and a frustration and challenge to healthcare providers interested in giving the highest quality, patient-centred care.
>
> The Centre has three main functions (2001):
>
> - education – teaching future and current professionals in law, medicine, nursing, pharmacy, social work and related disciplines about patient-centred care
>
> - applied research – assembling a national resource of research information, supporting a network of faculty which conducts applied research, developing information on patient perspectives for research purposes, and disseminating research knowledge about patient centred care models and practices
>
> - public service – supporting better healthcare for patients through service learning in patient-centred care, application of research knowledge and other public service.

> Although the Centre provides information and services intended to empower patients to make decisions about their own care, in partnership with providers, and to get the care they need, it does not litigate on behalf of patients.   Where legal services are required, patients are directed to appropriate professionals by the Centre.   In addition, it does not advocate that patients be the only deciders concerning healthcare.   The goal is to promote well-informed decisions in partnerships with providers, rather than patients unilaterally dictating their own care and financial coverage.
>
> http://www.law.wisc.edu/patientadvocacy/

Australia

Consumer participation is increasingly seen as linked to improvements in the quality of healthcare and improved health outcomes, and as a result is being encouraged by commonwealth, state and territory governments.   The Australian Health Strategy of 1993 identified the major benefit of increasing patient and public participation in health service as follows:

> ….by setting up a framework that lets people have a say in their healthcare decisions, the health system will provide more appropriate care to people, and to communities, particularly for people who are disadvantaged by current arrangements.   This can assist in improving the health of all Australians.
> (National Health Strategy Background Paper, 1993)

A range of formalised organisations, supported by the commonwealth, has since been developed to elaborate on the concepts of patient and public participation.   These include the Consumer Focus Collaboration (see Chapter 3), a multi-faceted organisation which aims to promote a consumer-focused health system. The Collaboration is a national body with representatives from consumer, professional and private sector organisations and all health departments.

In 1995 a study on quality in Australian healthcare (Wilson, Runciman and Gibberd et al) identified a significant level of adverse events in the acute health sector.   In response, the health ministers established the Task Force on Quality in Australian Healthcare.   A recommendation from the Task Force report (1996) was that healthcare processes and systems be redesigned to ensure a strong focus on consumers.   Following the Task Force report two groups were formed in 1997 – the National Expert Advisory Group on Safety and Quality in Australian Healthcare and the Consumer Focus Collaboration.   The Advisory Group made recommendations about safety and quality matters that would benefit from national co-ordination (1999).   The primary area recommended for national action was increased support for consumer participation in healthcare.

Draper and Hill (1996) recommended that a national centre be established with the objective of supporting health services in involving consumers at different levels in the health services as a key element in improving the quality and effectiveness of health services. A later report (Draper, 1997) identified many worthwhile projects being undertaken by hospitals in the area of consumer feedback and participation, but noted that most of the activity was at the level of consumers providing feedback rather than health professionals working with consumers as active participants. This study indicated that health professionals needed to become aware of the broader range of methods of developing 'working partnerships' with consumers and that hospitals needed to develop overall consumer participation strategies, rather than engaging in a procession of ad hoc projects. In this context the Commonwealth Department of Health and Aged Care provided funding to establish a resource centre as part of the Acute Health Reform Program.

Case Study: The National Resource Centre for Consumer Participation in Health

The Consumer Focus Collaboration was established under the umbrella of the National Expert Advisory Group. The membership of the Collaboration was made up of professional and consumer organisations, and Commonwealth, State and Territory Health Departments. The Collaboration was established to develop strategic alliances and projects that would promote the development of a more consumer-focused healthcare system. As part of its remit, the Collaboration supported an initiative to set up a National Resource Centre for Consumer Participation in Health (otherwise known as the National Resource Centre), funded by the Commonwealth Department of Health and Aged Care with endorsement by the Australian Health Ministers' Advisory Council.

The aim of the National Resource Centre for Consumer Participation in Health was to provide information about, and expertise in, methods and models of community and consumer feedback and participation.

The key objectives include

- increasing the access of health service managers and providers, consumers, community based organisations/groups, researchers and policy-makers to quality information about methods and models for community and consumer feedback and participation through a national clearing house

- enhancing the capacity of the organisations/departments/groups to integrate community and consumer feedback participation into strategic, service and facilities planning, policy development, service delivery and care processes, and review and evaluation of care and services

- contributing to research and evaluation of specific methods or models of community and consumer feedback and participation in health.

The National Resource Centre has two closely related functions:

- a Clearing house for information about methods and models of community and consumer feedback and participation and associated concepts

- a Centre of Excellence in consumer participation where clients can seek advice and assistance to develop, implement and evaluate feedback and participation methods and models.

The Centre also

- critically analyses the various methods and models of consumer participation

- promotes the benefits of community and consumer feedback and participation

- undertakes special projects

- provides advice and information about various methods and models of community and consumer feedback and participation

- publishes resource materials from projects of the Centre.

http://www.latrobe.edu.au/nrccph/

Northern Europe

The issue of choice has become increasingly important in healthcare reform across Northern Europe. The proper role for patients and clients vis-à-vis physicians and other professional providers on the one hand, and health sector administrators and managers on the other, is under increasing scrutiny in publicly operated health systems in the Nordic countries. This search for a new role for patients reflects the current period of what Saltman (1994) has termed 'paradigm flux' that affects health service delivery in many industrialised countries. Due to pressures exerted by an increasingly ageing population, complex technology, and economic considerations, health system managers in Europe have been forced to re-evaluate their systems' internal capacity to produce health services more efficiently and effectively. Pressures generated by social and economic change now require a much higher level of person involvement in the day-to-day behaviour of health professionals and health managers.

Saltman has drawn up a typology of patient empowerment with reference to different countries in Northern Europe. Starting with patient advice and appeals, the typology moves from the least to the most empowered priorities for the individual patient. This continuum is characterised by the change from moral 'suasion' (or the ability only to ask to be heard),

through formal political control (or the ability to select key health-related officials) to countervailing power (the ability to control one's organisational destiny).

Case Study: Patient Partnerships at Haukeland University Hospital, Norway (Enehaug, 2000)

Haukeland University Hospital is located in Bergen, Norway. The hospital has 1,050 beds and a patient hotel of about 150 beds.   A total of 54,000 in-patients and 230,000 out-patients are treated each year.   The total staff is almost 6,000 people with about 620 physicians and a nursing staff of 2,100.

The main tasks of Haukeland University Hospital are patient care, teaching and research.   There is a close co-operation with the University and the colleges of Bergen.   Haukeland University Hospital has chosen total quality management (TQM) as the leadership philosophy.   Through an extensive evaluation of six Norwegian hospitals, Øvretveit and Aslaksen (1999) give recommendations for TQM work in this area.   One of the eleven recommendations is to '…engage people to use and develop their potential, and awaken the hope that we can make things better'.   If this means all people in the organisation, it must therefore include patients and their relatives.   A patient/relative panel at Haukeland University Hospital has been set up as an arena to support dialogue between partners in healthcare and is grounded on a philosophy of equality and solidarity in order to create mutual trust and understanding between the partners in healthcare.

The patient/relative panel was founded in April 1997 as a result of quality initiatives at the hospital.   The panel is composed of seven people, with a minimum of two being either patients or relatives.   The members of the panel have a two-year term of office.   Meetings are held six times a year.   Close co-operation among health professionals, patients and relatives means that each group is given the opportunity to create new roles and to learn from the others.   Patient participation also requires a change in the role of the patient, from that of recipient to that of partner, and this may be difficult or even intimidating.   The patient/relative panel represents an opportunity of meeting over time, enhancing trust and confidence.   In contrast to a focus group, the members are part of the panel for a minimum of two years.   The panel is also used to evaluate written information at the hospital. The panel is '…a living example of including patients in the processes of planning, learning and decision-making (Enehaug, 2000).

(Website only available in Norwegian)

The Haukeland type of partnership requires a mature organisation which heeds the knowledge of consumers.   Some of the patient/relative panel's most difficult experiences relate to an inability of the system to use the feedback from the panel constructively.   The panel depends on the permission of the wider health system for it's continued existence, and this is its greatest weakness.   If the panel becomes too demanding it may be removed – if it is too accommodating it may become the 'hostage' of the hospital regarding consumer involvement.

The United Kingdom

The UK health system functions as a four-country system (England, Wales, Scotland and Northern Ireland) with separate development of strategy documents.

England

Partnership and the increased involvement of patients have been goals of the UK NHS for a number of years. The Patient's Charter of 1990 identified the standards of care patients could expect and demand from their health service.

The Health Information Service was set up in 1993 and provided information about local services, standards and particular medical conditions.   Although these initiatives highlighted the importance of transparency in the provision of services, the extent to which they provided a system for patient involvement was limited.   In July 2000 *The NHS Plan: a plan for investment, a plan for reform*[1] was launched with the primary aim of providing 'a health service designed around the patient'.   This document acknowledged the disempowered status of patients and, to some extent, the failure of what went before (Department of Health, 2000).   In summary, the plan announced :

> For the first time patients will have a real say in the NHS.   They will have new powers and more influence over the way the NHS work.

The launch of the NHS Plan was followed by a number of consultation exercises and discussion documents and by the development of strategic plans.   Several documents describe these processes and their outcomes: Extending choice for patients (Department of Health 2001); Involving patients and the public in healthcare (Department of Health 2001); and Shifting the balance of power (Department of Health, 2002). The Plan set a context for a ten-year period. The major implication of the NHS plan was the devolution of power to the 'coal face' of the health service and to patients and the public.   Consequently plans to reinforce public participation were to be developed relative to structural, cultural and managerial change in the NHS.   The NHS policy for involving patients in healthcare acknowledged the need to directly support patients who require information or assistance for their immediate healthcare, as well as the need to support and encourage citizen participation in the broader planning and provision of healthcare.   Proposals for developing participation were published in a discussion document (Department of Health, 2001)[2].   Comments from the general public and from specific hard-to-reach population groups were sought and their views were incorporated to the final document, *Involving patients and the public in healthcare: response to the listening exercise.*

The partners referred to in the NHS framework for partnership consisted of three groups – patients and the public, NHS staff and elected representatives.   Six criteria were to guide the development and evaluation of the patient participation strategy – effective, accessible,

[1] See http://www.nhs.uk/national plan/
[2] http://www.doh.gov.uk/involving patients

accountable, integrated, independent, and adaptable arrangements. The arrangements for participation were described at local, strategic and national level. Consideration was given to the support (for example training, resources) necessary to develop the structures and to the necessary legislative changes – for example empowering local authorities to set up Overview and Scrutiny Committees with powers to inspect NHS services, imposing a duty on the NHS to involve patients in planning and to make independent advocacy services available to people wishing to make a complaint against the NHS. Similarly the mechanisms for support and participation (for example the Patients' Forum) were both statutory and embedded in the NHS local and national structure.

Scotland

Our National Health: plan for action, plan for change[3] (Scottish Executive Health Department, 2000) devoted a specific section to involving patients, with the following goals: 'Give patients a stronger voice'; 'Involve people and communities in the design and delivery of health services'.

Our National Health also made the distinction between individual patient involvement and public involvement. However the strategy document was very much the beginning of a process. While initiatives and aspirations were detailed, there was no overarching framework to nurture and support patient and public participation. For example, initiatives are detailed in relative isolation from each other and there is a large emphasis on communication and information processes, funding is dedicated to train healthcare staff to promote and accept participation, patient information across Scotland will be audited and patient-held record/smart card initiatives will be piloted. While the local health council structures already operational in Scotland are to be preserved (unlike their counterparts in England and Wales), little attention has been paid to the resource and training needs which may underlie an increase in patient and public participation.

Wales

The title of the current health strategy for Wales reflects patient involvement as an ideology – *Improving Health in Wales: a plan for the NHS with its partners* (NHS Wales, 2001). The Welsh plan acknowledges the need for management changes in the NHS if patient involvement is to be achieved. The thrust of the plan is to develop a transparency around the extent to which patients and the public are involved in decisions and policies which affect their care. Trusts are now obliged to conduct a baseline assessment of patient participation and to go on to develop patient participation strategies and annual reviews of the mechanisms employed and the outcomes achieved. The distinction between individual and collective participation is upheld in this document.

A comprehensive supporting guideline, *Signposts*[4] (NHS Wales, 2001), followed the publication of the health strategy. This resource document provides support information to those who may be implementing participation programmes for the first time: it outlines a framework for

[3] http://www.scotland.gov.uk/library3/health/onh-00.asp
[4] http://www.wales.gov.uk/signposts

participation, makes distinctions between process and outcomes, identifies components of a strategy and provides examples of participation schemes in operation throughout Wales. The success of the Welsh approach to fostering patient participation places a high priority on audit and accountability. In many ways, however, it is not as systemic as the model described for England.

Northern Ireland

Northern Ireland's health service is a part of the NHS and the Department of Health, Social Services and Public Safety has responsibility for both health and social care.[5]

The most recent strategic plan governing policy development for health is *Investing for Health*, published in 2002. This document outlines the goals and targets for health services over the coming years. There is an explicit acknowledgement of the need for increased partnership and participation in order to implement the strategy over time. Health promotion activities in different settings – including schools, hospitals and workplaces – are emphasised. There are chapters on 'Working with communities' and 'Progress through partnership'. Individuals' responsibility for their own health forms the ideological basis for increasing participation in health issues.

Links with individuals and their representative community groups are illustrated in the document and the community development model has informed some of the initiatives to date. The need for training and supports in order to maximise community groups' capacity to act as equal partners is identified and a grant fund has been established for community-led initiatives addressing health and well-being issues.

Partnership is explored in all its manifestations – regional and local, statutory and voluntary. The *Investing for Health* strategy ring-fences funding for the development of existing partnerships and the formation of new alliances.

Restructuring the NHS

The structural changes to the NHS during the 1990s saw the service taking on a purchaser-provider split, whereby health authorities purchased healthcare on behalf of patients from the direct providers (hospitals or trusts). This structural change resulted in increased consultation with patients about the quality of health service they received and the shortcomings they perceived. It was in this market economy that the term 'consumer' entered the language of health services. The current strategic plan for NHS development in the first decade of the new millennium has developed its model by decentralising or 'shifting the balance of power' to the local purchasing authorities or 'Strategic Authorities'. These authorities are obliged to consider patient comment in their healthcare planning: *'patients' views on local health services will help decide how much cash they get'*. Patient participation in the process is underpinned by an elaborate system of local and national structures. New legislation under the Health and Social

Care Act (2001) requires the provision of independent advocacy services in the health and social services, and legislation also provides for the setting up of Patient Forums in each hospital trust and primary care trust in the UK. Individual patient requirements for help or desire to give feedback will be facilitated by Patient Advice and Liaison Services (PALS) within each health trust; complaints will be facilitated through local Independent Complaints Advocacy Services (ICAS). Local structures designed to integrate patient involvement into the health service are supported through the National Commission for Patient and Public Involvement in Health which sets standards and provides training. The Commission itself consists of the local networks and a national body with a remit to support and facilitate effective public and patient partnership.

Ireland

A distinct participation perspective was put in place in Ireland with the launch of the Department of Health and Children's policy document, *Quality and Fairness: A Health Service for You*, in November 2001. Overall, the healthcare system has undergone a significant shift towards a more holistic and integrated approach since the establishment of the Department of Health in 1947. The emphasis on the curative and regulatory aspects of the health services and on the need to develop the acute hospital sector in particular, remained the defining characteristic of health policy in the decade following the passing of the 1947 Act. The period from 1970 to the mid-1980s was marked by a consistent development of services in accordance with the policy commitments in the 1966 White Paper, *The health services and their further development.* The National Health Strategy, *Shaping a Healthier Future* (Department of Health, 1994), signalled a significant change in direction, with its emphasis on the achievement and measurement of 'health gain and social gain' and its commitment to organise and manage the system 'as an integrated whole'. (Department of Health, 1994). It also saw patients as partners in this process although mechanisms to achieve this were not outlined.

The new National Health Strategy, *Quality and Fairness: A Health System for You*, outlined a number of principles which illustrate the continuing shift towards a person-centred ethos in healthcare. These principles are concerned with

- equity and fairness

- a people-centred service

- quality of care

- clear accountability.

Quality and Fairness was the first document to enshrine person-centred care as a distinct objective in healthcare policy, planning and delivery. It recognised that there are now greater expectations about openness and shared decision-making in relation to individual healthcare.

A number of practical actions were proposed which, by their nature, necessitate the development of participatory approaches to care delivery and planning at all levels:

- a national standardised approach to measurement of patient satisfaction is to be introduced

- best practice models of customer care, including a statutory system of complaint handling, is to be introduced

- individuals and families will be supported in the management of their own healthcare

- an integrated approach to care planning for individuals will become a consistent feature of the system

- provision is to be made for the participation of the community in decisions about the delivery of health and personal social services.

Unlike the other countries discussed here, Ireland does not currently have an established national participation policy for the public and patients, nor does it have a national centre to co-ordinate patient participation and partnership activities. Patient interests are represented through such groups as the Irish Patients' Association, or through a range of disease-specific groups such as the Cystic Fibrosis Association or the Alzheimer Society of Ireland, or 'topic' or population groups such as the National Council on Ageing and Older People. A case study outlining the building blocks for people-centered services is included below for a number of reasons – it is based on an Irish initiative, it acknowledges the increasing multi-agency and team approach to holistic healthcare and, finally, it identifies requirements for true participation.

Building blocks to people-centred services – A Case Study

This example illustrates tailored care planning for children with disabilities. Its unique features are the special emphasis on family involvement and the identification of essential building blocks for participation. Teams are established on an individual needs basis and a negotiation model provides a framework to balance and ensure contribution of the knowledge of families and professionals respectively. The example is realistic and identifies particular challenges.

Background: The acknowledgement that early intervention will benefit children and family, optimising the appropriate use of services (i.e. needs based).

Building blocks:
Child-centred and family-centred approach: A commitment to service delivery where families are partners, an understanding of family systems and dynamics underpinning actions.
Partnership: Beyond consumer and empowerment models to a negotiating model acknowledging that professional and parent have separate but valuable contributions.

Collaboration: Shared responsibility for mutual goals, focus is on shared purpose, a premium on communication and support.

Interdisciplinary/transdisciplinary teams: Features of this are an integrated approach, commitment to communication and the opportunity for disciplines to learn from each other. Transdisciplary teamwork includes parents as equal partners but has specific implications for team members, including crossing disciplinary boundaries, releasing aspects of role and expanding others.

Individual family service plans: Identification of the parents' concerns, priorities, and resources (CPRs), A focus on increased decision making by parents and engaging parents in child assessment are features.

Outcomes-focused approach: An outcome should be developed as a result of collaboration between parents and service providers as collaborating decision-makers. Outcomes include: child related child outcomes, family related child outcomes, child related family outcomes and general family outcomes.

Implementing, reviewing, evaluating: A quality assurance system and ongoing evaluation and review.

Services closer to families: Positioning services closer to families involves changes in the way services are provided. It builds on the principle of inclusive communities, outreach services and increasing home and community visits. (Walls, 2001)

A number of participatory initiatives have recently been implemented by health boards or by individual hospitals or voluntary organizations, indicating an increased awareness of the importance of patient-centered care. Some examples of these are provided in table 3.2.

The examples listed in table 3.2 are chosen to represent a range of activities across health boards and other organisations. *They are in no way reflective of the number of projects ongoing.* A thorough overview of projects underway was beyond the scope of this discussion paper. The fact that it may be difficult for those in health settings to identify others throughout Ireland who have engaged in similar projects means that there is a difficulty in building on expertise to continually develop and improve initiatives.

The examples can be supplemented with some of the findings from workshops convened for this discussion paper. The purpose of the workshops was to capture patient support and advocacy groups' views of patient participation and partnership in Ireland.

The discussions at the workshops were characterised by participants' efforts to define the constructs. As an abstract notion they spoke about *needing to clarify before one attempts to say how you achieve it* . Levels of participation were distinguished – for example consulting at an individual level with patients or at a more community and policy level with advocacy groups. Because patients and their advocates organise in support groups which share common illness or disease experiences, these participants also discussed the fact that some patients were poorly represented – for example those with learning disabilities, those with complex health concerns such as head injury, and patients in the mental health system. The potential to achieve

participation and choice was noted as being resource dependent: *...there aren't any choices in the Irish health system.   You take it or leave it, you get in one queue and you stay there. That's not the basis for partnership.*

While these focus group participants could identify attempts at partnership at a health board level in their areas, they could with more ease identify examples of its absence.

Several of the principles and approaches outlined in the discussion paper up to now have placed an emphasis on the systemic requirements for partnership.   For staff, government and patients to enter into participative relationships at all levels, the prerequisites of will, vision and support are essential.   A dynamic image of participation and partnership allows us to view some of the 'pulls towards' and 'away' from participation which may be relevant to the Irish context (table 3.1).

Table 3.1: Factors which enable or mitigate against public and patient participation in healthcare

Towards participation	Against participation
Intrinsic respect for patient/dignity of choice	Rational/paternalistic model of medicine
Opportunity to increase patient co-operation and adherence	Fear of loss of control by health professionals/administrators/policy makers
Increased public education, awareness and responsibility for health	Inequity in socio-economic or educational system
Intrinsic rewards for staff, increased patient contact and relationships, i.e. a 'caring model'	Lack of time/other pressures
Development/progress emphasis in 2002 Health Strategy	Lack of support for staff/lack of resource/lack of training

The framework for any partnership or participation strategy requires consideration at the start-up phase of the types of dynamics identified in table 3.1.   These dynamics, in particular the factors which militate against participation, will need to be addressed in each setting and reviewed if true participation is to be achieved and maintained.

Table 3.2: Patient participation projects in Ireland representing different approaches and levels of complexity

Location	Title	Level	Setting	Description
SEHB St Joseph's Hospital, Clonmel	Creating partnerships with patients	Individual and care management	Hospital	Co-ordination, facilitation and launch of a Patient Representative Association at St Joseph's Hospital, Clonmel. Group represents the public view and supports patient advocacy and partnership between patients and hospital staff. Aims: • to encourage and assist patients to have an input into ongoing developments in quality, service delivery, cost-effectiveness and efficiency • to address areas of problematic service delivery and initiate change • to recognise and develop the contribution made by patients and their families and to assess their views, opinions and values • to promote mutual co-operation and respect in the true sense of partnership
ERHA/SWAHB Quarryvale, North Clondalkin	Community planning for better health	Community	Clondalkin community	• Multi-disciplinary group (health, community and voluntary sectors) to facilitate 'bottom up' health planning process • Multi-disciplinary group (health, community and voluntary sectors) to facilitate 'bottom up' health planning process • Two open workshop community planning meetings in Quarryvale using Participatory Rapid Appraisal (PRA) techniques • 60+ people participated in the planning meetings • Tasks included making charts, maps, and sketches to record local knowledge, analyse relevant issues and draft a five-year plan for the area • Resulting report = starting point for change in the community outlining a framework for co-operation between agencies and the community

Location	Title	Level	Setting	Description
NEHB	Men Talking A Study of Men's Health in the North Eastern Health Board http://www.nehb.ie/mentalki.html	Community	Community	• To engage in consultation with men in the North Eastern Health Board region, so as to explore their health beliefs, attitudes and perceptions. Submissions were also sought from the public • To gain insights into the health seeking process adopted by men in times of illness • To explore men's views and experiences on current health service provision in the North Eastern Health Board region • To identify men's suggestions for improvement and changes for the future • To elicit men's reaction to suggestions or new ideas
WHB County Mayo	Packages of Care	Care management	Community	Co-ordinator of packages of care worked as part of a large multi-disciplinary team. Liaised with older people to assess needs and decide on best delivery package. Services available included meals-on-wheels, occupational therapy, physiotherapy, respite care, general practitioner, family support, day hospital, home help, and public health nursing
NWHB County Donegal	Growing up in the North West	Policy	Adolescent community	• Consultation with over 100 adolescents in County Donegal in 1999 as part of a wider profile of child and adolescent health in the NWHB. • Key topics = understandings of mental health, top five issues affecting mental health, coping skills, knowledge of services, attitudes to counselling, how services could be more young-person friendly, advice on mental health promotion • Mental health module focusing on mental health as part of 'Lifeskills' programme for transition-year students • Mental health day available to any school where mental health module is taught. Series of small group workshops as well as drama presentation

Location	Title	Level	Setting	Description
MWHB	Changing professional practice in community mental health residences through participatory action research	Individual	Community mental health residences	• Participatory Action Research approach • Aimed to introduce more effective practices to improve quality of life for persons in community mental health residences • Change in staff-client involvement assessed using a staff activity instrument • Community attitude surveys undertaken on attitudes to mental health and perception of the residents • Significant positive shift to improved quality of life found • Particular improvements in resident experiences of dignity • Attitude of local communities indicate limiting factors in residents opportunities for normalisation, i.e. use of community facilities and employment
NAHB, Beaumont Hospital	'Home First'	Individual and care management	Hospital and community	• Aims to facilitate older people's discharge from hospital • Project co-ordinator liaises with patient, family and community services • Project co-ordinator deals with changing needs • Scheme operates out of normal hours
SHB	'We consult but who decides? – a qualitative study of consultative processes between Traveller groups and statutory agencies in Cork'	Community	Community	• The Traveller Visibility Group commissioned study of consultative processes • Consultation analysed under six headings – Format; Participation; Power and Influence; Supports; Demands and Pressures; Outcomes. Ladder of Citizen Empowerment used to rate from Citizen Non-Participation to Citizen Empowerment • Policy documents reviewed to identify approach to consultation. Positive towards consultation but not power sharing • Individual interviews and focus groups gathered data on experiences of participation • Elements of good consultation practice within THU identified and recommendations for improvements made, in particular in relation to format of meetings, language and further sharing of power • Limitations of THU to influence wider SHB policy identified. Also identified that THU and SHB are limited in efforts to improve Travellers' health by lack of authority to challenge local authorities on poor Traveller accommodation

Location	Title	Level	Setting	Description
East Coast Area	Client involvement in service planning	Individual and care management	Residential and community services	• Anonymous feedback through client satisfaction questionnaire • Trainee representative committee shapes and changes nature of services • Trainee newsletter provides honest feedback on the programmes • Infoshare groups and community meetings – feedback to programme co-ordinator • Multidisciplinary approach includes views of families and clients
NWHB Counties Donegal and Sligo	Consumer Panels at Service provision level	Community local provision policy	Hospital – physiotherapy, renal dialysis and paediatrics	• Service user and provider representatives • four or five meetings per year • Discuss issues and new developments, share views • Independent chairperson • No individual complaints considered
Western Care Association, County Mayo. (Partnership site for Federation of Voluntary Bodies)	Building Consumer Directed Services using the Personal Outcomes Measures	The individual as the focus of Total Organisational Performance		• Person-centred planning is a key principle in the Health Strategy. Personal Outcome Measures (POMs) are specifically designed to measure this • Western Care Association measured total organisational performance as determined by people with learning disabilities using the POMs. This measures organisational responsiveness to what really matters to service users from their perspective. Organisational leadership, systems, quality management and planning are also evaluated. The extent to which corporate efforts are connected to what matters most to the people receiving supports and services is determined • Organisations wishing to be accredited with the POMs are evaluated by trained external review teams. External reviewers interview service users and those who know them best as part of the review using a standardised interview system scoring with 0.85 Inter Rater reliability • The Accreditation Project in Western Care was undertaken as a partnership site for the Federation of Voluntary Bodies between March 2001 and May 2002. During this period over 50 staff training events took place involving more than 1000 training places • The entire procedural support framework was redesigned. The average number of outcomes achieved in a representative sample of service users increased by over 100% across the period • The Association received a two-year accreditation without conditions

Location	Title	Level	Setting	Description
Sunbeam House Services, Bray, County Wicklow	Introducing a service quality system.	Service users and staff		• Introduction of a Service Quality System into an organisation providing care to adults with diagnoses of intellectual disability • The staff team of twenty-eight individual centres operated by Sunbeam House Services had to learn, adapt and be responsive to the needs and choices of people in all branches of its service Many organisational practices had to be altered, in such areas as staff recruitment practices, performance appraisals, policy procedures and guideline manuals. Financial and budgeting practices were fine-tuned to reflect the personal choice of service users. Other changes include a shift away from organisation-wide budgeting to unit and client-centred budgeting

Chapter four
Developing public and patient participation in Ireland

Why engage in participation?

What are the impacts of involving patients and the public in healthcare decision-making? Involvement can impact at a number of levels:

- Impact on service delivery levels, causing improvements; development of new services; and improving interactions and understanding between health professionals and service users

- Impact on policy and strategy such as better information for organisations and health boards; measurable changes in policy and strategy; and community-generated proposals

- Impact on relationships between stakeholders such as improved communication between key stakeholder groups (for example health professionals; service users; the public and the community and voluntary sector).

Starting the process – planning for participation

Public and patient/client involvement should not be an afterthought or an add-on to core corporate aims and priorities.   How patient/client involvement fits in with organisational priorities, and how money spent on involvement initiatives balances with spending on the provision of care, should be carefully considered before initiating the process.

Clarifying aims and objectives
Health managers need to plan carefully before undertaking a public or patient partnership initiative.   The aims and objectives of the initiative must be clear – it is important to know what the desired outcome of the initative should be.   Aims and objectives can include

- learning more about patient/client experiences of care

- learning more about staff's perceptions and reactions to participation and partnership ideas

- improving the quality of care

- identifying unmet needs

- getting input into policy and planning, including planning for change

- gaining ideas about healthcare priorities

- giving people increased ownership over provision of services

- developing a shared agenda with all relevant stakeholders

- building trust and creating good relationships by creating the conditions where an ongoing dialogue can develop

- fostering motivation for partnership.

One way of helping to clarify aims and objectives is to base them on a clear set of principles which inform the planning and implementation of patient/client participation.

Principles for partnership

Three main sets of prinicples have been identified in the literature: principles underpinning the process of partnership; principles for policy-making; and principles for the personal and day-to-day implementation of partnership on behalf of health managers.

Both De Burca (2001) and Davies (1999) set out principles they felt should inform the process of partnership.   De Burca concentrates on the organisational culture and communication in the formulation of his set of principles.   Communication, challenging dominant ideologies and adopting a rights-based approach are central themes.   Davies, on the other hand, combines attitudinal dimensions such as motivation, honesty and commitment to the task with more structural aspects such as access, communication, flexibility, monitoring and evaluation (see Appendix 2 for a comparison).

The NHS publication *Signposts – a practical guide to public and patient involvement in Wales* (NHS Wales, 2001) set out eight core 'values' which should underpin policy-making as it pertains to involvement in healthcare.   Although some of these values echoed those of Davies and De Burca, in this case they were explicitly linked to decisions being made at the policy level. Appendix 3 outlines these core values or principles.

Service managers who promote partnership initiatives require principles to guide them, principles which take account of their situation and needs in terms of partnership (Skelcher, 1997).   These should include honesty about what can be achieved and what the limitations are; that is to say keeping promises.   Skelcher felt this was important because keeping one's word is used by the community as a key indicator to judge and assess individuals, and by implication the agency they represent, regarding commitment to patient/client partnership.   The principles should also provide guidance on matters which may affect local situations, such as ethnic origin, cultural background and social class.   Sometimes particular features may help service providers to work with service users or communities, but sometimes they may present significant barriers to co-operation. Emphasis should be placed on the process of partnership as well as the outcome.   Where a consultation process is poorly designed, people may feel alienated and isolated even though the ultimate decision is a popular one.   Finally, the importance of having a personal support network in place for those working 'at the boundary between the community and the agency' is emphasised – in order to support all participants in times of stress.

If these various principles are brought together, they can be rationalised to produce a set of core values which can then be applied throughout the system in order to promote an attitudinal and cultural ideology of equality and partnership, supported by the appropriate structures in order to sustain innovation and change for the future.   In Ireland, commitment to such change and the energy to drive it are necessary if true partnership is to be achieved.   To this end, a set of principles to support and inform public and patient partnership initiatives in Ireland are proposed (table 4.1).

Table 4.1:   Proposal for principles of public and patient partnership in healthcare in Ireland

A **rights-based approach** to public and patient partnership
A commitment to creating an atmosphere where **building trust** is supported and encouraged
A **flexible and accessible communication process** that is honest and open about the implications of healthcare decisions
Motivation and commitment to partnership on the part of both service users and service providers
Flexibility and willingness to adapt to changing circumstances
An ethos of **fairness and accountability** which includes in-built monitoring and evaluation systems
Mutual co-operation and support in times of difficulty
A concern for **process** as well as outcome – respecting how things are done as well as the end result
A commitment to **delegate power** equally across all parties in a partnership
A commitment to **embedding** partnership within the structure of the health system and across all sectors at all levels within the system
A commitment to **financial** support

By definition these principles are a starting structure and will be considered, amended or perhaps replaced by 'partners' when they establish ground rules for co-operation in healthcare. Indeed, an overly prescriptive set of principles or structures may actually hinder the development of partnership.   By focusing prematurely on outcomes it is possible to neglect the process of agreeing how to proceed in partnerships.

Implementing patient partnership

In order to achieve best practice, it is essential to understand both the underlying dynamics of partnership initiatives, including the mediation of power, and the pragmatic actions that need to be taken in order to implement partnership effectively.   In addition, good practice varies according to the level at which it is envisaged a partnership approach will be implemented; either at the level of individual clinical encounters, service delivery level, community level, or policy level.

Choosing the right approach

Many methods for the involvement of patients in healthcare have been developed (these were summarised in table 2.4). Some general points need to be made about approaches to participation at the policy level.

- Agencies involved in participation initiatives should **prioritise areas for development**. For example, an agency that has conducted focus groups with service users for some time might consider moving on to more proactive or community-based activities in order to develop community participation and to access users who are not targeted by focus groups.

- It is essential to **build capacity across the organisation** to make participation 'part of everyday business' (NHS Wales, 2001). If there are service gaps that need to be targeted through participation, specific criteria of best practice already developed could usefully be applied, both in terms of motivation for participants to continue the process and to establish findings that could be applied further to other sectors.

- **Flexibility** is a key quality. Decisions must reflect local circumstances. It is essential to prepare the ground for whatever techniques are going to be used. This means thinking how people may wish to be involved.

- There needs to be **clarity about the aims and objectives of consultation** meetings and events. Professionals may come to meetings expecting strategic discussions, whereas members of the public might see meetings as a forum for questions and answers about individual problems. It may not be possible to move to strategic discussion without first attempting to address the here and now of individual problems.

- **Professionalism is essential.** Whatever work needs to be undertaken must be done by those who know what they are doing and who display good personal and professional skills. If this does not happen, participants may become reluctant to remain involved.

Involving the right people in creating partnership

In deciding who needs to be involved, three groups should be considered from the 'public' perspective:

- those who have direct experience of services – patients, clients or carers

- members of the wider public

- those who represent community interests.

Decisions about who should be involved should be made in consultation with community groups and service users. Different sub-groups might be needed during various phases of

work. Systems may be needed in order to include people from marginalised groups such as the homeless, refugees, those from different ethnic backgrounds including travellers, older and younger people.

Consideration of who will 'represent' health services is also important:

• a balance of junior and senior staff

• a balance of administrative staff, policy makers, 'frontline' professional staff and other service providers.

Clinical encounter level partnership

Partnership at the level of the clinical encounter mainly refers to one-to-one interactions, and shared decision-making is the most frequently used approach in this setting. There are several recommended steps for shared decision-making (Towle, 1997):

• develop a partnership with the patient/client

• establish or review the patient/clients' preferences for information – for example amount and format

• establish or review the patient/client's preferences for role in decision-making

• ascertain and respond to patient/client's ideas, concerns and expectations

• identify choices and evaluate the evidence from research in relation to the individual patient/client

• present evidence, taking into account the above steps, and help the patient/client reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle

• make or negotiate a decision in partnership, manage conflict

• agree on a plan of action and finalise arrangements for follow up.

Service-delivery level partnership

Tower (1999), in a paper advocating increased user participation in palliative care services, recommended looking to mental health initiatives in the UK for examples of best practice. She cited a number of projects which have achieved significant success in involving mental health service users in decision-making at both policy and practice levels. For example, a research project commissioned by Birmingham City Council, *Keeping in Touch with the Talking*, aimed to plan mental health services that were both structured and informed by the views of services

users (Ritchie et al, 1988). The research was conducted in a way that allowed people with mental health problems to describe their service needs in the context of their experiences and their day-to-day lives. The research used qualitative methods (in-depth interviews) with sixty-seven service users. The resulting information was used to inform service developments in mental health in Birmingham. The views of patients who had been detained under the Mental Health Act (1983) were sought six months after their detention. They assessed the services of approved social workers who were involved in assessment and detention. Changes in the approved social worker practices were implemented following the project.

More recently, mental health services in the UK have developed mechanisms for consulting both service users and their carers/relatives using the mandatory Care Programme Approach[6]. Health and social services are required to collaborate in providing systematic arrangements for assessing the health and social care needs of people accepted by specialist psychiatric services (Department of Health (UK), 1990). In most areas, the local interpretation of this mandate has resulted in service users receiving a copy of their care plan to sign, indicating their commitment to the treatment plan. Mental health service users and carers are allocated places on the joint service advisory teams, which are key fora for planning service delivery. In addition, the development of a range of advocacy service users' views in mental health have been financially supported by health and social services throughout the UK.

Community level partnership

Pickin et al (2002) have reviewed the literature and have identified the following best practice approaches that enable partnership between communities and statutory agencies:

- whole system working

- senior involvement to lend status and power to partnerships (Smithies and Webster, 1998; Barnes et al, 1999)

- training for staff engaging with communities (Laughlin and Black, 1995)

- developing clear aims and objectives and relevant methods of evaluation (Craig, 1996)

- performance management of statutory organisation responsiveness to communities Barnes et al, 1999)

- structures that allow community participation in strategic planning (Laughlin and Black, 1995).

Pickin et al (2002) have also argued that understanding the relationship and power balance between individuals and communities on the one hand and statutory organisations on the

---

[6] The Care Programme Approach was developed in conjunction with the Care Management approach to care for older people and people with disabilities in the UK in 1990 (see Delaney et al, 2001, for more information).

other is crucial to the promotion to the health and well-being of a population.   Policies must broaden the capacity of statutory organisations to develop more participatory and equal relationships with local populations.   This will require a radical shift in how agencies think and behave.

Evaluation centred on effective approaches to participation is important in identifying features which lead to success. One such evaluation was completed by O'Keeffe and Hogg (1999).

Case Study: The HealthLINK project

HealthLINK was a project set up in 1992 by the Camden Community Health Councils (CHC) and the Camden Healthy Cities Project.   It's initial goal was to open up access to CHC services to people who found it difficult to attend meetings due to either impairment, social and/or economic circumstances or disabling environments.   HealthLINK was supported by the statutory agencies in Camden and by the voluntary sector.

Criteria were developed which could serve as features of best practice for future community development models of participation in healthcare, especially those that deal with older people (O'Keefe and Hogg, 1999).   The features that led to the success of HealthLINK, compared with other attempts to encourage vulnerable older people to participate, were identified as

• The establishment of trust through the continuing involvement with members as individuals

• The establishment of contacts over a long period of time.   Collective activity does not provide quick results and is only meaningful if an infrastructure is built up to allow dialogue between staff and members and amongst members

• The delivery of 'benefits' (such as improving services for individuals and providing opportunities for service users to learn from each other and to increase a sense of connectedness); this so that members can judge what they get for the cost of their time and energy

• Independence of the organisation – this enables users to feel free to comment on services without fear of reprisal.

The community development model, according to the authors, can provide a way of thinking about need based on empowering people to take responsibility for contributing towards the definition of needs.   O'Keeffe and Hogg proposed that HealthLINK can provide an example of good practice to a range of community groups, statutory agencies and CHCs by providing means of involving groups of people that would otherwise be marginalised.

Overall, two categories of skills and actions contribute to the establishment of good practice in implementing partnership throughout the health services (table 4.2).

Table 4.2: Requirements for good practice in public and patient partnership

Inter-personal skills
Understanding the power relations at work in healthcare encounters at all levels and working to equalise these
Adopting comprehensive and holistic communication strategies
Developing good working relationships built on trust
Providing conflict resolution skills where necessary
Developing a culture of participation
Changing traditional professional and organisational cultures
Networking with community and voluntary groups
Respecting the service user's point of view

Concrete actions
Developing a clear understanding of the respective roles of the actors involved in participation activities
Planning participation activities well in advance
Setting up an independent organisation to support and maintain patient participation initiatives
Agreeing clear aims and objectives
Adopting appropriate techniques depending on the situation
Displaying flexibility in the design of participation activities
Appropriately targeting service users/public
Delivering tangible results
Monitoring and evaluating agreed outcomes

Monitoring and evaluation of partnership activities

Evaluating the involvement process

It is important to gather information about how well partnership initiatives have worked.
Important questions for consideration are outlined in table 4.3

Table 4.3: Key questions for monitoring and evaluation of partnership projects (NHS Wales, 2001)

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

How?
• Was it the right approach?
• Were roles and responsibilities clear?
• Were partners involved appropriately in planning and delivery?
• Was it clear how results of involvement would feed into decision-making processes and how feedback would be provided to participants?
• Were timescales realistic and clear to those involved?

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

Who?
• Were the right people involved?
• Did those involved reflect the social and cultural composition of the target population?
• Were people appropriately supported to participate (i.e. were venues and timings appropriate)?

Evaluating the involvement outcomes

Participative care planning, known as 'individual programme plans' has been developed and used extensively in work with people with a learning disability. The process is intended to maximise personal growth and the opportunity for self-determination. The extent however to which participation is an actual feature of the process is rarely recorded. Alexander and Hegarty (2001) developed a checklist to evaluate the process and to gauge actual participation. Such a development reinforces the necessity of considering evaluation and monitoring at design stages and not as a later 'add-on'. Table 3.2 illustrates an Irish example where measures of participation (Personal Outcomes Measures) were developed specifically to ensure a person-centred care approach. Personal outcome measures allow accreditation and the clear demonstration of individualised and participation outcomes (http://www.thecouncil.org/).

Evaluating the outcomes of public and patient involvement requires a much longer-term view than evaluating involvement processes. Some outcomes may follow relatively quickly after an initiative is started, others may take much longer to become apparent. Outcomes may occur at a number of different levels so it is necessary to have clear guidelines to help one focus on which kinds of outcomes should be assessed. Longer-term changes will need to be judged via a variety of health indicators. It is helpful to look at evaluation in terms of the three levels mentioned earlier: service delivery; planning and policy; and relationships between stakeholders.

Lessons from participation initiatives

Many existing participation initiatives have challenges and opportunities which provide valuable lessons for health service professionals promoting public and patient/client participation in the future.

Taylor (1997) has identified some factors which contribute to better user participation initiatives. He noted the importance of having allies within different parts of the organisation. Allies at senior levels of management were seen as helpful when user involvement activities experienced obstacles or threatened to be disruptive. The energy and commitment of staff prepared to work over and above what is strictly necessary was described as a crucial factor in implementing new initiatives. Having the backing and support of organisatons and significant individuals outside the health service was seen as giving extra legitimacy to user involvement within the health service. The ambition of some sections of the health service to be seen as centres of excellence and the drive of some staff to develop a reputation for innovation were found to act as motivators for starting user-involvement activities.

Obeid (2001), in a study of health professional perceptions of user participation, has identified two key themes which health professionals perceive as restraining forces to user participation: the organisational context and personal characteristics. Health professionals have not always been in a position to facilitate participation due to their own unempowered position within the healthcare system.

Person-centred care is often viewed as the antithesis of the objective medical model. The implications of developing person-centred care in a traditionally medical-centred activity (psychiatry) are well described by Williams et al (1999). Among the most fundamental challenges were role conflicts – and these were experienced both by service users and by staff. Staff are advised to work within clearly defined principles of equity and partnership yet are also required to maintain responsibility; quality and organisational procedures are rarely sensitive enough to facilitate these types of processes. Interdisciplinary and transdisciplinary teamwork which includes, for example, parents as team members in all phases of service provision from assessment to implementation to review, is subject to similar conflicts – for example the boundaries between disciplines and the dynamics of role expansion and role release (Tuchman, 1996; Walls, 2001). Moreover, service users themselves hold expectations about the extent of decision-making they welcome.

In addition, partnership and participation may result in unanticipated outcomes – for example an increase in criticism, expressed dissatisfaction and negative feedback, or disagreements between staff and users. Education and training about participation and partnership should be realistic about the actual and potential outcomes of increased participation (Williams et al, 1999).

Training and education for patient participation and partnership

Education and information programmes are essential to developing   partnership.   These programmes should focus ideally not only on providing knowledge and raising awareness but on confidence building, and on developing the interpersonal skills for participating in working models of partnership.   The level of educational intervention required in both general terms and specifically for enhancing participation are described by Consumer Focus Collaboration (2000).   The report identifies four pillars of education and adapts these to reflect training and education for participation in healthcare:

- learning to know (information and knowledge)

- learning to do (skill)

- learning to understand others (action learning, group work, reflective opportunities)

- learning to be (self directed).

An Australian needs assessment conducted by the National Resource Centre for Consumer Participation in Health (1999) identified a range of needs. The preference was for in-house training, tailored to local information requirements.   These requirements are listed in table 4.4.

Table 4.4: Range of topics on which information is required for consumer participation (National Resource Centre for Consumer Participation in Health, 1999)

Strategies for consumer participation, including how to get an organisation ready for working more effectively with consumers, roles and responsibilities of service providers and consumer participants, specific strategies such as lobbying, negotiating and how to involve consumers in reviewing and evaluating a service
How to be an effective consumer participant
How to identify and make links with consumers and community groups
How to integrate consumer feedback into quality improvement processes
The role of consumer councils and advisory committees
Consumer feedback and participation and why it is important
Patient satisfaction surveys (specific tools, development issues and uses)
Working with groups who are usually excluded from giving feedback

A recent project in the United Kingdom examined the training and support needs of lay representatives in the health service.

> ### Case Study: Voices in Action   (Bradburn, Fletcher, et al, 1999)
>
> The *Voices in Action* research project set out to identify lay representatives' training needs and to develop a programme and evaluation strategy for training programmes.   The comprehensive recommendations of the project report recognise the context of participation training as an important determinant of its success.   The necessity for a local dimension to training is therefore highlighted. The potential barriers to attendance need to be acknowledged and therefore training needs to be provided in accessible and supportive locations.

A further training issue identified in *Voices in Action* is the need to train professionals and lay representatives in the dynamics of working together.   The extended list of recommendations on training is given in Appendix 1.   In summarising the approach to training for patient participation at the individual and community level, a number of questions can usefully guide the approach.   These are illustrated in table 4.5.

Table 4.5:   Questions to guide training approaches for public and patient participation

Who will be trained?
- 'The public' – existing lay representatives, potential lay representatives, healthcare professionals and policy makers

What form will the training take?
- Information/awareness raising - through campaigns, internet etc
- Formally convened training programmes - local, learning objectives, action learning etc
- Training specific to a particular participation structure, for example a patient participation group at the GP surgery
- Orientation needs? Skill needs? Attitude/cultural change? Systemic change?

What will the training content be?
- Communication/negotiation/assertiveness skills
- Presentation skills
- Committee process skills
- Health services context
- Research, audit and evaluation
- Networking
- Obtaining the views of others/hard to reach groups

What is the context of training?
- How does the training programme link to organisational commitment, to patient participation and partnership?
- Are cost/expense of training initiatives accounted for?
- How will the training be evaluated?

Chapter five

Conclusion

This discussion paper outlines some of the approaches to increasing patient/client participation and partnerships which have taken place and are continuing in different countries around the world in order to achieve person-centred care. It has described different levels of participation which have implications for individuals, health service providers and management throughout the health system in Ireland. The challenge is to articulate the philosophy of participation, to acknowledge its value and to make a start in planning the best way to its achievement.

The paper serves as a basis for discussion and also as a resource, directing the reader to helpful articles, books, websites and supports. Several points deserve highlighting in order to assist discussion and planning.

- A common theme throughout the paper has been the emphasis on process as much as outcome. Participation and partnership are not 'achieved' per se but developed through time. By definition they are responsive and are contingent on individuals, community groups and health services' staff and on their preferences, resources and abilities over time.

- Several of the participation movements identified here originated from the 'quality in healthcare movement' and from patient safety initiatives (e.g. UK, Australia). Irish initiatives in the area of participation might well look to the quality in healthcare movement in Ireland with a view to sharing resources and expertise.

- Dedicated structures (legislative, administrative and educational) and co-ordinating centres were developed to support participation in the US, UK and Australia. The importance of such a co-ordinated approach is manifold:
  - it provides a remit/legitimacy for patient participation
  - it ensures that local services maintain autonomy in their implementation of participation schemes. Local knowledge is preserved but is supplemented by central resources and expertise
  - it provides a resource for education, research, training and consultation which aims to maintain flexibility while ensuring that the patient voice is heard at many forums, increasing the potential for policy change.

- The 'partners' in partnership are explicitly identified, for example in the NHS strategy, as including patients, NHS staff and government. The evidence of staff was not sought for this brief discussion paper. Rather the paper itself is intended to begin the process of raising awareness, to acknowledge the challenges for staff and to allow staff to consider their own reactions to the 'paradigm shift' of patient as insider and powerful player in the health context. An important investigation remains – to identify the extent to which staff themselves recognise a need for change in the arena of patient participation, and to further explore their needs in a changing and more participative healthcare context. It is only by having staff fully participate in this process that the challenge of seeing them work as partners with patients and the public in a wider partnership can be achieved.

References

Alexander, M. and Hegarty, J.R. (2001). Measuring client participation in individual programme planning meetings. *British Journal of Learning Disabilities.* 29:17-21.

Al-Assaf, A.F. (1993). Introduction and historical background. In A.F. Al-Assaf and J.E. Schmele (Eds.). *The Textbook of Total Quality in Healthcare.* Florida: St Lucie Press.

Arnstein, S.R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners.* 35:216-24.

Barnes, M., Harrison, S., Mort, M., Shardlow, P. (1999). *Unequal partners: user groups and community care.* Bristol: The Policy Press.

Beresford, P. (1997). User views on user involvement. In S. McIver and C. Skelcher (Eds.). *Consumerism and User Involvement in Public Services: Public Paper:* Occasional Paper. Birmingham: School of Public Policy, University of Birmingham.

Bradburn, J., Fletcher, G. and Kennelly C. (1999). *Voices in Action: training and support for lay representatives in the health services.* College of Health.

Bubela, N., Galloway, S., McCay, E. (1990). Factors influencing patients' information needs at time of hospital discharge. *Patient Education and Counselling.* 17:441-445.

Chappell, A., Goodley, D. and Lawthom, R. (2001). Making connections: the relevance of the social model for people with learning difficulties. *British Journal of Learning Disabilities.* 29:45-50.

Charles, C. and De Maio, S. (1992). *Lay participation in health care decision-making: a conceptual framework.* CHEPA working paper series No. 92-16. Ontario: McMaster University.

Charles, C., Whelan, T. and Gafni, A. (1999). What do we mean by partnership in making decisions about treatment? *British Medical Journal.* 319:780-782.

Consumer Focus Collaboration (2000). *Education and training for consumer participation in health care.* Canberra, Australia: Consumer Focus Collaboration.

Consumer Focus Collaboration (2001). *Review of existing models of reporting to consumers on health service quality: summary report and guidelines.* Canberra, Australia: Consumer Focus Collaboration.

Craig, P. (1996). Drumming up health in Drumchapel: community development health visiting. *Health Visitor.* 69:459-461.

Davies, A. (1999). Promoting participation: principles and practice. In T. Ling (Ed.). *Reforming Healthcare by Consent: involving those who matter.* Oxon: Radcliffe Medical Press.

De Burca, S. (1997). *Changing Professional Practice in Community Mental Health Residences through Participatory Action Research.* Limerick: MWHB.

De Burca, S. (2001). *Patient as participant.* Presentation to the European Society for Quality in Healthcare Third Spring Workshop, May 17th, 2001. Balaton, Hungary: unpublished.

Delaney, S., Garavan, R., Tynan, A., McGee, H. (2001). *Care and Case Management for Older People in Ireland.* Dublin: National Council on Ageing and Older People.

Deloitte & Touche, in conjunction with the York Health Economics Consortium (2001). *Audit of the Irish health system for value for money.* Dublin : Department of Health and Children.

Department of Health and Welsh Office (1983). *Mental Health Act 1983.* London: HMSO.

Department of Health (1990). *National Health Service and Community Care Act.* London: HMSO.

Department of Health (1994). *Shaping a Healthier Future: A strategy for effective healthcare in the 1990s.* Dublin: Stationery Office.

Department of Health (2000). *The NHS Plan: a plan for investment, a plan for reform.* London: Department of Health.

Department of Health (2001). *Health and Social Care Act.* London: HMSO.

Department of Health (2001). *Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995.* London: Department of Health.

Department of Health (2001). *Extending choice for patients.* London: Department of Health.

Department of Health (2001). *Involving patients and the public in healthcare.* London: Department of Health.

Department of Health (2001). *The Expert Patient: a new approach to chronic disease management for the 21st century.* London: Department of Health.

Department of Health (2002). *Shifting the balance of power: the next steps.* London: Department of Health.

Department of Health and Children (2001). *Quality and Fairness: A Health System for You.* Dublin: Stationery Office.

Department of Health, Social Services and Public Safety (2002). *Investing for Health.* Belfast: DHSSPS.

Donabedian, A. (1988). Quality assessment and assurance: unity of purpose, diversity of means. *Inquiry.* 25:173-92.

Draper, M. and Hill, S. (1996). *The role of patient satisfaction surveys in a national approach to hospital quality management.* Canberra: Australian Government Publishing Service.

Draper, M. (1997). *Involving consumers in improving hospital care: lessons from Australian hospitals.* Canberra: Commonwealth Department of Health and Family Services.

Emanuel, E.J. and Emanuel, I.L. (1992). Four models of the physician-patient relationship. *Journal of the American Medical Association.* 267:2221-6.

Enehaug, I. H. (2000). Patient participation requires a change of attitude in healthcare. *International Journal of Healthcare Quality Assurance.* 13(4):178-181.

Finlay, L. (1997). Good patients and bad patients: how occupational therapists view their patients/clients. *British Journal of Occupational Therapy.* 60(10).

Fitzpatrick, R. and Hopkins, A. (1983). Problems in the conceptual framework of patient satisfaction research: an empirical exploration. *Sociology of Health and Illness.* 5:297-311.

Fraser, D.M. (1995). Client-centred care: fact or fiction. *Midwives.* 108(1289):174-177.

Garavan, R., Winder, R. and McGee, H. M. (2001). *Services for Older People (HeSSOP). Consulting older people on health and social services: a survey of service use, experiences and needs.* Dublin: National Council on Ageing and Older People.

Gerteis, M., Edgman-Levitan, S., Daley, J. and Delbanco, T. (Eds.). (1993). *Through the patient's eyes.* San Francisco: Jossey-Bass.

Goodare, H. and Lockwood, S. (1999). Involving patients in clinical reseach improves the quality of research. *British Medical Journal.* 319:724-725.

Hardy, GE., West, MA. and Hill, F. (1996). Components and predictors of patient satisfaction. *British Journal of Health Psychology.* 1:65-85.

Her Majesty's Government of Great Britain and Northern Ireland (2001). *Health and Social Care Act, 2001.* London: HMSO.

Jewkes, R. and Murcott, A. (1998). Community representatives: representing the 'community'? *Social Science and Medicine.* 46:843-58.

Johnston Roberts, K. (1999). Patient empowerment in the United States: a critical commentary. *Health Expectations.* 2:82-92.

Kohn, L.T., Corrigan, J. M. and Donaldson, M.S. (2000). *To Err Is Human: Building a Safer Health System.* Washington, DC: Institute of Medicine. http://books.nap.edu/catalog/9728.html

Laine, C. and Davidoff, F. (1996). Patient-centred medicine: a professional evolution. *Journal of the American Medical Association.* 275:152-6.

Laughlin, S. and Black, D. (1995). *Poverty and health. Tools for change: ideas, analysis, information, action.* Birmingham: Public Health Alliance.

Lehr, H. and Strosberg, M. (1991). Quality improvement in healthcare: is the patient still left out? *Quality Review Bulletin.* 17:326-329.

Littell, J. H. (2001). Client participation and outcomes of intensive family preservation services. *Social Work Research.* 25(2):103-113.

Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., Ferrier, K., Payne, S. (2001). Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *British Medical Journal.* 323:908-911.

Lutz, B. and Bowers, B. (2000). Patient-centered care: understanding its interpretation and implementation in healthcare. *Scholarly Inquiry for Nursing Practice.* 14(2):165-187.

McGee, H.M. (1993). Patient choice in managing cancer. Editorial. *Drug and Therapeutics Bulletin.* 31:77-79.

McGee, H.M. (1998). Patient satisfaction surveys: are they useful as indicators of quality of care? *Journal of Health Gain.* 2 (2):5-7.

McIver, S. and Skelcher, C. (Eds.) (1997). *Consumerism and User Involvement in Public Services: Public Paper: Occasional Paper.* Birmingham: School of Public Policy, University of Birmingham.

McKinstry, B. (2000). Do patients wish to be involved in decision-making in the consultation? A cross sectional survey with video vignettes. *British Medical Journal.* 321:867-71.

Midgley, J. (1986). *Community participation, social development and the State.* London: Methane.

Miller, N.A. (1997). *Theoretical nursing: development and progress (3rd ed).* Philadelphia: Lippincott.

National Expert Advisory Group on Safety and Quality in Australian Health Care (1999). *Implementing Safety and Quality Enhancement in Health Care; National Actions to Support Quality and Safety Improvement in Australian Health Care.* AGPS, Canberra.

National Health Strategy Background Paper no.12 (1993). *Healthy participation: achieving greater public participation and accountability in the Australian healthcare system.*

National Resource Centre for Consumer Participation in Health (1999). *Needs Assessment. La Trobe University:* National Resource Centre for Consumer Participation in Health.

NHS Wales (2001). *Improving health in Wales : a plan for the NHS with its partners.* Cardiff: The National Assembly for Wales.

NHS Wales (2001). *Signposts – a practical guide to public and patient involvement in Wales.* Cardiff: The National Assembly for Wales.

Obeid, A. (2001). Perceptions of user participation in health care. *Journal of Community Nursing.* 14(4):13-19.

O'Keefe, E. and Hogg, C. (1999). Public participation and marginalised groups: the community development model. *Health Expectations.* 2:245-254.

Oliver, M. (1996). *Understanding disability: from theory to practice.* Basingstoke: Macmillan.

Øvretveit, J. and Aslaksen, A. (1999). *Integrated quality development in public healthcare. A comparison of six hospitals' quality programmes and a practical theory for quality development.* Oslo: Norwegian Medical Association Publication Series: Continuing Education and Quality Improvement.

Pickin, C., Popay, J., Staley, K., Bruce, N., Jones, C., Gowman, N. (2002). Developing a model to enhance the capacity of statutory organisations to engage with lay communities. *Journal of Health Services Research and Policy.* 7(1):34-42.

Preston, K. (1994). Rehabilitation nursing: a client-centred philosophy. American Journal of Nursing. 92(2):66,68-70.

Reiser, S. J. (1993). The era of the patient: using the experience of illness in shaping the missions of healthcare. *Journal of the American Medical Association.* 269(8):1012-1017.

Riseborough, M. (1997). The SEW Group: involving women in designing out crime on Bloomsbury Estate. In S. McIver and C. Skelcher (Eds.). *Consumerism and User Involvement in Public Services: Public Paper:* Occasional Paper. Birmingham: School of Public Policy, University of Birmingham.

Ritchie, J., Morrissey, C., Ward, K. (1988). *Keeping in touch with the Talking. Research Report Number 1.* Birmingham: Social and Community Planning Research.

Rose, H. (1990). Activists, gender and the community health movement. *Health Promotion International.* 13:129-48.

Ruhnke, G.W., Wilson, S.R., Akamatsu, T., Kinoue, T., Takashima, Y., Goldstern, M.K., Koenig, B.A., Hornberger, J.C. and Raffin, T.A. (2000). Ethical decision making and patient autonomy – a comparison of physicians and patients in Japan and the United States. *Chest.* 118:1172-1182.

Saltman, R. B. (1994). Patient choice and patient empowerment in Northern European health systems: a conceptual framework. *International Journal of Health Services.* 24(2):201-229.

Scottish Executive Health Department (2000). *Our National Health: A plan for action, a plan for change.* Edinburgh: The Stationery Office.

Shaw, C. (1997). Healthcare league tables in the United kingdom. *Journal of Quality in Clinical Practice,* 17:215-219.

Skelcher, C. (1997). Consumer-led services: some questions of strategy. In S. McIver and C. Skelcher (Eds.). *Consumerism and User Involvement in Public Services: Public Paper:* Occasional Paper. Birmingham: School of Public Policy, University of Birmingham.

Smith, R. (2002). The discomfort of patient power: medical authorities will have to learn to live with 'irrational' decisions by the public. *British Medical Journal.* 324:497-8.

Smithies, J. and Webster, G. (1998). *Community involvement in health: from passive recipients to active participants.* Aldershot: Ashgate Publishing.

Stuart, G (1999). Government wants patient partnership to be integral part of NHS. *British Medical Journal.* 319: 788.

Taskforce on Quality in Australian Health Care (1996). *The Final Report of the Taskforce on Quality in Australian Health Care.* Canberra: AGPS, Canberra.

Taylor, P. (1997). Swindon Health Authority Consumer Involvement Project. In S. McIver and C. Skelcher (Eds.). *Consumerism and User Involvement in Public Services: Public Paper: Occasional Paper.* Birmingham: School of Public Policy, University of Birmingham.

Torre, D.A. (1986). *Empowerment: structured conceptualisation and instrument development* (dissertation). New York: Cornell University.

Towle, A. (1997). *Physician and patient communication skills: competencies for informed shared decision-making.* Canada: University of British Columbia.

Tower, B.A. (1999). Seeking the user perspective in palliative care. *International Journal of Palliative Nursing.* 5(5):240-243.

Tuchman, L.I. (1996). The team and models of teaming. In P. Rosin, A. Whitehead, L.I. Tuchman, G.S. Jesien, A.L.Begun, and L. Irwin (Eds.). *Partnerships in family-centered care* (pp. 119–143). Baltimore: Paul Brookes Publishing.

US Congress, Office of Technology Assessment (1992). *Evaluation of the Oregon Medical Proposal.* OTA-H-531. Washington DC: US Government Printing Office.

Walls, M (2001). *Building blocks to best practice - an exploration into the factors which influence the successful implementation of an Integrated Holistic Model of early intervention in a voluntary organisation providing services to children with physical disability.* Unpublished Masters in Education thesis. University of Sheffield.

Watt, A. and Rodmell, S. (1988). Community involvement in health promotion: progress or panacea. *Health Promotion*, 2:359-68.

Webster, G. (1995). Public participation in health: empowerment or control? In S. Edgell, S. Walklate and G. Williams (Eds). *Debating the Future of the Public Sphere.* Aldershot: Ashgate.

Webster, B. (1997). User involvement in service review: under-fives in Gloucestershire. In S. McIver and C. Skelcher (Eds.). *Consumerism and User Involvement in Public Services: Public Paper:* Occasional Paper. Birmingham: School of Public Policy, University of Birmingham.

White, D. (2000). Consumer and community participation: a reassessment of process, impact and value. In G. Albrecht, R. Fitzpatrick and S. Scrimshaw. *Handbook of Social Studies in Health and Medicine.* London: Sage.

Williams, B., Cattell, D., Greenwood, M., LeFevre, S., Murray, I. and Homas, P. (1999). Exploring 'person-centredness': user perspectives on a model of social psychiatry. *Health and Social Care.* 7:475-482.

Wilson, M.R., Runciman, W.B., Gibberd, R.W., Harrison, B.T., Newby, L., Hamilton, J. D. (1995). The Quality in Australian Health Care Study. *Medical Journal of Australia.* 163, 458-471.

Winkler, F. (1987). Consumerism in healthcare: beyond the supermarket model. *Policy and Politics.* 15:1-8.

World Health Organisation (1998). *Health21: the health for all policy framework for the WHO European Region.* European Health for all series, no. 6.

Zakus, J.D. (1998). Resource dependency and community participation in primary healthcare. *Social Science and Medicine.* 46:475-94.

Useful websites

Building a safer NHS for patients: implementing an organisation with a memory (2001)
www.doh.gov.uk/buildsafenhs

Centre for Health Quality Information (2002)
http://www.hiquality.org.uk.

The Center for Patient Partnerships at the University of Wisconsin
http://www.law.wisc.edu/patientadvocacy/

The College of Health
http://homepages.which.net/~collegeofhealth/

The Council on Quality and Leadership. Information on US system of accreditation focusing on Personal Outcomes
http://www.thecouncil.org/

The Expert Patient: a new approach to chronic disease management for the 21st century (2001)
http://www.ohn.gov.uk/ohn/people/expert.htm

Final Report of the Bristol Royal Infirmary Inquiry (2001)
http://www.bristol-inquiry.org.uk/final_report/index.htm

International Classification of Functioning, Disability and Health (WHO)
http://www.who.int/whosis/icd10/

Involving patients and the public in healthcare: a discussion document (2001)
www.doh.gov.uk/involvingpatients

National Resource Centre for Consumer Participation in Health
http://nrccph.latrobe.edu.au/

The NHS Plan: a plan for investment, a plan for reform   (2000)
www.nhs.uk/nhsplan

Shifting the balance of power – creating strategic health authorities (1996)
www.doh.gov.uk/shiftingthebalance/

Welsh NHS Participation document – Signposts (2001)
www.wales.gov.uk/signposts

World Health Organisation, Declaration of Alma Ata, 1978
www.who.int/hpr/archive/docs/almaata.html

World Health Organisation, Jakarta Declaration on Health Promotion in the 21st Century, 1997
www.who.int/dsa/cat95/zjak.html

World Health Organisation, Ottawa Charter on Health Promotion, 1986
www.who.int/hpr/archive/docs/ottawa.html

Appendix 1

Recommendations for training and support from *Voices in Action* (Bradburn et al, 1999)

- The training and support scheme should meet the needs of potential as well as current lay representatives

- Lay representatives and groups should be encouraged to gather views of people whose voices might not be heard, using a variety of methods

- Training and support for lay representatives should be supported by community development and capacity building

- Training should be
  - based on individual assessment
  - modular in its format
  - developmental
  - evolutionary to reflect changes
  - combined with experiential learning
  - reflective of the needs of partnership working
  - drawn on local as well as wider knowledge
  - based on an active learning approach
  - a combination of contextual information, personal development and skills training

- The way in which training is delivered should not reinforce barriers

- Training should be delivered in a manner appropriate to those being trained – in local areas this will mean in local areas, with facilitators who have local knowledge

- Training should not be exclusive to a selected group of people but should be targeted

- Preparatory work might involve mapping existing training, identifying existing lay representatives, raising awareness of the opportunities for having one's voice heard and identifying excluded groups and their particular needs

- Training should be made locally available through local voluntary training agencies, colleges and the NHS. It should be nationally available through the College of Health, through other national voluntary organisations and possibly through the Internet

- Training should be delivered as face-to-face training to groups backed up by a manual

- Evaluation should include
  - individuals setting outcomes for themselves based on a skills assessment
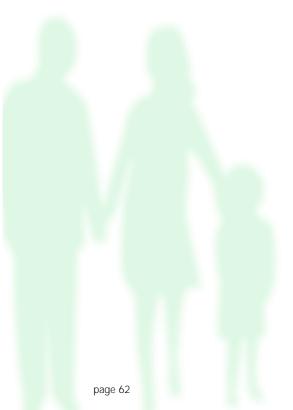 - individual assessment of the course in terms of meeting objectives

- a self-assessment after six months
- a 'trusted other' assessment – feedback from other members of committee or other mentors

- Training for health professionals in how to engage in effective partnerships

- Joint training of lay persons and professionals designed to learn how to work together

- If user involvement is to become part of mainstream activities, existing training budgets and opportunities for multi-agency funding need to be reviewed

- Lay representatives should be able to access existing training courses

- Lay representatives and groups should be able to apply for funds for training courses

- Committees should make more money available as part of user-involvement initiatives

- Local reviews of funding and training should be undertaken on a multi-agency basis

- Mutual support through linking lay representatives to a national central association

- National funding accessible to all

- On-going training and support for lay representatives but also joint training of lay representatives and professionals.

Appendix 2

Principles underpinning the process of partnership (De Burca, 2001 and Davies, 1999)

De Burca	Davies
• Citizen rights and responsibilities for their own health and well-being • Citizen rights are worthy of respect	*Motivation* • Clear vision of the aims and objectives of participation • Motivation of participants
• Facilitated dialogue at every level • Partnership is a process of mutual discovery and informed consent	*Honesty* • Honesty about the aims and objectives of participation • Honesty about the potential products of participation
• Manage one's own life and health journey in changing situations • Develop care competencies • Challenge dominant culture of dependency	*Commitment* • Both material and ideological support • Genuine agreement that participation is a valuable thing
• Co-operation within user and carer groups and across traditional boundaries • Flexible co-operation	*Access* • Mechanisms to facilitate partnership should not exclude people through social or physical barriers
	Communication • Reduce tensions and conflicts with policy and decision-making processes
	Flexibility • Flexible structures of communication and conflict resolution strategies
	Monitoring and Evaluation • Monitoring and review should take place in parallel with partnership activity • Activities and processes undertaken as part of participation should be regularly evaluated in comparison with desired aims and objectives
	Learning • Participation = process of mutual education and learning for all involved
	Continuity • One-off events can have a negative effect and mitigate against future participation
	Accountability • Accessible process by which service providers give accounts of their actions to, and are held accountable by, participants

Appendix 3

Principles for policy making (NHS Wales, 2001)

Principle	Implications for policy
Fairness	The fairness of provision and access to services in relation to need on various dimensions such as geography, socio economic status, demography, care groups
Effectiveness	The extent to which services are: • clinically effective (evidence-based) • appropriate to need • timely • in line with agreed standards • targeted and effective, e.g. health promotion programmes • provided by organisations whose services conform to best practice • delivered by appropriate levels of trained, competent and educated staff
Efficiency	The extent to which the NHS provides efficient services including • cost per unit of care/outcome • productivity of capital estate • labour productivity
Responsiveness	The extent to which services are • focused around the individual needs and preferences of patients • demonstrate patient involvement, good information and choice • address waiting time and accessibility • are progressively improved
Integration	Evidence of • effective participation in the use of local Health Alliances • joint planning within health improvement programmes and community plans of the local authorities, e.g. development of joint training for 'cross boundary' staff • joint use of resources through joint investment plans for use of new powers to pool resources • the developing role of local health groups, e.g. percentage of LHGs managing devolved budgets

	• integrated delivery of services both within and outside the NHS, reflected in long-term agreements
Accountability	Evidence of • effective benchmarking practice aimed at consistently improving performance • effective management of services at a local level • long-term agreements which have a patient focus and reflect thee key priorities of the local Health Improvement Programme • local performance management arrangements, e.g. in relation to progressing the local Health Improvement Programme • implementation of corrective action plans where performance and efficiency fall short of expectation • open decision-making processes • public involvement in planning, implementation and monitoring • measures to encourage the public to take responsibility for their own health and use of health services
Flexibility	The extent to which the NHS provides flexible services which • respond to individual need and preference • adapt to changing needs • take advantage of joint working with local authorities and the voluntary sector
Independence	Evidence of shifts in demand for services linked to the growing independence of users

Notes