DEVELOPING A DIALOGUE ON HEALTH: USER INVOLVEMENT IN HEALTH AND HEALTH SERVICES

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Abstract

In common with other areas of public services, recent years have seen a shift in the National Health Service (NHS), with increased power and authority transferring from professionals towards the users of services. As a result, user involvement has come to form a central element of government policy on public services, and health in particular, with a series of specific policy commitments to give users a stronger voice and to involve them in the health service having been published by both the Westminster and Scottish parliaments. These seek to increase users' involvement in making decisions about their own care and treatment, in examining and improving the quality of services and in policy and planning activity. In doing so, this policy aspires to respond to the changing culture of personal and societal expectations of health and the health service; to build democratic participation in the difficult targeting and rationing decisions faced by health agencies and, thus, to help renew public trust and strengthen confidence in the NHS. These are ambitious aims with far-reaching implications as they represent a transformation in the interaction between users, health professionals and health policy makers.

This thesis examined how this policy has been understood and implemented in the NHS by exploring the scope, relevance and quality of the user involvement processes available in three health service settings. In order to develop a better understanding of the issues in user involvement it explored the nature of user participation; the character of user representation and the barriers and facilitators to user involvement in maternity, gynaecological oncology and mental health services. The study examined the response to this policy within these three settings; the functioning of existing user involvement mechanisms and their capacity to involve users in determining their individual health care and in shaping health services and policy to their definition of need. From this examination it defined the key features of a model process for user involvement within the professional service culture and organisational ethos of the NHS. The study then drew conclusions on the capacity of these current user involvement processes to deliver on the policy directive to develop both individual treatment and health services in ways that are responsive and accountable to users.

Finally, the thesis identified those areas that require further research before proposing the lessons for the further development of this significant and potentially influential policy directive.

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Author's Declaration

This empirical study was designed, conducted, analysed and written up by the author.

Introduction

Recent years have seen a power shift in the National Health Service (NHS), away from professionals and towards the patients and users of services. In line with developments in other areas of the public sector, users of the NHS now have higher expectations of services, are more aware of their right to choice and participation in decision-making and have increased familiarity with the wider context of health provision (Barnes & Evans 1998; Bury 1998; Hogg 1999a; Brooks 2001; McCrae et al 2002). In the pluralistic context of health the views of patients and users are increasingly recognised and, as a result, the creation of dialogue between the NHS and its users has become the focus of much innovation in public policy, moving to a position high on the policy agenda (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). This thesis examined how this policy, defined as user involvement, has been understood, interpreted and implemented within health services. It has sought to describe the extent and nature of user involvement in health and explored how users are involved in managing their own health and in shaping health services to their definition of need. As such, this study was concerned with a major policy consideration for the NHS, as how the NHS engages with users has been dubbed "the greatest challenge for health services at the beginning of the twenty-first century" (Brookes, 2001) and one that is "critical to its future development" (Barnes, 1997).

This study drew on social policy and was underpinned by a philosophy that derives from an understanding that users have a democratic right to involvement. Central to current public policy on user involvement are the concepts of democratic accountability and citizenship and the desire to make services more responsive to users' definition of need (Brooks 2001; Scottish Executive 2001; McCrae et al 2002). User involvement can be seen as related to both a specific debate about appropriate governance for the NHS, and to a series of broader debates about democracy and citizenship in the United Kingdom (UK). A growing body of multi-disciplinary literature concerned with both theoretical and ideological discourse as well as more practical issues reflects this increasing priority.

Such is the perceived importance of user involvement to the future of public services that most government departments, including the Cabinet Office (1998), the Department of the Environment, Transport and the Regions (1998) and the Department of Health (1998), have published guidance on the philosophy and methods of effective user involvement in public services. In Scotland the health policy context is set by a series of national documents, *Designed to Care* (1997); *Our National Health* (2000), *Consultation and Public Involvement in Service Change* (2002) and *Delivering for Health* (2005), while

guidance on the implementation of user involvement in the health service was provided in the policy document *Patient Focus and Public Involvement (PFPI),* published by the Scottish Executive in December 2001. These documents place users at the centre of health service delivery and planning by promoting partnership in care and user involvement in decisions over service provision. They seek to increase dialogue with health users, forge new alliances between them and professionals and develop debates about the role of the NHS in partnership with its users. This is proposed as the basis of effective, accountable and responsive services and is conceived as having the potential to challenge traditional perceptions of health and to negotiate agreement and consent with the rationing and targeting decisions increasingly required of the health service (Brooks 2001; Scottish Executive 2001; McCrae et al 2002).

The current policy imperative on user involvement has led to a requirement on all sections of the health service to prioritise, at the highest level, the examination of their services from the perspective of patients and users, and to make changes designed to improve their experience of the NHS. Increased organisational commitment and resources have accompanied the policy leading to a proliferation of involvement activity. There is little doubt that the aspirations for this policy are ambitious, seeking as they do to change the culture of the NHS, the nature of the relationship between users and health professionals and to build public confidence in potentially contentious rationing and service re-design decisions. This study aimed to explore the influence of the policy on user involvement on health services. It was designed to explore how far the policy aspirations were, and could be, met within the current culture and organisational ethos of the NHS and to identify the defining features of a model process for user involvement for the future. The detailed aims of the study are described in the next section.

The Aims of the Study

This study aimed to investigate the implementation of this policy by describing the nature of user involvement in three health service settings. It sought to explore the extent to which the policy aspirations of changing the culture of the health service, the ways in which the NHS interacts with people and the ways in which services are delivered were being achieved. Furthermore, the study was interested in examining the extent to which users were involved in health service processes and, in particular, the capacity of services to engage with those who are described as marginalized. A group that the literature on user involvement suggests are marginalized is women.

One influence on the social circumstances of life that has been acknowledged as having an important influence is gender; that is the way that society constructs our life experience

based on whether we are female or male. There is evidence to suggest that gender and an understanding of the wider social determinants of health should underpin user involvement as, apart from the obvious sex differences, men and women have different social roles and expectations, differential access to services, experience different health difficulties, use services differently and finally, want different things from their health providers (Papanek 1990; United Nations 1994; Janzen 1999; Horne et al 1999; Scholle et al 2000). Furthermore, women, to a greater extent than men, utilize the health care system to access services for themselves and other family members (Horne et al 1999; Willson & Howard 2000; Donner 2003). Women in focus groups have been found frequently to discuss health care expectations not just in terms of their own experiences, but also their experiences obtaining care for others, including children, spouses or parents (Scholle et al, 2000).

Evidence from a MORI poll undertaken in 1991 found that 20% of the adult population they surveyed had served on a committee in a voluntary capacity and of this group there was a higher proportion of men than women (MORI, 1991). However, this is a rare finding on user representatives who are almost always homogenised as a single group. Diversity with respect to gender has rarely been taken into account and, as a result, it has been argued that women's voices have not been heard despite the available evidence suggesting that they are major health care providers in professional as well as informal care and major health service users (Horne et al l999; Willson & Howard 2000; Donner 2003). As a consequence, it has been reported that women remain under-represented in decision-making in health care (Gijsbers van Wijk et al 1996; Willson & Howard 2000; Donner 2003). Women as a constituency have sought to add their views to traditional policy making through standard organising and lobbying techniques and feminist researchers have explored ways to incorporate a diversity of women's positions into policy-making (Vickers et al 1993; Horne et al 1999; Donner 2003). However, there is little evidence to suggest that such influences have been mainstreamed into the user involvement agenda.

The assertion that women were more likely to be users of the NHS but are less likely to be influential in user involvement was significant in the choice of women as a group of health users for particular examination within this study. This focus on one under-represented group was underpinned by a supposition that if the structures and systems for user involvement were sufficiently sensitive to incorporate the participation of one marginalized group then they would be accessible to other marginalized or hard-to-reach groups.

Three settings were chosen for detailed examination. Each had a different history of user involvement, used a different model of care and had differing relationships with its users. These conditions were established in order to generate contrast and comparison and to enable an examination of the facilitators and constraints upon the further development and

implementation of this particular policy. The three settings chosen were gynaecological oncology, maternity and mental health services. All three of these settings shared a number of characteristics. The first was that each had statutory responsibilities towards user involvement as defined by the current policy context. Second, and of particular importance to this study, was that each had women as users and third, each had some level of existing user involvement activity. However, they also differed in some aspects.

The first service setting chosen was gynaecological oncology services. This was a setting with little history of user involvement in service and policy processes but with a substantial record of patient-centred care that had sought to involve users in their individual care and treatment. Furthermore, gynaecological oncology services operate within a traditional bio-medical model of health, with its relationships with users characterised by a dominant clinical elite and a paternalistic view of patients. The second setting was maternity services. Unlike gynaecological oncology, maternity services have a significant, documented history of user involvement in service and policy processes as well as in patient-centred care. In addition, maternity services differ from gynaecological oncology in that service users are not ill and as a result a woman-centred or partnership model of care has evolved.

The third setting was mental health services where patient-centred, also known as person-centred, care is well established. User involvement has a substantial presence in mental health service and policy processes although its history in mental health services is neither as extensive nor straightforward as that of maternity services. Indeed, it has been suggested that mental health services have a history of user movements that have often been viewed as confrontational and challenging (Hogg, 1999a). Mental health services also differ from the other two settings in that its users are both male and female.

The first aim of the thesis was to explore how this policy had been implemented in these three settings in order to describe the activity, outcomes and impact attributed to user involvement. It set out to examine the general approach to user involvement mechanisms in health and to describe in detail those used within the three service settings. In doing so the thesis sought to explore the philosophy and nature of existing user involvement mechanisms, with particular reference to their capacity to involve users in shaping the policies and delivery of their health services.

Second, through an examination of the uses, outcomes and difficulties experienced in each of the specific service settings, the study sought to identify the facilitators and barriers to user involvement in health. In order to investigate the scope of views within each setting a number of different perspectives were explored. Four groups of respondents were

identified as representing diverse positions on user involvement. These groups were managers, clinicians, users and strategists. Each had an interest in the issues under examination but held different roles in relation to the development and implementation of the policy. The third aim was to develop the key features of a model process for effective and meaningful user involvement. The study sought to achieve this through an analysis of the facilitators and barriers and an examination of the issues identified as arising from the implementation of user involvement. Finally, the study aimed to draw conclusions for the development of future, systematic user involvement that has the capacity to inform both policy and practice. In summary, the aims of the study were:

- To describe the current processes by which users within three health service settings - maternity, mental health and gynaecological cancers - are involved in defining their individual health and health needs; shaping the services they use and setting strategic direction for the health service

- To describe the barriers and facilitators to effective user involvement

- To describe the dimensions of a user involvement model that leads to meaningful participation in both personal health and in shaping policy and planning decisions in health services

- To explore the conditions for future user involvement in health services

A qualitative methodology was adopted for the study. Different approaches were used to develop three case studies in order to build an explanatory account of user participation in shaping health services. The emphasis in qualitative research is on 'the perspective of those being studied rather than the prior concerns of the researcher, along with the related emphasis on interpreting observations in accordance in accordance with the subjects own understandings' (Bryman, 1989). Of particular concern to this study was the analysis of process. How and why user involvement developed, how and why this influenced services and how and why, or indeed why not, was it important in each of the three settings identified. A qualitative approach afforded this through its concern with context.

The methodology of this study is discussed in detail in chapter seven but one issue that emerged at an early stage as a potential bias was the researcher's known commitment to the principles and practice of user involvement. The researcher had a background in social policy and health services research as well as substantial experience in advocacy and user participation. With current employment in a team with a remit to engage non-clinical interests in the Acute Services Strategy for Glasgow, it was recognised that this study was of particular interest to the researcher. It was also acknowledged that her personal philosophy, knowledge and values could influence the study and introduce an element of

bias. A particular concern of the methodology was to minimise the risks of such bias. The strategies adopted to achieve this are discussed, along with other aspects of the trustworthiness of the study, in chapter seven.

The Scope of the Study

User involvement in health is a wide-ranging and ambiguous concept that required a degree of clarity before being explored in depth. There were a number of elements to the conception that required definition. The first of these was the concept of 'user involvement' itself. User involvement is an umbrella term to which a plethora of meanings have been attached and considerable diversity over definitions can be found in the literature. It is broadly about seeking users' views of a specified phenomenon although the actual activity is widely interpreted (Drewitt, 1997) and hence variously named and represented. User involvement is also a term that encompasses a wide range of activities within which qualitative distinctions can be made between different levels or degrees of interaction between service users and service providers. The range of relationships between users and service providers can be represented as a continuum along which different levels of involvement from communication, which has been defined as establishing meaningful dialogue; consultation, which is asking user views, and partnership where equal relationships exist between users and professionals have been distinguished (Taylor 1996; Scottish Association of Health Councils 1999). For the purposes of this study 'user involvement' was defined as the direct engagement of individuals or user groups in their personal health and in health service policy and decision-making processes. Chapter one will explore the conceptualisation of user involvement and the dimensions of this definition in order to further refine the scope of the concept and of this study.

A second element that required definition was the use of the term 'user' to describe the subjects of involvement activity. An analysis of the literature revealed that there was no one word that could be comfortably used to describe the individual receiver of health care. Patient, client, customer, consumer and user have all been used and each has different implications. The word 'patient' implies a compliance and passivity that reflects the unequal power between patient and health professional. As such, this was a term that two of the service settings under review were uncomfortable with. 'Patient' also excludes carers and people who may use services in the future. 'Customer' or 'consumer' was often used as this fitted with the business ethos that was introduced into the health service in the 1990s, but people receiving health care do not see themselves as customers or consumers and rarely have the choice that this implies (Hogg, 1999a). Another term used in the literature is 'the public'. This implies the wider participation of those who while not current users of the health service, nevertheless are stakeholders as they have the potential

to be future patients or carers. 'User' was identified as a term that could include patients, potential patients and carers and so throughout this thesis the term 'user' is used in its widest possible meaning. 'User' will include individuals receiving health care and everyone who may use services in the future, either as patients or carers.

Finally, the scope of the health services under examination was defined as the NHS in Scotland. This study was concerned with the Scottish policy context and as such explored the operation of health services in Scotland. The term 'health agencies' is used throughout this thesis to describe a range of Scottish health structures and systems that includes NHS Boards, known as Health Boards until 2005; NHS executive organisations, these include groups such as Quality Assurance Scotland and the Clinical Standards Board for Scotland; NHS Divisions, described as NHS Trusts until 2005 and local services, such as hospitals and general practices. Part two of the literature review will focus on three particular clinical settings: maternity, gynaecological oncology and mental health but the first part of the review examines the wider range of health provision in Scotland.

The conceptualisation of user involvement is explored in greater detail in chapter one but this section will first outline the literature search strategy used in this study.

Literature Search Strategy

The literature review for this study combined an electronic search of medical, nursing, social policy and healthcare management databases with a hand search for grey literature and contact with experts and user groups.

The first element of the literature search was an electronic search of biomedicine and health journals, newsletters and scholarly reports encompassing life sciences, behavioural sciences, public health and health policy development over the period 1970 – 2008, using the Medline and PubMed databases. Particular care was taken to explore the journals reporting on oncology, maternity and mental health services with a view to identifying descriptions of user involvement within the literature on these services. The search terms were produced by a combination of discussion with colleagues and the research supervisor, appraisal of keywords from review articles and an investigation of thesaurus and medical subject headings (Mesh terms) on bibliographic databases. The search terms used related to user, carer, public and patient involvement; user, carer, public and patient participation and user, carer, public and patient engagement. These were combined with research design terms that included qualitative investigation, focus groups, evaluation, controlled clinical trial and research design. The initial search generated relatively few examples of peer-reviewed literature leading to a widening of the search terms to include patient

information, shared care, collaborative care, self-management, patient-centred care; expert patient and patient held records.

It was noted that there were only a small number of studies that reported directly on user involvement, and particularly few descriptions of the processes involved, within the traditional medical and nursing journals contained within the biomedical databases covered by Medline and PubMed. As a result the search was widened to include the HEBS (Health Education Board for Scotland) and Embase databases in order to include health education and social policy literature. A further strategy was to search directly for the names of organisations or commentators that had emerged as significant contributors to the field. Searches for organisations such as The Joseph Rowntree Foundation and authors including Angela Coulter and Christine Hogg were conducted in order to identify position papers, reports and editorials that could yield further references. These references then triggered further searches.

To complement the published, peer-reviewed work on user involvement, and to address the limitations of the electronic search, a hand search of the grey literature was undertaken using the same search terms. As user involvement is a relatively new phenomenon with its roots in collaborative or community action, it was anticipated that there would be a number of unpublished reports, conference reports, accounts and evaluations of involvement activity. This search of the grey literature was assisted by contact with a network of experts in this field, user groups and organisations. These were approached for advice and guidance in identifying and acquiring unpublished material. As with the electronic search, these generated further authors, papers and references that could then be followed up.

It was noticed that the electronic search generated a significant body of literature that reported on user satisfaction surveys. However, the decision was made to exclude surveys of user satisfaction that were researched by health authorities as these did not involve any form of partnership or collaboration with users. User surveys have been increasingly accepted in health services over recent years but they have also been subject to much criticism (Cheetham 1993; Williams 1994; Williams & Wilkinson 1995; Avis et al 1997; Spencer et al 2000). A particular criticism in relation to user involvement has been the lack of reporting on the use and impact of survey results. It became clear at an early stage of the review that it would not be possible to judge the likely influence of user surveys in policy or service planning and delivery without such reporting. Therefore, it was decided that, while it would be appropriate to review surveys as a methodology of user involvement and to discuss their use in the health setting, they would not be included as examples of user involvement in the literature review.

Overview of the Thesis

The first part of this thesis is a literature review. The first chapter will further define the concept of user involvement in terms of type of activity, degree of interaction and reactivity. It will describe the social and policy trends that have shaped the conceptualisation and history of user involvement in order to investigate how these have influenced the development of the current the Scottish policy framework. Chapter two will consider how this policy directive has been understood and implemented within the health service, by exploring the evidence for the involvement of individuals in making decisions about their own care and treatment, involvement in examining and improving the quality of services and involvement in health service policy and planning.   Chapter three will then examine the barriers to user involvement that have been identified and the implications these reveal for the core concepts, relationships and culture of the NHS.

The second part of the literature review will explore how the policy on user involvement in health has been understood, interpreted and implemented within each of the three settings chosen for detailed review - maternity, gynaecological oncology and mental health. Chapters four, five and six will discuss the history and development of user involvement in each setting and examine the opportunities for women's involvement in three types of user involvement. These are involvement in making decisions about individual care and treatment, involvement in examining and improving the quality of services and involvement in health service policy and planning.

Chapter seven outlines the research methods adopted by this study.   It was recognised that there were a number of practical and ethical considerations affecting the way the study was carried out and these are discussed here. This chapter describes the methodology implemented in an attempt to balance these concerns and some difficulties experienced with bias. Chapters eight, nine and ten present the findings around the themes of the nature of user participation within health and health services; the character of user representation and the barriers and facilitators to user involvement. In doing so it will seek to build an account of the extent to which women within maternity, gynaecological oncology and mental health services are involved in determining their health care and in shaping health services and policy to their definition of need.

The final discussion chapter draws together the findings from the data chapters to address the aims of the study and the research questions. First, it reports on the current implementation of user involvement and the limitations identified in this. Next, the chapter describes the implications of these limitations for the aspirations of this policy to transform the nature of the relationship between health service users and health

professionals and thus, the organisational and professional service culture of the NHS. This chapter will then discuss the issues in representation and its repercussions for equity in health services. Finally, it reports on the defining features of a model for the implementation of user involvement in health services. The chapter concludes by noting the limitations of the study, but also suggesting the contribution to the existing literature, and the implications for policy and further research.

The first chapter will begin by examining the conceptualisation of user involvement and how it has moved to prominence in the political agenda for the NHS.

Chapter 1: The History and Conceptualisation of User Involvement in Health

At the heart of the current government commitment to public services and the NHS in particular, is the concept of user involvement. User involvement aims to engage the users of health services in their own care and in the services they use by providing information to and learning from users. It aspires to change the culture of the health service, the ways in which the NHS interacts with people and the ways in which services are delivered (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). User involvement in health is a rapidly developing field, which for many is seen as a new enterprise requiring fresh skills and innovative approaches (Barnes 1997; Foote & Plesk 2001; McCrae et al 2002). However, health services also have a substantial history of patient-centred care that has sought to place the needs and preferences of users at the centre of their interaction with services. This history has led some to propose that user involvement is already both familiar and established in health (Barnes & Evans 1998; Scottish Association of Health Councils 1999; McCrae et al 2002).

It would, then, appear to be important to achieve clarity on the concept and how it is understood within the health sphere. This chapter will begin by describing the literature on the concept of user involvement and how it has been interpreted within health services. Then, in order to better understand the context within which user involvement has developed and the aims articulated for it, this chapter will describe the social and policy trends that have shaped the history of user involvement in the health service and the policy framework that has subsequently been developed.

Definitions and Conceptual Framework

User involvement is a generic or umbrella term to which a plethora of meanings have been attached. There is considerable diversity over definitions to be found in the literature and different conventions are in widespread use. 'User involvement' is broadly about seeking users' views of a specified phenomenon although the actual activity is widely understood and interpreted, and hence variously named as consultation, collaboration, involvement, participation or research (Drewitt, 1997). Some authors have used 'consultation' as a term to convey a range of approaches to involving users (Laird et al, 2000) while others describe these as 'user participation'. For some 'user involvement' is viewed as a proactive pursuit while 'consultation' implies a passive or even tokenistic attempt to engage with the stakeholders in public services (Amstein 1969; Scottish Association of Health Councils 1999; McCrae et al 2002). While such ambiguity may militate against the development of

a shared understanding, Richardson (1983) also identifies how the many meanings associated with the concept of user involvement, or 'participation' as he defines it, has helped to facilitate the widespread adoption of the idea.

> "The ambiguity attached to participation has helped to foster its own cause. Because so many different hopes have been linked with it, so many different expectations about what it will achieve, spokesmen of highly varying political hues have embraced it.   Consumers have advocated participation in order to achieve their particular ends and the service providers have similarly welcomed it in order to serve theirs.   The very uncertainty of its impact has enabled a common rallying call." (Richardson, 1983, p. 99)

Within the broad concept of user involvement a number of dimensions can be identified. These include the types, reactivity and proactivity and levels of involvement.   These will be explored in order to assist in defining the nature and focus of the ideas explored in this thesis.

The first dimension that has been defined is the different type of involvement. It is possible within the literature to distinguish three main types of activity described as 'user involvement'. These are the involvement of individuals in making decisions about their own care and treatment, involvement in examining and improving the quality of services and involvement in health service policy and planning (Charles & De Maio 1993; McIver & Brocklehurst 1999; McCrae et al 2002). Involvement in individual care and treatment decisions is also described as 'patient-centred' care (WHO, 1978). This is a philosophy of care based on the concept of health professionals working in partnership with users and emphasises the importance of communication, informed choice and responsiveness. Recent years have seen increasing support for this approach (Toop, 1998) with many health settings actively promoting this model of care.

User involvement in shaping services, policy and planning has had a less substantial presence in the health service but is based on the belief that the people who use services can be the best judges of their strengths and weaknesses (Wilson, 1999) and that by providing a different perspective there is the potential for different and innovative solutions to the contentious and potentially divisive decisions facing health agencies (McCrae et al, 2002). Some authors distinguish between involvement in services, policy and planning at a national level, as well as involvement in locality commissioning (Barnes 1997a; McCrae et al 2002). Additionally, it is usually seen to be helpful to differentiate between individual and collective involvement but this does not necessarily equate with the types of activity in which each can be involved. For instance, both individuals and user groups can be involved in assessing and evaluating service quality, in strategic planning and service development.

These three types of user involvement would appear to provide a valuable framework for the examination of user involvement for two reasons. First, they encompass the capacity of user involvement to address both the public and personal aspects of health. They recognise that health has a unique resonance in people's lives, being both a uniquely 'public' good on the one hand and an intensely private individual matter on the other. Policy, planning and service decisions include public issues such as the perception of priorities in health care while the private, personal issues in health are addressed by the values of patient-centred care. Second, these three types of involvement demonstrate the four broad purposes of user involvement identified by Barnes (1997a). Barnes has argued that the first purpose was to achieve individual empowerment, enabling people to become effective users of health services and to take action to improve their own health status. A second purpose was to meet the needs of the organisation by learning how users perceive services, measuring quality, effectiveness and equity. Third, user involvement could enable the expression of aspirations and become 'an agent of change at a systems level" and lastly, involving people in health services was proposed as helping to enhance democratic accountability and citizenship.

Therefore, these three types of user involvement - the involvement of individuals in making decisions about their own care and treatment, involvement in examining and improving the quality of services and involvement in health service policy and planning will be used as an organising principle in this thesis. The activity and outcomes of user involvement will be explored using these headings in the literature review and, in later chapters, this structure will again be used in order to organise and report on the findings of the study.

The next dimension is the description of user involvement as either 'reactive' or 'proactive' (Mullen & Spurgen, 2000). This distinction concerns not only the approach taken to involvement and the methods used but also the view taken of the purpose and nature of involvement. Where involvement is 'reactive', the health care system asks users to react to activities, services plans, proposals and priorities. In contrast, 'proactive' involvement means users becoming involved in initiating and formulating definitions of need and making proposals for new or improved services.

The third dimension identified in the literature is the level of involvement because, in addition to examining the type of involvement, qualitative distinctions can be made between different levels or degrees of interaction. The Scottish Association of Health Councils (1999) differentiated between three levels of involvement, which can be described as a continuum. These were communication, which they defined as establishing meaningful dialogue; consultation, which is asking user views, and partnership where

equal relationships exist between users and professionals. In England and Wales the Department of Health funded INVOLVE programme, that promotes public involvement in NHS, public health and social care research, illustrates these levels in their definition of involvement in research as "an active partnership between the public and researchers in the research process rather than the use of people as the 'subjects' of research". They also propose that active involvement may take the form of consultation, collaboration or user control and distinguish public involvement in research as doing research 'with' or 'by' the public, rather than 'to' or 'about' or 'for' the public.

The 'ladder of participation' developed by Arnstein (1969) is an expression of this idea of different degrees of interaction expressed within the context of wider power relations. This is described below.

Citizen control
Delegated power   Degrees of citizen power
Partnership

Placation
Consultation   Degrees of tokenism
Informing

Therapy
Manipulation   Non-participation
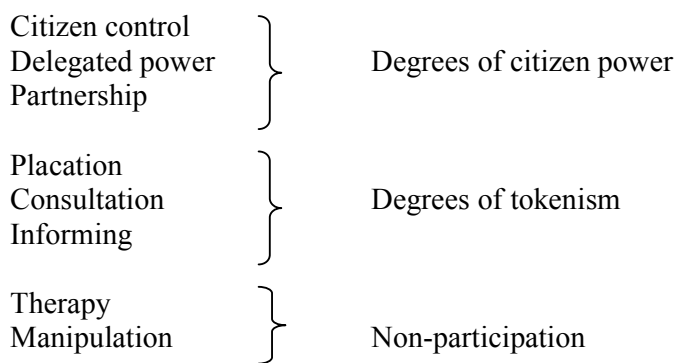
Arnstein suggested that only the top three rungs, partnership, delegated power and citizen control, concerned genuine involvement or dialogue with people. A number of studies since the publication of Arnstein's ladder of participation have refined this conceptualisation, including Hoyes et al (1993) as cited in Small and Rhodes (2000) who described the following ladder of empowerment in user involvement:

High   Users have the authority to take decisions
              Users have the authority to take selected decisions
              User views are sought before decisions are finalised
              Users may take the initiative to influence decisions
              Decisions are publicised and explained before implementation
Low   Information is given about decisions made

Whilst widely acknowledged as a useful model, there are some criticisms of the ladder of participation in its presentation as a linear process and its failure to take account of the range and complexities of relationships between users and service providers (Laird et al 2000; Small & Rhodes 2000). Nevertheless, it is considered helpful to have ways to distinguish between involving users from merely giving or gathering information about peoples' views of services; one-off focus groups or surveys and by longer-term initiatives offering user control (Taylor 1996; Scottish Association of Health Councils 1999).

Thus, user involvement appears to offer a myriad of potential opportunities with a wide range of activity distinguished in terms of type, collective or individual action, pro or reactivity and by the level of involvement. For the purposes of this study 'user involvement' is defined as a form of involvement that entails the direct engagement of individuals and user groups in making decisions about their own care and treatment, in examining and improving the quality of health services and in health service policy and planning processes.

Chapter two will describe how this wide range of opportunities has been understood and implemented within the health service in pursuit of the policy aims of user involvement. However, in order to better understand the context within which user involvement has developed, the next section will describe the social and policy trends that have shaped the history and development of health service policy on user involvement.

The Development of User Involvement in Health Services

The emergence of a social movement for health with its roots in partnership and collaboration, explicit policy statements and central government initiatives have all converged to encourage the growth and development of user involvement in health services. UK and Scottish government reforms and policy documents provide a timeline for this development while commentators have identified a number of social and cultural contributory trends to explain the surge of interest in user involvement.   This section will first explore the history of user involvement within the health service before going on to describe how this history along with the prevailing cultural, social and ideological trends has shaped the current policy context.

The History of User Involvement in Health Services

Many commentators view the late 1960s and 1970s as a crucial period in the growth of interest in user involvement. This was a period generally regarded as a time of social, political and cultural volatility when progressive movements of citizens, intensely dissatisfied with their social status, promoted public resistance to major social institutions (Mullen & Spurgen 2000; Irvine 2002). This dissatisfaction extended to the health sphere, described then by critics as a closed system, authoritarian and secretive, with a resistance to user discourse and participation (Asher 1984; Bates & Linder-Peltz 1987). As a result users, unhappy with health service institutions and decision-making processes, were impelled to challenge a service provision viewed as dominated by professionals seen as inattentive to their interests and preferences (Irvine, 2002).

This period also witnessed a significant growth in single-issue self-help or mutual-aid groups concerned with health and social care (Lieberman & Snowden 1993; Elsdon et al

2000; Munn-Giddings & McVicar 2007). These groups, in which peers who shared similar circumstances or medical conditions met to discuss and share ways of coping, flourished in many areas such as physical disability, mental health, maternity care, groups for carers and addiction. The initiators and members of these groups perceived that their needs were not met, or could not be met, through existing health institutions (Kicksbusch & Hatch, 1983). The emergence of such groups represented a challenge to the traditional model of paternalism within an National Health Service (NHS) that assumed 'professionals' knew best, and required users to trust the skills, knowledge and ability of clinicians. As such, these groups represented the start of a general move towards more forms of self-management and a consequent increased appreciation and acceptance of lay rather than professional knowledge (Barnes & Evans 1998; Olzsewski & Jones 1999; McCrae et al 2002).

Within this social and cultural context the genesis of the current policy imperative for user involvement can be identified within the NHS. As a marker of this change, the post of Health Services Commissioner (HSC), the ombudsman for health, was introduced in 1974 as a part of wide-ranging reforms of local government and health services. This was a (UK) national post, although with an office in Scotland, and resulted from concerns about the treatment of individuals within the NHS. The role and remit of the HSC, however, was constrained as the jurisdiction was limited to non-clinical areas and the Commissioner could only act after complaints had gone through the normal complaints procedures. The formal nature of these procedures meant that inevitably they tended to be used mainly by the articulate and well-informed user (Hogg, 1999a).

The 1974 reforms also saw the establishment in Scotland of Local Health Councils in each Health Board area with a brief to represent the user interest. This was envisaged as a mechanism for local accountability (Lupton et al, 1998). Local Health Councils had the right to be consulted about any closure, substantial variation of use or development of services. These formal consultations generally involved hospital closures and followed a pattern of the issuing of an official document that was circulated to interested bodies to seek their comments. However these consultations were the subject of criticism and it was later argued that involving users through this channel established an "unhelpful" and "somewhat limited" style of public consultation (Hogg, 1999a). Typically, the information provided was often inadequate and written in ways that were hard for the layperson to understand. Furthermore users and user groups alleged that consultations were often carried out when decisions had already been made. This set a style for consultation in which NHS managers resented the delays caused by consultation and users felt that the process was superficial and a waste of time (Hogg, 1999a).

In addition, the 1970s saw the development of joint planning mechanisms that sought to integrate local authority and Health Board planning. Although there were many who criticised these structures and questioned their efficacy, one benefit was the provision of opportunities for involving a broader range of people in planning through the inclusion of the voluntary sector, despite the enormous organisational, representational and practical difficulties that accompanied the process (Ham, 1992).

However, by the end of the 1970s new ideas were emerging about the organisation and delivery of public services as politicians reacted to the economic and social difficulties of the period. These proposals were to have a profound influence on the development of user involvement. One powerful concept that emerged at this time was that of 'consumerism'. The consumerist approach was based upon the private sector notion of 'market research' to identify the preferences of individual customers and so enhance an organisation's market competitiveness. It emphasised the rights of consumers to information, access, choice and redress in relation to specific products or services. Within health care consumerism was often presented in terms of personal empowerment and freedom of choice, representing a shift in the conceptualisation of the subjects of health care from 'patient' to 'consumer'. Within a consumerist model individuals were assumed to be in charge of getting the 'best buy' and that, with internal competition, they could decide to take their custom elsewhere if they did not like what they received (Hogg, 1999a). This, it was proposed, corresponded with the emergence of a new active citizenship rather than the passivity and diminished capacity for independent decision-making implied by 'patient' (Brock, 1995). Critics of the established, medically dominated health care system anticipated that once health was 'consumer-focused' it would better serve the interests and needs of users (Bates, 1983).

The development of consumerism intersected in the 1980s with reforms driven partly by a shift in the organisational ethos of the NHS and partly by an ideological concern to reduce the size and cost of the public sector. The 1982 reorganisation of the health service represented an attempt to shift the organisational ethos of the NHS from professional paternalism to managerial dominance with the introduction of a structure that fostered internal competition and a focus on the user as a consumer of health services. Central to this shift was an increasing disillusionment with the underlying beliefs that shaped the NHS. The health professional was no longer uncritically accepted as having a monopoly on defining or identifying need and people no longer believed in the infinite capacity of medical science to deliver miracles. This represented a change to the balance of power within health and a challenge to the decision-making monopoly of clinicians (Klein, 1984).

Further reforms were prompted by the need to decrease levels of bureaucracy and to increase the extent of control exerted at a regional level by Health Boards. The 1983

Griffiths Report (Department of Health & Social Security, 1983) spearheaded the introduction of managerialism into the NHS. The underlying thrust of his report was to increase managerial control over doctors by, in part, drawing them into management themselves (Ranade, 1995). One area on which the new 'General Managers' were encouraged to place greater emphasis was that of attending to consumer preferences. A consequence was that throughout the 1980s there was a growth in the mechanisms for identifying consumer satisfaction by hospitals and Health Boards (McIvor, 1991). This focus on ascertaining the direct views of individual users was driven both by the desire to curb the power of the professionals and to scrutinise the performance of managers. However, there was little further development of user involvement and its reference in the *Griffiths Report* has been described as 'vague' (Harrison & Pollitt, 1994), referring only to a basic lack of knowledge about whether services were delivering what users wanted.

At the same time though, the 1980s saw a renewed interest in public health with a movement with its roots in the values of community participation and collaboration emerging. The 'new' public health advocated a community development approach that emphasised the knowledge of individuals and communities, drawing on this as a source of expertise to define problems and solutions (Jones & MacDonald, 1993). Likewise, there was an emergence of community health projects, self-help groups and user groups with a health and social care focus (Lupton et al, 1998). The proliferation of single issue interest groups in the health field in the late 1970s and early 1980s has been attributed to not only an increased dissatisfaction with the delivery of health care services, but also a concern to directly influence health care decision-making (Boaden et al, 1982).

A significant milestone in user involvement was the introduction of the Patient's Charter in 1991 (Department of Health, 1991). This Charter represented an attempt to translate into the NHS a wider policy of defining, in consumerist terms, the standards to which the public was entitled in the delivery of public services. The Charter spoke in terms of patients having rights, for example to be treated within a specific period of time and to have any proposed treatment, including the risks involved and any alternatives explained to them before agreeing consent. In practice however, although the charter played some part in bringing about a change in outlook within health services (Scottish Health Feedback, 2000) it had a 'contentious public reputation' due to the lack of clarity about its aims and inadequate user and staff involvement in its creation (Farrell et al, 1998). However, despite the wide scepticism it engendered, research conducted by Farrell et al (1998) found that user groups, NHS managers and clinicians were all agreed that it had raised staff awareness of users' needs, issues and rights and had helped to move NHS culture towards a 'user perspective'. Commentators such as Klein (1995) have suggested that its

importance lay not so much in its specific content as in the "new rhetoric and a new set of expectations in the NHS, marking precisely the kind of shift of power from providers to consumers envisaged in the *Griffiths Report*".

Under the successive Conservative governments of the 1990s efforts to involve users in the health service was a recurring policy theme. However, the focus was consistently upon the individual as a consumer of the health service. As the 1990s drew to a close some commentators became increasingly critical of this consumerist approach to health and its implications for the participation of users in decisions on their health care and health services (Barnes & Evans 1998; Williams & Grant 1998; McCrae et al 2002; Baggott et al 2004). Some, like Williams and Grant (1998), argued that while the involvement of users in their services might include 'consumerism', it also goes beyond it. They proposed:

> "People are more than consumers. To be people-centred and to value
> individuals requires an appreciation of the totality of the individual and not
> concentration on a specific role. This is surely the same criticism that has been
> laid at the door of the medical profession: in treating people as patients they
> have reduced the individual and thus devalued them" (Williams & Grant, 1998)

Other commentators, such as Hogg (1999a), observed that while individual choice and personal freedom might be important values, they may also shift the focus away from the community and collective approaches that are necessary to advance the health and well-being of the population as a whole. Despite these concerns, however, overall the consensus was that the translation of the market and consumerism into public services could be seen as a key development in user involvement as it brought to the NHS the concept of the user as consumer. This subsequently led to greater accountability of services to those who used them and a greater degree of authority vested within those who had need of services. In keeping with the ethos of consumerism, health services could be seen to have adopted a culture with an emphasis on responsive services, quality assurance, charters and users as experts (Dick & Cunningham, 2000) and throughout the 1990s studies repeatedly demonstrated the evidence for a number of benefits accruing from user involvement for the users, as well as the commissioners and providers of health services (Department of Health, 1999a). These benefits included better outcomes of treatment and care; a positive impact on self-esteem and self-confidence; services becoming more appropriate, responsive and more effective as they become more tailored to peoples' needs; increased accountability of public services leading to increased confidence in health services; improvements in staff and user morale and the development of alternatives when user involvement acts as an agent of change (Doyal 1998; NHS Executive 1998; Department of Health 1999a; Scottish Association of Health Councils 1999).

At this time further impetus was not only provided by the demonstration of the positive benefits of user involvement but also by the emergence into the public domain of a series of medical scandals. Public inquiries were established in response to significant public disquiet at the events in the Bristol Children's Cardiac Surgery Unit between 1984 and 1995 which resulted in a number of avoidable infant deaths; the circumstances surrounding the unlawful and unethical removal, retention and disposal of human tissue, including organs and body parts from children, at the Royal Liverpool Children's NHS Trust and at the conviction of an English GP, Dr Harold Shipman, following the deaths in unlawful or suspicious circumstances of a large number of his elderly patients (GMC 1998; Redfern 2001; Smith 2004). The public inquiries that followed these separate revelations further prompted the cultural shift towards user involvement and characterise the changing nature of the relationship between users and the NHS. Two of them, the Bristol Children's Cardiac Surgery Unit inquiry and the investigation into post mortem practice at the Royal Liverpool Children's NHS Trust, focused on issues of professional accountability and governance and the nature of the partnership between healthcare professionals and healthcare users (GMC 1998; Redfern 2001). Similarly, at the heart of the inquiry into the actions of Dr Harold Shipman was an examination of professional accountability and governance as it scrutinized the actions of the statutory bodies and authorities, including the General Medical Council, concerned in the procedures and investigations that followed the deaths of his patients (Smith, 2004).

An issue clearly identified in both the *Bristol Inquiry Report* (GMC, 1998) and the *Royal Liverpool Children's Inquiry Report* (Redfern, 2001) was the need to develop a systematic approach to ensuring that the views of users influence the quality of services provided by front line professionals (Chambers et al, 2003). The fifth report of the Shipman Inquiry *Safeguarding Patients: Lessons from the Past – Proposals for the Future* (Smith, 2004), however, went further by questioning the extent to which users' interests could be acknowledged and acted upon within the existing professional culture of the health service. Dame Janet Smith, the Chair of the Shipman Inquiry, was highly critical of the General Medical Council (GMC), which then acted as both the regulatory and representational body for clinical interests. She concluded that the GMC as a body was not always proactive in the interest of users and that, where there was a conflict of user and clinical interests it would, in the majority, support the medical profession's view (Smith, 2004). Several commentators, for whom it had also become clear that user involvement would require much more than cosmetic changes, shared the demand for a more systematic approach and cultural change within the health service (McIvor 1991; Hogg 1995; Barnes & Evans 1998). One consequence of these three medical scandals was a change in the

public perception of the NHS. This arguably gave the government authority to introduce new structures for the health service that would enhance professionals' accountability to users, one such structure being the further development of user involvement.

Like previous governments, the Labour administration under Tony Blair (1997-2007) continued to introduce initiatives to obtain the views of users with an emphasis on connecting government with individuals. However, public dissatisfaction with the notion of the 'consumer culture' and its emphasis on the individual, in conjunction with the perceived culture of professional insularity in the NHS led at the beginning of the new century to the emergence of a movement for increased democracy within public services (Baggott et al, 2004). This was in response to rapid developments in health technologies and scientific knowledge that had raised ethical, moral and political issues which were now felt to require wider public debate (Barnes & Evans 1998; NHS Executive 1998). Furthermore, it became increasingly clear that the acceleration of health care costs and the focus on rationing and targeting of services would require consultation and consent if these were to be negotiated and acceptable solutions agreed with users (Barnes & Evans 1998; McCrae et al 2002). That such consent was missing could be seen in the adverse public reaction to controversial policy and service re-design decisions.

Public reaction included the emergence of campaign groups opposed to changes in local health service provision. These adopted effective media and political strategies to voice their opposition to government policy (Haarni, 2007). There had been public opposition to health policy before; most notably to the introduction of community care and the subsequent closure of mental health hospitals and long-term elderly care facilities. However, the creation of a Scottish Parliament in 1999 with devolved responsibility for health was seen to create greater opportunities to raise and progress such public disquiet. The Scottish Parliament had devolved powers for primary legislation in education, health, agriculture and justice although the UK parliament retained responsibility for UK fiscal, economic and monetary systems; defence and national security; energy; employment; social security; foreign policy and relations with Europe among other matters. It could be argued that with their reduced agenda, the Scottish Parliament had greater scope for addressing matters relating to health and the health service and for debating the health issues raised by constituents, campaign groups and health charities, and there is some evidence that this was the case. A cursory analysis of the official records of business of the Scottish Parliament and Hansard for the year 2000, the first full year of the Scottish Parliament, revealed the extent to which health services came under increased scrutiny and debate within the Scottish Parliament compared to Westminster. In 2000, the official reports of the Scottish Parliament recorded 23 health-related motions that were debated

(Scottish Parliament Official Report, 2000) while Hansard recorded only similar 7 motions in Westminster (Hansard, 2000).

Not only was greater parliamentary time now available to health matters in Scotland but the election of 129 Members of the Scottish Parliament (MSPs), many of whom as list or regional representatives had no constituency to service, also provided a resource for campaign groups in lobbying for their preferred options for the health service and in identifying support for their opposition to government policy. The election of a single-issue representative to the Scottish Parliament in 2003 with a mandate to save a local hospital threatened with a series of changes to service provision represented the culmination of this movement in Scotland.

Although public opposition to health decision-making was sometimes dismissed as a minority view, it became increasingly apparent that there was a public appetite for involvement in the management and priority setting of the NHS. In a study of public attitudes to the NHS in Scotland (MORI Scotland & System Three and the Scottish Executive Central Research Unit, 2001) the vast majority of people (93%) felt that the public should have some influence over the way the NHS is run and the priorities it sets. The desire for influence was particularly strong among younger groups, who also tended to be more critical of the services provided by the NHS. MacDonald (2002) demonstrated the degree of suspicion that existed between health agencies and users in a study that conducted interviews and focus groups with NHS staff, members of the public and representatives from Local Health Councils. She found general agreement that user involvement had not always been done well in the past. As a result she identified scepticism with user groups suspicious of Health Boards and NHS groups concerned that special interest groups would use policy on user involvement to try to force them into unnecessarily elaborate exercises for relatively small and subjective issues.

Faced with growing unrest over the perceived democratic deficit within the health service, a series of initiatives sought to embed within it a more democratic, collective voice by giving users, in their capacity as citizens and taxpayers, rights to contribute or participate with others collectively in the services they use (Baggott et al, 2004). This democratic approach emphasised equity and empowerment with participation as a key concept (Lupton et al, 1998). Two strong principles underpinned it: the first is that user involvement is beneficial to maintaining a healthy democracy and in allowing people to become full citizens, and second, that the diversity of interests in society should be fully expressed in the political process. This led to a shift in the political rhetoric of the NHS from the market model and the notion of users as consumers, to the ideology of citizenship and democratic accountability (Barnes 1997; McCrae et al 2002).

One consequence of the democratic approach could be seen in the increasingly close co-operation between user groups and both the UK and Scottish governments throughout the 1990s and early years of the 21st century. In a review of more than 120 UK health user groups to find out how they represented and promoted the interests of users at the national policy level, Baggott et al (2004) found that groups had increasingly been in contact with the UK government on policy matters and many had developed active relationships with politicians and civil servants in the previous three years. Whilst around half the groups they questioned described their primary purpose as service provision, over four-fifths identified influencing policy at national level as 'very important' or 'important'. They proposed that:

> "Health consumer groups have themselves become more active in recent years, raising concerns and highlighting good practice. Their links with patients at grass-roots level gives valuable expertise based on the needs and priorities of membership and public, the capacity of people to manage their own illness and their experience of using health services." (Baggott et al, 2004)

Alliances were found to be a major feature of the development of this sector, enabling resources to be pooled and even small groups to be brought into discussions. These allowed groups to identify common concerns and speak with a coherent national voice on broader issues affecting users. Collectively user groups were assessed as becoming an increasingly influential stakeholder in the health service (Baggott et al, 2004).

In addition to the democratic movement in health, a cultural shift towards more equality between lay and expert knowledge in health care could also be identified. This was attributed to the shifting role of medicine brought about by people's increasing interest towards and knowledge of their own health (Bauman 1998; Bury 1998; Featherstone & Hepworth 1998). Increasing user knowledge was demonstrated in the generous supply of medical information on health and illness that was becoming widely available and accessible. The popular media addressed matters of health and illness on a daily basis; users actively searched for health information from the Internet and there existed a plethora of user organisations and self-help groups (Haarni, 2007). There were also a growing number of people living with long-term illness who had frequent contact with health care, especially in the field of chronic illnesses where users were recognised to hold an important understanding of their condition (Holman & Lorig, 2000).

It has been proposed that today enlightened health users have become more equal partners with doctors (Bury, 1998) and that this has contributed to changes in users' and doctors' roles and positions. The traditional expert role of medicine has become challenged (Williams & Calnan, 1996) leading to a growing rejection of professional dominance and a change in the traditional understanding of users as passive recipients of services. The shift

seen in recent years within health services from acute to chronic health problems (Brearley 1990; McCrae et al 2002) has resulted in an increasing recognition of more forms of self-management programmes (Barnes & Evans 1998; Olzsewski & Jones 1999; McCrae et al, 2002) and consequently a move from the traditional model of paternalism within health towards a partnership model that views the giving and receiving of health care as a negotiation agreed between the user and professionals (Hogg, 1999a). Furthermore, an increasing body of literature has highlighted the principles of user involvement in research (Telford et al 2004; Faulkener 2004; SURGE 2005) and it's value in the design, commissioning and conduct of health care research has been recognised within the NHS R&D Programme, the UK Clinical Research Collaboration and Networks and the Department of Health funded INVOLVE programme of the National Institute for Health Research (NIHR) (INVOLVE, 2008). As a result, health service research is increasingly underpinned by partnership and a belief that the active involvement of users produces research that reflects their needs and views, leading to more relevant research and results that can improve practice in health and social care (INVOLVE, 2008).

It is, thus, within a social and cultural context of increasing acceptance of users as experts in their health, the acknowledged benefits of user involvement but also the widespread dissatisfaction with policy and targeting decisions within the NHS that UK and Scottish government policy has sought to create the conditions for the increased influence of users in the health service. The next section will describe the how the Labour/Liberal Democrat administration of the Scottish Executive responded to this social, cultural and political context with a series of specific policy commitments to give users a stronger voice and involve people in the design and delivery of the NHS. In doing so, it will also describe the policy context within which this study was conducted.

The Development of Scottish Health Policy on User Involvement

In Scotland, the first significant health policy that helped to shape the subsequent ethos and policy of user involvement was the 1997 White Paper *Designed to Care* (Scottish Office Department of Health, 1997). It advocated patient-centred care, enhanced information and, within the context of clinical governance, obliged Scottish NHS Trusts to ensure users became fully involved in determining the quality of services. This underlined governmental interest in promoting partnership between those who use health services and the professionals who delivered them to bring about a 'patient focused service'.

> "To redesign services from the perspective of patients – and to reflect this in all aspects of health service planning – requires finding out what patients and communities want; and consulting them over proposals for change."   Designed to Care (Scottish Office Department of Health, 1997)

The concept and operation of user involvement was further developed in *Our National Health – A plan for action, a plan for change* (Scottish Executive, 2000). This plan, launched in December 2000, recognised the need for culture change in the way the health service interacted with the people it served and the way services were delivered, proposing that it was 'no longer good enough to simply do things to people; a modern healthcare service must do things *with* the people it serves'. In common with *Designed to Care,* it also advocated a "patient-focused" NHS, that is a service that exists for the user and which is designed to meet the needs and wishes of the individual receiving care. The plan advanced the position of user involvement within the policy agenda by including a commitment to strengthen user influence in the NHS, and to create opportunities for 'real partnerships' and 'real change' across Scotland.

> "We value the NHS as a public service which belongs to the people. Patients, staff and communities have a right to be involved in decisions which affect them." Our National Health (Scottish Executive, 2000, p 50)

Our National Health proposed that developing effective, meaningful ways for people to become involved in the NHS was key to developing a modern, accountable health service in Scotland. It stressed that a patient-focus needed to be embedded in the culture of the NHS and, in order to achieve this, proposed that listening, understanding and acting on the views of users would be given the same priority as clinical standards and financial performance. Within *Our National Health* user involvement was defined through a series of specific commitments to give users a stronger voice and involve them in the design and delivery of the health service. This commitment was described in a programme of four types of activity. These were building capacity and communications; patient information; involvement and responsiveness. These four types of activity constituted a framework within which, it was proposed, the NHS would be supported to develop services that reflected the needs and wishes of those who used them.

Our National Health provided for investment in training and national demonstration projects to help build the NHS capacity to work in partnership with users; the establishment of a national source of patient information and advice; the development of patient-held records and the introduction of a revised, credible and independent NHS Complaints Procedure. Furthermore, in order to monitor and ensure compliance with these directives revised accountability mechanisms, including an annual reporting system, were introduced for NHS bodies to account for how they are involving users and how that impacts on services. There was also a review of the statutory guidance on user involvement, to ensure that it met the needs of modern healthcare systems and an expectation established that all sections of the health service would make explicit

commitments to systematic assessment of user needs and to capturing the experiences and views of the people they serve.

The subsequent policy document *Patient Focus and Public Involvement* (Scottish Executive, 2001) expanded upon the broad framework outlined in *Our National Health* and provided detailed guidance on its implementation at an individual, local and national level. Among the major provisions of *Patient Focus and Public Involvement* was an expectation that, at a national level, all specialist groups would include lay representation. Each Health Board, now called an NHS Board, would have a designated director with responsibility for user involvement who would ensure that it was embraced by the whole organization. NHS Boards were also charged with working closely with community planning partners and voluntary organisations in developing user involvement procedures. They would now be expected to take a pro-active and positive approach to user involvement on issues of potential service change, offering an inclusive process that must be able to demonstrate that the NHS listens, is supportive and takes account of views and suggestions. The needs of users, including marginalised groups or those with additional difficulties, were to be addressed through the provision of advocacy services and a duty was placed upon NHS Boards to work with local authority partners to develop advocacy arrangements.

The role of Local Health Councils was also addressed in *Patient Focus Public Involvement*. Guidance was provided to give clarity to the role of Local Health Councils and a new national body, the Scottish Health Council was established.   This incorporated a national office responsible for infrastructure, staff support, training and dissemination of good practice; local offices and a Health Service Users Forum in each NHS Board area. In addition, the UK-wide Patient's Charter was replaced with a comprehensive package of patient information, standards focusing on entitlements and information about medical records, legal rights and the NHS complaints procedure. The package was to be produced in partnership with NHS Boards, the Scottish Consumer Council, Local Health Councils and the public to ensure it was relevant for local people and communities.

A subsequent policy document *Consultation and Public Involvement in Service Change* (Scottish Executive Health Department, 2002) continued to define and clarify NHS Board responsibilities in relation to user involvement in decisions over service change. It encouraged a pro-active and positive approach to user involvement in areas of potential service change and the use of more innovative methods to help maximise user input. The key principle advocated was that involving users was part of an integrated process of communication and discussion; where users and NHS staff would have opportunities to influence decision-making. It recognised that while an inclusive process may not always

result in universal support for a proposal, it should demonstrate an NHS that listens, is supportive and has genuinely taken account of views and suggestions. The NHS Reform (Scotland) Act 2004 subsequently placed a duty on NHS Boards to involve service-users, and those likely to use services in the future, in the planning and development of services and in decisions "significantly affecting the operation of those services". The emergence of *Delivering for Health* in 2005 (Scottish Executive, 2005) then required NHS Boards to demonstrate "how they are working to achieve year-on-year improvement by involving the public". NHS Boards would now be expected to clearly demonstrate that they had followed the principles of engagement in the NHS Performance Assessment Framework, which now incorporated assessment standards for user involvement.

In addition to detailed guidance, practical resources and national initiatives were also developed to support health agencies in their response to this policy. The '*Designed to Involve'* project, funded by the Scottish Executive (2001), concentrated on encouraging and supporting initiatives in Primary Care and worked extensively through contacts with Local Health Care Co-operatives (LHCCs). This project was succeeded by the '*Involving People'* initiative with a wider focus on encouraging involvement across the board in the NHS in Scotland. Both provided training, information and practical support to health agencies in their implementation of the user involvement agenda. In 2005 the Scottish Executive recognised the need for further guidance in the development of user involvement and published national standards for community engagement (Scottish Executive & Communities Scotland, 2005). Developed with the involvement of over 500 people from communities and public sector agencies from across Scotland, these sought to provide a practical tool to aid participants in user involvement in public services achieve better working relationships. These standards set out the key principles, behaviours and practical measures that underpin effective engagement with the public and were designed to provide a framework to help people influence the planning and delivery of public services, including health.

Thus, it can be seen that the creation of dialogue between NHS Boards and users has become the focus of much innovation in public policy. The current Scottish policy context as set by the national documents, *Designed to Care* (1997); *Our National Health* (2000); *Patient Focus and Public Involvement* (2001); *Consultation and Public Involvement in Service Change* (2002) and *Delivering for Health* (2005) seeks to increase dialogue with health users, forge new alliances between them and professionals and develop debates about the role of the NHS in partnership with users and user organisations. User involvement is seen as a method that reduces the risk of providing inappropriate services or services that do not meet the users' needs or wants. By providing a different perspective

that could otherwise be overlooked, it is proposed that there is the potential for innovative and acceptable solutions to the challenging resource and prioritisation decisions faced by health services. As such, not only could treatment and services be developed in ways that are responsive to users but furthermore, in the current context of a perceived democratic deficit, user involvement is proposed as a catalyst for change, helping to build public trust and strengthen confidence in the NHS.

As a consequence, the understanding of user involvement in the health service has been extended from merely a model of partnership in individual care and treatment to include a formal range of assessed and measurable commitments to a pro-active and positive approach in areas of service change, policy development and planning. As such, both the concept and policy on user involvement can be seen to have come a long way from their genesis in the 1970s as a mechanism for resolving complaints about individual treatment and formally consulting on substantial changes to services. However, the ambitious aspirations of user involvement have led some commentators to propose that it could have significant implications for the overall culture of the NHS and the interaction between users and professionals. As illustrated by Foote and Plesk (2001), the challenges this presents to the core concepts, services and entitlements of the health service should not be underestimated.

> "The culture of charity in the NHS has often resulted in a take-it-or-leave-it philosophy in our delivery of care. The provision of service further tends to imply that the recipient is a passive receiver of a fixed product. As a result, there are unequal degrees of obligation on the part of the provider and recipient, which may be a barrier to development of the mature healing relationship that is needed in health care." (Foote & Plesk, 2001, p52)

The consequences of such a paradigm shift in the understanding and application of user involvement for the health service are discussed in chapter two.

Summary

A significant advance in the health service in recent years has been the formal recognition of user involvement (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). The concept of user involvement has proved difficult to define and a multitude of understandings and definitions have been attached to it (Amstein 1969; Drewitt 1997; Scottish Association of Health Councils 1999; McCrae et al 2002). However, despite this ambiguity there has been widespread support for the idea of identifying, articulating and incorporating into health services the interests of users (Richardson 1983; Scottish Association of Health Councils 1999). For the purposes of this thesis 'user involvement' has been defined as a form of involvement that entails the direct engagement of individuals and user groups in

making decisions about their own care and treatment, in examining and improving the quality of health services and in health service policy and planning processes.

A number of social, cultural and political trends have converged to foster an interest in the views and preferences of users. These include a drive towards more equality between lay and expert knowledge in health, a move from the traditional model of paternalism within health towards a partnership model, the shift from acute to chronic health problems and the subsequent growth in self-management (Barnes & Evans 1998; Bury 1998; Hogg 1999a; Olzsewski & Jones 1999; McCrae et al 2002).   Furthermore, in a climate of widespread dissatisfaction with policy and rationing decisions within the NHS, the need for public negotiation and acceptance on policy and targeting judgments has helped to create the conditions for the increased influence of users in the health service (Barnes & Evans 1998; NHS Executive 1998; McCrae et al 2002).

In response, a series of specific policy commitments to give users a stronger voice and to involve them in the design and delivery of the health service have been published (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). The current Scottish policy context seeks to increase users' involvement in making decisions about their own care and treatment, in examining and improving the quality of services and in policy and planning activity. This is proposed as the basis of new alliances between health professionals and users; effective, accountable and responsive services and is conceived as having the potential to challenge traditional perceptions of health (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005).

Whilst initially the development of user involvement could be viewed as simply a mechanism for identifying users' needs and preferences for their care, an analysis of the history and development of this policy demonstrates that it has also come to signify a paradigm shift in the health service, representing as it does a transformation in the interaction between users, health professionals and health policy makers (Williams & Grant 1998; Coulter 1999; McCrae et al 2002). Thus, in embracing user involvement repercussions can be anticipated for the organisational and professional service culture of the NHS and the nature of the relationship between health users and health professionals (Barnes & Evans 1998; Foote & Plesk 2001; McCrae et al 2002). These challenges will be explored further in chapter three, but first chapter two will describe the techniques used by health agencies to engage with users and explore how the policy directives on user involvement have been understood and implemented within the health service.

Chapter 2: User Involvement in Health

As discussed in the first chapter, the creation of dialogue between the health service and users has become the focus of much innovation in public policy and, as a result, user involvement has moved to a position high on the health policy agenda (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). This chapter will explore how health agencies have responded to this policy imperative. It will first describe the methodology of user involvement and the techniques that have been implemented by health agencies in the opportunities presented for involvement. In doing so, it will begin to investigate the current understanding of the nature and purpose of user involvement, as this will have a major bearing on the techniques adopted.

The chapter will then go on to consider how this policy directive has been understood and implemented within the health service by exploring the evidence for user involvement in each of the three types of involvement described in the literature. These are the involvement of individuals in making decisions about their own care and treatment, involvement in examining and improving the quality of services and involvement in health service policy and planning.

Techniques of User Involvement

McCrae et al (2002) argued that if services are to be shaped by users' views then the techniques of engaging people must be both methodologically sound and appropriate to the purpose, and there must be clarity about the type of individual to be approached. A number of factors need to be considered in determining the appropriateness of techniques. These include whether the aim is to draw on the direct experiences of users, to inform users and then ask their opinions, to explore uninformed views or to empower them to define the problem and propose solutions. Furthermore, it will be important to clarify whether the intention is to involve a cross-section or a representative group, or to involve specific groups of users who have been historically excluded from decision-making (Cabinet Office 1998; Barnes 1999a).

For the purposes of this review a range of techniques drawn from the methods of academic and market researchers are discussed using the following classification: qualitative techniques, quantitative techniques and community development approaches. There has been little evaluation of user involvement activity and, as a result, the effects identified for different approaches are not empirically grounded. Accordingly, some commentators feel that much of the methods debate within the literature tells us little more than could be gleaned from discussions of the strengths and weaknesses of techniques as found in

standard social sciences texts (Drewitt, 1997). However, where these techniques have been evaluated in a health service setting this is discussed.

Qualitative Techniques

Qualitative techniques would appear to be ideally suited to user involvement as they provide the opportunity to identify peoples' perceptions, attitudes and ideas and to facilitate the identification of their own agenda. The hypothesis-generating nature of qualitative techniques also allows for greater exploration of peoples' understanding and perceptions, the meanings they attach to things and what is important to them. As such these techniques are often chosen when the aim is to draw on the direct experiences of users; to ask their opinions; to explore uninformed views; or to empower people or groups to define the problem and propose solutions. Qualitative techniques allow for flexibility in design and application to suit and encourage participation. However, such approaches, while providing a rich seam of information, also tend to be both time-consuming and expensive (Bowling, 2002). Nevertheless, a review of the literature shows that a number of qualitative techniques have been applied successfully and that these have facilitated the inclusion of the user perspective in health services. The most popular of these are written consultation, public meetings and focus groups. Each is described below.

Written consultation is the formal means by which people have traditionally been invited by health agencies to comment on policies and proposals. This technique generally follows a pattern of the issuing of a formal document, circulated to interested bodies to seek their comments. The aim is to reach a range of key stakeholders and to determine their views on a particular issue. Written consultation on planning and policy documents produced by NHS bodies became synonymous with involvement during the life of Local Health Councils (Hogg, 1999a). However, such consultation documents have been criticised for providing inadequate information written in ways that are hard for lay people to understand and for being carried out when decisions have already been made. Thus, they are constrained as a methodology by both the difficulties of providing comprehensive and accessible information and by the perception on the part of the public that the process is superficial and a waste of time (Hogg, 1999a). Despite this, they continue to be popular with health agencies and remain the established technique for publicising decisions before implementation and for inviting comment on proposed planning and policy changes.

Public or open meetings are meetings arranged to enable users to express their views on a particular topic, policy or proposal. They are often used in conjunction with written consultations to gather user views on service change. Such meetings have been described as the traditional and "anachronistic" technique of ensuring public scrutiny of health plans (Mullen & Spurgeon, 2000). Research has identified a number of weaknesses of public

meetings, finding them poorly attended, expensive and vulnerable to lobby groups (Edwards, 1995). Other authors have also identified their unrepresentative attendance as a significant drawback, finding that they are not representative of the community as a whole and that participants tend to be "well educated, well spoken and well off" (Phillips 1995; Jewkes & Murcott 1998). Nevertheless, as with written consultations, they remain a popular technique for informing and inviting comment on proposed planning and policy changes and continue to be widely used by health agencies.

Focus groups are a technique that allows for greater exploration of a topic. This technique, popular in market research, media studies and action research, involves a small (6-10) group of individuals, led by a trained facilitator, brought together with the purpose of discussing a topic. In the exploration of user satisfaction, focus groups have provided 'rich and meaningful feedback on standards of care' (Evanson & Whittington, 1997) and have also been found to be a powerful method for identifying problems affecting the quality of existing services (Lewthwaite & Haffenden, 1997), for channelling potentially destructive criticism into constructive recommendations for change and to be applicable across a wide range of services (von Ruesner, 1999).

Laird et al (2000) found focus groups to be a popular user involvement technique with health agencies although other studies have emphasised the need for skilled, independent facilitation in order to ensure credibility and to give weight to the views expressed by participants (Morgan 1993; von Ruesner 1999). A further key condition has been identified as the creation of a safe and non-judgemental atmosphere to enable participants to feel that their views are taken seriously (Courcha & James, 1999). The drawbacks of focus groups have been identified as a narrow focus on perceptions; the danger that they may be unrepresentative and biased as invitations are normally issued by the organiser; the reliance on participants who may not be informed about the issues they are asked to discuss; marginalized groups may not be invited to participate and the high costs in terms of time and other resources (von Ruesner 1999; Chambers et al 2000). Nevertheless, the focus group methodology is often referenced in the literature on user involvement in health and appears popular when exploring user satisfaction or asking their opinions.

A number of other qualitative techniques have also been described in the literature including health panels, citizen's juries, rapid appraisal and conferences. These techniques have all been found to be appropriate when the aim of involvement is to allow users to raise their own concerns, debate issues and identify preferences or possible solutions (Davies et al 1998; Green 1999; MacDonald & Scott 1999; Mullen & Spurgen 2000). However, each has a number of disadvantages associated with their use, the primary ones being a perceived selection bias in members (Stewart et al 1994; MacDonald & Scott 1999;

Chambers et al 2003) and concerns around the degree of planning and expense involved (COSLA 1999; McIver 1998; Chambers et al 2003). As a result, health panels, citizen juries, rapid appraisal and conferences appear under-utilised within the health arena with health agencies continuing to use the traditional approaches of written consultations, public meetings and focus groups to provide opportunities for involvement. This choice of techniques suggests a limited understanding of the nature and purpose of user involvement as while they are appropriate techniques for drawing on the direct experiences of users; informing users or asking opinions, they would appear to provide less scope for exploring uninformed views or empowering users to define problems and propose solutions.

Quantitative Techniques

In contrast to the discursive methods of qualitative techniques, quantitative techniques are concerned with measuring the prevalence and significance of particular views, opinions and behaviours. Questioning in quantitative techniques is pre-determined or structured, reflecting the current knowledge of the researchers. Samples can be designed so that they are statistically representative of the target population and responses can be analysed statistically in order to test for significance, correlation and causal explanations (Bowling, 2002). However, while quantitative techniques such as surveys, citizen's panels, deliberative polling or referenda reflect the current knowledge of researchers, they may not truly reflect the interests and concerns of users. Thus, while they are an appropriate methodology when the aim is to draw upon the experience of users, they are less suited to activity that seeks to empower them to define problems and propose solutions or when a more in-depth understanding is sought of users' beliefs and values.

The most commonly used quantitative technique in all areas of health care has been the user survey (McIver, 1999). Williams (1994) argued that this has arisen because of a belief that surveys are relatively inexpensive, a demand for quantitative data and a distrust of qualitative methods. He argued that this had led to an over-reliance on this technique, resulting in a lack of innovation and imagination to involve users in ways that are more meaningful. Surveys can be a useful method of obtaining reliable information but, if poorly designed or responded to, the results can be misleading and a number of problems have been reported with their use in this way (Williams & Wilkinson 1995; Avis et al 1997). In research about the funding of local services Spencer et al (2000) found that, although some respondents were positive about this technique, local authorities were concerned that low response rates and self-selection skewed the balance of respondents. Other disadvantages identified include the inability of surveys to allow sufficient exploration of issues and limitations in reaching those with communication, literacy or language difficulties (Williams & Wilkinson 1995; Avis et al 1997). User satisfaction

surveys have also been criticised for their "blandness and tendency to produce undifferentiated positive responses"; their failure to take account of variables such as age, gender and ethnic origin; and for their focus on satisfaction as an end product (Evanson & Whittington, 1997). It is widely argued that the limited focus on satisfaction as an evaluative measure of health services has 'trivialised' the concerns of users, by focusing mainly on the 'hotel' aspects of care and issues regarding the interpersonal and communication skills of professionals, while neglecting more fundamental aspects such as outcomes, appropriateness and effectiveness of health services (Fitzpartick & White, 1997). Furthermore, fluctuations in peoples' responses over time, the likelihood of polite responses and the difficulty of ensuring compound variables such as users' expectations all question the reliability of the instrument (Cheetham 1993; Williams 1994).

However, surveys have been used to complement other techniques, such as focus groups and, when used in conjunction with them, found to enrich and enhance the audit process (Conning et al, 1997). Nevertheless, concerns persist that surveys can provide only a limited range of information from users and that, while they can provide a wealth of information, less is known about whether users found treatments helpful in relation to their problems than about any other dimension of quality of health care. This does little to illuminate the processes that have led to satisfaction or dissatisfaction (Locker & Dunt, 1978).

A range of other quantitative techniques which have their roots in market research have been used as a means of involving people in the planning or design of public services (COSLA, 1999). These include citizen's panels, deliberative polling and referenda. In each a sample of the population is asked its opinion on a topic or options for change that have been predetermined by the consulting organisation. As such, they offer little scope for introducing new ideas or variations on the proposed changes (Lomas 1997; Laird et al 2000; Spencer et al 2000). These techniques have proved popular with local authorities but have been less widely taken up by health agencies and so remain largely untested as a technique of involving users in shaping health services.

Thus, health agencies continue to rely heavily on surveys as the principle quantitative methodology for gathering users' views on health. As with the popular qualitative techniques, this appears an appropriate technique for drawing on the direct experiences of users or for asking opinions but provides little scope for exploring views or empowering users to put forward solutions.

Community Development Approaches

The qualitative and quantitative techniques described above illustrate a number of approaches for gathering opinions and involving users in deliberation on an issue.

However, they do not necessarily provide on-going opportunities for users to have their say in national and local health services nor do they provide much scope for users to define problems and propose solutions. Community development approaches differ in that they provide a long-term, pro-active approach to empowering individuals and communities to be involved in identifying gaps in health services and in developing new services.

The explicit focus of community development is on reducing inequalities and empowering the most marginalized communities (NHS Executive, 1998). It uses a variety of methods and activities such as self-help, local action groups, lobbying, information, network building and pump priming community initiatives with small grants. The key characteristic of community development is that it starts from the experiences and perspectives of communities (Jones & MacDonald, 1993). Community development approaches challenge the definition of health as an individual problem for which there are individual solutions and health care systems that treat the symptoms and not the root causes of ill health (McCormack, 1993). Instead, such approaches emphasise the knowledge and expertise of individuals and communities, drawing on this source of expertise to define problems and solutions. An example of this would be Public Health Nurses working alongside mothers in the community to empower less experienced mothers (Johnstone, 1993).

However, a number of difficulties have been identified for community development approaches in the context of health care (Jones & Macdonald, 1993). While there is support for the idea of extending these approaches into mainstream health services, Jones and Jones (2002) found that in reality organisations are not always receptive to the idea of a longer-term dialogue that might lead to significant change or into areas not previously considered. A DHSS (Northern Ireland) document (1999) found that community development approaches were still at an early stage of development within mainstream agencies, that most NHS agencies did not have a stated policy for community development and that there was a lack of focus for this work with few instances of staff training in these approaches. It would appear to be important to provide training for staff as these techniques, which value working with people, sit uneasily alongside the traditional paternalistic model of health within which professionals hold the knowledge and work on behalf of users. As a result, few health professionals are expert in community development approaches, except perhaps Health Visitors and Health Promotion staff. The extent of the gulf between community development and other approaches has led some commentators, such as Johnstone (1993), to advocate that the education and training of health workers should include the possibility of working in partnership with rather than for people.

McKnight (2001) also highlighted core differences between the shape and function of communities and public sector systems as a barrier to the further development of community development approaches within health. Communities, he proposed, were based around individuals and families, informal relationships, formal groups and relationships defined by choice. Service systems, on the other hand, had hierarchical structures designed to produce services to uniform standard, formal relationships defined by the service structure and formal groupings. Each structure has its own rationale, ways of working and communicating and these are very different. The two kinds of systems, therefore, often find it difficult to engage constructively together. As a result, community development approaches are relatively rare within the continuum of health authority approaches to engaging with users.

Thus, despite local successes in community development (Johnstone 1993; DHSS (Northern Ireland) 1999; Jones & Jones 2002) and the apparently wide range of qualitative and quantitative approaches available, health agencies appear to remain reliant on a small number of involvement techniques: primarily written consultations, public meetings, focus groups and surveys. This is despite the recent proliferation of innovative approaches, many of which have sought to engage users through the use of more discursive techniques. In a review of user involvement approaches, Laird et al (2001) found that the bulk of involvement activity taking place at the time of their study could not be characterised as innovative, even though there was enthusiasm for newer approaches. Accordingly, guidance has been made available to health agencies aimed at stimulating greater innovation in methods by promoting the use of more discursive, qualitative approaches and demonstrating that it would be possible to combine techniques (Barnes 1997a; Cabinet Office 1998; NHS Executive 1998; Laird et al 2000; Ridley & Jones 2002). However, the literature review for this study found no examples of, and few recommendations for, a combination of techniques.

The continuing dependence on traditional techniques is concerning if it suggests that health agencies have a limited understanding of the nature and purpose of user involvement, relying as they do on techniques that offer little scope for users to define problems and propose solutions as a way of making services more responsive to their definitions of need. These traditional techniques appear to be limited in their capacity to meet the aspirations of user involvement to facilitate effective, accountable and responsive services; to challenge traditional perceptions of health and to embed a democratic approach within health policy and decision-making processes.

Furthermore, they all are open to the criticism that they exclude some groups of users. Qualitative techniques such as surveys have been criticised for limitations in reaching

those with communication, literacy or language difficulties (Williams & Wilkinson 1995; Avis et al 1997), while qualitative techniques have a perceived selection bias resulting in many participants being "well educated, well spoken and well off" (Phillips 1995; Jewkes & Murcott 1998). Their capacity to involve marginalized or 'hard-to-reach' groups would appear then to be limited. Nevertheless, there is evidence that the implementation of these techniques has delivered some benefits in the health setting and it is these that will be reviewed next.

The Implementation of User Involvement in Health

An exploration of the meaning and history of user involvement highlights that its development in health is complex as the existing literature indicates that, despite a rash of involvement activity in many different health settings, the "reality does not fully live up to the ideal" (McCrae et al, 2000). In 1997, McFadyen and Farrington assessed the development of user involvement in the NHS as appearing "slow to date" while Bell (2000) concluded that the NHS had no history of involving the public in "any meaningful way". Other commentators have been equally pessimistic in their assessment of the health services' record in user involvement. Following a review of user involvement in a proposed conversion of a mental health unit to an NHS Trust, Peck (1998) concluded that the legacy of involvement in the health service was, at best, one of 'ambiguity', while at worst, one of 'duplicity' in its approach. Similarly, Pickard et al (2002) studied the extent to which users were engaged in quality improvement activities in primary care in England and concluded that progress has been very slow and that the few changes that had occurred were patchy and superficial. A review of the arrangements for involving users by Jordan et al (1998) found them similarly restricted:

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

Taken overall, this would suggest that the implementation of user involvement has been slow and uncertain but, as discussed in the following section, there is evidence of activity throughout the health service that suggests that such a reality is changing, albeit slowly. The extent to which such activity has influenced health is considered using the three types of involvement identified in chapter one. To remind the reader, these 3 types are the involvement of individuals in their own care and treatment, the involvement of users and user groups in examining and improving services and in shaping policy and planning.

Involving Users in Their Own Care and Treatment

The first type of user involvement that is proposed as bringing benefits for both the user and the health service is one in which the user becomes involved in their own care and

treatment decisions. The World Health Organisation (WHO) promoted the rights of users to be involved in their own health care as long ago as 1978 in an approach they described as 'patient-centred' (WHO, 1978).   Since then, the growth of user involvement and changing societal norms with regard to the 'expert' status of health professionals have resulted in increasing support for this approach to health (Toop, 1998).

A growing body of evidence shows that user involvement in treatment decisions and in managing their own care can improve their experience and often results in more appropriate and cost effective utilisation of health services and better health outcomes (Coulter, 2002b). A study by Greenhow et al (1998) showed user satisfaction to be positively correlated with involvement while in a study of the involvement of users in the care programme approach to mental health, Carpenter and Sbaraini found that those involved in planning their own care and treatment had more choice in treatment options and were better informed about rights and services (Joseph Rowntree Foundation, 1997). Having direct involvement in treatment has also been linked with a reduction in missed appointments and an increase in the completion of treatment (NHS Executive, 1998).

A recent survey carried out among randomly selected populations in eight European countries found strong support for more involvement in treatment choices (Coulter & Magee, 2003). Three out of four respondents (74%) reported that they wanted to be involved in treatment decisions. But, while some research has demonstrated a considerable demand for more involvement in treatment choices, other research that examined preferences for a 'patient-centred' approach in primary care found that not all users wanted to be involved (Little et al, 2001). Little et al (2001) argued that doctors should be sensitive to those who are likely to have a strong preference for patient-centeredness, as well as those who do not. Trnobranski (1994) suggests that characteristics such as cultural background, age, gender, diagnosis, previous health care experience and educational background are likely to influence the extent to which users want to be involved in decisions about their care. In addition, some users of mental health services turn to service providers because they recognize that they need help in making decisions about certain aspects of their lives. They therefore relinquish decision-making to health professionals, acknowledging that they have expertise that the user does not (Meethan & Thompson, 1993). Other surveys have consistently suggested that a significant minority do not want the ultimate responsibility for making choices, even though they would like more health information (Entwhistle et al 1997; Olszwski & Jones 1998).

A recent international study has shown that patient-centred care is not yet well established in the UK (Schoen et al, 2004). Drawing on a survey of 8,672 adults selected at random in Australia, Canada, New Zealand, the UK, and the United States, this study focused on

users' experience in primary care. It found that British users were generally more positive about the organisation and funding of health care than those in the other countries, but that patient-centred care is not yet the norm. Although users in Britain experienced greater continuity in primary care and much lower costs than those in the other countries, there were also indications that health care was delivered in a more paternalistic fashion in the NHS as the UK performed worse than the other countries in relation to information about medicines, shared decision-making, users' access to records, preventive advice and self-management of chronic disease.

Nevertheless, patient-centred care has been the subject of both attention and investment in the UK, resulting in the development of three major health initiatives that each reflects the domains of this model: communication, partnership and health promotion. These initiatives, which have been developed and supported by guidance, training and investment, are the 'Expert Patient' programme, the development of shared decision-making and the introduction of patient-held records. These are discussed next.

The Expert Patient

The Expert Patient Programme is a self-management programme for people living with chronic illness. It was designed in 1999 by the Department of Health in England and Wales as a means of harnessing the resources of users in addressing the growing burden of chronic disease and promoting their active participation in the management and treatment of long-term conditions (Lorig 1999; Donaldson 2003). Self-management programmes are typically a formalised user education programme aimed at providing the user with the information and skills necessary to manage their condition within the parameters of a medical regime (Cooper & Clarke, 2001). They are underpinned by an acknowledgement that users have expertise that contributes to their treatment and a desire to be involved in making decisions about their own health care (Wilson 1999; Department of Health 2001b). When consistently applied, self-management programmes have been shown to have a positive impact on health behaviours, health status and health care utilisation (Lorig et al 1999; Cooper 2001) and in the long term to provide a cost-effective compliment to existing health care provision (Barlow et al, 2002).

Self-management has been most effectively adopted in the UK by users with long-term chronic conditions such as asthma, diabetes, arthritis, disfiguring facial conditions and liver related conditions (Cooper & Clarke, 2001). A network of almost 100 voluntary organisations, called the Long Term Medical Alliance (LTMA), was established in England and Wales in the mid-1990's to support the aims of self-management. A similar network called the Long Term Conditions Alliance Scotland operates in Scotland (LTCAS, 2006). Both aim to compliment existing health care provision and encourage the

development of a partnership between the user and the health professional, in which the user becomes the manager of the condition, learning to make the best use of the resources available, one of which is the health professional (Cooper, 2001).

The Expert Patient is based on valuing the credibility and authority of users' expertise and giving this an equal footing with that of professionals. The implication of creating a partnership is that it will bring about a shift in the traditional relationship between users and heath professionals (Small & Rhodes, 2000). For some health professionals, at least, this appears to represent a challenge. A survey by the pharmaceutical industry body reported that only 21% of doctors were in favour of the proposals on the Expert Patient; 58% predicted an increase in the workload of general practitioners; 42% believed it would increase NHS costs; and only 12% thought it would improve relationships between doctors and users (Association of the British Pharmaceutical Industry, 1999). A more recent MORI survey of health professionals found that 63% of doctors believed that in the long run better informed users would require more of their time (MORI, 2003). Some have suggested that, for anxious and overworked doctors, the Expert Patient appears to be the demanding patient, the unreasonable patient, the time consuming patient or the patient who knows it all (Shaw & Baker, 2004).

However, some commentators point to the research that shows that expert patients make less and better use of health professional's time (Lorig et al 1999; Barlow et al 2001; Lorig et al 2001), proposing that training, education and a change of name to 'involved users' would reassure health professionals that expert patients are different from the unappealing stereotype of the dissatisfied, middle class user they fear (Shaw & Barker, 2004). However, despite the evidence on the benefits of the Expert Patient such a shift in perception may not be straightforwardly achieved within the NHS.

Shared Decision-Making

One aspect of the changing relationship between health professionals and health users described in chapter one, has been a social and clinical movement for shared decision-making. This concept received formal recognition and acceptance in 1998, when the NHS Executive asserted that users who are well-informed, active participants in decision-making about their own care and treatment have improved clinical outcomes. Coulter (2000a) described shared decision-making as representing a partnership in which doctors are well informed about diagnosis, treatment and prognosis while users possess first-hand experience of what it is like to live with a medical condition, their social circumstances, individual values and preferences. Within this partnership, shared decision-making has four essential elements: partnership, communication, information giving and agreement,

and is seen as the middle ground between informed choice where decisions are left entirely to the user and traditional, paternalistic medical decision making (Jordan et al, 2002).

A range of studies has demonstrated the value of this concept. Research examining the impact of shared decision-making through randomised trials found that it improved users' knowledge of their medical condition, satisfaction with the decision-making process, general perceptions of their health and physical functioning (Barry et al, 1997). A growing body of evidence shows that user engagement in treatment decisions and in managing their own health care can improve their experience and often results in more appropriate and cost effective utilisation of health services and better health outcomes (Coulter, 2002b). In addition, encouraging users to take more control when they are ill is proposed as an effective tool for improving public health as well as personal health, as paternalistic styles of practice tend to create dependency and undermine self-reliance (Coulter & Rozansky, 2004). Coulter and Rozansky (2004) proposed that promoting involvement, empowerment, and a sense of ownership of health care could be the best way to ensure that people adopt healthier lifestyles.

However, despite the potential benefits, a number of studies have demonstrated that this concept has not been widely embraced. Elwyn et al (1999) found that shared decision-making in primary care was the "neglected second half of the consultation" and a more recent review of the literature on shared decision-making by McCrae et al (2002) agreed, concluding that the concept has been poorly defined and that in reality it seldom occurs. There would appear to be a number of barriers to the widespread adoption of this model. The first of these is an apparent resistance to the concept among health professionals. Critics of shared decision-making have argued that most users do not want to participate in decisions; that revealing the uncertainties inherent in medical care could be harmful; that it is not feasible to provide information about the potential risks and benefits of all treatment options and, in common with the fears expressed about the Expert Patient, that increasing user involvement in decision-making could lead to greater demand for unnecessary, costly or harmful procedures which could undermine the equitable allocation of health care resources (Coulter, 1997).

Nevertheless, a study of experienced GPs showed some positive attitudes towards involving users in decisions, providing this was what users wanted (Elwyn et al, 2000). This finding was consistent with those studies that have shown that not all users are the same and that some groups are more likely to be involved. Nease and Brooks (1995) found that women, younger, highly educated and affluent people were most likely to want to be involved. This is a finding that worries some commentators such as Bastian (2003), who have argued that the trend towards empowering individuals is deepening inequities in

health care, as the better equipped users are able to become more involved and take up more of their doctor's time at the expense of those who are not so well educated, articulate or demanding.

In a small-scale qualitative study of 20 people with cancer Henman et al (2002) threw some light on the complexity of users' views on shared decision-making. Initially, many said they wanted to be involved but closer questioning showed that only a small proportion wanted to weigh up the evidence and make decisions themselves. The authors concluded that users wanted to know that they could trust the doctor to make the right decision for them. They argued that their findings called into question the percentage of users who really do want to be involved in decisions or what users understand by the term 'involved'. However, this does not, they argued, imply that the health service should continue in its paternalistic ways. They proposed that, given the wealth of evidence suggesting that users do better if they are actively involved in their care, the message for health services is rather that they should make it easier for users to do this.

A further barrier is the lack of resources available to support users who wish to play a more active role in shared decision-making. Central to the concept of shared decision-making is the ability for people to make informed choices. To do this they must be able to gain access to high quality, balanced, accurate, full and up-to-date information as well as have it effectively communicated to them (Garlick, 2003). Many studies demonstrate that users appreciate information (Rose, 2001) and a range of different types of potential benefits have been identified for improved communication and information provision between health providers and the users of services. These include increases in patient satisfaction (Jones et al, 1999); psychological adjustment and coping, reduction in distress (Audit Commission, 1996); greater concordance in treatment decision-making, improved response to treatment (Royal Pharmaceutical Society, 1997) and, in combination with reinforcement and self-monitoring, can help people to follow prescriptions (Haynes et al, 2002).

Conversely there is evidence to show that poor communication between doctor and user can have a negative effect on therapy, treatment and the long-term management of illness (Olszewski & Jones 1998; Elwyn et al 1999). Olszewski and Jones (1998), in a review of the literature on the uses of user information, concluded that users wanted to have more information about why the doctor recommends one treatment over another. This, they proposed, was in preference to demanding a major role in treatment decisions. In this sense, the authors suggest, information can be seen as a "means of establishing trust" between user and health professional. Providing more and better information is widely accepted as a priority in health services, although Entwhistle et al (1998) argued that this

would require substantial resources if it is to be done well and so facilitate the further development of shared decision-making.

A third set of barriers relate to the skills and resources of health professionals (Edwards & Elwyn, 2006). Barriers identified to widespread implementation include time pressures, incentives to hit targets, unwillingness to share power, difficulties expressing uncertainty, managing conflicting information sources and the absence of risk communication aids (Holmes-Rovner et al 2000; Stevenson et al 2000; Ford et al 2003; Stevenson 2003; Charles et al 2004; Coulter 2005). These factors have led some commentators to argue that there is a paucity of knowledge about the circumstances in which shared decision-making should be encouraged and the effects of doing so (Coulter 1997; Entwhistle et al 1998; Charles et al 2004; Coulter 2005). Medical training has also proved slow to adapt to shared decision-making, continuing to focus on disease and treatment without offering similar insight into the understanding of users (Corke et al, 2005). Florin and Coulter (2001) suggested that shared decision-making required specific skills that were not yet widely taught while Elwyn et al (2000) similarly proposed that the skills required to achieve shared decision-making needed to receive higher priority at all levels of policy and practice. Elwyn et al (2000) agreed with other authors that there was a need for the development of knowledge and skills if shared decision-making is to be effectively progressed. However, Skelton (2005) proposed that shared decision-making probably requires attitudinal shifts by clinicians as well as the conventional communication skills currently taught within medical education.

Thus, while there exists a wealth of evidence pointing to users' desire for increased information and support for shared decision-making there are a number of barriers that would appear to have hindered its widespread implementation.

Patient-Held Records

A common feature of both the Expert Patient and shared decision-making is their emphasis on enhancing the exchange of relevant medical and personal information and thus, on improving communication. The third programme of patient-centred care, patient-held records, has been proposed as one means of addressing the problems of poor communication between health professionals and users and as having the potential to give increased control and autonomy to users. The concept of patient-held records has been around for many years and has been effectively adopted in maternity care and child health. Clinical trials in cancer, mental illness, general medicine and antenatal care have found that when users hold their own records they find it easier to communicate with health professionals and feel more satisfied and in control (Elbourne et al 1987; Horner et al

1999; Jones et al 1999; Drury et al 2000; Warner et al 2000; Williams et al 2001). However, this has yet to be tested in a wider range of clinical areas.

One reason for the lack of wider implementation may be revealed by a review of patient-held records that included one Cochrane Systematic Review and numerous randomised controlled trials covering a variety of areas (NLH Primary Care Answering Service, 2005). The evidence for their usefulness was mixed with some studies showing their acceptability (Lecouturier et al 2002; Lester et al 2003), but most concluding that there was no evidence on which to base the widespread promotion of patient held records (Drury et al 2000; Warner et al 2000; Ayana et al 2001; Cornbleet et al 2002; Lecouturier et al 2002). However, whilst these studies may suggest that they are not necessarily useful for services, user support for the concept has been shown by other research. For example, Hayward (1998) found that most cancer sufferers in a small study had been positive about patient-held records while Wright and Young (1994) demonstrated enthusiasm from older people for the idea of a health record containing information useful in an emergency. This enthusiasm was not unconstrained though as Wright and Young (1994) also highlighted the complex issues around access to health records such as reservations about costs, comprehensibility and confidentiality. Hayward (1998) found resistance from some professionals to filing them in. The Scottish Partnership Agency for Palliative Cancer Care reported similar resistance and recommended further research on patient-held records in order to illuminate the areas of uncertainty in their use and hence, help to address the barrier of limited participation by health professionals (Scottish Partnership Agency for Palliative Cancer Care and National Council for Hospice and Specialist Palliative Care Services, 1998). Nevertheless, Hayward (1998) also reported that once patient held records were established within a medical unit, communication and compliance improved.

Whether or not they exercise such rights, users have the right to access their medical records following legislation such as the 1998 Data Protection Act (c.29) and the Access to Health Records Act, 1990 (c.23). Since April 2004 they have had the right to receive copies of all correspondence between clinicians working in the NHS as a matter of course. In one study of 300 users who had received copies of the letters sent to their GP following attendance at acute clinics or hospital episodes, 97% reported that they would like to receive copies in the future and 80% believed this should be routine NHS policy (Jelley et al, 2002). Results such as these suggest that users welcome this development and that there would be support for the introduction of patient-held records in a wider range of clinical areas than is currently the case. Nevertheless, there are some concerns from both user groups and professionals, most notably around the issue of ensuring comprehensibility, maintaining confidentiality and administrative issues regarding

resources (Jelley et al, 2002). As a result, a multi-disciplinary working group was established to advise the Department of Health on the development of guidelines on copying letters to patients (Meredith, 2002). They were concerned to see the policy rolled out as quickly as possible given its importance as one means of improved communication with patients, enhancing their ability to share in the management of their care and treatment and to make informed choices. It is not clear from the literature why patient-held records have only been adopted in a small number of health settings but, despite the criticisms of the concept and the fears expressed by clinicians, they have been successfully maintained within both maternity and child health settings over a number of years.

Thus, the policy directive to ensure that users have the opportunity to be involved in their own care and treatment would appear to have been supported by these three major programmes of activity, although none of the Expert Patient, shared decision-making or patient-held records have been consistently put into practice across the entire range of the health service with only selected clinical settings including primary care, maternity, and cancer services having made progress in their implementation.

The three programmes discussed above are evidence-based but despite the apparent benefits, the implementation of patient-centred care and its associated model of partnership have highlighted some challenges to the traditional medically dominated paradigm of the health service. Whilst they appear to offer benefits to the nature of the relationship between doctor and user, they also present challenges to the traditional control held by clinicians over treatment decisions and equity of provision and as a consequence, a number of practical and attitudinal barriers have resulted in irregular acceptance and implementation.

Involving Users in Examining and Improving the Quality of Services

The second type of involvement under review is the involvement of users in shaping accountable, responsive services. Involvement in examining and improving the quality of services is based on the belief that the people who use services can be the best judges of their strengths and weaknesses (Wilson, 1999). This extends the conceptualisation of user involvement from individuals shaping their own care and treatment based on personal preferences and understandings, to the application of collective experience to the evaluation and development of service systems, delivery and outcomes. As the NHS Executive (1998) proposed:

> "The involvement of users organised into advocacy groups, voluntary organisations and self-help groups can enable the collective, accumulated knowledge of service users to play a role in overall service planning and development." (NHS Executive, 1998, p 8)

In a review of user involvement Dickens (1994) found that no matter how service quality was defined and measured, the consistent finding from research was that quality derived from users' expectations and experiences and the satisfaction or dissatisfaction that those experiences provide. He, therefore, proposed that it would be imperative that users were involved in defining what quality is and measuring quality in services. However, while there is a growing tradition of involving users in compiling quality standards in social work this has not been so well established in health services.

For several authors the first step towards participation in setting health care standards is to ensure user involvement in all stages of clinical practice or evidence based clinical guidelines (Bastian 1996; Duff et al 1996; Wersch & Eccles 2001). Guidelines are set up to influence not only the quality of care, but also access to care and the availability of choices. Involvement in clinical guidelines has been suggested as one way of "bridging the knowledge gap between health professionals and users" so that joint decision making becomes more of a reality (Duff et al, 1996). Therefore, it has been argued that users have a considerable stake in being involved in such activities. Researchers advocate the use of different strategies in combination to ensure users' views are incorporated into guidelines and standards: for example, the involvement of accountable user representatives in group decision-making, involvement in user surveys, and the use of research literature describing people's experiences (Bastian 1996; Wersch & Eccles 2001). However, Wersch and Eccles (2001) also found that while involvement was desirable it was not always straightforward, especially when users were included in guideline development groups that also included professionals. The researcher's investigation concluded that there was no 'one right way' to involve users in this process and that further work was needed on how to achieve it.

There would appear to be few examples in the literature that describe services that have effectively involved users in setting and measuring standards but one example, however, is Bradford's Home Treatment Service, a community-based service for people with mental health problems (James, 2000). This service directly involved users in defining quality in services through an innovatory appointment of a service user within the clinical team. He was given a specific role within the team with powers to decide how users are treated. As a member of the clinical team, the user had "equal say on all matters" and was felt to have helped shape the nature of service provision:

> "As a user Peter knows what it is like to be talked about by professionals. He has helped shape the team's culture away from a feeling of them, the users, and us, the professionals. He can also communicate with users in a way the rest of us cannot" (James, 2000, p6).

There are other examples of how users have been involved in both defining and measuring quality. At the core of the 'Quality Network', a joint initiative between the National Development Team, British Institute of Learning Disabilities, People First Scotland and Speaking Up!, is the belief that people with learning disabilities are the experts on their own lives and therefore, best placed to say what they want from services and whether services are doing a good job. This initiative ensures that people with learning difficulties, carers, staff and service managers work as a team to review services using quality indicators that aim to reflect users' experience of receiving services. The network trains people with learning difficulties in order that they can participate fully in the local networks and service reviews that constitute the quality initiative (Quality Network, 2002). Another example is the quality assurance framework for hospital services devised by the Royal Edinburgh Hospital Patients Council which defines aspects of quality for hospital services for people with mental health problems, and how to measure them from the users' perspective (Royal Edinburgh Hospital Patients Council, 1998).   As with the Quality Network users are involved in both defining the indicators of quality and in measuring how far these have been achieved.

User involvement in the subsequent evaluation of how far quality standards have been achieved follows logically from their participation in defining the standards, and as a result, obtaining user feedback when measuring how effective a service is performing is considered a fundamental principle of 'good practice' (Knox & McAlister 1995; Morris 1995). Knox and McAlister (1995) proposed that the importance of involving users in evaluations lay not only in addressing the issues and concerns of those directly affected by the service, but also in building ownership of the suggestions or recommendations arising from the evaluation. However, what each of these three examples has in common is that, whilst they discuss the presence of users within the mechanisms for examining services, they do not report on the recommendations arising from evaluations or of any outcomes that could demonstrate how services have responded or become more sensitive to the users' perception of need. Similarly, a number of national bodies such as the Sainsbury Centre for Mental Health (Rose, 2001) and the National Cancer Alliance (Bell et al, 1996) have carried out extensive research with and by users that provided a rich seam of information about what users say about the services they use but, once again provided little to indicate that this information contributed to service planning.

Thus, while there are a number of projects that have done much valuable work on how to make the views of users central to creating service quality, there are still few good examples in the literature of the involvement of users throughout the whole evaluation process. Furthermore, in common with other aspects of user involvement, the extent of

involvement in evaluation and audit has been characterised as restricted to one-off events, with a particular criticism being that the findings are poorly disseminated within and outside the sponsoring organisation thus, greatly constraining the opportunities for the organisation to learn from the findings (Kober, 1994). Barnard's review (1998) of the extent of user involvement in clinical audit carried out in the South West of England confirmed this. He found that despite nearly all NHS Trusts involving users in clinical audits in some way, the scope of involvement was restricted. The majority had carried out user satisfaction surveys (67%) but only 13% of Trusts had involved users and their representatives in setting standards and even fewer (3%) had involved users in devising or deciding outcome measures.

Nevertheless, the examples discussed here demonstrate the capacity of users to define quality standards and contribute to judgements about the extent to which these have been delivered. However, it has been acknowledged that if there is an interest in user involvement then simply knowing users' preferences is insufficient. It is equally important to understand how, and to what extent these preferences can and do influence the delivery of health care (Fitzpatrick & White, 1997), but the impact and outcomes of user involvement remain aspects that appear absent from the accounts of user involvement in examining and improving the quality of services.

Involvement in Policy and Planning

The third type of user involvement under review is the involvement of users in health policy and planning; that is "concerned with strategic direction" (Barnes, 1997a). This includes the participation of users in developing, interpreting and implementing policy at both a local and a national level. Bringing the needs, aspirations and personal experience of those who use services to policy and planning is proposed as essential. Fisher (2001) argued that by asking local people about health issues that mattered to them, health planners could arrive at clearer recommendations and that by pursuing these ideas collectively implementation was more likely to be achieved. Users who have been involved in the planning and development of health services report improved self-esteem (Smith 1984; Silva 1990; Berger et al 1996; Barnes 1997b; Elizabeth 1998) and benefits are also reported for staff and organisations. These include improved organisational attitudes towards users (Barnes 1992; Lord et al 1998), more open organisational culture (Gummer & Furney, 1998) and the instigation of further initiatives aimed at strengthening user involvement (Harris 1989; Barnes & Wistow 1994).

Since the 1970s, UK and Scottish government departments have increasingly developed national health policy in consultation with outside interests. This may take place through a variety of channels: standing advisory committees, *ad hoc* enquiries or working groups set

up to advise on particular issues, and through an informal pattern of negotiation and discussion in which the Scottish Executive engages with pressure groups of various kinds. Sometimes these are extremely close links, as in the contact enjoyed by the medical profession through its representative groups the British Medical Association (BMA) and the Royal Colleges. The position of user groups is somewhat weaker but the Scottish Executive does consult regularly and systematically with national user organisations such as the Scottish Association for Mental Health (SAMH) or the National Childbirth Trust (NCT). The users' position is much less secure than professional groups and is heavily dependent on them being able to offer advice, information and expertise. Unlike professional groups their co-operation is not normally seen as vital to the implementation of policy and they cannot threaten sanctions, such as withdrawal of participation. As a result not all groups are equally well integrated into the policy-making process and, as a consequence, this process tends to be dominated by the well-organised groups who have a role in the provision of services (Ham, 1992).

However, policy and planning decisions are not only made at a national level as, subject to broad guidance from the Scottish Executive, NHS Boards have considerable freedom to determine what policies to pursue in their areas. From this bottom-up perspective the local autonomy of both NHS Boards and the medical profession permits the development of policies that are appropriate to local circumstances and local preferences (Ham, 1992). Barnes (1997a) highlighted a need for users to be involved in both local and national policy development as capacity for change is constrained and shaped by policy and resource decisions taken at national policy level, over which local health services have no direct control.

As discussed in chapter one, *Our National Health* (Scottish Executive, 2002) contained an expectation that all specialist groups working at a national level would include lay representation. This has led to a number of enhanced opportunities for users and user groups to participate in national policy and planning debates. That user groups have taken up these increased opportunities is illustrated in a survey of 186 user groups in England and Wales conducted by Allsop et al (2002). They investigated the ways in which user groups participated in the policy making process with the UK government and found a high level of contact and involvement. The majority of respondents (82%) ranked influencing national policy as 'important' or 'very important' although only 16% said their main aim was to influence policy. Most groups thought that the opportunities for relationships with government had increased over the past three years and this was especially prevalent among cancer (71%) and mental health groups (67%). Seventy five percent of respondents reported that their organisation had been in contact with central

government over policy issues in the past three years and nearly half (48%) reported frequent contact with the UK government, civil servants, MPs and peers.

In contrast, participants highlighted barriers to political influence such as lack of resources in terms of staffing (83%), finance (80%) or political contacts (75%) and the need for clearer 'rules of engagement' as their own lack of knowledge of policy processes was an obstacle (55%). The authors identified a link between the size of groups and their participation in policy processes, with smaller groups having a high commitment, but very little knowledge or resources to respond to policy processes.   More than half of those surveyed had a membership of less than 1,000 and an income of less than £100,000 a year. Contributing to a key policy document or a national service framework was thus, a drain on scarce resources. Allsop et al (2002) proposed that this inequality was significant and required the development of financial support, such as payment for people who sit on committees, as they identified a shortage of people who had the time, funds and willingness to take part in such activity. Nevertheless, they concluded that user groups were now routinely involved in advisory, consultative and executive bodies that formulated and implemented health policy and that this had a bearing on the health policy agenda.

One particular strand of the strategic approach to user involvement advocated in *Our National Health* (Scottish Executive, 2000) was the aim of empowering people to contribute to decision-making on contentious issues such as priorities and rationing. These are issues characterised by a requirement for value-based judgements, choices and assessments of equity and social justice, complexity and controversy (NHS Executive, 1998). User involvement in such debates is founded on the principle of making health services more democratically accountable, acknowledging that such decisions are essentially political in nature (Coote & Lenaghan 1997; Combe 1999). The research evidence on involvement in rationing and prioritising is, however, contradictory.

Some studies have found public reticence at becoming involved in setting priorities, except when these are at a very high level of generality (Bowling et al, 1993). From their research Bowling and her colleagues (1993) concluded that users did not want to take responsibility for collective decision-making and that the more specific the levels of enquiry, the more 'ill-equipped' people felt. On the other hand, Lenaghan et al (1996) concluded from their pilot evaluation of citizens' juries to consider priorities for health care, that given enough time and information, users were willing and able to contribute to this debate. Dolan et al (1999) showed the users' views on setting priorities differed systematically when they were given more opportunities to discuss and deliberate. With a greater recognition of the complexities of choices and rationing decisions, came more sympathy for the manager's role and an increased understanding of the issues.

After reviewing 20 deliberative user involvement exercises Combe (1999) concluded that what users thought about rationing was unclear. However, the review was not necessarily methodologically sound, as Combe found it difficult to synthesise the findings from different activities as the methods used and the wordings of questions were often not comparable. Other conclusions reached were that the amount of time and money currently being spent on involving users in rationing decisions was potentially wasteful because experience was not being shared and lessons not being learned. A number of studies have reported concerns over the characteristics of those who are the most vocal in putting forward their views, that is, primarily well educated and articulate people (Phillips 1995; Jewkes & Murcott 1998). As a result, some have argued that it is "morally wrong" to involve users in such decisions and that the principle of equity and fairness should be protected from "collective and individual arbitrariness" (Doyal, 1996).

However, quite apart from the substantial methodological issues that emerge with regard to the difficulties of obtaining reliable and representative views, unease has been reported about the finding that user values can very substantially differ from those of health professionals (Bowling et al, 1993). Users are often constructed as an interest group, to be balanced with doctors, managers and others (Harrison & Mort, 1998) but, as already discussed, these groups are not equally integrated into policy and decision-making processes and, as a consequence, users may not have the authority required to influence decision-making on contentious issues such as priorities and rationing. Herd and Stalker (1996) emphasised the importance of acknowledging power differentials in planning, such as the imbalances between the different planning participants in terms of their funding, power and obligations within the process. They proposed that such imbalances should be recognised and addressed in the planning process, as although users would be able to contribute knowledge and opinions on the experience of receiving services, they traditionally would also be the stakeholders with the least power. In order to address this imbalance some groups have focused on informing and empowering excluded groups in order that they can also contribute to involvement activities (National Service Users Association 2000; Scottish Youth Housing Network 2000). However, some still argue that the views of users are among a number of factors that influence change in health services, and providers of health care remain the final arbiter of how much weight is attached to their views (Elizabeth, 1998).

Studies have explored the conditions for effective user involvement in policy and planning. One, from the Social Services Inspectorate with the National Health Service Executive (Department of Health, 1994), explored the implementation of community care and found that styles of meetings, the language used and the complexity of the organisational systems

all acted as hindrances to involvement. As a result they found that if users were involved it was more likely to be at a day-to-day level than at a strategic planning level (Department of Health, 1994). A study of involving users in mental health services had similar findings (Bowl, 1996) as, despite an emphasis on user involvement most of the users interviewed were confused as to the purpose of various planning committees. This research demonstrated the critical role of professionals in encouraging action and providing the practical support needed to facilitate involvement, while other research found that user involvement in health planning presents many challenges in terms of cultural change and how best to engage users (Kirk et al, 1997). These researchers found that, despite high recognition of the principle of user involvement, there were no clear models developed or evaluations to help implement this objective.

As a consequence of these difficulties the literature suggests that, whilst the principle that users should be involved in the policy and planning of health services has become accepted, it remains challenging to health agencies to find effective ways of involving users in the longer term rather than in one-off consultations. Furthermore, there is little to indicate the extent to which such involvement influences policy or planning. In a large scale review of 337 studies involving users in the planning and development of health care Crawford et al (2002) found a lack of reporting on the results of user involvement. They found that only 12% of studies described the outcomes of involving users and, where this did occur, it was generally in case studies where project administrators had commented on what the project achieved.

Several of the reports they reviewed described new services being commissioned as a result of the requests of users. These included advocacy services (Gummer & Furney 1998; Pilgram & Waldron 1998), employment opportunities (Wistow & Barnes, 1993; Pilgram & Waldron, 1998), complementary medicine (Woods, 1994), crisis services in mental health (Lord et al, 1998) and fertility treatments (NHS Executive, 1998). Two reports described how involving users had led to proposals to close hospitals being modified or abandoned (Heginbotham 1993; Broderick 1997).   However, the most frequently reported effect of involving users was the production of new or improved information resources (Hendessi 1994; Pagett 1994; Williams 1994; Woods 1994; Pilgram & Waldron 1998; Millett 1999). Other changes included efforts to make services more accessible through simplifying appointment procedures (Richardson & Bray 1987; Pagett 1994; Williams 1994), extended opening times (Richardson & Bray 1987; Pilgram & Waldron 1998), improving transport to treatment centres (Wistow & Barnes 1993; Pagett 1994; Woods 1994) and improved access for disabled people (Pagett, 1994). Whilst these developments were in response to users' definitions of service needs and as such

represented a positive contribution to service development, it could be argued that they are neither strategic nor policy outcomes.

Thus, it can be seen that despite the policy directive on user involvement and substantial evidence of involvement activity in policy and planning, there is less evidence of a real shift in power within health services or that users are able to influence health agencies to any significant extent. In particular, there is currently little that sheds light on how to link the outcomes of user involvement to policy and service development. Whilst considerable attention appears to have been made to developing evidence in the form of information on the users' perspective, there is little to suggest that similar effort has been applied to the structures and processes required to ensure this is appraised, measured and applied and this has not necessarily been linked to mechanisms giving control over policy and service delivery processes.

Summary

It can be seen that there has been a plethora of activity in response to the policy imperative on user involvement. A range of techniques that have the potential to gather the views and opinions of a wide range of users in the health service have been developed or adapted from existing academic or market research methods (NHS Executive 1998; COSLA 1999; Laird et al 2000; Ridley & Jones 2002) and significant activity has demonstrated user involvement in individual care and treatment, in examining and evaluating services and, at a strategic level, in shaping health policy and planning (Schoen et al 2004; James 2000; Allsop et al 2002; Crawford et al 2002). However, an examination of these developments reveals limitations in their impact and application.

First, the aim of these participative mechanisms may appear simple in that they are concerned with broadening the range and number of users who are involved in either their own care or in a particular health service delivery or policy process. This is proposed to result in a more informed, considered input, which in turn could aid service and policy development (Wilson, 1999). However, a review of the approaches employed in user involvement reveals that health agencies are heavily reliant on a limited number of techniques that are appropriate for drawing on the direct experiences of users; informing users or asking opinions, but appear to provide less scope for empowering users to define problems and propose solutions, particularly in shaping service delivery and policy processes. Furthermore, they all are open to the criticism that they are limited in their capacity to involve marginalized or 'hard-to-reach' groups (Lomas 1997; Laird et al 2000; Spencer et al 2000). As such there would appear to be a need for the implementation of more innovative methods and techniques that encourage dialogue and allow for the

expression of the perceptions, attitudes and ideas of users. A review of techniques also reveals the importance of clarity over the aims and purpose of user involvement in terms of deciding upon appropriate methodologies thus, ensuring that the ambitious aspiration of influencing health care in accordance with users' definitions of need is achieved (Cabinet Office 1998; Barnes 1999a; McCrae et al 2002).

Second, while there exists a wealth of evidence that the active involvement of users in their own care and treatment has significant benefits for both individuals' health and for health services (Joseph Rowntree Foundation 1997; Greenhow et al 1998; NHS Executive 1998; Coulter 2002b; Coulter & Magee 2003), the evidence on user involvement in service development, policy and planning is less unambiguous. In particular, there is currently little that sheds light on how to link the outcomes of user involvement to policy and service development (Kober 1994; Barnard 1998; Crawford et al 2002). The complexity of changing behaviour is now well recognised and the naive assumption that evidence when made available is appraised and applied in practice is largely discredited. However, whilst considerable attention appears to be made to developing evidence in the form of information on the users' perspective, this has not necessarily been linked to mechanisms giving control over policy and service delivery processes (Fitzpatrick & White, 1997). Nevertheless, despite the apparent lack of influence, the interests of users are frequently evoked in health service negotiations (Elizabeth 1998; Harrison & Mort 1998; Allsop et al 2002; Crawford et al 2002), sometimes in support of health professionals and managers who appeal to users to support them achieve the health care system they aim for.

In 1998 Barnes and Evans claimed the development of user involvement was 'historically weak' for two main reasons. The first was a general lack of focus and confusion about what user involvement is and second, many innovations have been one-off projects and not perceived as integral to the way the health service works. This chapter has demonstrated that both of these remain important reasons for the continuing lack of user involvement with ambiguity over definitions and continuing criticism of user involvement as peripheral to the operation of the health service (Crawford et al, 2002). The next chapter will explore further the barriers to the implementation of user involvement arising from the cultural, organisational and practical difficulties identified this far. In doing so, it will seek to identify those limitations that would need to be addressed in order to facilitate the continued development of user involvement as a health service policy and the subsequent delivery of its aims.

Chapter 3: The Barriers to Developing User Involvement in Health Services

As demonstrated in chapters one and two, there are a number of strong political, moral and social arguments, as well as a range of acknowledged benefits, for the implementation of user involvement in health services (Joseph Rowntree Foundation 1997; Barnes & Evans 1998; Bury 1998; NHS Executive 1998; Hogg 1999a; Olzsewski & Jones 1999; Coulter 2002b; McCrae et al 2002; Coulter & Magee 2003). However, an examination of the literature on developments in user involvement has revealed limitations in their application and impact (Kober 1994; Fitzpatrick & White 1997; Barnard 1998; Crawford et al 2002). Commentators such as Anderson et al (2002) and Oliver (2005) have pointed to the need for appropriate skills, resources and time in order to develop productive approaches to user involvement, while others have identified a number of obstacles that stand in the way of developing effective engagement in health services.

Principal among the barriers identified are concerns over the representativeness of those who are engaged in user involvement activity, but Pickard et al (2002) identified additional barriers to effective involvement in a programme concerned with facilitating engagement in health and health services. They found that the main factors preventing health agencies from forming effective and equal relationships could be grouped into five domains. These were described as the users' capacity to engage, the health services' capacity to engage, the professional service culture, the organisational ethos of the health service and the dynamics of the national and local political system. These barriers would appear to be important to the understanding of user involvement and so each will be explored in turn.

Representation and Representativeness in User Involvement

An examination of the literature on user involvement demonstrates that, while there is agreement that its value lies in the different perspective brought to debates and discussions on health, the identification of a representation of that perspective has presented a number of challenges for the health service. Traditionally, health agencies have equated the provision of a user perspective with 'lay representatives' (Hogg, 1995). They have often been identified as recent or present users, those with links to a local health council or a 'safe pair of hands' already known to the health agency (Hogg, 1999). However, with the development of user involvement there has been a concomitant increase in the opportunities and demands for user participation in the treatment, service delivery and policy-making processes of the NHS. The traditional model of 'lay representation' has often proved inadequate to these increasing demands, both in terms of the availability of representatives and in the appropriateness of the 'fit' between this model and variety of

opportunities now presented. It is possible to distinguish three areas of concern: who represents the user perspective in health agency structures, to what extent is the diversity of user views represented and whose interests do user representatives advocate? Each of these questions has created difficulties for health agencies in trying to meet their responsibilities for user involvement and so each is explored below.

Who Represents the User Perspective in Health Service Structures?

There are two commonly used strategies adopted by health agencies when seeking to involve users in service delivery or policy processes.   The first is to invite an individual who is currently using or has recently used services as the legitimate representative of other users. The second is to use an advocate or proxy for individuals; this is most often a user organisation.

Using individuals as representatives has apparent advantages for health agencies in that their identification and recruitment is relatively straightforward and, by using recent or past users who are well known to them, health professionals may feel reasonably confident in their knowledge of and agreement with the user perspective. Hogg (1999) illustrates this:

> "When looking for the elusive community 'voice' statutory services have tended to look to the individuals that they know and feel comfortable with" (Hogg, 1999)

Users themselves have advocated this strategy, with many dismissing those who have not been through the relevant experiences as unable to represent the user perspective. That people should be able to represent themselves wherever possible is a fundamental principle for developing user involvement. However, this approach could weaken the position of more vulnerable users who have difficulty in putting forward their case.   One good example comes from the field of sexual health. While many gay men who are HIV positive are part of a supportive community and are willing to speak out, the situation is different for women and people from ethnic minority groups who are HIV positive. They are often isolated and may not be willing to be identified (Hogg, 1999).

A number of other concerns have been identified with this strategy. Chief among these is the fear that individuals will not be able to represent the views of other users. Williamson (1995) argues that users cannot represent other users' points of view because they seldom know what they are.   In common with other commentators, she proposes that in order to function effectively as representatives the understanding of users' interests and concerns should be wider than that of an individual. Williamson and others have proposed that individuals should have close links with other users by, for example, continually referring back to a reference group or by having access to regular feedback from representative

samples of users to balance the views of special interest groups or those 'with an axe to grind' (Lindow 1991; Williamson 1995; Hogg 1999; Coulter 2002a).

A further difficulty relates to the perception of some users as a 'safe pair of hands' and thus, unlikely to challenge the health agency. The perception of user representatives as benign and unchallenging may be reinforced by research that has identified the anxieties of those who wish to become involved as a result of being critical of the service. Being faced with criticism may be uncomfortable for health professionals but, it is argued that this is also difficult for the user as they are going against the traditionally strong cultural view of the NHS as generally positive and for which individuals should be grateful and supportive. The perseverance of this need to be explicitly supportive of the NHS is continually demonstrated in public opinion polls. Despite the rise of user groups willing to voice concerns over some aspects of services, overall support for the NHS appears unshaken (Lupton et al, 1998). Such a situation may serve to inhibit those who wish to voice an opinion, but who do not wish to appear disloyal to the service overall. Particularly in the context of health services a reluctance to complain should not be taken as the absence of concerns. Some people may need considerable reassurance about the confidentiality of their views and, in some cases, may only feel able to voice their opinions once their treatment is finished or they receive assurances that they can seek help elsewhere (Taylor, 1994). A particular concern relates to being seen as a 'troublemaker' by professionals in a service vital to survival and quality of life and at a time when users are most vulnerable. Hogg (1995) underlines this:

> "The difficulties of making a complaint should not be underestimated, particularly for people who feel vulnerable, and are dependent on the hospital for their on-going care. They feel, sometimes rightly, that a complaint will be held against them." (Hogg, 1995)

These issues are illustrated in the experience of Maternity Service Liaison Committees, which were set up in 1984 as a forum where providers and professionals could work together to plan and co-ordinate local maternity services. It was accepted that there should be members representing mothers' views from the beginning and later it was recommended that a user member should be the chair of the committee (NHSE, 1996). Many committees tried to recruit women who had recently had a baby as members. Their value was seen to be in contributing their recent experiences of the service, not necessarily their contacts with other users or their understanding of the complex politics of maternity care. However, there are a number of issues raised in relation to this recruitment strategy that make representation difficult. For example, a new mother would be unlikely to be able to contribute a wider user perspective, to have the time or energy to understand the complexity of health service planning decisions or the technical arguments about the

evidence base for guidelines and policies. She would be most likely to have been recruited through maternity staff and so be sympathetic to them. As such, she may be inhibited from expressing views and may not want to antagonise professionals, especially if she was likely to have another baby at the same unit (Hogg, 1999).

A further difficulty for individual users is that some committees insist on confidentiality about their discussions, which can leave a user member isolated. Unlike other members, confidentiality means that they are not supposed to seek information or advice from colleagues outside the committee. Thus, not only could individuals be disadvantaged by their lack of knowledge and expertise but, as an isolated individual, they may struggle to make an effective contribution to an established committee of professionals who all know each other (Hogg, 1999). However, while those who regularly volunteer or are chosen as user representatives may be in a position to develop knowledge and expertise, a particular criticism of them is that they are perceived as partisan and different from other users. They are seen as 'professionals'; that is, they are seen by some as closely allied to health professionals, having become overly sympathetic to the constraints under which the professionals operate (Hogg, 1999).   Health professionals too have challenged the 'professional' user as a representative of user views, proposing that they are alienated from the wider group they purport to represent. As Lindlow (1991) observed:

> "Staff members expect to be patiently tolerant of a shaking client at their committee meeting but are surprised and sometimes feel threatened by someone who is briefed on the issues. They then suggest that this person is not a proper service user because he or she is too articulate" (Lindlow, 1991)

Therefore, individual representatives would appear to face a dilemma in that they are criticised for being both uninformed and inexperienced in health agency structures and also for becoming well-briefed and articulate advocates.

The alternative to recruiting individuals to represent the user perspective is to utilise the growing networks of user groups as a proxy or advocate. The voluntary sector provides a channel for three types of user advocacy. These are voluntary service, community projects and mutual-aid groups. Familiar forms of voluntary service in the health field include hospital leagues of friends and the Women's Royal Voluntary Service (WRVS). Community projects emerged during the 1980s in an attempt to respond to the problems of inner city areas, particularly in London and Glasgow, and took the form of health-orientated community development in a given locality (Hatch, 1984). In the sphere of mutual aid there are many self-help and patient groups. Most forms of chronic disease or disabling condition have such a group, usually linked in a national network. Mutual-aid groups vary greatly in their structures, aims, methods and philosophy of care but share a

base in a specific problem and situation. They are usually formed by peers who have come together for assistance in satisfying a common need, to overcome a common handicap or life disrupting problem and to bring about desired social and personal change (Kicksbusch & Hatch, 1983). Mutual-aid groups often spring up to fill gaps in the provision of information, counselling and support in existing services. They also have a value in providing opportunities for users to meet up with others in a similar situation and share experiences (Lang & Path, 1994).

However, despite their shared values user groups can vary significantly in their style and aims; they can be user led, professionally or commercially dominated, usually by drugs companies (Hogg, 1995). They range from user led groups such as the Association for Improvements in the Maternity Services (AIMS) or Radiotherapy Action Exposure Group (RAGE) that contest clinical practice to groups like the National Childbirth Trust (NCT) or Action for Sick Children that tend to be less overtly challenging. Groups that are professionally led, like the British Diabetic Association (BDA) or the Multiple Sclerosis Society (MSS), can support professional definitions of users' interests so thoroughly that other factions, the Insulin Dependent Diabetes Trust (IDDT) and the Association for Research into Multiple Sclerosis (ARMS), have split from them (Williamson, 1999). This range of interests among mutual-aid groups has led to a number of tensions and is best illustrated by the debate around the funding and support of user groups by pharmaceutical companies. Examples of industry funding include Pharmacia and Pfizer's sponsorship of Arthritis Care's campaign for the prescribing of a new COX-2 inhibitor and Diabetes UK, who have received funding from 11 pharmaceutical companies manufacturing diabetes drugs. Such is the perceived strength of these groups, and their power to influence the NHS, that calls have been made for commercial interests in funding to be declared. Some commentators have proposed that groups accepting industry funding should declare it as a conflict of interest to enable users to question their independence and that of the perspective they provide (Hirst, 2003).

Nevertheless, engaging with user groups as representatives of users has been shown to have a number of benefits for health agencies. Studies have found that user groups can put their experience at the disposal of those planning services (Evans, 2001), can play an effective part in raising the profile of a condition and can put pressure on purchasers to meet an identified need (Morris, 1995). There is recognition that opinions from user groups are not the only ones that count, but some commentators consider them to be usually representative, thoughtful and mature (Goodare, 2002). However, they may not represent the entire spectrum of user views as some users may not attend mutual-aid groups due to reluctance to share their feelings with strangers (Galinsky & Schopler, 1994)

and despite the obvious benefits of recruiting user representation from established groups with a particular interest in a specific condition, there are also associated difficulties.

One particular difficulty is the differing capacity of groups to respond to and exert influence within health agency structures. Critics have argued that user groups only increase the opportunity for middle class activists and frequent attendees of health services to have their say in the running of services (Wood 1984; Allsop et al 2002). This, it is proposed, has led to fragmentation and uneven service developments whereby groups that are well resourced and effectively linked into decision-making structures have benefited from being able to lobby successfully around specific issues (Hogg, 1999). However, as many user groups are informal and poorly funded, they do not necessarily have the energy or skills to maintain a group, let alone work with or lobby a health agency. Moreover, the existence and survival of groups is likely to reflect the presence of a few particularly committed or inspirational leaders, rather than the incidence of needs.

Some chronic health problems may prevent users taking part in collective action altogether, for example those with debilitating illnesses such as ovarian cancer or neurological conditions like Alzheimer's disease (Hogg, 1999). In such cases, very often the carers have come together to form their own organisation but some would question how closely their agenda and interests match those of the user (Hatch, 1984). Studies have shown that carers may not always be good judges of users' needs and wishes as demonstrated by evidence from cancer research that suggests carers are likely to overestimate physical discomfort at the expense of psychological and spiritual distress (Higginson, Wade & McCarthy 1990; Higginson, Priest & McCarty 1994; Field et al 1995). Carers may feel unable to cope with a person's suffering and ask for greater pain control (Lewis, 1996) whereas the user may prefer to be suffering and conscious rather than sedated and unaware of their surroundings. Thus, a number of commentators have argued that it may be unwise to assume that what users want is the same as what carers want, or vice versa, and that it is important to recognise that carers may articulate their own needs when asked to speak on behalf of those they care for (Barnes & Walker 1996; Grande, Todd & Barclay 1997; Small & Rhodes 2000).

Thus, despite the ease with which user groups can be engaged, questions have been raised over their representativeness of the range of user experience. There can be seen to be a potential inequity in them representing the user perspective as the characteristics of these groups and the interests they advocate can be influenced by a number of factors. This means that both recruitment strategies, using individuals and user groups to represent the views and experiences of others, have been challenged over their ability to deliver a user

perspective that is representative of the diversity of user views. Thus, it is the issue of representativeness that will be examined next.

How Representative are User Representatives?

The issue of representativeness is one that has caused great unease in the implementation of user involvement with many commentators expressing concern over a perceived lack of diversity in the user perspective brought to health structures. As a public service, the NHS needs to recognise, understand and interpret the perceptions of users distinguished in terms of a variety of social, demographic, ethnic as well as health characteristics if it is to obtain clear, reliable and representative views. Thus, there has been much debate on the range of views brought by those who volunteer, or are invited, to represent the user perspective.

An inclusive approach to user involvement was highlighted in *Patient Focus Public Involvement* where NHS agencies were told to ensure that the needs of users from marginalized groups were addressed (Scottish Executive, 2001). However, wide scale involvement exercises have shown how difficult it is to engage with marginalized or 'hard to reach' groups (Bowling 1996; Ham 1998). Groups who have been regularly identified in involvement initiatives as particularly susceptible to exclusion include people with learning difficulties; people with multiple impairments; people who do not communicate verbally; elderly people with impairments; black and minority ethnic users and refugees (Beresford, 2007). However, this is far from a comprehensive list. In his discussion of excluded groups, Steel (2005) identified a much longer list, including, for example, travelers, homeless people; people with addiction problems; single parents; people in poverty; people using mental health services; prisoners; and people with chronic and life-limiting illnesses and conditions.

As discussed in the introduction, a further, and larger, group that the literature on user involvement suggests are marginalized is women. The evidence suggests that gender should underpin user involvement as not only are women more likely to be users of the NHS (Horne et al 1999; Willson & Howard 2000; Donner 2003) but also men and women have different social roles, differential access to services, experience different health difficulties and want different things from their health providers (Papanek 1990; United Nations 1994; Janzen 1999; Horne et al 1999; Scholle et al 2000). However, there is little evidence to suggest that gender has been mainstreamed into the user involvement agenda. Studies on user involvement almost always homogenise women and men as a single group and diversity with respect to gender has rarely been taken into account. As a result, it has been argued that women's voices have not been heard and it has been reported that women are under-represented and marginalized in decision-making in health care (Gijsbers van Wijk et al 1996; Horne et al 1999; Willson & Howard 2000; Donner 2003). As discussed

earlier, the paradox that women are more likely to be users of the NHS but less likely to be influential in user involvement was significant in the choice of women as a group of health users for particular examination within this study. This focus on one under-represented group was underpinned by a supposition that if the structures and systems for user involvement were sufficiently sensitive to incorporate the participation of one marginalized group then they would be accessible to other marginalized or hard-to-reach groups.

One commonly cited explanation from managers and health professionals for not taking user involvement seriously is because of the particular characteristics of the representatives (Taylor & Lupton, 1995). A particular criticism is that representatives tend to be drawn from the "well educated, well spoken and well off" and that the emphasis on user involvement panders to a middle class consumerist agenda that has little to offer people whose opportunities are severely constrained by low incomes, poor living conditions or multiple health problems (Coulter, 2004a). Information on the characteristics of those who take on representative roles could assist in addressing this issue but whilst there are a number of small studies that explore individuals' subjective experience of involvement, there are few providing information on the characteristics of those who are active.

A 1987 survey by the Charities Aid Foundation (CSAF, 1987) found that 19% of people serving on committees were from professional and managerial backgrounds, compared to only 5% from an unskilled manual background. Similarly, the General Household Survey (OPCS, 1987) found a greater propensity for volunteers from professional backgrounds to take on formal responsibilities, such as committee work. However, other research indicates that the backgrounds of those involved may be more disparate. A survey by the Patients Association in England and Wales (Brotchie & Wan, 1993) examined the experience of user involvement across a wide variety of health service related participatory mechanisms including mutual-aid groups, Community Health Councils, advocacy schemes, community health projects and directly in health agency committees. Its findings challenged the assumptions typically made about the importance of different socio-economic backgrounds. Whilst having the necessary confidence and skills was seen to be important, many activists did not possess these characteristics at the beginning of their involvement. Many went through a process of personal development in order to sustain the complex levels of involvement they ultimately held. Motivation, personal characteristics and opportunities for information, support and encouragement were all relevant to that process (Brotchie & Wan, 1993).

To ensure diverse involvement, that is to say, the involvement of all groups of users, it would then appear to be important to provide appropriate support to increase people's capacity to be involved, whatever their circumstances or identity. The experience of user

involvement projects such as '*Shaping our Lives'* (Shaping Our Lives National User Network, 2003) suggests that appropriate support includes the acquisition of relevant skills and experience, confidence-building and the raising of self-esteem, the resourcing of people's involvement through payment and the meeting of costs incurred and the provision of opportunities to get together with each other (Branfield & Beresford, 2006). If these are not addressed, then Branfield and Beresford (2006) propose that user involvement is likely to be partial, and reflect broader social divisions and exclusions.

However, it has been suggested that it is not possible to engage all perspectives, and therefore, involvement will inevitably be unrepresentative. Alternatively, others have argued that users who are involved can claim no real mandate, so that the basis on which they are involved is always likely to be questionable (Hogg & Williamson, 2001). In response to these arguments, users suggest that other stakeholders are not expected to be 'representative' and that generally they have no special mandate, so why raise this particular argument in relation to users (Beresford, 2007). Similarly, Hogg (1999) proposed that while the test of 'representativeness' tends to be used against user members it is rarely questioned in other members of the same committee.

> "…the representativeness of the consultant obstetrician or community midwife, for example, is not questioned" (Hogg, 1999)

Thus, it can be seen that difficulties with the concept of representative participation are often at the core of concerns about involving people (Hopton & Hill, 2001). Concerns about finding representatives who are able to focus on broad rather than single issues, involving marginalized or 'hard to reach' groups, and ensuring that forums for user involvement are not dominated by specific interest groups lie frequently at the heart of the hesitation to involve users (Hogg 1999; Beresford 2007). The lack of evidence on the characteristics of those active in involvement provides little to challenge the strongly held perception that those who take on such roles are unrepresentative and as a result this remains an issue that is been used to contest the perspective presented by users or user groups when it is challenging to other stakeholder interests.

Whose Interests are Represented?

A further concern in representation is that of whose interests are represented by users. In a review of the interests and understanding of lay representation Hogg and Williamson (2001) argued that, although user representatives are generally assumed to be working for user interests, they tend to support professional or managerial interests rather than user interests, as users would define them. They suggest that user representatives fall into three broad categories: supporters of dominant or professional interests, supporters of managerial interests and supporters of user interests.   They proposed that it is possible for

a representative to have any of the three characteristics described above, whether an individual or drawn from a user group.

Both the extent and character of user involvement are susceptible to professional and statutory interests as some organisations rely on Scottish Executive grants to allow them to operate at a national level, while NHS Boards fund user initiatives at a local level. Support from medical professionals has often been shown to be of great importance in initiating and sustaining user organisations and mutual-aid groups (Hatch, 1984). Such financial or organisational links could dispose user representatives to a sympathetic stance in relation to professional interests. The events at the Bristol Royal Infirmary demonstrated that lay representatives might support the dominant health professionals' interests. During the inquiry into avoidable deaths in paediatric cardiac surgery, non-executive directors were shown to have known of the allegations of high mortality rates for some paediatric cardiac surgery but asked no questions (GMC, 1998). User contribution from a managerial perspective is also well established following the extensive appointments during the 1980s of people from industrial, managerial and financial backgrounds to act as lay representatives on NHS Boards and Trusts (Cooper et al, 1995).

Supporters of user interests have also been challenged. It has been argued that the motivation of users acting for themselves may be the result of suspicion of or grievances against health professionals (Hatch, 1984). Piette (1990) groups individuals who get involved into two broad categories of 'defenders' and 'protestors'. The defenders are those whose primary motivation for involvement stems from a desire to support a particular service while protestors are those whose involvement is triggered by a concern to express dissatisfaction or bring about change. However, individuals' original motivation for becoming involved may change or evolve as a result of their experience. Defenders may grow more critical as they understand the organisation better and protestors may modify their stance, as they perceive the constraints surrounding the provision of service. This may result in them being perceived as moving towards a position as a supporter of professional or managerial interests and, as already discussed, subsequent criticism that they are closely allied with and sympathetic to health professionals (Hogg, 1999).

Thus, it can be seen that representation and representativeness are significant issues in the development of user involvement, with some commentators suggesting that the potential contribution of users has been compromised by the lack of clarity over what constitutes a user opinion and the reasons for their involvement. Nevertheless, increasing numbers of representatives from user groups are being appointed to health service committees, groups and decision-making fora. Whilst such an increase is to be welcomed Hogg and Williamson (2001) argue that care must be taken to ensure that the term 'user' can be

recognised within health service structures and that these representatives can consistently speak for users' interests, especially when these conflict with the interests of professionals.

Barriers to User Involvement

Although a critical area for the progress of user involvement, representation is not the only difficulty identified in the literature that serves to limit the aims and aspirations of this policy directive. Further barriers have been described by Pickard et al (2002) under the domains of the users' capacity to engage, the health services' capacity to engage, the professional service culture, the organisational ethos of the health service and the dynamics of the national and local political system.   The next section will examine the nature of these challenges to user involvement.

The Users' Capacity to Engage

The first set of barriers relates to the capacity of users and user groups to participate in the involvement opportunities presented. As already discussed, some commentators have pointed to the need for user involvement to be adequately resourced (Ham 1992; Hogg 1999; Allsop et al 2002; Branfield & Beresford 2006). This plea is supported by research by the Long-Term Medical Alliance that found that, while many smaller user organisations wished to be involved in shaping and monitoring the NHS, they were frequently limited by a shortage of financial and human resource and needed support to maximise their contribution (Levenson, 2001). Harrison and Mort (1998) found evidence of a similar lack of user capacity in a review of user groups operating in the areas of mental health and services for people with physical disabilities. They found that whilst managerial and professional respondents were ostensibly overwhelmingly in favour of user involvement in general, their enthusiasm was tempered by their criticisms of user groups. These frequently related to the representativeness of the groups, whom it was felt were neither representative of society at large or of all users. Other criticisms were of internal feuding, poor management and organisation and lack of care for their own members.

Oliver (2005) in a review of user involvement in research and development agenda setting in the NHS found that users faced a number of barriers including lack of skills, resources and time. These barriers, which largely arose from users' unfamiliarity with research and research programmes, could, she proposed, be addressed by facilitated debates and an investment in communication, training and support. She concluded that greater success in user involvement might be expected if research programmes embarking on collaborations with users provided well-networked users with information, resources and support to empower them in the key roles associated with the role of user representative.

The capacity of user groups to engage with the structures and expectations of the health service may also be substantially influenced by their composition and style of working. In a study of user involvement activities of six London primary care organisations, Anderson et al (2002) identified a number of obstacles to involvement. They found that user members performed a key role in keeping user interests alive in Primary Care Board and sub-group meetings, but faced a number of challenges in summarising and conveying the diversity of views they represented. Furthermore, the authors identified a lack of sound local infrastructure of contacts with appropriate voluntary and community groups, including hard-to-reach groups. In their recommendations, however, they made clear that they held the responsibility for building and investing in user involvement with the organisation that seeks to benefit from it, and not with user representatives.

The Health Services' Capacity to Engage

Research into the implementation of user involvement has demonstrated that the NHS needs to develop 'significant capacity' in order to implement this agenda. A number of factors have been identified as serving to limit the capacity of the NHS to respond fully and effectively to the policy imperative. In a survey of Primary Care Groups senior health managers identified the problems in implementing the involvement agenda as shortages of expertise, time and money (Shepherd, 2001). From this list, it is the concerns regarding the perceptions, skills and competencies of health services staff that have been identified as a major challenge. The challenge includes recognition of the deficit in training at both pre and post qualifying levels as many health service staff have not been trained in working in partnership with users. The NHS Executive (1998) stated that, because of their professional training and background, health service professionals could feel threatened by the notion of user involvement. *Our National Health* (Scottish Executive, 2000) identified the need for radical change to bring about a 'patient centred NHS'. As, the Scottish Association of Health Councils (1999) concluded:

> "The NHS has a fine record of working for people, providing expert services and care: moving towards working with the public will need changes in organisational culture and new skills for managers and staff." (Scottish Association of Health Councils, 1999, p 19)

However, Brown et al (2000) argued that the implementation of the user involvement agenda would require more than simply rectifying a training deficit. It would necessitate a redefinition of user and professional relationships with, at a minimum, a common language and shared definitions.

Authors have repeatedly commented on the impact of staff workloads and staff shortages on the potential success of the implementation of user involvement. For example, Poulton (1999) in a review of two user involvement projects identified staff resistance grounded in

the fear that involvement would increase user expectations and add to the pressures of overworked primary care teams.   Similarly, Levenson (2001) reported that for many health service staff, involvement feels like an added burden onto an already overwhelming workload. Read and Wallcraft (1992) highlighted adequate resourcing as a prerequisite to empowering users, proposing that if staffing levels are low, making it difficult for staff to spend time with service users, then it is less likely that users will end up fully informed. Several authors (Read & Wallcraft 1992; Taylor et al 1992; Trnobranski 1994; Rodwell 1996) suggest that it is difficult for health care workers to empower users if they do not feel empowered themselves. If front-line staff have little power in decision-making, then the extent to which they can shift power to service users is also limited. Seeking to increase the involvement users have in decisions about their care, then, requires a resource commitment if it is to be successful.

Cole (2000) also proposed that the obstacles of cost in terms of time and money should be acknowledged. For organisations, decisions to incur the extra costs of prioritising involvement will weigh heavily on the managerial conscience when they have to be taken alongside decisions about spending money on direct services. This is further underlined by Summers and McKeown (1996) who proposed that enthusiasm for the general idea of involvement needs to be matched with "realism and honesty about what can be achieved". Taken together these factors of training, cost, resources and a lack of shared understandings suggest a need for a shift in organisational culture rather than a simple reorganization of financial or training shortfalls.

The Professional Service Culture

Moving towards more democratic forms of health care also implies a shift from the traditional 'professional model' of accountability, whereby the doctors' accountability was through professional organisations, towards one of partnership (McCrae et al, 2002). This represents a significant change to the traditional professional service culture of paternalism and professional authority. Some commentators have suggested that paternalism is endemic in the NHS and, that although benign and well intentioned, it has the effect of creating and maintaining an unhealthy dependency that is out of step with other currents in society (Coulter, 1999). In fact, some have suggested that the implications of user involvement seem likely "to prove far more radical than first envisaged" as it will challenge the long held assumption that health professionals know best and can make decisions on behalf of users without involving them (Williams & Grant, 1998). To facilitate user involvement, then, health professionals would have to accept that users would be able to be involved in decision-making.

However, the assumption that illness can only be diagnosed and treated by expert health professionals still pervades the health care system. This notion that health professionals know best was taken up by Handy (1990), who suggested that users are expected to co-operate with health professionals because their therapy is seen as being in the patients' best interests. Rogers et al (1993) suggested that assumptions about the inability of users to hold valid opinions are held by 'therapists' of all kinds. If professionals hold such views then the extent to which users can be involved in decision-making will remain severely restricted. Health workers, they proposed, should not underestimate the extent to which socialization into the 'professional' culture has been internalized and thus influences practice. Read and Wallcraft (1992), for example, found that staff felt threatened or undermined by moves to empower users and Higgins (1994), identifying challenges faced by staff through the introduction of an advocacy project, found that both managers and front-line workers reported difficulty in coming to terms with the implicit criticism they received as a result of user involvement. He noted that nurses, in particular, found it difficult not to internalize the criticism, perceiving it as questioning their professional judgement and competence.

According to Coulter (2004b), in many quarters paternalistic attitudes to health care are still the norm and this makes many users reluctant to make demands of professionals for fear of being labelled 'difficult'.   Small and Rhodes (2000) comment that an interest in user involvement does not mean, "traditional conflicts between service providers and users go away". Indeed these authors suggest that professional support for involvement might be limited if it impinges on their sense of expertise and judgement while others have gone further, proposing that "user involvement is only welcome when it conforms with what the professional wants to hear" (Pearson 1995, cited in Small & Rhodes 2000).

If professional culture is to facilitate involving users in decision-making, the challenges posed by changing the power relationship between professionals and users must be addressed. For some commentators (Coulter 2002c; Pickard et al 2002), the key to this lies in patient-centred care and the interaction with health professionals. They propose that by emphasising the principles of shared decision-making and promoting collaboration between users and health professionals, a new relationship of partnership could be developed that could have onward benefits for those users struggling to make their voice heard in committees, to work constructively with other, often more powerful, stakeholders. However, despite the challenges to the role and authority of health professionals represented by increasing user involvement there is little in the literature to clarify how the power differentials between the parties in this new partnership will be managed.

The Organisational Ethos of the Health Service

One particular feature of Scottish Labour/Liberal Democrat government policy was that it sought to develop debates about the role of the NHS in areas that had been previously less well understood. *Designed to Care* (Scottish Office, 1997) includes in its core objectives the promotion of partnerships between the health service and other organisations whose work contributes towards an improvement of health and the quality of services. This implies greater partnership with organisations whose relevance to health has been hitherto unappreciated and is consistent with a social model analysis of health that identifies the quality and quantity of health care as only one component in quality of life and well being.

The social model of health is different from the bio-medical, or medical, model that understands health and illness as opposite sides of the same coin (Doyal, 1998). The medical model believes that individuals create their own health or ill health: either by accident, depending on their own biology and genetic inheritance, or deliberately, through their lifestyle choices. When health is viewed in this way, medical care seems the best way to address ill health and disease. The medical model is part of the scientific tradition that claims to be rational and objective. It is reductionist, considering the body as a series of component parts that can be studied independently of the society in which they function. In contrast, the social model allows for a broader understanding of the creation of health, and links it to social and economic inequalities. In this analysis, health cannot be divorced from the social circumstances of life and all aspects of people's lives have the capacity to affect their emotional, physical and mental health. This implies that a wide variety of public and community agencies have a role in ensuring or maintaining a healthy population. However, the social model may not be an approach with which health professionals are either familiar or comfortable (Warshaw, 1993).

Drewitt (1997) proposed that the 'medical model' approach to health care is powerful cultural influence and that this militates against the development of an effective user voice. Within the medical framework, individuals are translated into case histories that are linked to medical pathology and problems. In contrast, the 'social model' approach to health directs professionals to provide an appropriate, systematic response in which health care would not be restricted to the treatment of presenting physical problems (Warshaw, 1993). Drewitt (1997) further argued that the medicalisation of health coupled with users perceived as possessing less expertise has had the effect of de-legitimising a role for users in defining and shaping services. In health care in particular, users' understanding is viewed as inferior to professional knowledge; the former is relegated to the status of personal and subjective, while the latter is elevated to the ranks of 'expert' (Ong, 1996). This would appear to be an issue for all user members of professional committees and

health service groups, whoever and however they are appointed. Because they are not 'experts' their views would not be given the same weight or respect as those of other members. Professional members start from a position of superior knowledge and perceive themselves as objective in comparison to users who may rely on their own and others experience (Hogg, 1999).

The literature suggests that, as a result of finding it difficult to view users as experts, some professionals could resist moves towards greater user involvement. Although there is evidence to suggest that professionals are generally supportive of user involvement, there are also discrepancies between expressed support and actual practice (Campbell, 2001). This could reflect professionals' perception of themselves as more supportive than users perceive them to be (Peck et al, 2002), resistance to the notion of sharing and transferring power to users, or a clash of professionals' 'scientific' and users' more 'social' ways of thinking and working (Summers, 2003). The pervasiveness of the elevated status of 'expert' knowledge has led some to argue that the dominance of the traditional, professionally driven approach to clinical care is the main obstacle to change (Williams & Grant, 1998). Some commentators have argued that users and health professionals have different, if equally legitimate perspectives and that both parties make a valid, albeit different, contribution (Popay & Williams 1994; Lewthwaite & Haffenden 1997). This position was supported as far back as 1991 in policy guidance from the Department of Health when it stated, "so long as they are competent, users' views should carry the most weight" (Department of Health, 1991). More recently *Our National Health* (Scottish Executive, 2000) stated that listening, understanding and acting on the views of users would be given the same priority as clinical standards and financial performance. However, this review found no policy guidelines or practice guidance that would assist health agencies in weighting these differing perspectives or in managing the conflicting constructions of health brought by the new partnership with users.

The Dynamics of the National and Local Political System

There has been little guidance to help health professionals balance the different contributions of professional and user interests and similarly there has been little guidance on how to manage the tension between the pressure to achieve performance indicators as set by national policy and to maintain aspects of clinical services that are important to users but do not feature on hospital league tables or other political priorities. Strong and Robinson (1990) cited in Lupton et al (1998) proposed that the historical legacy of the NHS presents difficult challenges and that NHS reforms overall have militated against increasing user involvement as health agencies have focused attention on implementing national agendas.

This is illustrated by Squires and Learmouth (2003) who reported on a consultation with users on the reorganisation of a clinic in order to minimise waiting room times and maximise throughput. This reorganisation was proposed as beneficial as it would ensure the hospital met the political imperative on waiting times.   However, the feedback from users overwhelmingly supported the established system that often ran behind time but which prioritised the quality of the consultation by allowing flexibility in appointments. This study showed that the desire to influence performance indicators could result in changes that are unpopular with users and similarly changes proposed by users may have a deleterious impact on the achievement of performance indicators. User preferences may also disagree with clinical guidelines (Mouton et al, 1997). This will have implications for clinical concordance and poses a challenge to health professionals to resolve such difficulties. Some doctors have expressed concerns that users will demand treatments that offer little benefit but which may be expensive. The conflict between individual and societal needs, individual and organisational priorities would appear to be particularly important to the publicly funded NHS and, as such, strategies will be needed to deal with these demands (Say & Thompson, 2003). However, how these conflicting pressures will be reconciled is as yet undefined.

The barriers represented in these five domains have led some commentators to propose that user involvement could have significant implications for the overall culture of the NHS and that the success of this policy will be highly dependent upon radical changes in the interaction between users and professionals (Anderson 2001; Foote & Plesk 2001). As Anderson (2001) noted,

> "The NHS is a gigantic institution that tends to be defensive and top-down.
> For patient involvement, the institution should ideally be flexible and open and
> listening and accountable." (Anderson, 2001)

A consequence of these barriers and the perceived challenge they present to the core concepts, services and entitlements of the health service has been a resistance on the part of health professionals to user involvement. In the absence of measures to address the major issues of professional culture, organisational ethos and the capacity for user involvement it would appear reasonable that staff would question the value of the concept and the usefulness of devoting extensive personal and professional resources to such a paradigm shift in the systems of the health service. In response to this resistance, detailed guidance practical resources and national initiatives have been developed to support health agencies respond to this policy (Scottish Executive 2001, Scottish Executive & Communities Scotland 2005). However, much of this work has focussed on only one aspect of the shortfalls identified, that being the lack of shared understanding of user involvement.

The NHS Executive (1998) proposed that when there is poor understanding of what user involvement is, involvement activities will be uncoordinated, there will be a lack of clarity about what is being asked of people and this will result in a lack of ownership across the organisation (NHS Executive, 1998). They cautioned against the myth of "perfectibility" or a perception that if first attempts do not succeed then the whole involvement agenda is abandoned. Entwhistle (1999) similarly proposed that this lack of clarity might not only undermine the potential effectiveness of user involvement but that it could also lead to disputes and disagreements over the merits of promoting participation in health care. She noted that while important steps have been taken towards description and measurement in some areas of user involvement, for example shared decision making (Charles et al, 1997) other forms of involvement are as yet only vaguely defined and, as the literature has shown, there are implications for culture, organisational ethos, capacity and the management of user involvement that require urgent development.

Summary

Thus, it can be seen that the policy on user involvement aspires to create dialogue between health agencies and health users and to broaden the range and number of users who are involved in either their own care or in a particular health service delivery or policy process. This is proposed as having the potential for building new alliances between users and professionals, forming the basis of effective, accountable and responsive services and for giving users a democratic voice in the policy and planning structures of the NHS (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). However, a number of barriers to user involvement have been identified and these reveal significant implications for the core concepts, relationships and culture of the NHS (Anderson 2001; Foote & Plesk 2001; Pickard et al 2002). Clearly the implementation of user involvement begins to uncover complexities not hinted at in the policy documents.

Prominent among these is the nature of representation and the obstacles to the health service forming effective and equal relationships with users. The literature on the barriers to user involvement in health appears to demonstrate the organisational implications of, and level of commitment required, in order to construct and maintain robust, representative user participation in treatment decision and health service structures (Bowling 1996; Ham 1998; Hogg & Williamson 2001). Indeed, some commentators have suggested that the potential contribution of users has been compromised by the lack of clarity over what constitutes a user opinion and the reasons for their involvement (Hogg 1999; Hopton & Hill 2001). Concerns about finding representatives who are able to focus on broad rather than single issues, involving marginalized or 'hard to reach' groups, and ensuring that

forums for user involvement are not dominated by specific interest groups are frequently at the heart of a reluctance to involve users (Hogg 1999; Coulter 2002a; Steel 2005; Beresford 2007).

For some commentators the failure of the NHS to identify and engage with a diverse and representative constituency of users has profound implications for the application of equity in health and health services. The literature reports on the fears held by many that user representatives tend to be drawn from the "well educated, well spoken and well off" and that the emphasis on user involvement panders to a middle class agenda that has little to offer people whose opportunities are severely constrained by low incomes, poor living conditions or multiple health problems (Hogg 1999; Coulter 2004a). Without action to ensure diverse participation, some propose that user involvement is likely to be partial, and reflect broader social divisions and exclusions with articulate, educated users empowered to demand treatments which others are unable to access and to shape health services to their definition of need (Hogg 1999; Coulter 2004a; Branfield & Beresford 2006). As discussed the conflict between individual and societal needs, individual and organisational priorities would appear to be particularly important to the publicly funded NHS and, as such, strategies will be needed to manage these demands.

These concerns in conjunction with the dominant medicalized construction of users as possessing less expertise has had the effect of user understanding being viewed as inferior to professional knowledge. Within this climate the user view is relegated to the status of personal and subjective and is often regarded as secondary or inferior (Ong 1996; Hogg 1999; Summers 2003). Further barriers can be seen to arise from the health services' lack of consensus on the definition and implications of user involvement (NHS Executive 1998; Entwhistle 1999; Shepherd 2001) and from the, as yet, unexplored and undefined implications for the culture and organisation of health and health care (Williams & Grant 1998; Brown et al 2000). The lack of strategies to assist health agencies in managing these emerging tensions in user involvement appears stark and the literature revealed little guidance on their future development.

Some commentators however, have proposed that the failure of the flurry of user involvement activity to have an impact can be ascribed to a fundamental flaw in the policy on user involvement that has promoted involvement in committees, planning groups and policy fora at the expense of the important issue for users which is patient-centred care and their interaction with health professionals. They propose that by emphasising the principles of shared decision-making and the need to promote collaboration between users and health professionals, a new relationship of partnership could be developed that could have onward benefits for those users struggling to work constructively with other, often

more powerful, stakeholders and to better manage the complex health service agenda over which they have little control (Coulter 2002c; Pickard et al 2002).

Thus, the literature on user involvement appears to suggest that whilst a commitment to developing effective, systematic mechanisms for user involvement is to be welcomed, it would not appear sufficient to ensure that health planning, decision-making and service delivery processes are responsive and accountable to the policy and philosophy of user involvement. This literature served to suggest a number of themes for this study. Following reflection on the prominent issues raised, a decision was made to address three key areas of concern. The first of these was a description of representation and the nature of those who actively participate in user involvement. In particular, this study aimed to explore the extent to which women, who the literature suggests are marginalized, were involved.

The second theme was identified as an examination of the extent to which women were involved in shaping the treatment, service and policy processes of the health service to their definition of need. The three types of user involvement identified in the literature were examined. To remind the reader these three types of user involvement are the involvement of individuals in making decisions about their own care and treatment; involvement in examining and improving the quality of services and involvement in health service policy and planning. In order to examine women's participation in these types of user involvement three specific health service settings were identified and each of these was, as described earlier, female centred.

The third theme was a desire to explore further the issues of capacity and the significant barriers identified in the culture and organisation of health and health care to the further development of user involvement. These were explored by way of describing a model process for user involvement that encompassed issues of representation, involvement in decision-making in treatment, service and policy processes and the capacity of the health service to respond fully to the ambitious aims of this policy.

The second part of this literature review will explore how the policy on user involvement in health has been understood, interpreted and implemented within each of the three settings chosen for detailed review - maternity, gynaecological oncology and mental health. It will discuss the context, history and development of user involvement in each setting and examine the opportunities for women's involvement in making decisions about individual care and treatment, involvement in examining and improving the quality of services and involvement in health service policy and planning. This involvement is discussed under the headings of individual care and treatment, examining services and strategic planning. The first setting examined is gynaecological oncology.

Chapter 4: User Involvement in Gynaecological Oncology Services

This chapter will describe the context and provision of gynaecological oncology services and how, within this health service setting, the policy imperative for user involvement has been interpreted and implemented. The inclusion of gynaecological oncology services in the thesis provided an opportunity to explore a medically led service where patients carry a significant burden of ill health. This setting suited the exploration of women's participation in user involvement as all patients are female. Nevertheless, men are also included as stakeholders in services. The burden of ill health often requires husbands, partners and sons to assume caring roles and, as such, they are recognised by services as having needs and interests of their own (Cancer Research UK, 2007).

In this setting the term 'patient' is in widespread use to describe the receiver of health care. Although the word 'patient' implies a compliance and passivity that reflects an unequal power between patient and professional, it is conventionally used in this setting where the traditional, hierarchical, bio-medical model of care dominates. This clinical dominance is proposed as partly a result of the nature of the disease and partly a consequence of the highly technical nature of the care and treatment regimes (Cancer Research UK, 2007).

This chapter will explore how this ethos of service provision has influenced the opportunities for, impact and outcomes of user involvement. It will begin by describing the context and provision of services before going on to describe the development and types of user involvement.

The Context and Provision of Gynaecological Oncology Services

Gynaecological oncology services diagnose and treat cancers of the female genital organs. These are known collectively as gynaecological cancers. Gynaecological cancers are a diverse group of diseases with different natural histories and responses to treatment. They encompass a number of tumours with different epidemiology, pathology, and treatment strategies. In general terms they are regarded as less common tumours, but are a major cause of disease and ill health (Kitchener, 1999). The most common group of gynaecological cancers affect the ovaries, cervix or endometrium, while cancers of the vulva, vagina and uterus are relatively rare. Gynaecological cancers accounted for approximately 730 deaths in Scotland in 2003, an overall rate of 27 per 100,000 women (ISD, 2006), just over half the breast cancer death rate. Ovarian cancer is responsible for more deaths than all the other gynaecological cancers combined, ranking fourth after breast, lung and colon and rectum as one of the leading causes of cancer death in women.

In 2003 it accounted for 4.6% of all new cancers in women in Scotland (Scottish Cancer Registry, 2006).

Ovarian cancer includes a heterogeneous group of tumours, some of which are borderline malignancy. The incidence is higher in older women, better educated women and women from higher social classes. Diagnosis of ovarian cancer can be difficult as the most common symptoms, abdominal distension, pain and feeling of pressure in the pelvis, can be caused by a variety of conditions and ovarian cancer may not be suspected. As a result, in the majority of cases the disease has progressed to a late stage by the time it is diagnosed (FIGO, 2005). Surgery is the first-line treatment but chemotherapy is also used. Prognosis after a diagnosis of ovarian cancer is poorer than for other gynaecological cancers and Scotland has one of the lowest survival rates for ovarian cancer compared with other European countries (Berrino et al, 1995). Figures for Scotland report that the 5-year survival rate is only about 41% (ISD, 2006).

In contrast, cancer of the cervix is one of the commonest cancers in women aged under 34 (ISD, 2006). In 2003 it represented 2% of malignant tumours in females (ISD, 2006). The main risk factor for cervical cancer is infection with the sexually transmitted human papilloma virus (Bosch et al, 2002). Multiple sex partners, early onset of sexual activity and smoking are all associated with cervical cancer. The disease is twice as common in women from lower social classes (IIIM, IV, V) as it is in social classes I, II and IIIN. Population screening to identify women with pre-cancerous lesions, which may progress to cancer, has been associated with a recent decline in its incidence. However, screening is not designed to detect adenocarcinoma, which accounts for around 10-15% of invasive cervical cancers (FIGO, 2005). Surgery is also used to treat early cervical cancers but radiotherapy is often necessary when the cancer is more advanced. A 71% 5-year survival rate has been reported for Scotland (ISD, 2006).

The incidence of endometrial cancer is low, under 2 per 100,000, in women under 40 years but rises rapidly after the menopause to around 44 per 100,000 (FIGO, 2005). It is most common in post-menopausal women and so is usually diagnosed at an early stage. Surgery (hysterectomy) is often sufficient to treat the disease but radiotherapy is used when the cancer is more advanced. Recent figures show that the 5-year survival rate is just over 80% (ISD, 2006). Vaginal cancer is similar in nature to cervical cancer but much less common. It occurs in 2 per 100,000 women (ISD, 2006). Vulval cancers are also rare, 3 per 100,000 women (ISD, 2006), particularly among younger women. Surgery is the main method of treatment for both. The 5-year survival rate is 51% (Berrino et al, 1995).

Health care professionals involved in the care of gynaecological oncology patients include dieticians, physiotherapists, occupational therapists as well as medical and nursing staff. A holistic programme of care is required to cope with the physical symptoms following surgery and the side effects from chemo and radiotherapy (FIGO 2005; Cancer Research UK 2007). Psychological, spiritual and emotional needs following diagnosis, changes in body image, altered sexuality and fear of recurrence also need to be addressed. Gynaecological cancer can precipitate a range of emotional and relationship problems in addition to the distress that is common to cancers of any site. It may leave women unable to conceive or bear children and can cause lasting damage to sexual experience and relationships. Psychological aspects of care are therefore particularly important (Gamel et al 2000; Stead et al 2001; Cancer Research UK 2007). Furthermore, palliative treatment and care of women with advanced disease accounts for a considerable proportion of the total management of these cancers (FIGO 2005). Thus, it can be seen that a variety of interventions, ranging from surgery to supportive care, may be necessary to improve the quality of life for women going through the stages of gynaecological cancer.

The next section will consider how this level of ill health and invasive treatment regimes has influenced the development of user involvement in gynaecological cancer services.

The Development of User Involvement in Gynaecological Oncology Services

User involvement in oncology services was catalysed by *The Calman-Hine Report* (Department of Health, 1995) which stressed the need for services to be not only patient-centred but also to take account of their views and preferences.

> "..the development of cancer services should be patient-centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care"(Department of Health, 1995, p6)

The momentum established by *The Calman-Hine Report* was carried on by subsequent NHS documents and plans, including *The NHS Cancer Plan* (Department of Health, 2000), which noted the need to empower patients in order to improve services. However, despite a plethora of books, papers and research reports on user involvement in health in general, there is surprisingly little research on involvement in the field of cancer (Department of Health, 2004a). Bradburn (2001) documented the potential systems employed, noted some changes introduced as a result and recommended the systematic establishment of Partnership Groups across cancer networks, while others have described experience with particular mechanisms (Hunt et al, 2002) or explored key issues arising from the process of implementation (Gott et al, 2002). Indeed user involvement was notable by its absence in an evaluation of the first phase of the Cancer Services Collaborative (CSC), which made

no mention of user involvement. Nevertheless, the CSC was underpinned by a user perspective and used various research methods to identify user views (Robert et al, 2003).

A three year, Department of Health funded study by Tritter et al (2003) addressed the key factors facilitating or limiting user involvement in oncology services. This involved interviews with users and professionals, but in addition entailed a mapping exercise of mechanisms for and case studies about the process of user involvement in three NHS Trusts. This research found widespread agreement on the importance of user involvement, but considerable disagreement on the appropriate scope or the people who should be involved. The views of professionals were felt to be key to the success of user involvement and a need for more training in this area was stressed.   However, they found few users with any experience of involvement and those that did primarily participated in drug trials, fund-raising and surveys. Many, in any case, did not wish to become involved and those who did were unclear as to how to do so. The literature identifies a number of factors that appear relevant to oncology services and to gynaecological oncology services in particular, that may explain the finding that many did not wish to become involved.

The first factor is the cancer user's level of ill health and the implications of this for their active participation in the service. Some commentators have reported on the fears that ill health could preclude user involvement and that some patients may be 'too ill to talk' (Small & Rhodes, 2000). Studies have shown that some people with serious illnesses prefer to defer active participation in decision-making about their treatment to their doctor, perhaps because it allows them to avoid responsibility for the consequences of "wrong" decisions (Charles et al, 1998). Ill health may also have a bearing on users' capacity to attend meetings or actively manage the workload associated with membership of policy or planning fora.   Thus, the more seriously ill and those most debilitated by ill health or aggressive treatments would be less likely to participate in user involvement, leading Coulter (1999) to propose that it will be important to find ways of offering user involvement that do not place an unwanted burden on sick people.

In addition, ill health has an influence on the nature of the contribution patients are able to make to policy and service developments. As people with declining health become progressively more ill, their needs will inevitably change and so too will the range and nature of services they require. Small and Rhodes (2000) proposed that not only will many be reluctant to think about a future of declining health and progressive impairment but they will also lack the knowledge with which to anticipate their future needs. Thus, it may be dangerous to rely too heavily on the capacity of people to speak for those who are more ill or even for themselves when their condition deteriorates. As a result, changes to service provision may be implemented in accordance with the views of those who participated but

to the detriment of other users or even themselves when their condition deteriorates (Small & Rhodes, 2000).

One alternative to patients speaking for themselves is the use of advocates or proxies. In common with other health service settings, cancer mutual-aid groups or user organisations, of which there are many in this field, are often considered as a source of user representation within service or policy fora. Some are national in scope while others are active solely in a local area. In addition, some are generic, with an interest in all types of cancer, while others take a particular interest in one form (Department of Health, 2004a). Very little research appears to have addressed the role of cancer support groups. A somewhat dated study (Bradburn et al, 1992) found such groups to be a valuable resource for cancer patients, offering mutual support together with a range of services not provided elsewhere. However, questions have been raised as to the representativeness of such groups as the collective organisation of people with cancer appears to face a number of challenges. The first of these lies in the consequences of ill health. Not only do unpredictable and fluctuating levels of illness present barriers to cooperation and collaborative effort (Small & Rhodes, 2000) but also people become progressively less able to maintain their social contacts when their health deteriorates and so they become more isolated within their communities (Young & Cullen 1996; Skillbeck et al 1997; Rhodes & Shaw 1998).

A further difficulty arises from the dominance of medical professionals in user activities within the cancer field, described by Shakespeare (1993) as "well nigh total" (Shakespeare, 1993, p 256). Urben (1997) reported on a Cancerlink survey from 1992 which that found that although the majority of user groups had been started by someone with cancer, or a relative of someone with cancer, at least forty percent had some form of professional involvement. Many studies have shown that professionals and users may hold different and even conflicting views (Barnes & Wistow 1992; Heritage 1994; Twigg & Aitken 1994). For example, professionals tend to place a lower value on people's quality of life (Spence, 1984) and to assess the severity of symptoms differently to users (Abbott, Dodd & Webb 1995; Pounceby 1997). For some commentators the involvement of professionals in user groups may then be thought to compromise a group's independence and their ability to represent a perspective different from, or challenging to, that of health professionals (Shakespeare 1993; Small & Rhodes 2000).

Furthermore, cancer patients may not identify user involvement as a priority, preferring that user groups focus on other functions. A review by Urben (1997) of cancer mutual-aid groups listed their main functions as the provision of emotional support, the sharing of information and ways of coping based on personal experience and the offer of direct

assistance to members, allowing them to live positively with an enhanced quality of life. However, there was little emphasis identified on advocacy, campaigning or input into health service planning and delivery. Consultation and dialogue with health services was not an objective and, because alternative approaches and therapies were advocated, relationships with professionals and services were often antagonistic.

The concerns regarding the appropriateness of user groups acting as proxies or advocates also extends to unease over the question of how representative cancer mutual-aid groups are of the population of people with cancer. Gott et al (2000) reported that only twenty percent of patients join support groups. For example, in 1998 the Directory of Cancer Mutual-aid and Support (Cancerlink, 1998) listed 155 breast cancer groups but only four for testicular cancer, two for colorectal cancer and none for lung or ovarian cancer.   For some cancers, such as ovarian cancer, the small numbers involved and the burden of illness may account for the low level of involvement (Gott et al, 2000). By contrast, the high numbers of mutual-aid groups for people with breast cancer has been attributed to a legacy of mutual-aid and mobilisation arising from the feminist movement and also to the levels of optimism which accompanies breast cancer treatment (Small & Rhodes, 2000). In addition, fewer men than women attend cancer mutual-aid groups and people from minority ethnic groups are also under-represented (Urben, 1997).

A further factor in gynaecological cancer may be that, unlike breast cancer, gynaecological cancers are still subject to significant stigma (Smith et al, 2005). Smith and colleagues investigated why people delayed going to the doctor when they have symptoms of cancer. They found that fear of embarrassment was related to the discussion of sensitive or sexual areas of the body and invasiveness of physical examinations. Such fears were not reported in studies of women with breast cancer.   Stigma and embarrassment would appear to have implications for women's willingness to discuss with others their experiences, whether in a mutual-aid group or in a health service or policy fora, and thus publicly identifying themselves as a user of gynaecological oncology services.

Some have proposed that the practicalities of implementing user involvement in cancer are fundamentally undermined by the burden of ill health carried by both individuals and the user groups and organisations that support them. For Florin and Dixon (2004) the very high expectations placed on often small and fragile bodies to bring an element of democracy or accountability into the health service, almost sets them up to fail. Nevertheless, some commentators have proposed that such groups do have the potential to influence planning, delivery and evaluation of services from a perspective that is grounded in their own experience and understanding of cancer (Zola 1987; Gray et al 1995; Gott et al 2000). Gott et al (2000) proposed that not only is a genuine partnership that improves

services possible but that this could also lead to increases in membership, a higher profile and increased hospital resources for such groups. However, the influences of ill health and stigma on representativeness remain unaddressed and unresolved.

The next sections of this chapter will describe how gynaecological cancer users have been presented with, and taken up, the opportunities offered by user involvement in individual care and treatment, in examining services and in strategic planning. It will begin by examining the involvement of gynaecological cancer patients in their care and treatment.

Individual Care and Treatment

As discussed in chapter two, three major programmes of activity have supported the involvement of users in their own care and treatment. These are the expert patient, shared decision-making and the introduction of patient-held records (Donaldson 2003; Coulter & Rozansky 2004; Meredith 2002). No published studies of patient-held records in gynaecological oncology were found and so this section will explore the extent to which the concepts of the expert patient and shared decision-making have influenced and been implemented within gynaecological oncology services.

The Expert Patient

As discussed in chapter two, the Expert Patient Programme was developed in response to the increasingly accepted concept of the patient as an expert in their own care and the benefits of self-management in chronic disease (Vashisht et al, 2000). This programme is not applicable to gynaecological cancer, as it is an acute rather than a chronic condition, but one aspect that has been extensively explored within cancer services is enhanced communication with patients. The importance of communication and information giving has been recognised and promoted widely in cancer services. Bell et al (1996) for the National Cancer Alliance found the provision of information to be a significant issue for cancer patients. A review by Ream and Richardson (1996) found that information resulted in more self-care behaviours being initiated, anxiety scores being reduced and patients reporting less disruption in their daily activities as information bolstered their ability to predict the experience. Research also suggests that it contributes to quicker and better recovery after surgery and leads to less depression and anxiety (Olszewski & Jones, 1998). The Nuffield Institute for Health and the NHS Centre for Reviews and Dissemination (1996) found women with breast cancer were less anxious when given full verbal and written information, as well as opportunities to discuss options with clinical staff. Similarly, the NHS Centre for Reviews and Dissemination (1998) found that patients with lung cancer who were given sufficient information were less anxious and expressed higher satisfaction.

Having reviewed the literature on information giving for people newly diagnosed with cancer, Mills and Sullivan (1999) suggest that information is a much individualised aspect of care. These authors concluded that users information needs can be influenced by a variety of factors and there is no definitive method of providing information that will suit everyone. However, despite the emphasis placed on information-giving by politicians, professionals and ethics bodies this would appear to be an area with which many patients remain dissatisfied. Studies show that information may be of poor quality, pitched at the wrong level and often not patient-based. For example, a study undertaken in England of women undergoing hysterectomy found that only 14% of information contained in the leaflets was based on patients' views (Scriven & Tucker, 1997). This study also indicated that 26% of the leaflets were illegible and that 80% of hospitals producing their own leaflets did not follow printers' guidelines, which resulted in the leaflets being difficult to read. In the United States, Folz and Sullivan (1996) found that the standard reading level required to comprehend cancer-related information was twelfth grade education or higher, yet 55% of the participants in their study could only read to seventh grade or lower.

Furthermore, the Nuffield Institute for Health and the NHS Centre for Reviews and Dissemination (1996) in presenting studies of consultations with cancer patients showed that patients and their doctors may disagree on the adequacy of the information given. While patients were often dissatisfied with information they received, doctors tended to over-estimate the amount of information given and might even disagree with the emphasis on the need to provide more information. These issues of specialist provision, quality of information and differing perceptions of need are illustrated by studies into the informational needs of women with gynaecological cancer.

Corney et al (1992) used semi-structured interviews to identify the need for information, emotional support and counselling among 105 patients who had surgery for gynaecological cancer. These women were interviewed 6 months after diagnosis. The topic most requested at this stage related to the psychological effects of their operations (36%). This was followed by information on the physical effects of operations (35%) and then the effects of operations on their sexuality and sexual activity (20%). This study illustrated the unique needs of this particular group, as their needs differed somewhat from those identified in another study of the information needs of women with breast cancer. The study by Luker et al (1996), which was subsequently used as a guideline for information provision, identified the priorities as information about the likelihood of a cure, extent of the disease and types of treatment. However, unlike those with gynaecological cancer, women in the study by Luker and colleagues ranked information relating to sexuality as least important to them.

Possibly because of the pre-diagnosis symptoms of gynaecological cancer and their effect on sexual function as well as the tendency for women diagnosed with gynaecological cancer to report lower levels of sexual functioning and valuing of self as a sexual person and partner (Lamb & Sheldon, 1994), some attention has been given to the effects of gynaecological cancer on sexuality and the subsequent informational needs of patients and their partners. Different sexuality information is needed at three different time periods: diagnosis and treatment period, recovery and first intercourse and the period of re-building sexual life. However, the type of information and the time when it is needed are not necessarily the same for all women and their partners (Gamel et al, 2000).

Other studies have also shown that sexual activity is affected and that communication about the topic is poor. In a qualitative study conducted with 15 women with ovarian cancer Stead et al (2001) explored the level of communication between women and health care providers. They found that women thought that a health professional should have provided them with written information or have discussed sexual issues with them. Although some women felt uncomfortable discussing sex, they felt that the benefits would outweigh any embarrassment. The attitudes and behaviours of healthcare professionals also showed a lack of comfort with the subject. All but one of the professionals surveyed thought that medical staff should discuss psychosexual issues but only 25% of clinicians and 19% of nurses did so. They identified a lack of knowledge about the impact of ovarian cancer on sexual functioning as a barrier, with few of the professionals being aware of the problems that can occur. The study concluded that detailed discussion of sexuality and sexual functioning might not be necessary, but that patients did seek reassurance to relieve their fears. A lack of information, explanation and support has been cited as the greatest cause of anxiety and stress in cancer patients (Evans, 1995). Furthermore, professionals who cannot provide consistent information cannot expect users to be compliant or cope with their diagnosis (Harris, 1997). It is therefore essential to assess and provide for users' information needs. This may not be a straightforward task as the evidence suggests there is not a simple relationship between user characteristics and the need for information.

Vashisht et al (2000), in a study of user satisfaction with the care provided at gynaecology oncology clinic, found no significant relationship between the duration of attendance at the clinic and the desire for more information. This, they argued, reinforced their opinion that while there may be an increasing trend for patients to request more information, it would be difficult to predict which patients these might be. They argued that this makes the implementation of rigid protocols regarding information-giving inappropriate. Rather, they proposed a patient-specific management of information with regular auditing of this aspect of the service. Furthermore, Olszewski and Jones (1998) highlight that the majority

of evidence on information need comes from professional perspectives while there is little research specifically investigating user perspectives on clinical information.

However, despite the considerable attention given to the issues in the communication and informational needs of gynaecological cancer patients there has been little work reported on other aspects of self-management or 'expert' programmes, namely the development of patient skills and a partnership approach.

Shared Decision-Making

The shared model of medical decision-making has been proposed as the preferred method of determining patients' treatments (Coulter 1997; Charles et al 1999; Montgomery & Fahey 2001). As with expert patient programmes there is evidence that several of the characteristics of shared-decision making have been explored in relation to gynaecological cancer, but no examination of shared-decision making in this context was identified.

Shared decision-making has four essential elements: partnership, communication, information giving, and agreement on the treatment to be implemented. However, such a partnership may not be easily achieved within cancer services, as there is evidence to suggest that the views of clinicians and users may be polarised. Attitudes towards chemotherapy among cancer patients were examined in a questionnaire study of two hypothetical treatments by Slevin et al (1990). One scenario presented a typical intensive chemotherapy regimen with associated side effects, the other a much milder treatment regime. Participants were asked to rate the benefits in terms of chance of cure, promulgation of life and relief of symptoms. In comparison with a control group, radiotherapists, medical oncologists, cancer nurses and general practitioners, patients were willing to accept intensive treatment with severe side effects for a much smaller chance of benefit in terms of cure. The hypothetical nature of the questions asked by this study makes interpretation of the results difficult but nevertheless, it illustrates that it cannot be assumed that clinicians are in a position to advise patients about treatment options based on what they would theoretically accept for themselves (Montgomery & Fahey, 2001).

Other issues in shared decision making have been identified as the need for users to receive adequate and objective information (Thomas et al 2000; Herxheimer et al 2000); the quality of information on non-medical factors such as quality of life (Fellowes et al 2001; Bezjak et al 2001) and the ability of doctors to predict which patients want an active, shared role in decision making, especially in areas such as palliative care (Bruera et al 2001; Gattellari et al 2001). As previously discussed, the informational needs of cancer patients are complex and cannot be contained within rigid protocols on information-giving. In a summary of the available evidence on methods of informing, communicating and sharing decisions with people who have cancer, the NHS Centre for Reviews and

Dissemination (2000) concluded that, despite NHS policy emphasising the need for good communication between health professionals and patients, the most common complaints made by people with cancer were about poor communication and inadequate information. Users cannot be involved in shared decision-making, or chose not to be involved, unless they are given sufficient and appropriate information, delivered in ways optimal for their own level of understanding (Fallowfield, 2001). Therefore, health professionals need to be able to elicit users' need and readiness for information as well as their desire for involvement in decision making.

Elit et al (1996) used a method known as a Decision Board to facilitate women's participation in deciding treatment preferences for therapy in advanced epithelial ovarian cancer. A Decision Board is a visual aid and written material, administered in an interactive fashion by the clinician to the patient during the medical consultation. It enhances communication between physicians and patients and supports patients in making decisions about treatment. Elit et al (1996) observed the feasibility of presenting poor prognostic information, patient comprehension in an emotionally charged situation and treatment choice. They found that all patients wanted to be fully informed of the choices for their disease and to be involved in treatment decisions. They proposed that the Decision Board was a reliable and valid method for sharing information about advanced ovarian cancer with users.

However, Fallowfield (2001) argued that a clear distinction was needed between a desire for information and a wish to assume responsibility for decision-making. True user participation, which may include an expressed preference by the user to assume a more passive role about the types of information they require and involvement in decision-making, would also require changes to the current system of health care delivery. In addition to a compelling need for training and other interventions to help communication between doctors and patients about preferred therapeutic goals and treatment priorities, a lack of support staff and over burdened clinics seriously constrain the ability of clinicians to adequately meet the informational needs of patients with cancer.

Some studies indicate that users may actively seek information to satisfy an aspect of psychological autonomy that does not necessarily include participation in decision-making. Sutherland et al (1989) found that although many users actively sought information a majority preferred the physician to assume the role of primary decision maker. Approximately 77% of the 52 cancer patients they surveyed reported that they had participated in decision making to the extent that they wished, while most of the remaining 23% would have wished a greater input. Similarly, in one study of women with breast cancer, improvements in quality of life brought about by reduced anxiety and better

adjustment were primarily related to satisfaction with the information they got, not merely involvement with decision-making about the type of surgery (Fallowfield & Hall, 1994).

In summary, there is considerable evidence of activity within this setting that has sought to give users a voice in their care and treatment plans. Much of this activity appears to relate to only one aspect of patient-centred care, that is, enhancing communication between professionals and users by providing adequate information. This has been shown to facilitate involvement in decision-making. However, studies have shown that not all users wish to have a significant role in treatment decisions and that the desire for involvement is complex. Thus, health professionals need to be able to elicit users' need and readiness for information, as well as their desire for involvement in their care and treatment.

Examining Services

The second type of involvement under review is the involvement of patients in shaping accountable, responsive services by the application of collective experience to the evaluation of service systems, delivery and outcomes. However, while guidelines, standards and protocols are widespread in clinical oncology these are, for the most part, based on randomised control trial evidence and professional consensus rather than seeking first hand the views of patients (Richardson et al, 2002). This has led authors such as Richardson et al (2002) to suggest that the goal of incorporating user views meaningfully into these guidelines remains elusive.

In respect of gynaecological oncology services, no studies were identified that reported on the involvement of users in the organisational aspects of care, such as the monitoring of care or the setting of service standards. There is some evidence from other settings that cancer patients with a similar level of ill health can make a positive contribution to professional standards. For example, Birchall, Richardson and Lee (2002) reported on a study that elicited the views of patients with head and neck cancer, on professionally derived standards of care. They examined the views of patients on the process of care for people with head and neck cancer in order to assess whether focus groups would be useful in this setting, to compare the priorities and standards identified with those published by health professionals and to incorporate the expressed views into existing national standards.

Like gynaecological cancer patients, those with head and neck cancers require complex multi-disciplinary care and professional standards exist for much of this. The authors found that focus groups were an effective and efficient means of assessing the views of patients on professionally derived standards of care in oncology. The focus groups provided detailed information on the views of patients on head and neck cancer care, with a high

level of satisfaction for the participants. Participants had clear and well-informed ideas about appropriate standards and these views could be included in established national standards for the process of care. However, a major difficulty arose where the views of patients and carers differed substantially from the views of professionals. Where a spectrum of views was expressed, either these were translated into more than one standard for the heading concerned or, where this was not practical, a consensus technique was used to identify the commonest theme. For any disagreement between the views of clinicians and others, the views of patients prevailed, with one exception. Patients felt radiotherapy should start within a month of the planning clinic but NHS resources made this unrealistic. Thus a longer time standard was adopted (Birchall, Richardson & Lee, 2002).

Birchall, Richardson and Lee (2002) acknowledged the potential limitations of the representativeness of their sample. Patients from rural areas were less well represented and some attrition in selection typifies this type of research in which inconvenience, a desire to forget events, ill health and unsuitable dates or venues all intervene. However, the degree of consistency suggests that the results would be unchanged by wider participation. Of particular importance was the methodology that allowed for the full participation of people with severe communication difficulties owing to a lack of larynx or oral structures. The views of the patients in this study were incorporated into the national standards on the treatment of head and neck cancers. The study demonstrated that the views of patients could be assessed and contribute to changes in professional standards in a manner that is acceptable to all parties. Birchall and his colleagues concluded with recommendations for a cyclic process for ensuring that the views of patients continued to inform standards.

In a further study of patients with head and neck cancer, their carers and bereaved carers Richardson et al (2002) also described a qualitative focus group methodology as effective for gaining the views of patients and carers on professionally derived standards in oncology. Their results, and the subsequent modification of national standards in response to the study, demonstrated that such a methodology was applicable even to groups traditionally viewed as 'difficult', such as laryngectomy patients, facially disfigured people and bereaved carers, but they cautioned that a professional qualitative researcher was required for such a methodology and that this approach was neither easy nor cheap.

However, while these studies appear to support the proposition that gynaecological cancer patients could contribute to the development and modification of service standards no studies were found that reported on such.

In respect of the evaluation of services, a number of studies have demonstrated the capacity of gynaecological cancer patients to contribute to the examination and

development of services. Studies such as Haas (1998) and Karimian-Teherani et al (2001) have explored women's perceptions of their cancer care and demonstrated their ability to assess and evaluate aspects of their care. In a questionnaire Karimian-Teherani et al (2001) asked women questions about their diagnosis, treatment and quality of life.   The authors reported that users had the capacity to identify those aspects of their care they were satisfied with and those gaps in services that required improvement. However, whilst their recommendations included the need for better hospital organisation there was no discussion of how such organisational requirements could be met or of the actions required to ensure such findings influenced service planning and development.

Similarly, in an audit of the views of gynaecological cancer patients regarding routine follow-up and discharge from a gynaecology clinic, Howells et al (1999) identified a user preference for discharge from a hospital setting if they were well with no symptomology or evidence of recurrent disease. In their discussion of these findings, they proposed a prospective longitudinal analysis of possible socio-demographic and psychological factors in order to better identify individuals and their possible reaction to care and treatment. However, there was no indication of any further consideration of the implications for the organisation and delivery of the service, despite the very clear assertion that women's stated preference was not in line with current practice. Thus, while these studies demonstrate the capacity of gynaecological cancer patients to be involved in examining the services that they use, there is little evidence that these views and preferences have been used by decision-making and development structures.

However, whilst not peer reviewed, local work may offer evidence that the patient perspective can be, and has been, integrated with service development. Williams (personal communication, 1st November 2005) carried out one such study in gynaecological oncology services in Glasgow. In a series of individual interviews with 31 women who were receiving chemotherapy for cancer of the ovary, uterus or cervix, Williams explored their experience of services and needs in relation to information and support. The study revealed a wealth of information on the emotional and practical informational needs of women. Crucially, this study was conducted under the auspices of, and directed by, the local Managed Clinical Network (MCN) (Scottish Executive, 1999). Before going on to consider why this link was important a word of explanation on MCNs would appear appropriate.

An MCN is a linked group of health professionals working in a coordinated manner, not constrained by existing organisational or professional boundaries, to ensure good patient care. The arrangements between the professionals are formalised and managed (Health Management Library, 2005). A cancer patient typically may need radiotherapy,

chemotherapy, physiotherapy, home care support and counselling. All these treatments are provided by different and often disconnected parts of the health care system. MCNs attempt to streamline the patient's journey through the system, providing services in an intrinsically 'joined up' way (Holmes & Langmaack, 2002). The association to the MCN thus ensured that William's results would be linked to an existing and integrated decision-making structure. In a discussion of her study at the Scottish Cancer Forum, September 2002, Williams was able to inform the meeting of how the implications of her work had been addressed by the MCN and of the progress made by a subgroup subsequently established by them to attend to the difficulties and gaps in information and support identified by users. As the MCN was the key co-ordination and management body for regional oncology services they were, thus, in an unparalleled position to ensure that the patient experience was used constructively in shaping local service delivery.

However, this chapter has identified little else that similarly reported on the utilisation of user involvement in service decision-making and development structures. The lack of integration of user involvement within formal cancer service planning or practice arrangements was reported in a three year study by Tritter et al (2003). This addressed the key factors facilitating or limiting user involvement in oncology services. Tritter and his colleagues found that user involvement was most often integrated with complaints procedures or clinical governance strategies, creating distrust among staff to be involved. There was limited evidence of formal user involvement policies in oncology services and little designated funding for such activities. Thus, the arrangements that did exist were often one-off exercises, not integrated into service planning or practice.

The lack of published work on user involvement in examining cancer services is of concern to some commentators at a time when the policy imperative to involve users could not be more pressing (Department of Health, 2004a). The lack of peer reviewed reporting on how users' views and preferences have been used by service decision-making and development structures means that there is currently little to provide clarity on the contribution of user involvement to service delivery, the difficulties encountered and perceptions of the impact they have had on service issues.

Strategic Planning

The Calman-Hine Report (Department of Health, 1999) set out a strategic framework for cancer care in England and Wales and remains the guiding policy for commissioning cancer services This document recommended that planning in oncology services should take account of the "views and preferences of patients" but, despite this direction, the nature of the illness associated with cancer would appear to limit user involvement in

strategic policy and planning. Gott et al (2000) examined the views of both patients with cancer (recruited from local user and mutual-aid groups) and service providers with responsibility for user involvement, about arrangements for involvement in cancer care services in one NHS region. These researchers found considerable consensus on the importance of user involvement, but at the same time much confusion about what was meant by the term. Both users and health professionals felt it was important to achieve a degree of partnership and for any systems not to be one-off or purely token exercises. Nonetheless, a number of difficulties were identified in implementing user involvement at a strategic level, including problems of recruitment to achieve representativeness, both of ethnic minority groups and people with less common forms of cancer, limited resources and a legacy of scepticism among professionals. At the operational level, there were problems of information, communication and training while some user groups were not keen to take part because they were focused on other issues, such as mutual support.

The nature, impact and extent of user involvement in the planning and delivery of oncology care services were further investigated in the Trent region of England in 2000 (Small & Rhodes, 2000). These authors identified cancer mutual-aid groups as the main conduit for the expression of user views. In an exploration of the characteristics of these groups the authors of this study interviewed a total of 35 user groups and 9 representatives of service providers. Several themes for user involvement were identified. First, many people in these groups saw their role mainly as providing support to patients and were reluctant to move towards the more difficult and uncomfortable role of advocacy. Other barriers to user involvement included lack of self-confidence and political awareness on the part of groups and negativity on the part of health professionals. The nature and capacity of support groups was highly variable. The 35 groups they described included some that were heterogeneous, mature and had good relationships with professionals but others were small, lacked experience and were afraid of offending clinicians.

A major problem was identified in the fragility of groups with most dependent on the energy of committed individuals, who may well wish to move on from the 'professional patient' role once they have achieved long-term remission. Furthermore, some client groups such as those with breast cancer were well represented whereas others, notably those with rarer cancers or poor prognosis such as ovarian cancer, had fewer spokespeople. The authors also identified a difficulty in attracting people from minority ethnic communities and problems with access for the elderly. A continuing problem of acceptance and legitimacy undermined efforts to represent the user perspective and training for the challenging work of representing user views in the fora where decisions were made was considered vital.

However, despite these barriers both providers and users in this review felt that involvement should extend beyond token, 'one-off' consultations and reflect a partnership approach whereby users would be able to have a real and on-going input into strategy. Whilst there had been negative stereotyping by both sides and poor dissemination of information, the authors found no fundamental differences between users and professionals in long-term aims and all perceived a rapidly changing situation. Such an optimistic assessment is shared by other commentators who believe that user groups could provide the best and easiest route to meeting the policy of listening to user views (Gott et al, 2000).

In Scotland, each of the three cancer MCNs that 'assist in the strategic planning and management of cancer services across their region' involve cancer user groups in respect of addressing the user perspective. Geographically these 'regions' are in the North, West and South East of Scotland. One network, The South East Scotland Cancer Network (SCAN), appointed a Patient Involvement Worker with the remit of involving cancer patients in the planning, design and delivery of oncology services in South East Scotland. The Network developed a Patient Involvement Network consisting of patients, carers, representatives from cancer support groups, action groups, information groups, workers from other UK cancer networks, the voluntary sector, local government and health professionals from the NHS with a specific interest in patient involvement (Inglis, 2002). SCAN is structured around 8 site-specific cancer groups. These groups have representation from all medical, clinical and managerial aspects of cancer care in the region. They report to the SCAN Forum, the Regional Cancer Advisory Group and ultimately to the Scottish Cancer Group. Many of the decisions regarding the future of oncology services in South East Scotland are made in these site-specific groups and so user representation would appear to be crucial. There are two user representatives, drawn from the Patient Involvement Network, on each group. The Patient Involvement Working Group, a sub-group that allows the representative to be briefed by and feedback to a wide range of users, supports these representatives. The views of individuals and communities are also sought through questionnaires, comment boxes and by close liaison with voluntary and support groups such as Cancer BACUP, Maggie's Centre and Macmillan Cancer Relief (Inglis, 2002). This approach once again demonstrates that a level of commitment and investment is required in order to facilitate appropriate and diverse user involvement.

However, this model has not yet been evaluated or replicated within other regions or at a national level. It was not clear why the SCAN approach had not been more widely adopted but the predominant model of user involvement remains that where one or two representatives are identified to sit on committees and groups in order to represent the user perspective. These representatives are drawn from user groups and voluntary

organisations. There would not appear to be the systematic briefing and feedback structures developed in the Patient Involvement Network of the South East Scotland Cancer Network nor the use of multiple methods of involvement that could facilitate representation from a wide range of interests.

Whilst this chapter has revealed a number of studies on the mechanisms by which a user perspective has been represented within policy and planning fora, it has also identified relatively little reporting on the impact and influence of such participation. Studies on user involvement in cancer services have demonstrated that research on user views can be influential on local policy and practice, either by being accepted as indicative of what should be done (National Cancer Alliance, 1996) or because it was commissioned expressly for this purpose (Birchall et al, 2002). However, little was found that reported on such influence or that addressed the integration of findings into strategic planning structures. This is illustrated by the following quote from Victor Barley, Lead Clinician for User Involvement at the Avon, Somerset and Wiltshire NHS Trust, host cancer network for the Department of Health, Health in Partnership Programme on user involvement.

> "There has been considerable improvement in the information given about cancer, but patients' experiences and good ideas are still not being linked to the strategic planning and service development arenas." (Barley, 2002)

Thus, as with user involvement in examining services, there appears to be little that supports the participation of gynaecological cancer patients in strategic planning. Despite the widespread acceptance of and initiatives to support the utilisation of users' views in planning and policy fora, reviews of this aspect of user involvement in cancer services have revealed the difficulties and limited impact of this. The paucity of reporting on mechanisms that could take advantage of the work underway to inform and gather views from users would appear to present a particular barrier to the integration of the user perspective within service and policy structures.

Summary

In summary, it appears evident that whilst there has been considerable attention to some of the elements that could facilitate the participation of those with gynaecological cancer in individual care and treatment there is less evidence of user involvement in the strategic planning, delivery and development of oncology services (Barley 2002; Richardson et al 2002; Tritter et al 2003). Furthermore, much of the activity in individual care and treatment appears to relate to only one aspect of patient-centred care; that is enhancing communication between health professionals and users by providing information (Corney et al 1992; Bell et al 1996).

There is evidence of a commitment to user involvement in shaping policy on cancer services but the links between user involvement and strategic planning and service delivery fora appear immature and under-developed (Barley 2002; Tritter et al 2003). Furthermore, the activity within this setting continues to demonstrate a reliance on user organisations as representative of users despite concerns over how representative they are of the population of people with cancer (Young & Cullen 1996; Skillbeck et al 1997; Urben 1997; Rhodes & Shaw 1998). However, few structures were in evidence that could support wider participation in the planning, delivering and examination of oncology services (Small & Rhodes, 2000).

The nature of the illness associated with cancer would appear to influence user involvement in service and planning fora with a number of concerns regarding the active participation of cancer patients identified. The level of ill health associated with cancer, the fragility of user groups and the desire of individuals to move on from the 'professional patient' role once they have achieved long-term remission have all been cited as reasons for the identification of cancer mutual-aid groups as the main conduit for the expression of user views (Gott et al 2000; Small & Rhodes 2000; Florin & Dixon 2004). Of particular concern to the user involvement agenda would be the issue of representativeness with activity appearing likely to involve only those most able to participate and exclude people, such as those with gynaecological cancers, who are more seriously ill or have a poor prognosis. These people have fewer spokespeople (Shakespeare 1993; Small & Rhodes 2000).

Ill health appears to have marginalised users' active participation both as a result of the debilitating effects of serious illness and by the use of proxies and advocates whose agenda can be seen to differ from that of patients themselves. Where user and mutual-aid groups were established these appeared to place little emphasis on advocacy, campaigning or input into health service planning and delivery (Gott et al, 2000). In this particular health service setting the issues of representativeness intersects with the dominance of the medical perspective and the perceived lack of independence from and reliance on health professionals (Shakespeare 1993; Small & Rhodes 2000; Florin & Dixon 2004). As a result, user involvement in oncology services may not be identifiable as a distinct position within which a perspective that is grounded in users' own experience and understanding of cancer is articulated.

Chapter 5: User Involvement in Maternity Services

This chapter will describe user involvement within the context and provision of maternity services. This setting was similar to gynaecological oncology services in providing an opportunity to explore women's participation in user involvement, as maternity users are exclusively female. Nevertheless, men do have a role in maternity services. Services have adopted a partnership model that seeks to include men in their role as the partners of pregnant women and as carers from within the woman's wider family (Pope et al 2001; Royal College of Midwives 2001). However, maternity services differ from gynaecological oncology services in that its users are not ill and being a service user has a positive outcome for most women in the form of a healthy baby. This is illustrated by the one of the leading user organisations in maternity, The National Childbirth Trust, who have argued that maternity is different from other services that are:

> "…life and death, fascinating, with lots of research, cardiology, heart transplants. Maternity is different. This is all about normal people having an everyday but very special life event" (Health Select Committee, 2003)

Maternity services also differ in that there is an existing social model ethos and convention to maternity care that is less evident in the traditional medically dominated cancer services. The prevailing philosophy within maternity services is that women expect to have a relationship with their health professionals that, unless there is a crisis, is characterised by partnership (Pope et al 2001; Royal College of Midwives 2001). As a result, the term 'user' rather than 'patient' is used to describe the receiver of services. A further difference between the settings is that maternity has a substantial history of user involvement that has led to an explicit commitment to the participation of users in the development of services.

> "Public and professional consultation should be fundamental to the planning, development and provision of local maternity services" (Scottish Executive, 2001)

This chapter will explore how the history and ethos of maternity services has influenced the development of user involvement. It will begin by describing the context and provision of services before going on to describe the history of user involvement in maternity and then how this has been implemented at the three levels of individual care and treatment, examining services and strategic planning.

The Context and Provision of Maternity Services

In Scotland maternity services provide a formal programme of maternity care for women and their babies that includes antenatal (before the birth), intrapartum (during the birth) and postpartum (after the birth) care. Maternity care is a complex, multi-dimensional, dynamic process of providing safe, skilled and individualised care. It responds to the physical,

emotional and psycho-social needs of women and their families. For most women pregnancy progresses smoothly to the birth of a healthy, much welcomed baby supported by family and friends. However, for some, pregnancy may be unplanned or unwanted and complications or adverse social circumstances may occur. The birth itself may be difficult and the outcome unexpected (Public Health Agency of Canada, 2002).

The origins of maternity care, as we see it today, can be traced to the 1920s when it became increasingly accepted that the provision of antenatal care for all pregnant women would make a major contribution to improving maternal and child welfare. The development of antenatal care also provides one of the earliest examples of women themselves lobbying for better maternity care. Following the women's suffrage movement's successful campaign for the vote in 1918, the goal of antenatal care became the major issue for which women's groups fought (Enkin & Chalmers, 1982). The following ninety years have seen major developments in maternity services and significant change in maternal mortality, with maternal deaths now very rare. Confidential enquiries into maternal deaths were established in 1928, with reports being regularly produced for England and Wales, Northern Ireland and Scotland from 1952 onwards. However, since 1985–87 reports have covered the United Kingdom as a whole, as the small numbers of deaths meant that separate country reports were no longer feasible (MacFarlane, 2002). Changes in remit and classification mean that direct comparison of the data is not possible but in the 1920's maternal deaths in England and Wales were put at 450 per 100,000. In comparison the most recent *Confidential Enquiry into Maternal and Child Health 2000 – 2002* for the United Kingdom reported the total direct and indirect maternal deaths as 13.1 per 100,000 (Lewis & Drife, 2002).

Much of this change can be ascribed to clinical and technological advances in maternity care as well as to the development of in-patient facilities; professional clinical teams; obstetric training for general practitioners; developments in the education of midwives and the recognition of midwifery as a discipline separate from, but complementary to, nursing. The Midwives Code of Practice, defined by the United Kingdom Central Council for Nursing, Midwifery and Health Visiting in 1992 and renewed in 2004 defines the role, responsibilities and behaviours of midwives (Nursing & Midwifery Council, 2004) while obstetricians are guided by the Royal College of Obstetrics and Gynaecology (The Royal College of Obstetricians and Gynaecologists, 2006).

The United Kingdom introduced policies for maternity services reform in the early 1990s that aimed to make the planning and delivery of maternity care more responsive to women's own needs and wishes and to improve women's ability to make informed choices about many aspects of their care. Three key reports, *The House of Commons Report*

(Winterton) (Department of Health, 1992), *The Scottish Office Policy Review* (Scottish Office, 1993) and the *Cumberledge Report (Changing Childbirth)* (Department of Health, 1993) all outlined key principles of choice, continuity and control and emphasised the need for women to be the focus of care. This led to a profound change in both the philosophy and delivery of maternity services.

The preparation of these reports included evidence gathered through representations from user organisations and user surveys. *The Scottish Office Policy Review* (Scottish Office, 1993), in particular, was derived from unprecedented consultation involving a series of national road shows and a study of Scottish maternity service users conducted through fifteen focus groups by Bostock. She concluded:

> "Women want health professionals to acknowledge them as individuals with specific and different needs" Bostock (1993).

This consultation, and others, stated that the system of maternity care in the United Kingdom did not provide the type of care the majority of women wanted and advocated a system where the woman and her family were at the heart of maternity care (Reid, 1994). In addition to its influence on the philosophy of maternity care *Changing Childbirth* (Department of Health, 1993) also made a number of recommendations that anticipated the growing movement for user involvement (Lincoln, 2004). These included giving women the right to choose where they would like their baby to be born; every practical effort made to achieve the outcome the woman believes to be best for her baby and herself; to have every reasonable effort made to accommodate the wishes of women and their partners and the opportunity to be fully involved in their care (Department of Health, 1993).

The current vision and philosophy for maternity services in Scotland was set out in *'A Framework for Maternity Services in Scotland'* (Scottish Executive Health Department, 2001). As with earlier policy documents it was seen as important that the framework was informed by women's perspective on maternity care. Research using focus groups and one-to-one interviews was conducted to ascertain the views of service users across Scotland. Although the women represented in the study reflected a wide range of backgrounds, experiences and needs, a clear and consistent picture of what women wanted from maternity services emerged from the study. These findings were in keeping with other consumer studies (Scottish Executive Health Department, 2001). In the policy a model of care was described by mothers and health professionals that would provide a family centred, locally accessible, essentially midwife managed, comprehensive and clinically effective model of safe care before, during and after childbirth. This reflected a multi-disciplinary integrated approach to care. It stated that pregnancy and childbirth were a normal physiological process; that women should be involved and consulted in decision-

making; that care should be safe and evidence based; that risks should be discussed and agreed by all and that care should be provided within the community setting when appropriate.   The attainment of a safe outcome for mother and baby was paramount.

This model illustrates the debate that is central to user involvement in maternity services. Services have had to ensure that a safe service was paramount, but this has had to sit alongside the strongly held view that women should have the right to choose less technical levels of care with fewer clinical interventions. This debate has often been polarised as health professionals and user organisations hold opposing views on the safe level of technological intervention in maternity care. At one end of the spectrum of views are those professionals who argue that confinement anywhere other than in a fully staffed obstetric unit carries unnecessary risks (Scottish Office, 1993). At the other end are women, user organisations and some doctors and midwives who have come to believe that a high proportion of women can be delivered in other, more homely and more convenient settings with no increased risk to either mother or child (Kitzinger 1984; Flint 1986; Tew 1990; Scottish Office 1993). In this well-rehearsed debate the arguments in favour of highly specialised obstetric provision were primarily about safety. The arguments against have largely stemmed from research, much of this completed in the 1970s and 1980s and often involving women researchers who were also users. These studies showed that women prioritised less specialised care in local hospitals, which have surroundings familiar to them and are convenient for their family and friends. As with earlier policy documents the *Framework for Maternity Services in Scotland* attempted to balance these competing arguments by proposing that any such local provision must include rapid access to specialist medical cover when emergencies arise (Scottish Office 1993; Scottish Executive Health Department 2001).

There are a number of other Scottish policy statements on maternity services. The Deputy Minister for Health led an Expert Group on Acute Maternity Services (EGAMS), which reported in 2003 (Scottish Executive, 2003). In addition, the regular UK wide confidential enquiries into maternal deaths and recent English Department of Health work on a *National Service Framework for Children and Young People* (Department of Health, 2004) have provided further policy direction. There is also a range of guidance available from professional organisations, including the Royal College of Obstetricians and Gynaecologists (RCOG, 2006), the British Association of Paediatric Surgeons (2006) and the British Association of Perinatal Medicine (2006). Each of these acknowledges and promotes user involvement in the planning and delivery of maternity services.

Maternity services have had a longer history of user involvement than the other two settings in this study and, as a result, user movements have a substantial presence within

the field. Thus, before describing the opportunities for women to influence their maternity care it will be useful to describe the history of user involvement in maternity services and identify how this has helped to shape the structures and processes currently in place.

The Development of User Involvement in Maternity Services

Women had held considerable power to determine labour and delivery events as long as childbirth remained at home. Until the 1920s and 1930s birthing women surrounded themselves with a network of supportive women who they knew and trusted. Thus, women, in strength, negotiated with the various experts they invited in to help determine what would be done to their bodies. However, when childbirth moved to the hospital in the twentieth century, the medical profession became dominant (Leavitt, 1986) and as the levels of technological intervention, organisation and pattern of care became more complex and fragmented, so did disputes over who should manage childbirth and where (Currell 1990; House of Commons Health Committee 1992).

While the history of campaigning on issues such as antenatal care date back to the 1920's, the roots of most maternity user organisations can be traced to the late 1960s and early 1970s when users spoke out against the trend towards inducements of convenience, the medicalisation of services and concerns about professional accountability (Stacey, 1988). Interestingly, two of the most prominent maternity user organisations have roots that predate the more recent debates. The National Childbirth Trust (NCT), originally the Natural Childbirth Association, dates back to the 1950s, while the Association for the Improvement of the Maternity Services (AIMS) was set up in 1960. Many more user organisations were set up in the 1970s including TAMBA (Twins and Multiple Births Association), established in 1977, the Maternity Alliance in 1980 while SATFA (Support around Termination for Abnormality) was set up in 1988 (Reid, 1997).

User organisations in maternity cover a wide spectrum of function and ethos. While some deal with specific conditions or problems, three of the most prominent are generic, tackling a wide range of issues. Easily the largest, the NCT is primarily concerned with education for parenthood. It has its own structure of antenatal classes and has played a major role in providing training and support to user representatives on one particular health planning group, the Maternity Service Liaison Committee. Another, AIMS, describes itself as a 'campaigning pressure group'. It maintains a high profile within maternity services with local branches that spearhead local and national campaigns.   AIMS focuses upon concerns over technology, the rights of mothers, and the availability of choice for women at all stages of pregnancy. The Maternity Alliance takes a wider remit, tackling issues such as maternity legislation, benefits and rights.

Other user organisations deal with problems, although the nature and type of the cause may vary. Many are concerned with difficult emotional and distressing situations, which Robinson and Henry (1977) proposed have been either poorly managed by the NHS or ignored. These would include the problems that arise around a termination for foetal abnormality (SATFA) or a stillbirth or infant death (SANDS - The Stillbirth and Neonatal Death Society). Some organisations deal with problems during pregnancy, others are concerned with circumstances that arise after childbirth such as postnatal depression (MAMA) or for those with twins or multiple births (TAMBA). The Health Select Committee - Second Maternity Services Inquiry (2003) recognised the value of such organisations when it identified the lack of specialised expertise of many health professionals in providing maternity services for those from disadvantaged groups, those from different cultures or women with disabilities. They proposed that health professionals, such as GPs, could not be expected to provide immediate advice in all cases but pointed to user organisations as valuable sources of the information required by prospective and new parents (Health Select Committee, 2003).

Typically, such organisations have a wide range of mutual-aid groups at local level, which serve two functions. First, they bring women together for information, education and support, and second they provide an extended local base for national organisations such as the NCT or AIMS. These rely heavily on their membership to raise with them the important issues to be tackled. Frequent contact with an extended network of members is an important way of ascertaining the issues and concerns of the membership (Reid, 1997).

The period from the early 1970s to the late 1980s stand out as the era of the user movement in maternity care. By 1980 the professionals providing maternity care had had to assimilate a sustained attack on their expertise. Beginning as a protest against high induction rates, this had quickly generalised itself to become a complaint about the dominance of the medical model of childbirth, in which pregnancy required care by high-technology means (Oakley, 1993). This culminated in the 1990s, when user groups played a key part in securing major changes to the way maternity care was delivered in the UK (Garcia et al, 1998).

As discussed earlier, the 1990s saw the introduction of policies for maternity services reform that aimed to make the planning and delivery of maternity care more responsive to women's own needs and wishes and to improve women's ability to make informed choices about many aspects of their care. Three key policy reports mentioned earlier, *The House of Commons Report (Winterton)* (Department of Health, 1992), the *Cumberledge Report (Changing Childbirth)* (Department of Health, 1993) and the *Scottish Office Policy Review* (Scottish Office, 1993) all emphasised the need for women to be the focus of care leading

to a profound development in both the philosophy and delivery of maternity services. This contrasted sharply with earlier policy documents such as the *Peel Report, Domiciliary, Midwifery and Maternity Bed Needs: Report of the Sub-committee* (DHSS, 1970) and the *Short Report, Second Report from the Social Services Committee Session 1979-80, Perinatal and Neonatal Mortality*, (Department of Health, 1980) that had promulgated the dominance of the medical model of childbirth with the Peel Report, in particular, recommending the transfer of all births from home to hospital.   However, the later reports not only represented a significant change in the underpinning philosophy of maternity services but also in the thinking on whose evaluations and expertise should be considered in their deliberations. In the earlier reports the evidence collected by the committees was, without exception, from representatives of Royal Colleges, professional associations, universities, the NHS and the civil service. The composition of both the Peel and Short committees reflected the reliance upon the expert, he or she being defined as pre-eminently the obstetrician (Stacey, 1988). However, by the 1990s maternity policy was being shaped by women's evaluations and experiences of maternity care. The nature of women's participation included representation drawn from user organisations and wide-ranging surveys of women who were or had been users of maternity services. These established the principle that the views of users were of importance to service providers.

Several social movements had converged to bring about this change in the status of user views and experiences. It was characteristic of the feminist movement of the late 1960s and early 1970s that some women began for the first time to criticise the way in which they were treated by the medical profession. Among the social developments responsible for the challenge to the hegemony of professionals were more education, greater familiarity in the mass media with social issues and the products of scientific and technological expertise (Oakley, 1984). The reactions of many women, not themselves feminists, to the increasingly passive and subordinate role which the new obstetrics put upon, them fuelled these arguments. Unrest among women was expressed through existing user groups such as AIMS and the NCT (Stacey, 1988). There was also a large fund of social scientific research carried out by individuals such as Shelia Kitzinger and Jean Robinson, then Chair of the Patients Association, which was available for care providers anxious to understand the attitudes of mothers towards the maternity services (Oakley, 1984). The Peel and Short reports may also have contributed to women's organisation. By barely acknowledging user groups and demoting women to the periphery of services they may have provided an impetus for women's groups to come together and lobby more effectively.

Users' desire to control their experience of pregnancy and childbirth had long been expressed through research studies, where the issues of choice, better communication and

improved continuity of care had been recurrent themes (Reid, 1994) but the evidence gathering strategies of the *Winterton Report* (Department of Health, 1992), *Changing Childbirth* (Department of Health, 1993) and the *Scottish Office Policy Review* (Scottish Office, 1993) provided the opportunity for such issues to find influence within the policy-making arena rather than simply giving voice to women's concerns. Thus, by the late 1980s and early 1990s high-level policy documents came to reflect far more closely the services and attitudes described in many user studies (Reid, 1994). Responses from midwifery and other health professionals to the proposals of these reports were favourable, leading to a widespread adoption of the key principles. User groups also welcomed them. In 1994 the NCT stated that the type of maternity care proposed by these policy documents was what they had been working towards over their forty year campaign (NCT, 1994).

As a result of their success in shaping policy, user groups now tend to have highly developed external relations and are aware of the channels to national policy makers, investing heavily in securing access to these. In a review of four national maternity user groups in the United Kingdom – AIMS, NCT, Maternity Alliance and the Toxoplasmosis Trust – Tyler (2002) reported that all of these groups now described campaigning and influencing as being as important as mutual-aid activities with women. In contrast to gynaecological oncology, where cancer user groups placed little emphasis on advocacy, campaigning or input into health service planning and delivery, these groups believed it was important to contribute a user perspective to both the planning and delivery of services. All therefore contributed to policy-making through research, publications, lobbying and networking. Even smaller groups have cultivated effective external relations and established credibility with key stakeholders. Groups have worked hard to position themselves alongside professionals who share their views, to demonstrate research-based evidence for their demands and to cultivate media attention for their particular cause. Thus, these groups could be seen to make the transition from 'outsider' to 'insider' groups with many now represented in the discussion of national policy (Tyler, 2002).

However, whilst they make a substantial contribution to maternity services one of the enduring criticisms of user organisations in maternity is that they are, in the main, run by and for middle-class women. As discussed in chapter three, there is little investigation to help understand the membership of user organisations in terms of their representation of social class, ethnicity, sexual orientation or disability but the perception of limited representativeness remains. The then Deputy Chief Medical Officer, Dr Sheila Adam voiced her concern in 2001 when launching a consultation on the future configuration of maternity services:

> "There are very good advocacy groups in the area but it is important to get real people involved as well, especially those who have just gone through the experience. And not just white, middle class women" (Adam, 2001)

The issue of representativeness may be of particular importance in maternity, as user organisations appear to have significant influence in policy and service development (Garcia et al, 1998). Having campaigned for and won a commitment to woman-centred care from policy makers, user groups are now largely concerned with implementation at a local level, playing an active role in assessing services on behalf of women and working with providers to bring about change. By forming alliances at local level and establishing credibility with key stakeholders, user groups have moved to a position of influence in both the delivery of services and the attitudes and behaviour of staff with many now represented in the planning of services at a local level and in the discussion of national policy (Tyler, 2002). However, the Health Select Committee (2003) heard that such user groups were overwhelmingly middle-class and that some failed to represent the experiences of women from disadvantaged groups. This had led a number of commentators including the Maternity Alliance (Health Select Committee, 2003) to argue that the weakness of the evidence base on the views of women from disadvantaged or hard-to-reach groups impedes service providers in their work to improve maternity services. If the needs and wishes of these women are not known then services will continue to be ill prepared to meet them. This issue is discussed further in a later section.

This lengthy history and evidence of its influence in national and local policy differentiates user involvement in maternity from the other two settings being examined. In order to explore how this history has shaped the involvement of women in maternity services a literature review was undertaken that examined user involvement at the three levels under consideration, in individual care and treatment, examining services and strategic planning.

Individual Care and Treatment

There are two elements of the previously discussed programme of user involvement in individual care and treatment that are well established within maternity services. The Expert Patient programme for self-management in chronic conditions does not apply but as discussed in chapter two, shared decision-making and patient-held records are evident in maternity practice. Within maternity services the concept of patient-centred care is interpreted as woman centred care (Pope et al, 2001). Woman-centred care is the term used for a philosophy of maternity care that gives priority to the wishes and needs of the user and emphasises the importance of informed choice, continuity of care, user involvement, responsiveness and accessibility (The Royal College of Midwives, 2001). The ethos that care should be provided based on individual need with the mother actively

involved is widely accepted and implemented within maternity services but a number of concerns have been raised concerning how far the aspirations of woman-centred care have been translated into individual choice and preference.

In the 15 years since *Changing Childbirth* (Department of Health, 1993) there have been many innovations in maternity services such as the development of Maternity Care Centres, Birthing Units and support structures for new mothers and babies such as Starting Well. However, development has been patchy and as a result of issues such as the increasing rate of caesarean sections, the reducing numbers of midwives in practice and the low numbers of women having completely natural births, some commentators suggest that women-centred care has lost ground (Page, 2003). The notion that high quality care depends on the recognition of individuals as having unique needs continues to be reflected in contemporary documents (Scottish Executive, 2001) and there is some evidence that the principles of choice, continuity and control have influenced practice. The Scottish Executive (2001) reported that the improvements made to maternity care provision following the *Scottish Office Policy Review* (Scottish Office, 1993) included a range of choices around childbirth, the provision of high quality local services that are acceptable and accessible to women with speedy and seamless access to specialist services when necessary.   However, they also acknowledged that there was still considerable scope for change (Scottish Executive Health Department, 2001).

In this assessment they concurred with other commentators who have challenged the extent to which pregnant women are able to have control over their own care and treatment and to have their individual wishes and preferences met. O'Cathain et al (2002) conducted a cluster randomised trial of the effectiveness of evidence based leaflets in promoting informed choice in maternity care. They found that there was no difference in the extent to which women felt they exercised informed choice in the units that used leaflets and in the control group. A qualitative study performed alongside the trial helped to explain this failure. The researchers observed over 800 antenatal consultations and conducted over 300 interviews with pregnant women and their health professionals. They found 'informed compliance' rather than informed care. Sometimes midwives withheld the leaflets because they discussed options not available locally; they made wrong assumptions about women's ability and willingness to use the information while the availability of technology and fear of litigation led to women being "bullied" into accepting interventions. The hierarchy in services meant that, in practice, it was obstetricians that defined the choices on offer. The authors concluded that evidence based leaflets were unlikely to promote informed choice unless they were introduced as a part of a wider strategy that addressed power imbalances.

In a similar study, Stapleton et al (2002) observed 886 antenatal consultations and interviewed 383 pregnant women about the use of a leaflet entitled '*Informed Choice'*. They found that competing demands and time pressures on professionals ensured that women complied with, rather than chose how they wanted to give birth. Women's trust in health staff meant that they complied with professionally defined choices and rarely asked questions or made alternative requests. As with O'Cathain et al (2002), they also found that fear of litigation; power hierarchies and technology further limited the choices available.

Those who argue that pregnancy, childbirth and the birthing process have moved into an institutional environment that generally reflects the paternalistic values of obstetrics, identify restrictions in choice arising from service provision (Nolan, 1999). In terms of choice, the NCT stated its concern about the medicalisation of childbirth and erosion of midwifery skills and confidence. It believed that women did not so much make informed choices as find themselves constrained by the unit they attended (Johanson et al, 2002). Whilst one of the key principles of maternity care is the provision of user choice, the decision to centralise services has narrowed the parameters of options available to the user not only in terms of choice of maternity unit, but also in terms of the clinical milieu. Thus, the closure of small and medium sized maternity units and their merger into large centralised units conditions user demand and limits their choices (Lincoln, 2004). Whatever the size of the maternity unit, managerialism compels budget-holding health care practitioners to direct their attention towards cost awareness and cost-cutting measures and away from user choices that are more resource intensive such as homebirths. Similarly, while continuity of care is women's preference for maternity care, Johanson et al (2002) suggested that medicalisation of the environment could be the dominant effect in the United Kingdom, over riding the potential benefits of continuity.

Hundley and Ryan (2002) investigated the effect of service provision on user preferences, in particular, whether women who had access to systems of care that offered particular attributes, such as continuity of carer, valued these attributes more highly than women for whom the attributes were not a realistic option. They used simple rating scales and a discrete choice experiment to assess the importance to women of different aspects of intrapartum care. The sample consisted of 301 women at low obstetric risk, identified from three geographical areas, each with a different system of maternity care provision. From the rating scales, completed anonymously by women at the booking visit, it appeared that women in the area with least continuity rated this aspect of care significantly lower than women in other areas. They concluded that the systems of care on offer did influence women's preferences. Women in areas where continuity of care was a realistic option

appeared to value this aspect of care more highly. The tendency for preferences to be influenced, not only by previous experience of a service but also by knowledge of its availability, has important implications for the inclusion of users' values in deciding whether to introduce innovations in care.

It has been suggested that greater user involvement may be a useful means of challenging the accepted view of what is important in health services and of facilitating change. However, the findings from this study suggest that user views may have the opposite effect. If users do prefer what they know, then a policy of tailoring health services to local preferences will simply reinforce the current provision of services, reinforcing existing inequalities in the provision of care (Hundley & Ryan, 2002).

Patient Held Records

One other development in the involvement of maternity users in their own care is the widespread adoption of women-held records. A unified maternity record for Scotland has been an aspiration for women and service providers for many years. *A Framework for Maternity Services in Scotland* (Scottish Executive, 2001) reiterated the case for such a record and made it a priority through the following principle:

> "There should be a national, unified and standardized woman-held maternity record that is available and accessible to both women and professionals" (Scottish Executive, 2001)

The Royal College of Obstetricians and Gynaecologists in 2003 (Health Select Committee, 2003) proposed that patient-held records had the vital function of passing on medical and health information to maternity care staff, allowing for some degree of continuity of care to be preserved even if a number of health professionals were involved. However, they also proposed that woman-held notes could also help pregnant women to become involved in discussing and making decisions about their own care:

> "…all pregnant women…should be invited to carry their own notes and take a full and active role in decisions about the nature of their care." (Health Select Committee, 2003)

Elbourne et al (1987) found that more women were satisfied with their care when they held their notes. However, the Health Select Committee - Second Maternity Services Inquiry (2003) noted that, in some areas, maternity services did not provide woman-held notes and in a submission to this inquiry, the Centre for Nursing and Midwifery Research identified further problems with the current system. According to the Centre, the value of woman-held notes in encouraging women to become actively involved in their maternity care was diminished because they were "rarely adapted to meet the literacy and comprehension needs of women with learning difficulties and those for whom English is not their first

language". Thus, the use of woman-held notes would appear to be a valuable way of passing on information crucial to the provision of appropriate care for women who see a variety of health professionals during their maternity care. However, they do not address the problems of identifying and reaching those women who do not make any contact with maternity services or of encouraging quieter groups to become more actively involved.

In summary, user involvement in individual care and treatment has been enshrined in maternity services as woman-centred care (Pope et al, 2001). Woman-centred care gives priority to the wishes and needs of the user and emphasises the importance of user involvement (The Royal College of Midwives, 2001). The ethos of the mother being actively involved in her care is widely accepted and implemented within maternity services and has led to many innovations including patient-held records and service developments such as Maternity Care Centres, Birthing Units and support structures for new mothers and babies. However, as the literature has shown, concerns have been raised concerning how far the aspirations of woman-centred care have been translated into individual choice and preference and furthermore the experience of maternity services appears to highlight the difficulties of integrating individual choice and preference into routine practice where other considerations such as resources and service systems hold sway.

Examining Services

The increasing acknowledgement that taking the user perspective into account can lead to better targeted and more effective services based on the needs identified by users is not a new idea in maternity services. Maternity services in particular, have been identified as being at the forefront of user involvement in service delivery (Gott et al, 2000). The Royal College of Midwives has stated its commitment to working nationally and locally with user representatives to develop accessible, cost-effective, high quality services that meet women's physical, emotional and social needs (Royal College of Midwives, 2001) as has the Royal College of Obstetricians and Gynaecologists who issued practical guidance on involving users in a wide range of short and long-term opportunities for involvement in maternity services (RCOG, 2002).

However, this commitment to involving women in examining services has most often been met through surveys that seek women's retrospective views of the services they used and care they received. The literature reveals that, for many years, both maternity services and users have had an interest in defining and measuring women's satisfaction with maternity services, with a significant volume of satisfaction surveys existing in all aspects of antenatal, intrapartum and postpartum care. Studies such as Seguin et al (1989), Proctor and Wright (1998) and Smith (1999, 2001) have sought to develop a multidimensional

labour satisfaction questionnaire that could validly and reliably record user responses to maternity services. Further, a range of satisfaction surveys have tried to develop an understanding of the dimensions of women's satisfaction and to determine explicative factors for these. Among the many dimensions examined are continuity of care (Morgan et al, 1998), midwife managed care (Shields et al, 1998), the midwife-woman relationship (Tinkler & Quinney, 1998) and pain relief during labour (McCrea & Wright, 1999).

A number of concerns have been raised about this method of identifying user preferences (Jacoby & Cartwright 1990; Reid 1994), but more significantly it is argued that surveys of user satisfaction researched by a provider or external funder do not constitute user involvement, as these do not involve any form of partnership or collaboration with users in terms of what is researched or how the findings are used to subsequently influence services. As discussed in chapter two, a particular criticism has been that such surveys can only play a limited part in enabling users to influence service delivery and it is rarely possible to judge the likely influence of the user surveys owing to the lack of reporting on issues such as context, consultation strategy and impact of results (Rea & Rea, 2000). Furthermore, in the current climate of user orientation in health, a clear need has emerged to not only understand users' needs and preferences in terms of placing individual women at the centre of their care, but also in terms of the involvement of childbearing women and their representatives in the process of delivering and improving the quality of services. This review of the satisfaction literature in maternity services revealed that this criticism held true with little or no reporting of the influence of such surveys. As such, while this setting was able to produce a significant volume of literature on involvement in examining services there exists a paucity of peer-reviewed reporting on how this information has been used to shape, improve and develop the quality of maternity services.

Strategic Planning

As previously discussed, maternity user groups have had considerable success in shaping national policy on maternity care and continue to contribute to policy-making through research, publications, lobbying and networking. However, while national policies provide a framework for services, it is regional planning and decision-making structures working within the confines of locally available resources, priorities and budgets that determine their interpretation and implementation within a local context. Maternity services are unique among the three settings examined in this study in that they alone have an established mechanism for facilitating women's on-going involvement in the detailed analysis and operation of policy at a service level and hence participation in the local planning and development of maternity care. Having campaigned for, and won a commitment to woman-centred care from policy makers, user groups are now concerned

with implementation at a local level, playing an active role in assessing services on behalf of the women using them and working with providers to bring about change (Tyler, 2002). Most user groups have developed local contacts with individual services and health professionals. By forming alliances at local level they attempt to influence both the delivery of services and the attitudes and behaviour of staff.

The current principal conduit for user involvement in service decisions is the Maternity Service Liaison Committee (MSLC). Established in England and Wales in 1993, although the model has been adopted by a number of Scottish Health Boards, MSLCs are an initiative stemming from *Changing Childbirth* (Department of Health, 1993). They arose from a perceived need to have a forum within which users and planners of maternity services could work together. MSLCs, as independent advisory bodies, have a key role in helping to develop woman-centred maternity services by taking an overview of the range of services available to women locally, providing regular feedback to providers and by providing a forum for providers and users to discuss current services and proposed developments. It was recommended that every District Health Authority should have an MSLC with lay representation reflecting the ethnic, cultural and social mix of the local population (Department of Health, 1993). According to the Department of Health, a minimum of one third of the core membership of each committee should be user members (1993). User groups such as the NCT support this proportion of user members, as they believe it makes it more likely that different perspectives will be covered and that user members will be supported by each other (NCT, 2002).

The Health Select Committee - Second Maternity Services Inquiry (2003) found that user groups were largely supportive of MSLCs finding that they "have been fantastically useful and they are also the place where women using the service can have a real input". In their first inquiry into the Provision of Maternity Services, users representing 15 maternity units across the country, nearly all of who were members of their local MSLCs spoke with confidence about a range of work being carried out to ensure that maternity services took full account of women's needs and wishes (Health Select Committee, 2003).

However, despite the aspirations of MSLCs as a model of user involvement in local planning and service decisions, a number of reports suggest that difficulties have been identified with the way they work. The Health Select Committee reported that women in some areas were not adequately served by active MSLCs, despite the publication of Department of Health guidelines on their role and organisation (Department of Health, 1996). The Royal College of Obstetrics and Gynaecology (RCOG) reported that although these guidelines were intended to "emphasise the role and place of the MSLC" across the country, the activity levels and efficiency of MSLCs varied widely. While fully supporting

the concept of the MSLC as a forum for user and professional dialogue and planning of appropriate local services, it regretted the wide variation in their effectiveness (RCOG, 2003). One explanation put forward for this was the demise of Local Health Authorities in England and Wales in 2002 and the lack of updated guidance on the management of user involvement in MSLCs. The running of MSLCs was felt by user groups to depend entirely on the local health authorities' approach. Thus reforms to restructure the health service could threaten the effectiveness, and even the existence, of MSLCs.

User groups have also voiced a concern that as the statutory basis of the funding for MSLCs was with health authorities, an unintended fallout of their demise was that the requirement to fund MSLCs fell by the wayside. As a result, MSLCs were felt to be patchy: some "brilliant", some of doubtful use and effectiveness (NCT, 2002). The Health Select Committee concurred, stating that in some places MSLCs continued to function well but in other places, the change in service structure had led to a lack of clarity about where they should be based and what they should be doing. A key concern was that the learning, skills and confidence that had been built into these committees and their user members needed to be kept in order that their role could continue (Health Select Committee, 2003).

As identified earlier, one particular problem that has been acknowledged with MSLCs was their lack of representativeness and, in particular the difficulty they have in finding appropriate user representatives from minority and disadvantaged groups. Even where MSLCs operated on a secure organisational basis, the Health Select Committee (2003) heard that they were overwhelmingly middle-class and that some still failed to represent or even register the experiences of women from disadvantaged groups. The NCT representative reported that they were concerned by the difficulties faced by women who could not afford classes and who maybe lived in areas where there was not an NCT. Newham Healthcare similarly reported that, although local MSLCs could play a significant role in maternity services, they tended to have women's representatives from the NCT group, mainly middle class white women, so did not accurately reflect other women from the community (Health Select Committee, 2003).

As long ago as 1994 Reid argued that our information about the likes and dislikes of pregnant women is heavily influenced by the attitudes of primiparous, low risk women, while the experiences of the hard-to-reach groups such as ethnic minority women, teenagers, travellers, homeless, refugee and disabled women remain under-researched (Reid, 1994). These groups have a variety of needs, with many showing higher than average rates for maternal and neonatal problems and so, paradoxically, may warrant greater time and attention. The Health Select Committee (2003) recognised this when it proposed that service planners needed to acknowledge that current provision was not based

on an accurate profile of local communities and, if an area was serious about hearing the views of its full local population, they could not simply rely on groups of people who are confident to attend and speak the language of meetings (Health Select Committee, 2003).

One factor which the Health Select Committee (2003) felt might partially explain the difficulty in recruitment was the financial burden of childcare and travel to MSLC functions, and in a written submission to the inquiry, the Centre for Nursing and Midwifery Research at the University of Brighton called for service users to be paid for formal participation at such functions (Health Select Committee, 2003). A number of other practical difficulties have been identified. Lewison (1994) discussed anecdotal reports that it was often difficult to put items onto agendas, to gain a place on the MSLC and that meetings were often held at inconvenient times for user members. Maternity Action (1995) agreed with Lewison (1994) when they highlighted the problem of user members carrying heavy responsibilities without support.

> "It is questionable whether lay members always feel able to speak out in such situations, particularly where the chair is a consultant or provider representative" (Maternity Action, 1995)

Such an unequal relationship created barriers for women in working alongside professionals in policy and service development fora and indeed users have reported difficulties sitting on committees with professionals with considerably more experience of such work (Maternity Action, 1995). Kelson (1995) reported on the increasing recognition of the need for training that was directed at both health professionals and users. In an early move to support user involvement the NCT were funded to provide a training and support package in England and Wales, *Voices*, for user representatives on MSLCs. *Voices* addressed the skills, knowledge and confidence identified for full participation in an MSLC, providing a training package that included issues of effective user involvement; how the NHS works; accessing policy documents and evidence; committee skills, confidence building and problem solving; considering the perspectives of healthcare professionals and exploring effective partnership working (NCT, 2002).

Voices remains one of the very few examples in the literature of systematic support for user representatives, despite the growing awareness that users on service fora may need to learn new skills to function effectively as representatives (NCT, 2002). Following on from the success of *Voices,* the NCT maintains a programme of training and support for user representatives as well as multi-disciplinary development for MSLCs, aimed at improving meeting dynamics, communication and decision-making; increasing understanding and respect between members and developing a work plan. Such activity acknowledges that professionals may also need to learn new skills in order to interact with users.

In summary then, women would appear to have an influence in both the national policy and local planning of maternity services. The stated commitment to involve them and the history of researching and describing women's experiences supply facilitators for this. The concept of the MSLC, and the mechanism for involvement it provides, appears to offer much scope for the meaningful involvement of users and their representatives in the interpretation of national policy and local planning of maternity services. However, MSLCs still face a number of challenges in relation to representativeness, access and equity in participation that require attention if they are to develop appropriate structures for involvement and thus fulfil their potential.

Summary

In terms of the user involvement agenda, maternity services can be seen to be at the forefront with both a substantial history of women's involvement and clear evidence of the inclusion of the user perspective in two of the three levels examined – strategic planning and individual care and treatment (Gott et al 2000; Pope et al 2001; Royal College of Midwives 2001; Tyler 2002). Women's influence has been credited with significant developments in maternity care and their preferred philosophy of care, that values choice, continuity of care and control, is enshrined in national policy documents (NCT, 1994). User groups have been identified as instrumental in shaping these national policy directives (Department of Health 1992; Department of Health 1993; Scottish Office 1993; Scottish Executive Health Department 2001). Similarly, the ethos that care should be provided based on individual need with the mother actively involved is also widely accepted and implemented as good practice within maternity services (Pope et al 2001; Royal College of Midwives 2001; Scottish Executive Health Department 2001). However, a number of concerns have been raised concerning how far the aspirations of woman-centred care can be translated into individual choice and preference (Tyler 2002; Page 2003).

A number of commentators have challenged the extent to which pregnant women are able to have control over their own care and treatment and to have their individual preferences met, proposing that women's trust in health professionals often results in compliance with professionally defined choices (Nolan 1999; O'Cathain et al 2002; Stapleton et al 2002). Furthermore, the hierarchy in services; competing demands and time pressures on health professionals; existing service systems; fear of litigation and technology have all been identified as factors that limit the choices available to individual users (O'Cathain et al 2002; Johanson et al 2002; Lincoln 2004). Thus, whilst recognising that women's right to choose continues to be central to user involvement in maternity services, there appears to be widespread recognition that the implementation of individuals' unique needs illuminates

a number of tensions for services in attempting to deliver these within service, managerial, resource and budgetary constraints (Lincoln 2004; Hundley & Ryan 2002).

Having won a commitment to woman-centred care from policy makers, maternity user groups have moved their interests to implementation at a local level playing an active role in assessing services on behalf of women and working with providers to bring about change (Gott et al 2000; Tyler 2002). However, involvement has been less well described in examining the quality of maternity services where services appear to rely on the traditional methodology of surveys, with no indication of any consideration of the implications for the organisation or the delivery of care arising from the outcomes of these (Jacoby & Cartwright 1990; Reid 1994; Rea & Rea 2000). The lack of peer reviewed reporting on how users' views and preferences have been used by service decision-making and development structures means that there is currently little to provide clarity on the contribution of user involvement to service delivery and its impact on service issues.

Nevertheless, maternity services are unique among the three settings examined in this study, in that they alone have an established mechanism for facilitating women's on-going involvement in the local planning and development of maternity services. This structure, the Maternity Services Liaison Committee (MSLC), provides a forum for user and professional dialogue in the examination and development of appropriate local services. However, despite the aspirations of MSLCs as a model of user involvement in local planning and service decisions, a number of reports suggest that they face a number of challenges in relation to representativeness, access and equity in participation that need to be tackled in order for them to develop appropriate structures for user involvement in planning and developing services (Health Select Committee 2003; RCOG 2003). One particular problem that has been acknowledged with MSLCs is their lack of representativeness and the difficulty they have in finding appropriate user representatives from minority and disadvantaged groups. Representativeness has traditionally been a concern in maternity services, where one of the enduring criticisms of user organisations is that they are, in the main, run by and for middle-class women and so fail to represent the experiences of women from disadvantaged groups (Garcia et al 1998; Adam 2001; Health Select Committee 2003). This issue may be of particular importance given the significant influence in policy and service development held by user groups, as the potential then exists for services to be shaped to middle-class women's definition of need.

However, despite the widespread recognition of this and of the need for methods that ensure the inclusion of the quieter voices of disadvantaged or hard-to-reach groups, these remain issues that, in common with other health settings, require further development.

Chapter 6: User Involvement in Mental Health Services

This chapter will describe the context and provision of mental health services and how, within this, user involvement is recognized and realized. Mental health services share a number of characteristics with the other two settings under examination but, while its users include women and it operates within a similar policy context, it also differs from them in four key ways. First, the users of mental health services are not exclusively women as in the cases of the other two settings. As discussed in the introduction, this study wished to explore the range of conditions under which the policy on user involvement was being implemented. Therefore, it was felt to be important to include a setting within which women were not the sole users but, where it is known that they have different issues and are treated differently. Mental health services appeared to provide such a setting, as there exists a significant body of evidence to suggest that gender is a factor in the development and treatment of poor mental health (Department of Health 1995a; Payne 1995).

Second, mental health services differ from maternity and gynaecological oncology services in that they are characterised by the wide of range of levels of ill health and types of treatment and support on offer. As a result, the language used to describe users is perhaps more varied in mental health than in any other sector of health. The term 'users' is most frequently used rather than 'patients'. To some commentators 'patient' implies users as objects of the clinical gaze of mental health professionals (Pilgrim & Rogers, 1999) and therefore in terms of their illness. However, 'users' can also be seen as consumers, survivors and providers, all of which imply different notions of the roles and responsibilities of people with mental health problems and the relationship between them and mental health services (Tait & Lester, 2005).

Third, people who have acquired a psychiatric history often experience discrimination. While there may also be a level of stigma associated with an illness such as cancer, it is argued that the term 'mental illness' often carries a multitude of emotive and negative connotations leading to a disproportionate level of stigma or discrimination (SAMH, 2005). The response from mental health services is thus extended from merely addressing medical and care needs, to include focusing on prejudice and addressing socially created barriers (Oliver, 1998). Finally, mental health services are unique in health in that they have a compulsive element (Perkins & Repper 1998; Ryan 2002; Rankin 2005).

The first section of this chapter will describe the context of mental health services and the particular issues that have influenced the development of user involvement before moving on to discuss its implementation in individual care and treatment, in examining services and in strategic planning.

The Context and Provision of Mental Health Services

'Mental illness' is a shorthand term for a variety of conditions that affect the functioning of the mind. It is a catch-all phrase that covers a wide range of symptoms and experiences, and has many permutations (SAMH, 2005). Mental illness often has a combination of causes. Genetic pre-disposition may make some people more susceptible while environmental factors such as lifestyle changes; social and economic circumstances or adverse life situations may also be involved. However, sometimes people develop mental illness or mental health problems as mental illness is also described, without any explanatory outside trigger (SAMH, 2005).

One in five adults in Scotland is affected by mental health problems at any one time, with nearly one third of GP consultations involving mental health (Scottish Executive, 2000). Mental health problems can refer to conditions as diverse as depression, anxiety, phobias, eating disorders and schizophrenia. A common classification divides conditions into those defined as 'severe and enduring' and those that are 'mild to moderate'. Severe mental illnesses are defined as those in which psychosis is likely to occur. Psychosis is the medical term used to identify symptoms where the individual experiences a loss of reality and cease to see and respond appropriately to the world to which they are used. The majority of people diagnosed with mild to moderate mental health problems experience affective disorders whereby their mood is altered to such an extent that it interferes with their ability to function, feel pleasure, or maintain relationships (Kleinman & Cohen, 1993).

Diagnosis is arrived at by a psychiatrist in conjunction with other health professionals. A full medical history, observation over time and pre-determined criteria are used to explore the person's behaviour and develop an understanding of how their condition has developed. Assessment follows one of the internationally agreed diagnostic schedules such as the International Classification of Diseases (ICD10) or the Diagnostic and Statistical Manual (DSMIV) (Priebe & Slade, 2002). Reaching a diagnosis can often be difficult and it takes time to be sure that the individual's symptoms truly indicate a particular mental illness. Some symptoms, such as hallucinations, can also appear in other medical conditions, for example high fever or brain tumour, and many different mental illnesses have overlapping symptoms making it difficult to tell the conditions apart (National Institute of Mental Health, 2005).

A diagnosis of mental illness can cover a wide range of symptoms leading to very different experiences for those affected. Being an acute in-patient is one aspect of the experience of those with mental health problems but beyond this group there are many more people who

are less visible. There are individuals with long-term, serious but stable mental health problems that live in the community. Many lead lonely, isolated lives with few close friends or social networks (Corry et al, 2004). There is yet an even larger number with relatively common mental health problems, many undiagnosed. Over 90% of all those with mental health problems are seen in primary care but despite this relatively few GPs appear to have a special interest in mental health (Boardman et al, 2004). It has been government policy for many years to transfer mental health services to the community, but despite this there have been very few hospital closures and the majority of resources continue to support acute inpatient services. In 1999, the NHS spent £224 million on adult mental health services with 78% invested in hospital inpatient care; however, 80% of people with mental health problems were then living in the community (MIND, 2003).

As the experiences of individuals can vary so significantly it will be worth describing the principal conditions that can affect individuals before going on to consider the extent and nature of user involvement in mental health.

Signs and Symptoms of Severe Mental Health Problems

In general terms, the signs and symptoms of a severe mental health problem is the presence of psychosis e.g. having hallucinations or delusions (American Academy of Child and Adolescent Psychiatry, 2001). With hallucinations someone may hear their own thoughts as if they are coming from an external source. They may see, smell or taste things that appear to be real but which are not being experienced at that time by anyone else (Health Canada, 1991). People who have hallucinations often try to find an explanation for them and may attribute them to beliefs that others may see as strange or delusional. This kind of distorted thought pattern might cause very severe anxiety called paranoia (American Academy of Child and Adolescent Psychiatry, 2001).

Schizophrenia is an example of a severe mental illness as it is a condition that distorts thoughts and perceptions. During what is sometimes referred to as "an acute episode" the mental processes of experiencing and thinking become distorted. When severe this can lead to intense panic, anger, depression, elation or over activity, perhaps punctuated by periods of withdrawal. Schizophrenia is mostly episodic; a third of people who have experienced schizophrenia only experience one episode and make a full recovery, for others it can mean years of fluctuating between good health and illness, while some experience severe long-term incapacity (Schizophrenia.com, 2005). About one in a hundred people worldwide experience at least one such episode at some time during their lives, although the highest incidence is in the late teens and early 20's (Health Canada, 1991). However, it is an illness that can be treated and new forms of treatment may lead to further improvement in rates of recovery.

Signs and Symptoms of Affective Disorders

Affective disorders include depression, bi-polar disorder and anxiety disorders. In contrast to the normal emotional experiences of anxiety, sadness or loss these disorders are persistent and can interfere significantly with an individual's ability to function.

Depression is one of the most common conditions in Scotland, affecting one in five people at some stage in their life. Everyone experiences variations in mood, but a depressive disorder is an illness that involves the body, mood and thoughts. It is a continuous and all consuming sense of hopelessness and despair that affects the way a person eats and sleeps, the way they feel about themselves and the way they think about things. A depressive disorder is a serious mental health problem whose symptoms include persistent sad mood, difficulty sleeping or oversleeping, physical slowing or agitation, feelings of worthlessness or guilt, difficulty thinking or concentrating and recurrent thoughts of death or suicide. A diagnosis of uni-polar major depression (or major depressive disorder) is made if a person has impairment in usual functioning nearly every day during the same two-week period. Episodes typically recur (Depression Alliance, 2003). Sometimes people will get better by themselves without intervention. Others will experience recurrent bouts of depression in-between periods of good health. Without treatment, symptoms can last for weeks, months, or years. However, more than 80% of those suffering from depressive illness can be treated successfully with medication (Depression Alliance, 2003).

Bi-polar disorder, also known as manic depression, is a brain disorder that causes unusual shifts in a person's mood, energy and ability to function. It is a depressive condition, punctuated by episodes of extreme euphoria. It usually occurs in cycles, with long periods of depression followed by a manic high. The symptoms of bi-polar disorder are severe, often resulting in damaged relationships, poor job or school performance and even suicide. Around 1% of the population age 18 and above in a given year has bi-polar disorder. It is often not recognised as an illness, and people may suffer from years before it is properly diagnosed and treated. Like diabetes or heart disease, bi-polar disorder is a long-term illness that must be carefully managed throughout a person's life (MDF, 2004).

Anxiety disorders, which are the most common form of mental illness, include generalised anxiety disorder, panic disorder, obsessive-compulsive disorder and phobias. Whilst anxiety, worry and fear are feelings that everyone experiences from time to time, some people experience these disproportionately to the threats around them (Royal College of Psychiatrists, 2004). They may feel excessively anxious in certain situations, such as when they are with other people, or anxious a great deal of the time. When fear and anxiety are excessive they can be a significant problem and can have profound consequences on life (National Institute of Mental Health, 2005). Obsessive Compulsive Conditions are

characterised by the performance of a range of bizarre and seemingly irrational rituals that assist the individual to manage their anxiety. While the person affected may be fully aware that this repetitive behaviour is fruitless, they are unable to stop (MIND, 2005).

Thus, it can be seen that the term 'mental health problem' describes a multiplicity of experience where, unlike physical illness, symptoms are not usually apparent to the outside world.

Women and Mental Health

Mental health services differ from the other settings explored in this study in that both men and women are potential users. However, it would appear that a gender-blind paradigm dominates in mental health that results in gender often being ignored in the understanding of, and treatment approaches for, people with mental ill health (Jennings 1994; Cogan 1998). Nevertheless, there exists a growing body of evidence to suggest that it is a factor in the development and treatment of poor mental health. Women have significantly higher presentations of mental health problems than men do and the types of disorder generally differ (Department of Health 1995; Payne 1995). Some specific mental health difficulties such as post-natal depression are either exclusive to women or affect them more (Doyal, 1995). They are more likely to experience depression; anxiety and other neuroses while men have more psychotic illnesses such as schizophrenia (Kendrick et al 1993; Department of Health 1995).

Within this review no papers were identified that explored women's perceptions of mental health services, nor any programmes designed to assist women to develop a voice in user involvement. User involvement activity was non-gendered, suggesting that the views of men and women did not need to be distinguished. Where women's views and experiences were reported these related to the nature of the service under investigation rather than to any specific attempt to engage with women as a separate group. Activity with women was most pronounced in services for eating disorders, where a number of studies were identified that explored the views of people with eating disorders. Interestingly, in all cases these papers described the views of "people" with eating disorders even though it was clear from the reported results that only women had taken part.

Thus, in the review of the extent and nature of user involvement in mental health it was not possible to distinguish women's views and participation and so, unless stated, the user perspective represents both men and women. The next section will examine how the multiplicity of experience, levels of ill health and types of treatment has influenced the development of user involvement in mental health services.

The Development of User Involvement in Mental Health Services

The policy and political imperative for the involvement of users comes for mental health services against a backdrop and history of user movements that have often been viewed as confrontational and challenging for services (Hogg, 1999a). Much of this perceived challenge arises from a fundamental conflict in the perception of mental health and the locus of its symptomology. As the previous section has shown, the traditional understanding of mental health is based on a medical model that locates the individual's difficulties in the symptoms of their medical condition. However, over the past 20 years the disabled peoples' movement has made considerable strides in promoting the understanding and adoption of the 'social model of disability' (Morris, 1998). This has influenced thinking in mental health and particularly had an impact on users' definitions and understanding of mental health.

Unlike the traditional medical model that defines disability in terms of the relationship between an individual and their physical, sensory or mental impairment, this model defines disability as the relationship between an individual and their environment. It recognises that people who have physical, sensory or intellectual impairments or mental health problems are denied opportunities, discriminated against and excluded by barriers created by society. Disability activists and academics have argued that mental health services are part of the disabled peoples' movement. Current service users, people who have been through the mental health system or who have otherwise acquired a psychiatric history often find their access to employment, housing and other necessities to a good quality life barred by others' discriminatory behaviour. In an understanding of disability as being about removing people's power, or denying access to power, people with mental illness are thus defined as disabled (McNamara 1998; Oliver 1998). Using this analysis, the range of appropriate service responses is extended from merely addressing medical and care needs to include focusing on prejudice, challenging inaccessible physical and communication environments, developing enabling technology and addressing other socially created barriers (Oliver, 1998). Many in mental health services, however, appear to have found such an analysis challenging as they are neither equipped nor resourced to tackle adequately issues of prejudice, stigma and discrimination and their impact on users.

This history and conceptualisation of mental health has also influenced how users and user representation are viewed within mental health services. For the user of mental health services one of the more important influences has been the perceived impact that their mental health has on their decision-making ability (Myers & MacDonald, 1996). Rogers et al (1993) suggest that the notion that psychiatric patients are continually irrational encourages the belief that they are incapable of giving a valid view and that users' views,

which do not support professional interests, can be rejected as irrational. It follows then, that if people with mental health problems are perceived as being incapable of making decisions, then it is unlikely that they will become part of the decision-making process. Accordingly, psychiatrists have expressed concerns over whether a user whose insight is affected by illness can play the role of consumer and concern about the role of user groups in developing psychiatric services has also been expressed (Crawford, 2001). Some have argued that psychiatry has a dual function in which the needs of users have to be balanced with a wider responsibility to society at large (Eastman, 1999) and that, as such, users are not in a position to make judgements as to the appropriate development and delivery of services.

User representation in mental health has also been questioned on the basis that unlike physical illness, mental illness is often hidden and symptoms are not usually apparent to the outside world. Many people prefer to keep their illness a secret, for fear of stigma or discrimination as the term 'mental illness' often carries a multitude of emotive and negative connotations (SAMH, 2005). In a recent study of service users perceptions of stigma, London and Scriven (2007) reported that both community and in-patient users continue to identify stigma as a barrier to social inclusion and an obstacle to care. They concluded that the experience of stigma resulted in a delay in seeking help, loss of self-esteem and was a serious inhibitor to social inclusion. This background of stigma and secrecy has profound implications for user involvement, as a pre-requisite for active participation is a willingness to be identified as a user of services. As a result, concerns have been expressed over the representativeness of those users who are prepared to come forward and identify themselves openly as individuals with a mental health difficulty (Mental Health Task Force 1995; NHS Health Advisory Service 1997; Department of Health 1999b; Crawford 2001). One particular criticism of those who act as user representatives is that some individuals may be 'too well', 'too articulate' or 'too vocal' to represent the views of users generally. However, Lindow (1999) suggests that the concept of representativeness may be used as a subconscious method of resisting user involvement:

> "When workers find what we [users] are saying challenging, the most usual
> strategy to discredit user voices is to suggest we are not to be listened to
> because we are too articulate, and not representative. Workers seem to be
> looking for someone, the 'typical' patient, who is so passive and/or drugged
> that they comply with their plans… We ask, would workers send their least
> articulate colleague to represent their views, or the least confident nurse to
> negotiate for a change in conditions?" (Lindow, 1999, p 166)

A further feature of mental health services that has served to raise concerns is the unique history of containment and compulsion. While a decision to receive medical treatment is normally one which is taken by the user and the giving of treatment against the will of an

individual can be grounds for legal action against the clinician, those diagnosed as mentally ill can be both forced to enter hospital and to receive treatment against their will. In the vast majority of cases those with mental health problems requiring hospitalisation give consent voluntarily but, the Mental Health (Care and Treatment) (Scotland) Act (2003) gives provision for instances where compulsory detention is necessary for the welfare of the person concerned or where there is concern for public safety, the latter being in a minority of cases.

In the first six months of 2005/2006 the Mental Health (Care and Treatment) (Scotland) Act was used on 2,410 occasions to detain individuals (Mental Welfare Commission for Scotland, 2006). While relatively small in comparison to the overall number of people who have severe mental health problems at any one time, it is still a significant number that, it has been argued, has a disproportionate impact on how professionals perceive users, how users respond to mental health services and how society regards mental health (Rankin, 2005). Leading practitioners have argued that the knowledge that treatment can be enforced overshadows peoples' interactions with services (Perkins & Repper, 1998). Services have also been criticised for a disproportionate concern with risk that serves to limit the self-determination and active involvement of users in decisions on their care and treatment (Ryan, 2002) and others have highlighted the difficulties experienced by both user and health professional should there be a relapse (Knight, 2003). Whilst recognising the positive benefits of user involvement, Knight (2003) proposed that the transition back to in-patient is particularly difficult should the Mental Health Act be applied. Mental health is thus unique in the provision of health services in that choice, one key aspect of user involvement, represents a significant challenge to the principles that underpin practice.

A more practical barrier identified by the literature is the financial and time costs of user involvement. A number of commentators have proposed that user involvement, if properly implemented, is financially expensive and time-consuming for both the organisation and users themselves (Ham 1992; Hogg 1999; Allsop et al 2002; Branfield & Beresford 2006). However, a survey of policy and practice in payments to mental health users and carers involved in service development in 46 mental health service organisations in England found that only 26% made transport available to users and 30% to carers. Furthermore, only 33% paid users and 26% paid carers for their time (Ryan & Bamber, 2002).

Finally, unlike both maternity and gynaecological oncology services, questions have been raised over the appropriateness of using user groups as a proxy or advocate for individual users. Barnes (1999c) found that mental health professionals saw organised groups of users as self interested and atypical and that this was the reason to question the legitimacy

of the position they take. However, Barnes (1999c) also concluded that user groups provided safe environments, in which users could be supported, and confidence and skills developed. Barnes and Shardlow (1997) similarly reported that participation in user groups demonstrates that mental health problems do not necessarily imply incompetence:

> "One of the major roles that we can play is actually to say, we are users, we can participate at this level, we can articulate, we can challenge, we can negotiate, we can write papers, we can do this, instead of [being] some bumbling idiot that doesn't know what they are doing" (Barnes & Shardlow, 1997)

Nevertheless, several reviews have described the user movement in mental health as largely marginalized, atypical and politically motivated with questions asked regarding its representativeness and authority (Mental Health Task Force 1995; NHS Health Advisory Service 1997; Department of Health 1999b).

Thus, the development of user involvement in mental health would appear to be influenced by a number of different, although often interlinked, barriers. The medical model paradigm that reduces users to an information-providing role, the historically based concerns that have served to marginalise those seen as active users of services, concerns over compulsion, representation, financial and time costs all emerge as issues that potentially constrain the scope for meaningful user involvement at the treatment, service and policy levels. The next sections will examine the evidence for user involvement in care and treatment, examining services and strategic planning. The first section will begin by examining the involvement of users in their own care and treatment.

Individual Care and Treatment

User groups have argued that traditionally mental health users have not been given the opportunity to become involved in determining and managing their own care, rather they believe that professionals have tended to recommend a plan for treatment (Sainsbury Centre for Mental Health, 2001). If users reject this plan they are likely to be viewed as non-compliant, with this taken as a sign that they lack insight into their own condition and steps may then be taken to persuade or coerce them into taking a treatment that they do not want (MIND, 2003). The available literature suggests that users may not have as many opportunities for involvement in their own care and treatment as they would like. The Users' Voices project (Rose, 2001), which included interviews with over 500 users in seven geographical areas across England, found very low levels of involvement in individual care planning, while Bhugra et al (2004) found that two-thirds of patients admitted to a psychiatric inpatient unit in South London felt that they had not been sufficiently involved in their own treatment planning.

However, over recent years several aspects of patient-centred care have begun to be systematically developed in mental health services. These will be discussed using the framework provided by the programmes of activity described in the earlier chapters; the expert patient, shared decision-making and patient held records.

The Expert Patient

As previously discussed, the Expert Patient is a Department of Health programme designed to increase collaboration between users and professionals in chronic conditions such as diabetes or heart disease. Some have argued that, because of the largely hidden symptomology of mental illness and the often lifelong experience of it, mental health users are also ideally placed to contribute to expert patient or self-management programmes. Borrill (2000), for example, emphasised the way in which users can predict when they are about to become unwell and formulate appropriate responses at an early stage. Mental health professionals, she proposed, could tap into this expertise and make their own jobs much easier by focusing on users' considerable strengths.

The Expert Patient programme has seen few initiatives in mental health but one programme that has been reported on and is currently under evaluation is the Self-Management Training Programme (SMTP) for Manic Depression. Begun by the Manic Depression Fellowship in 1998 it is entirely user-developed and user-led. The programme is designed to enable individuals with a diagnosis of manic depression to gain confidence in their own capacities and to take control of their lives. It is currently the subject of a randomised control trial (RCT) with good outcomes to date including improvements in mood sustained 3–6 months after completion of the course (Department of Health, 2001b).

However, whilst the early indications suggest that this particular programme is an effective example of the expert patient approach in mental health, there has been no discernible work on other aspects of self-management or 'expert' programmes, namely the development of patient skills and a partnership approach.

Shared Decision-Making

Although promoted as a mechanism by which users can play an active role in managing their own treatment, this literature review failed to identify any studies that reported on shared decision-making programme within mental health. As with gynaecology oncology services though, there was some reporting on one particular element of shared decision-making and, in common with cancer services, this was enhanced communication.

As previously discussed, the NHS Plan seeks to improve communication with patients and has identified copying clinical letters to patients as one means of improved communication, enhancing patients' ability to share in the decision-making process about

their care and treatment and to make informed choices. There is little evidence on what people with mental health problems want in this area but, the Royal College of Psychiatrists, Faculty for the Psychiatry of the Old Age (2004) investigated the concerns and needs of older people with mental health problems. Their review of the literature suggested that users' concerns were around good communication, accurate and timely information about diagnosis and management. The copying of letters, they proposed, would not be a substitute for good verbal communication. As a result of their review, the College issued advice on the quality of information and communication that included, but was not limited to, copying letters.

Patient-Held Records

Whilst no studies were found that described shared care with people with mental health problems, there was some investigation of one element of shared care; that is patient held records. A review by Henderson and Laugharne (1999) found a gap in the evidence regarding patient held, personalised, accessible clinical information for people with psychotic illnesses. They concluded that it could not be assumed that patient held information would be beneficial or cost-effective without evidence from well planned, conducted and reported randomised trials.

Since their review, one study has been completed that described shared record keeping with people with a mental health problem. Lester (2001) examined the use of patient held record cards for patients with schizophrenia. The shared care record card was developed using an iterative process with mental health service users. The trial achieved its sample size, recruiting 210 patients and 74 practices. However, despite the enthusiastic participation of users, the shared record appeared to have no significant clinical value for this group of patients. In both primary satisfaction and psychopathology scales, and secondary measures, there was no significant effect in the use of services, consultation rates, admissions or use of the mental health act.

Both these reviews examined the usefulness of patient held records for people with severe mental health problems. No other reviews were found that explored patient held records for those with affective disorders, such as depression or anxiety disorders where, it could be anticipated that more effects might be seen. Certainly, patient held records are established practice within maternity services where it has been suggested that 10% of new mothers may have a diagnosis of post-natal depression (Royal College of Psychiatrists, 2006). However, no further exploration of this element of communication between users and professionals was found.

Thus, a description of the basic elements of user involvement in their own care and treatment would appear to be lacking from the literature on mental health services.

However, more significant evidence of progress in this area can be found within the unpublished literature and from an analysis of the web sites on mental health. Examination of the mental health web sites and information resources used in this literature review revealed that users and user groups had been actively involved in the production of these resources and in enhancing communication about treatment regimes and care pathways. A number of web sites for mental health organisations such as MIND, the Scottish Association for Mental Health, the Depression Alliance, Schizophrenia.com and the Manic Depression Foundation (MDF) were accessed during the period 2006-2007. Each of these provided details of the context and provision of available services as well as wider information on the nature, prognosis and treatment of the particular mental health conditions addressed by these organisations. In all these web sites reference was made to the active participation of users in the work of the organisation and to their direct influence in enhancing communication about mental health in general, and the specific conditions addressed in particular. In some sites, users had been responsible for the design and content of information resources, while in others they had worked alongside staff in their production. However, there was no reporting on the process of such involvement, the techniques for partnership working with users, nor the influence of users in setting the agenda, tone and detail of the information resources. This appears to indicate that there is some acceptance and implementation of user involvement within the mental health field and in particular within the communication elements of patient-centred care. However, in conjunction with the paucity of peer reviewed, scholarly literature there is a lack of reporting that could provide clarity on methods. Reporting on issues such as the identification of a user perspective; weighting of perspectives; the difficulties encountered and perceptions of the usefulness of user involvement could greatly facilitate the further development of such opportunities.

Furthermore, there is evidence of the introduction of a person-centred model of care and treatment, the Tidal Model, being introduced in Glasgow. The Tidal Model is an interdisciplinary model of care, which emphasises the need for empowerment (Barker, 2007). It recognises that many different individuals, groups and disciplines may be required to arrange and deliver patient-centred care, from traditional health and social care workers to family members, friends and others who have had experience of the journey to recovery. However, although there are reports of staff and user satisfaction with the model, as yet its implementation, and the role of users in that, has not been formally peer-reviewed or evaluated.

Examining Services

Taking the user perspective into account in services would appear to be of particular importance within the mental health setting where it has been reported that users and mental health professionals often have very different perspectives on services. Lindow (1999), for example, highlights the way in which users and service providers may have very different priorities, with users more concerned about poverty and housing than local commissioning arrangements. As a result, involving users could provide insights that would prompt practitioners to re-evaluate their work, challenge traditional assumptions and highlight the key priorities that users would like to see addressed. Furthermore, it has been reported that user involvement can be therapeutic. Being involved in decision-making and helping to shape services, particularly when users work together collectively, can help to increase confidence, has been shown to raise self-esteem and develop new skills (Mental Health Foundation, 2003). In the words of Read and Wallcraft (1992)

> "Many of us believe that empowerment and control over our lives is essential to emotional healing" (Read & Wallcraft, 1992, p 9)

However, in common with the other settings under review user involvement in examining and improving the quality of services appears under-reported.

One area of mental health service delivery that initially appeared to have a high level of user involvement in its development was eating disorders. A number of surveys were identified that explored the views of people with eating disorders (Yager et al 1989; Deeble & Bhat 1991; Newton et al 1993a; Newton et al 1993b; Rorty et al 1993; Griffiths et al 1998; Newton 2000). The users who were involved were current or former users of eating disorders services; many had been hospitalised in psychiatric hospitals. In all these surveys they were asked to evaluate treatment approaches. The treatments ranged from highly structured medical interventions, such as individual psychotherapy to nutritional therapy or self-help groups. In these surveys people with eating disorders, their relatives and friends, as well as groups representing them were found to have expressed views about the nature of eating disorder service provision in the UK. The authors recognised that the comments made by users provided important insights into the issues for people with eating disorders presenting for treatment. However, there was no discussion identified that indicated how user preferences or concerns had impacted on services or been used to shape or influence service delivery.

In a review of the involvement of users in the delivery or evaluation of mental health services a number of randomised controlled trials and other comparative studies were reported by Simpson and House (2002). Of particular importance was evidence on

involving users and the outcomes of involvement on those receiving services. Five randomised controlled trials and seven other comparative studies were identified which examined user involvement in service delivery and evaluation (Polowczyk et al 1993; Cook et al 1995; Felton et al 1995; Solomon & Draine 1995a; Solomon & Draine 1995b; Lyons et al 1996; Solomon & Draine 1996; Klein et al 1998; Clark et al 1999; O'Donnell et al 1999; Paulson et al 1999; Wood & Wilson-Barnett 1999; Chinman et al 2000; Clark et al 2000; Chinman et al 2001). Eight studies focused on involving users as service providers, mainly working as case managers in services for clients with severe mental illness. Two studies looked at the effects of involving users as trainers, and two studies considered involving users as interviewers. The users who were involved were current or former users of mental health services who had had serious psychiatric illness, most commonly schizophrenia or bipolar disorder; many had been hospitalised.

The reported results focused on the individual benefits to users accruing from their involvement in services. There were no reports of the benefits identified for services or of any adaptations or changes made to service planning and delivery as a result of the participation of users. However, the employment of users in services did appear to have an impact on service delivery (Solomon & Draine 1996; Paulson et al 1999; Wood & Wilson-Barnett 1999). Services employing people who were or who had been users did not have lower client satisfaction (Solomon & Draine 1995b; Klein et al 1998; O'Donnell et al 1999; Chinman et al 2000) and the influence of trainers who had been users on the attitudes of trainees was positive. Involving users in training gave trainees a more positive attitude toward users who had been mentally ill and mental illness in general (O'Donnell et al 1999; Wood & Wilson-Barnett 1999). Furthermore, evaluators who had been users may have brought out negative opinions of services that would not otherwise have been obtained as when interviewed by other users, clients reported being less satisfied with services (Clark et al 1999; Polowczyk et al 1993).

However, the studies included in this review of the involvement of users in the delivery and evaluation of mental health services had a number of methodological weaknesses. The review included 12 comparative studies, only one of which was British. Five randomised trials were found, only one of which indicated the randomisation method used (Cook et al, 1995). Researchers collecting data were not blinded to treatment group in any of the studies. Some studies were not set up to investigate users' involvement and the results were from a later analysis of routinely collected data (Felton et al, 1995). Some had more than two study groups and did not directly compare involving users with involving those who had not been users (Felton et al, 1995). Few standardised outcome measures were used unmodified. Measures included adapted versions or selected subscales of existing

scales (O'Donnell et al 1999; Solomon & Draine 1995a; Klein et al 1998; Felton et al 1995; Chinman et al 2000; Polowczyk et al 1993) or outcome measures constructed for the particular study (Cook et al 1995; Felton et al 1995; Wood & Wilson-Barnett 1999). The use of modified rating scales could have led to bias, as has been shown for unpublished scales (Marshall et al, 2000). Only small numbers of users were involved, with numbers ranging from one user to eight users in a team, making it difficult to apply findings to involving users in general (Cook et al 1995; Lyons et al 1996).

A further methodological weakness was that authors interpreted their findings. When discussing a finding, such as users being less likely to hospitalise clients, they proposed that this might be because of the users' own previous bad experiences; because they had more tolerance for behaviour arising from symptoms; used previous experience to help clients stay out of hospital or more readily engaged with clients needing hospitalisation (Lyons et al 1996; Clark et al 2000). That interviewers who had been users obtained a higher proportion of negative satisfaction scores might be due to clients feeling more able to be honest with users, thus increasing validity, or it might be that they perceive dissatisfaction as the socially desirable response (Polowczyk et al 1993; Clark et al 2000). However, these possibilities were not explored.

Nevertheless, the studies identified suggested that users of mental health services could be involved as employees, trainers, or evaluators without damaging them. In some studies, benefit was indicated for clients of employees who were or who had been users of services, and there were no serious disadvantages. However, involvement would appear to depend on adequate support, as all studies reported details of the support provided to users. Such support included training and payment for involvement. Service providers gave practical and personal support to users (Cook et al 1995; Solomon & Draine 1996) and this was clearly distinguished from treatment.

Thus, in summary, the published work on examining and improving service quality appears patchy, has substantial methodological weaknesses and where there is reporting this has tended to focus on the impact of involvement on users rather than on the development of services. Government policy strongly supports the development of involving users in the evaluation and delivery of mental health services (Mental Health Task Force 1995; NHS Health Advisory Service 1997; Department of Health 1999b; Scottish Executive 2001). The emphasis on user involvement has potentially significant implications for the development of effective, accountable and responsive services with the potential to challenge traditional perceptions of mental health and for how interventions, from medication to mass media anti stigma campaigns, are evaluated. However, the

evidence that exists on the effectiveness of such activity appears unreliable and unfocussed and so more formal evaluations are needed.

Strategic Planning

A review of the literature within mental health suggests that although the concept of user involvement appears regularly in policy documents, it may be less meaningful in practice. This view is supported by a survey of the mental health user movement in England, which found that 'local service user groups play a very important role in mutual support, combating stigma, helping people to recover and stay out of services and participating in local service planning and development' (Wallcraft, 2003). However, most groups were small, recently formed, poorly funded and not representative of black and minority ethnic communities, all of which limited their capacity to achieve change. In 2001, a large cross-sectional survey of users and providers of psychiatric services across Greater London found that none of the Trusts had systems for involving users that met national standards (Crawford et al, 2003). Crawford et al concluded that although there were many active user groups, it appeared that their influence was limited, with an emphasis on sharing information rather than partnership or user-led developments.

In 2002, Crawford reviewed the literature on service planning examining the process and outcomes of user involvement as well as the extent to which user groups were satisfied with the current arrangements for involving them in planning (Crawford, 2002). He identified examples of user involvement but his review suggested that user involvement in planning was limited to consultation with managers retaining decision-making powers. Users' influence was most apparent in the outcomes of time-limited projects with well-defined boundaries.

The studies reviewed highlighted the need for service providers to be explicit about the aims and limits of user involvement in planning and the need for users to see changes resulting from their input if involvement is to be sustained. Contextual factors, such as organisational openness to user involvement, appeared to have a greater influence on the success of user involvement initiatives than technical factors related to how a particular model is implemented. Both users and providers felt that health services could involve a broader range of users by offering greater transparency about their expectations of users and the limitations of their participation. Reliance on the ability of users to integrate into health planning meetings without training, support or encouragement from the services limited the type of user able to participate to those who were sufficiently educated, articulate or confident. These factors also influenced users' ability to consult with their constituency.

Crawford (2002) found that user-led forums, where users rather than health professionals set the agenda were highly valued by users but nursing staff stated that they felt excluded from alliances between managers and users and, as a result, were disinclined to promote user involvement until this was addressed. Other barriers to user involvement included organisational change that may break relationships between users and providers and national directives, which limit the effect that local voices can have on directing service developments. There were also concerns about the ability of users to represent the views of people who are not involved. Crawford concluded that this should stimulate efforts to engage others in user involvement rather than being used to question the contribution of those who are involved.

Rose (2004) carried out a literature search of user involvement in change management in mental health. She investigated the most important factors in bringing about change in organisations in respect of the involvement of users. As with Crawford (2002), organisational culture was found to be the most important factor in determining the success of change management. Entrenched power differentials had a negative effect on user involvement, as did a lack of resources. She concluded that user involvement in mental health services was not a 'bolt-on' extra, which it could be if users were only involved at the beginning and end of the change process. Users, she proposed, should be involved throughout the change process, as process in mental health was as important as outcomes. Given the barriers identified, however, this would require innovative thinking and practice from managers in order that mental health users might properly be engaged.

Summary

Through a series of legislative and policy programmes the government has outlined its commitment to involving users in mental health services. This commitment strongly supports the development of user involvement in individual's own care and treatment and in the planning, delivery and evaluation of mental health services (Mental Health Task Force 1995; NHS Health Advisory Service 1997; Department of Health 1999b; Scottish Executive 2001). However, as this review has shown, little evidence exists on the effectiveness of such activity, more formal evaluations are needed and deliberate steps are required to ensure that users' voices are identified and heard (Rose 2001; Simpson & House 2002; Crawford et al 2003; Bhugra et al 2004; Rose 2004). Despite its benefits and the significant political encouragement in recent years, user involvement in mental health services remains patchy, with an emphasis on consultation rather than influence, partnership or control (Ryan & Bamber 2002; Crawford et al 2003; Rose 2004)

User involvement in mental health would appear to be influenced by a number of barriers including a medical model paradigm that reduces users to an information-providing role, historically based concerns that have served to marginalize those seen as active users of services, concerns over compulsion, representation, financial and time costs (Mental Health Task Force 1995; NHS Health Advisory Service 1997; Department of Health 1999b; Eastman 1999; Lindow 1999; Crawford 2001; Allsop et al 2002; Ryan 2002; Ryan & Bamber 2002; Rankin 2005; Branfield & Beresford 2006). These potentially constrain the scope for meaningful user involvement at treatment, service and policy activity. While the barriers to user involvement may be similar to the difficulties in other health settings, the profound philosophical differences in the understanding of mental health and the significant consequences of the medical model paradigm adopted would appear to present a more fundamental challenge to the development of meaningful user involvement. The continued dominance of the medical model in mental health, as in gynaecological oncology, has profound implications for user involvement as this model perpetuates a view of empiricism that recognises positivist approaches to evaluation and development rather than the interpretist or qualitative approaches that offer such scope for the inclusion of user voices.

Furthermore, a lack of published evidence appears to represent a major challenge for the development of user involvement in mental health, as despite the apparent proliferation of activity, there is a lack of published work that could provide clarity on the process and perceived usefulness of user involvement mechanisms. This was particularly apparent in the response to user involvement in individual care and treatment. Some have argued that, because of the largely hidden symptomology of mental illness, and the often lifelong experience of it, mental health users are ideally placed to contribute to patient-centred or self-management programmes (Borrill, 2000). However, there have been few peer-reviewed initiatives in patient-centred care in mental health and there has been no discernible work on aspects of self-management or 'expert' programmes, namely the development of patient skills or a partnership approach. In common with oncology services only one element of patient-centred care had been reported and that was enhanced communication (Henderson & Laugharne 1999; Lester 2001; Royal College of Psychiatrists, Faculty for the Psychiatry of the Old Age 2004). Thus, a description of the basic elements of user involvement in their own care and treatment would appear to be lacking from the literature on mental health services, but evidence of progress within this area can be found within the unpublished literature. Formal reporting on issues such as the identification of a user perspective; weighting of perspectives; the difficulties encountered

and perceptions of the usefulness of user involvement could greatly facilitate the further development of such opportunities.

As with both maternity and gynaecological oncology services user involvement in examining services appeared patchy with few formal mechanisms reported for linking the outcomes of user involvement to service decision-making structures (Simpson & House 2002; Crawford et al 2003; Rose 2004). However, unlike the other two settings, reporting also tended to focus on the impact of user involvement on users rather than on the development of services (Simpson & House, 2002). In strategic planning, the concept of user involvement appears regularly in policy documents, but may be less meaningful in practice as although there were many active user groups, it appeared their influence was limited, with an emphasis on sharing information rather than partnership or user-led developments (Crawford et al, 2003). Furthermore, user involvement in strategic planning appeared limited to consultation with managers retaining decision-making powers (Crawford 2002; Crawford et al 2003; Rose 2004).

The review also found little to support an understanding of the gender dimensions of mental health. No studies were found that described women's involvement in services. Where involvement activity had addressed women's perspectives, this appeared to be as a function of the nature of the service under review rather than an explicit attempt to identify a gender perspective on services, their design and delivery (Yager et al 1989; Deeble & Bhat 1991; Newton et al 1993a; Newton et al 1993b; Rorty et al 1993; Griffiths et al 1998; Newton 2000). An analysis of the range of activity undertaken, and of the gaps in such, demonstrates the need to attend to the methodological issues and other factors that serve to marginalize women's voices.

The poor level of reporting in user involvement in mental health and the paucity of activity relating to women's perspectives is striking at a time when the political imperative to involve users could not be more pressing. Some of the impediments to involvement are common to all three settings and relate to issues of methodology, process and the integration of the user voice within policy and decision-making structures. Most importantly, though, while there has been a significant move towards more discursive forms of user involvement this has not necessarily been linked in any of the settings explored to mechanisms giving increased control over service delivery or policy processes (Simpson & House 2002; Crawford et al 2003; Rose 2004). However, the literature on user involvement in mental health services differed from the other two settings in that it appeared to demonstrate a greater concern with the process of user involvement and on the cultural and practical barriers encountered by both services and users (Hogg 1999a; Lindow 1999; Ryan & Bamber 2002; Knight 2003). As such, it appeared that this setting,

more than maternity or gynaecological oncology services, had begun to identify the

tensions and complexities associated with the implementation of the policy directive on

user involvement.

Chapter 7: Methodology

This study used a qualitative case study methodology and an inductive approach to research (Bryman 1989; Bowling 2002; Yin 2002). That is, it did not begin with a prior hypothesis or theory to be tested in the course of the analysis, but rather was based on a number of broad research questions from which it intended to generate an explanatory theory of the processes associated with user involvement in health and health services. It used several qualitative methods in order to explore and build an explanatory account of women's participation in the decision-making processes of some of the health services they use. As such, it proceeded from an interpretive stance drawing on a social constructionist perspective of reality rather than a search for social facts (Kennedy, 1999). By seeking to explore the philosophy and nature of existing user involvement mechanisms, with particular reference to their capacity to involve women in shaping the policy and decision-making structures of health, the emphasis was on the perception of the interviewees and their interpretation of events.

Social research is generally identified as having two contrasting approaches; positivistic and interpretive. Although there arguably exists a range of positions between the two, the approach adopted by the researcher will have a major impact on the aims, methods and outcomes of their research. A positivistic approach, based on the theories of Comte, Durkhein, Popper and Parsons among others, proposes that society can be measured objectively. It argues that the methods for analysis used in the natural sciences can be appropriated to social science and applied in the search for 'reality' or a set of 'social facts' that are objectively identified (Kennedy, 1999).

In contrast, the interpretive tradition of theorists such as Weber, Goffman and Garfinkel seeks understanding, meaning and the significance of the social world to the people who live in it, rather than explanations or predictions. In this approach the emphasis is on social constructs (Kennedy, 1999). Adherence to one or the other tradition will determine the research methods chosen. Adoption of a positivistic approach would imply the use of a hypothetical deductive model, whereby a hypothesis is logically deduced from a general theory and then tested through empirical research. An interpretive approach would, however, suggest theory development through induction, which is the creation of theory from a series of observations. This tradition, commonly associated with qualitative research, emphasises the depth of understanding achieved. While positivists are likely to use quantitative, survey or experimental methods, those from an interpretive approach will be associated with qualitative methods such as unstructured interviews and observation.

An inductive approach was proposed as best suited to the exploratory nature of this study as there was very little by way of existing studies or theories to draw on that could provide a basis for a comparative or theory testing analysis. The emphasis on 'theory generation' however, does not mean that this approach is theory free. In adopting an interpretive stance it may be argued that a theoretical decision has been made in seeing the purpose of the research as being to explore 'social constructs' rather than to search for 'social facts'.

Evidence, however, does not speak for itself and must be interpreted for quality and likelihood of error. Interpretation is never completely independent of a researcher's beliefs, preconceptions or theoretical commitments and is subject to a number of common interpretive biases. However, far from being problematic, the interpretive process is a necessary aspect of science and often represents an ignored, subjective and human component of rigorous medical enquiry (Kaptchuk, 2003). The influence of bias and the steps taken to manage this are discussed later in this chapter. First, the qualitative methodology used in the study will be discussed in greater detail.

Qualitative Research

The emphasis in qualitative research is on 'the perspective of those being studied rather than the prior concerns of the researcher along with the related emphasis on interpreting observations in accordance with the subjects' own understandings' (Bryman, 1989). Bryman (1989) has identified six distinctive features of qualitative research which suggest that it does represent the appropriate methodology for this study. These are the delineation of context; the emphasis on process and the unfolding of events over time; flexibility and lack of structure; viewing of phenomena as socially constructed; the need to retain close proximity to the phenomena being studied and the identification of primary data sources through observation and interviews.

Of particular concern to this study was the analysis of process. How and why had user involvement developed; how, why and whether this influenced health policy and practice and how and why, or indeed why not, was user involvement important in each of the three identified settings. Qualitative analysis, through its concern with context and the common use of multiple methods such as observation and interviews, enabled such an analysis of process. Quantitative methods appeared to be less well suited to the exploratory nature of the study, as they demand a prior decision on a hypothesis and the vigorous construction of a framework within which the research is to be conducted. This would arguably have determined the scope of the analysis at the outset of the study, rather than being open to the possibility of new ideas emerging.

This was a descriptive study that employed a range of qualitative methodologies in order to examine one aspect of service delivery and its implications for practice and policy development. One particular methodology, a case study approach, was adopted to explore three distinctive health service settings.

A Case Study Approach

Yin (2002) proposes that a case study should be defined as an empirical inquiry that investigates a phenomenon within its real-life context. It involves a process of moving from description to understanding the setting through exploration in data collection to the development of an exploratory account. Case study research, which can include quantitative evidence, relies on multiple sources of evidence and is proposed as the preferred research strategy when 'how' or 'why' questions are asked and when the researcher has little control over events (Yin, 2002). The strengths of a case study approach are in the depth and colour gained from the analysis of social processes. According to Hartley (1994) case study research involves:

> '…a detailed investigation, often with data collected over a period of time, of one or more organisations or groups within organisations, with a view to providing an analysis of the context and process involved in the phenomenon under study. The plan is not isolated from its context … but is of interest precisely for its relation to its context' (Hartley, 1994)

Case study research appeared appropriate for this study as there was a strong accent on the context surrounding the three settings being examined; inferences could be made about process and there was an emphasis on theory generation through an in-depth analysis of the settings. A case study approach is similar to other qualitative methods in that it is an extended process of generating, gathering and analysing data. This prolonged process was proposed as beneficial to this study as it facilitated an analysis of the three cases where the primary concern was with the development of an understanding of the processes associated with each. It was also considered that comparison of the three settings would give a degree of clarity as to those aspects that were particular to each case and those more common to a variety of contexts.

Furthermore, a case study approach was proposed as having the benefit of increasing the trustworthiness of the data collected through the utilisation of multiple methods to gain information from different sources. In this instance the multiple methods were interviews, observation and document review. The use of multiple data sources benefits research by increasing construct trustworthiness (Hartley 1994; Bowling 2002). Writers such as Hartley (1994) and Bowling (2002) propose the use of a combination of methods, partly because complex phenomena are best approached through several methods and partly

deliberately to triangulate and thereby improve trustworthiness. The issue of trustworthiness is considered later in this chapter but first the case study settings chosen and the criteria used in this selection are described.

Selection of the Case Study Settings

The case study settings were chosen against a number of criteria. The first, and of particular importance to this study, was that settings should have women as users. Chapter two highlighted the need for an inclusive approach to user involvement and the requirement for NHS agencies to ensure that the needs of users from marginalized groups are addressed (Scottish Executive, 2001). This study sought to explore women's participation, as they are one group that has been suggested as marginalized in relation to user involvement (Gijsbers van Wijk et al 1996; Willson & Howard 2000; Donner 2003). As discussed in the introduction to this study, there is evidence to suggest that although women are more likely to be users of the NHS, paradoxically they are less likely to be influential in decision-making in health care systems and policy processes (Papanek 1990; United Nations 1994; Janzen 1999; Horne et al 1999; Scholle et al 2000; Willson & Howard 2000; Donner 2003). This assertion was significant in the choice of women as a group of health users for particular examination within this study. The need to identify settings that included women as users ruled out some sub-specialities such as prostate and testicular cancer.

Second, in order to facilitate a comparison of processes, settings needed to be currently active in user involvement. This meant that only settings that had some level of user involvement activity could be considered. The criteria were very broad in this respect with all types of involvement included, whether that was involving users in their own care and treatment, participation in examining and improving the quality of services or having a role in strategic policy and planning.

Finally, the settings needed to operate under different conditions in order to generate contrast and comparison. The conditions against which settings were compared were the nature of the illness or condition treated; the focus and outcomes of treatment; the qualifications and role of staff; user prognosis and the expectations of user involvement. The settings chosen were proposed as being sufficiently different in respect of these conditions so as to engender contrast. Using these criteria the chosen settings were maternity, gynaecological oncology and mental health services. Each setting was familiar to the researcher, not only in terms of their structure and operations but also some of the staff and user representatives involved. The potential for this to introduce bias into the study is discussed later.

Each setting met the criteria identified. First, each had women users. In the cases of maternity and gynaecological oncology services, users are exclusively female while in mental health users could be male or female. Second, each setting was active in developing and maintaining processes for involving users in their services and two had a substantial history of user involvement. Maternity services had a long history of women's groups campaigning for change in services that had resulted in an on-going collaboration between professionals and women; at the beginning of the study gynaecological cancer services were actively involving patients in a Service Re-design Programme managed by the Scottish Executive's Centre for Change and Innovation and, as a result, had begun to develop on-going user involvement processes. Mental health services also had a history of user movements and, at the time of this study, had a wide range of initiatives operating across the city that were designed to increase the scope of user involvement in both local and city-wide services.

Finally, each setting operated under different conditions. Maternity services work with women who generally welcome the condition of being pregnant; this is a time-limited condition that may or may not recur. Such recurrence is usually viewed as positive and not as a relapse or the re-occurrence of ill health. The prevailing philosophy within maternity services is that users are not ill and, in general, expect to have a relationship with their health professionals that, unless there is a crisis, is characterised by partnership (Pope et al 2001; Royal College of Midwives 2001). Gynaecological oncology on the other hand works with women who have a serious illness and may, as a result, experience a debilitating burden of ill health. In addition to the physical effects of the illness and the distress that is common to a diagnosis of cancer at any site, gynaecological cancer can precipitate a range of emotional and relationship problems. Management requires a holistic programme of care that includes a range of health professionals such as medical and nursing staff, dieticians, physiotherapists, psychological services and, in the case of women with advanced disease, palliative care (Gamel et al 2000; Stead et al 2001; Cancer Research UK 2007).

Mental health services are different again in that they are characterised by the wide of range of individuals, levels of ill health and types of treatment and support they offer with some individuals requiring treatment in acute in-patient wards, while others are managed in the community (Corry et al, 2004). Furthermore, unlike users of maternity and cancer services, people who have acquired a psychiatric history often experience discriminatory behaviour. As discussed in chapter six, while there may also be a level of stigma associated with an illness such as cancer, it is argued that the term 'mental illness' often carries emotive and negative connotations leading to a disproportionate level of stigma or

discrimination. Such discrimination extends the range of responses from mental health services; from merely addressing medical needs to include focusing on prejudice and addressing socially created barriers (Oliver, 1998). Mental health also differs from other health specialities in that it has a unique element of containment and compulsion in treatment (Perkins & Repper 1998; Rankin 2005).

Thus, these three settings were selected on the basis that they met the criteria set for the study and that they would allow for a meaningful comparison of sites and input variables. Furthermore, in order to investigate the scope of views within each setting a number of different perspectives were explored. Four groups of respondents were identified as representing diverse positions on user involvement. These groups were managers, clinicians, users and strategists. Each had an interest in the issues under examination, but held different roles in relation to the development and implementation of the policy. Interviews were conducted with those key stakeholders in the national, strategic planning and development of user involvement in order to identify the aims and philosophy outlined for the policy and the established or developing links between the evolving policy and local health service responses. The groups of managers and clinicians came from local services and were more closely concerned with the practical implementation of the policy and, along with user representatives, were active participants in the current conceptualisation and functioning of user involvement.

It was anticipated that these three settings and four perspectives would facilitate the case study methodology of comparison to reveal those aspects that were particular to each case and those more common to a variety of contexts. These four perspectives will be described in the discussion of the sampling strategy for the study. The next section will discuss the ethical considerations of the study.

Ethics

Ethics approval was sought through the formal Research & Development mechanisms of NHS Greater Glasgow and Clyde. The project was reviewed by the Chair of the Research Ethics Committee, North Glasgow University Hospitals NHS Trust and was registered as a non-commercial project on the National Research Register by them. The Chair was satisfied that a formal ethics review was not required as there were no ethical issues involved in the study. His decision that there was no need to proceed to a formal review was based on three factors. The first was that the participants in the study were judged to be staff rather than individuals or patients. In making this judgement it was determined that all participants would either be employees of the NHS or user representatives drawn from voluntary organisations, user groups and charities. Therefore, all would have access

to formal sources of support and supervision that could assist them in deciding whether or not to contribute to the study, in managing their interaction with the researcher and in reviewing and reflecting on their participation. The second factor was that there were no issues of intellectual property attached to the study, and the third was that there were no resource implications for the NHS. A copy of the letter received from the Research Ethics Committee is attached in appendix 1.

Three further ethical matters were identified by the researcher as requiring attention in the conduct of the study and each of these, and the steps proposed to manage them, was discussed in the application for ethics approval. These ethical matters were risk, informed consent and confidentiality. The management of these is discussed below.

The first ethical issue considered was the issue of risk. There were no anticipated risks involved in the study as the participants were either health professionals or users who were also user representatives and therefore familiar, in some measure, with reflecting on and discussing their role and responsibilities within user involvement. However, additional care was taken when contacting user representatives to ensure that they understood fully the purpose and conduct of the interviews and that they felt confident about participation. A debrief was also offered to all participants following the interviews to ensure that there were no contentious or distressing issues raised that would cause difficulties for them.

The second issue was that of participant information and consent. A number of measures were put in place to ensure that participants were fully acquainted with the aims of the study and the requirements of participation and thus, able to give informed consent. Interviewees were initially approached by letter to request participation. A copy of this letter is attached in appendix 2. The letter explained the aims and methodology of the study, the risks involved, benefits of participation and gave the potential interviewees the necessary background information to assist them in making a decision as to participation. Interviewees then contacted the researcher to confirm participation and, in some cases, to request further information. Only one refusal was received. This was from a subject who was shortly going on maternity leave and so felt she did not have time to take part in an interview. Written permission was gained from all interviewees before progressing.

The third ethical issue that needed to be considered was that of confidentiality. It was important to be able to reassure participants that their contributions to the study would be treated as confidential. This would ensure that individuals felt free to speak openly and to raise issues or difficulties that may have been critical of, or contentious within, their organisation. In order to protect confidentiality all interview transcripts were anonymised and each participant referred to throughout the transcripts, and in any other correspondence

or paper work, by an allocated code. The researcher alone held the key to the coding system. Where, in the analysis, quotes or excerpts are taken from the interview transcripts these are identified only by the participant's code. The researcher ensured that the coding key and all the original tapes of the interviews were kept secure.

Only one other person had access to the original tapes of the interviews and that was the typist who transcribed them. This typist was experienced in providing administrative support to research projects and had worked on a number of PhD studies. She did, then, have both a knowledge and understanding of the issue of confidentiality and of its central importance to research of this nature. Discussions were held with her prior to her appointment and assurances received on her ability to manage the quantity and confidentiality of the data she would be transcribing.

The next section will describe how individuals who were able to discuss the processes and outcomes of user involvement in each of the settings under examination were identified and how a representative sample was constructed.

Sample and Sampling Strategy

The sampling strategy for the research was based on a combination of two approaches. These were non-random purposive sampling and snowballing. A non-random purposive strategy was applied initially and augmented by a snowballing strategy.

A non-random purposive sampling strategy is defined by judgement. Participants are selected according to criteria established by the researcher. These criteria are chosen for their potential to identify those who can make a contribution to the aims of the study, such as those whose status or previous experience endows them with special knowledge (Burgess, 1984). The researcher identified eight stakeholders in user involvement for initial interviews. These were selected on the basis of their pre-existing participation in and contribution to the mechanisms for user involvement, either nationally or within local service settings. In all cases the interview subjects were actively involved in user involvement, some in the development of involvement mechanisms, others in detailed implementation. These eight consisted of two stakeholders from each of the three service settings, maternity, gynaecological oncology and mental health that had been selected for the study. A further two interviewees were selected for their knowledge of, and responsibility for, the development of the policy framework of user involvement and hence, had a more strategic overview. Of the initial eight interviewees two were strategists, two were clinicians, two managers and two were user representatives. The researcher knew all but one of these interviewees through previous joint work on service re-design, research or project work.

The initial eight interviewees were straightforwardly identified as they were known to the researcher, pre-eminent within their settings and each had an acknowledged role in the development and implementation of the policy. As such, they were quickly and easily chosen, but it was recognised that they represented a select group who had a considerable degree of experience in the development, application and implementation of the policy on user involvement. The parallel use of a snowball recruitment strategy was adopted in order to widen participation to include those who were less centrally involved in the introduction of the policy but who, nevertheless, played a strategic role or were active within their setting in the progress of user involvement.

The initial interviews served two purposes. First, they were used to explore the usefulness and appropriateness of the interview schedule. Second, they were used to trigger the snowball strategy as each interviewee was asked to identify further potential subjects that could make a contribution to the study. Snowballing refers to the process by which a small group of informants are asked to put the researcher in touch with their friends and contacts. These are subsequently contacted by the researcher with a view to them being included in the project (Burgess, 1984). The rationale for introducing a snowball strategy at this stage was to introduce new subjects by taking advantage of others' knowledge of the field. Whilst the researcher was familiar with the field of user involvement, it was recognised that this was a time of unprecedented development and that new appointments and additional resources were being developed at a rapid rate. Furthermore, owing to the ambiguity of the concept and diversity in definition these appointments and resources often had varying titles and descriptions, making it difficult to identify where new resources had been introduced. Thus, it was considered appropriate to utilise the knowledge of the eight subjects identified in the purposive sampling and the contacts and networks of the subsequent interviewees.

The snowball strategy was operationalised in two ways. Firstly, each interviewee was asked to identify further contacts for the study from their personal networks. This was initially achieved by asking for their contacts in user involvement and if they knew of other people who could make a contribution to the issues under consideration. However, this approach was soon judged to be generating a very narrow pool of contacts as many interviewees were nominating those with whom they had a shared experience of service re-design projects, working groups or user forums. Because of the small numbers of service re-design projects, working groups and user forums this resulted in participants repeatedly identifying a limited group whose experience was very similar to their own. Thus, the enquiry was amended to include greater specificity in the type and nature of the contact's

participation in the implementation and functioning of user involvement and to ask participants to also nominate others who had a different or specific experience.

This element of the snowball strategy was assisted by the second approach to operationalisation; the identification of key stakeholders within each setting and the use of their experience to facilitate the widening of the snowball strategy. Key stakeholders were identified as those individuals with a range of experience, who were significant members of local networks within user involvement. Discussions were held with these key stakeholders in order to map out the number and range of opportunities for user involvement within each setting. This assisted the researcher in applying the snowball strategy as, when participants were struggling to identify contacts, it was possible to prompt them to consider activities with which the researcher had become familiar during the mapping exercise. As an example, it was noted at an early stage that participants within the gynaecological oncology setting were only identifying contacts from one particular forum, the re-design of ovarian cancer services. This had been a significant project within gynaecological cancer services, but had involved a relatively small number of staff and users. The mapping exercise, however, had also identified other activities such as user involvement in a Clinical Standards Board review or in educational meetings and so participants could be prompted to also reflect on these in their consideration of contacts. From these two approaches it was anticipated that a broad range of experiences would be represented within the sample and that it would not be limited to the participant's most immediate or familiar networks.

These approaches illustrate the major disadvantage of a snowball strategy; that it includes only members of a specific network (Bowling, 2002). Thus, whilst the snowball strategy generated a large number of interviewees an element of judgement was retained in order to ensure that each setting, maternity, gynaecological oncology and mental health, and each perspective, strategist, clinical, managerial and user, was fully represented. Where a particular perspective or setting was under-represented or was not generating contacts using the snowball strategy then the judgement strategy was re-applied and efforts made to address this shortfall.

Using the snowball strategy a further twenty-seven interviews were held across all settings and perspectives. Sampling was concluded when data saturation was reached. Data saturation was judged to have been achieved when the interviews were no longer generating new material, additional ideas or fresh perspectives. The use of the snowball strategy to bring unfamiliar interviewees into the study was designed to facilitate the collection of a wide range of views and perspectives, but it was noted that within the sample of respondents there were few examples of the practical implementation of user

involvement reported and little experience was described in the process and mechanisms required for its effective functioning. A small number of examples were repeatedly discussed, similar barriers and facilitators were identified in each setting and by each group of respondents and, furthermore, there was a limited range of experience and practice evident in the responses of the interviewees. Many respondents attributed their lack of experience to the relative newness of the policy and the recent introduction of the formal range of assessed and measurable commitments for which they were now accountable. Thus, data saturation was achieved in the context of the efforts made to widen the sample of respondents and to include those from out with the researcher's familiar networks.

The final sample consisted of thirty-five participants. This comprised twelve subjects from gynaecological oncology services, ten from maternity services, ten from mental health services and three subjects with a strategic overview of the policy and implementation of user involvement. The sample represented four perspectives within health services. Ten were user representatives, twelve were managers, ten were clinicians and three were strategists. However, it was noted that the participants could not always be easily categorised into these distinct groups. Nearly a third of the user representatives had previously worked in the health service in a clinical capacity and two-thirds of managers also came from a clinical background. Furthermore, many health professionals, whether strategists, managers or clinicians, described their own use of health services and pointed to their role and experience as service users. This was not necessarily as users of their own services but, nevertheless, they recognised that they had a dual role; being both a health service professional and a health service user.

Thus, the final sample was judged to represent national and local observations on user involvement and the position of three distinct service settings. However, it was recognised that there was a degree of ambiguity in the perspectives of those groups that made up each service setting as there was considerable overlap between the sample groups of user representative, strategists, managers and clinicians.

Data Collection

Three methods were used to collect data for the study. These were interviews, field notes and a document review. Each is discussed below.

Interviews

The principal method of data collection was one-to-one interviews conducted with a range of stakeholders within each of the three service settings. These included the strategic, clinical, managerial and user perspectives selected using the sampling strategy outlined above. This is a method of data collection that attempts to 'generate data which give an

authentic insight into people's experiences'. According to Silverman (1997) interview subjects construct not just narratives but social worlds. As Charmaz (1995) observes:

> "We start with the experiencing person and try to share his or her subjective point of view. Our task is objective in the sense that we try to describe it with depth and detail. In doing so, we try to represent the person's view fairly and to portray it as consistent with his or her meanings" Charmaz (1995).

Thus, qualitative interviewing provides a means for exploring the points of view of research subjects while granting these points of view the culturally honoured status of 'reality'. While some research methods, such as surveys, can limit the responses that can be made, for example through the use of closed questions, the personal interview is a method of gathering information that permits the respondent to have considerable control over what is recorded. Semi-structured interviews were proposed as the most appropriate method for gathering respondents' knowledge, views, beliefs and understandings of user involvement processes, structures and outcomes. Semi-structured interviews ensure that all relevant questions are answered whilst retaining flexibility to allow new ideas and information to enter the research. As such they are both descriptive and exploratory (Bowling, 2002).

The interviews aimed to elicit understanding of the user involvement processes used within services, feedback on the perceived usefulness of mechanisms, their contribution to health and health services, the difficulties encountered and perceptions of the impact they have had on service delivery and policy planning issues. Finally, the mechanisms established to respond to the outcomes of user involvement were explored. As a first step, an interview schedule was developed based on an exploration of the dimensions of user involvement that had emerged from the literature review. These were:

- The extent and nature of user involvement
- The existing structures and mechanisms for involvement
- The perceived legitimacy and usefulness of user involvement
- Structures for accountability, monitoring and evaluation of user involvement
- The nature of user perspectives on each setting
- Barriers to effective participation and meaningful involvement

A topic guide was developed based on these issues with areas of interest grouped into a number of broad categories.

From this topic guide, interview schedules were developed for use with both respondents from health service settings and with strategists. Copies of the interview schedules for service settings and strategists are given in appendices 3 and 4. The development of an interview schedule with a defined set of questions assisted in the trustworthiness of the data collected by ensuring that the interaction between the interviewer and respondent was

limited to the research questions and not unduly influenced by the interests and agenda of the interviewer. However, rigid limiting of interaction between interviewer and respondent may result in frustration for the reader when an extensive study seems to yield rather obvious, albeit reliable, results (Daly et al, 1997). It is often noted by researchers that it is the "off the cuff" comments made by respondents that are of most value (Daly et al, 1997). In these respondents are able to amplify and explain rather than simply categorising their answers. The adoption of a semi-structured rather than a structured interview methodology in this study allowed for a balance between these competing interests by facilitating both a reliable set of data and richness in the information gathered.

The interview schedule was piloted with the initial eight interviewees and reviewed following the completion of their transcribed tapes. Following this review, a number of minor changes were made to the sequencing of the topics and, where there appeared to be ambiguity, greater clarity introduced into the questioning. One additional question was introduced. This was to ask interviewees to give a practical example of where they felt that user involvement had influenced their service. This question encouraged interviewees to describe the realities of practice within their setting rather than simply focusing on policy expectations which, it was noted during the pilot, some had a tendency to do. The question of a practical example also appeared to help participants settle into the interview and, in discussing their experience, encouraged them to discuss, unprompted, a wide range of issues in user involvement.

Conduct of the Interviews

Within the final sample there were a number of interviewees; strategists, managers, clinicians and users with whom the researcher was familiar and, as a result of the application of a snowball recruitment strategy, others who were unknown. However, an analysis of the field notes revealed that all interviews followed the same structure and format, each addressed the prepared interview schedule and that all were a comfortable and constructive encounter. Consideration was given to the conduct of the interviews in order to ensure that any differences between interviewees, arising from their familiarity with the researcher, position and status within their organisation or recognition within the field of user involvement, were minimised.

All interviews were conducted on a one-to-one basis in a venue chosen by the interviewee. All venues were a private, quiet and comfortable setting. Before beginning the interview the aims of the study were covered and the interviewees given the opportunity to ask questions and clarify any issues they may have had. Several points were covered in the pre-interview discussion including confidentiality, assurances on anonymity, advice on not answering questions that were difficult or that subjects did not wish to answer and a

reminder that interviewees could withdraw from the study at any time. However, no interviewee refused any question, none expressed any concerns regarding confidentiality and no one withdrew from the study.

The purpose of the pre-interview discussion was to provide information, establish rapport with the subject and to put them at their ease. An analysis of the field notes from the interviews revealed that about a third of the interviewees expressed feelings of nervousness or anxiety before the interview. This appeared to relate almost entirely to their concern that they would not be able to contribute usefully to the study. However, further examination showed that all became relaxed as the interview progressed. The pilot study assisted with this as it facilitated a sequence that began with questions that allowed for a straightforward description of current practice, thus allowing participants to ease into the interview.

Interviews lasted between 50 and 80 minutes. Despite the fears expressed by some that they may not have anything useful to contribute to the study, this proved not to be the case. Of the eight individuals who shared this concern, all but one were either nursing staff or user representatives, only one was a Consultant. All other interviewees, mainly medical staff and managers, were relaxed and confident about their participation.

However, while interviews were the major data source for this study there were additional data sources and these will be discussed in the next section.

Additional Data Sources

There were two additional data sources.   The first was field notes and the second was a document review.

Field Notes

Field notes were kept of observations and interviews. In these a record was kept of what was observed during interactions with settings and in interviews. Field notes recorded details of the environment as well as the unspoken aspects of the interviews such as mood, attitude, body language and non-verbal communication. Such aspects would not be recorded on the transcriptions of the tapes but were necessary to assist in the interpretation of the responses given by interviewees. A difficulty with field notes is that readers only have access to the notes in the form made by the researcher (Silverman, 2000) and consequently to the interpretation of events as determined by them. In order to help to systematise field notes, and thus their reliability, and to make 'deeper and more general sense of what is happening', Spradley (1979) suggests that observers keep a number of separate sets of notes. These could include short notes made at the time, expanded notes made as soon as possible after each field session and a fieldwork journal to record

problems and ideas that arise during each stage of fieldwork. In this study these three sets of field notes were made.

The first were short, contemporaneous notes of observations and interviews. These covered several areas including physical surroundings, mood of the subject, body language and non-verbal communication. The second set of field notes were made soon after the observation or interview and expanded upon the areas described in the contemporaneous notes. These expanded notes included the researcher's reflection on the overall tone and tenor of the interaction as well as highlighting what were considered to be significant or particularly insightful comments by the participants. These comments were transferred to the fieldwork journal as they suggested codes for the data analysis.

A third type of field note, the fieldwork journal, was kept as a record of the ideas and insights that arose throughout the fieldwork and of any problems. This journal was used to direct the sampling strategy and the interview schedule in that it suggested areas and issues that required further exploration. It was also used to assist with the development of the analysis as it began the process of identifying codes and of narrowing the focus of the data.

Document Review

The second additional data source was a document review. Documents provide a useful additional source of data, as they are independent of the researcher and relatively non-reactive. Other advantages include convenience and low cost, particularly in relation to a resource-intensive method such as one-to-one interviews (Bowling, 2002).

A search of policy, protocol and service guidelines for the three settings was conducted in order to gather background information. Publicly available documents were searched for using the NHS Greater Glasgow and Clyde website and the staff intranet. Other material was provided by interviewees who were asked to provide the researcher with copies of any documents they referred to or discussed within the one-to-one interviews. Once again, key stakeholders in each setting were approached to assist with the search for appropriate and relevant documents. Documents containing information on organisational structures, available resources, user representation, organisational expectations and links to policy and service development structures were investigated. This assisted in identifying and quantifying the understanding and functioning of user involvement.

The document review searched for dedicated policies that would give direction to the policy, protocols on the recruitment and selection of user representatives and detailed guidance on mechanisms to support the participation of individuals and user organisations in NHS meetings and forums. Examples of documents identified by this review included a mental health service policy on Patient Focus Public Involvement in which the aims and

principles of user involvement were outlined; a newsletter from the re-design of ovarian cancer services project that described the progress of the project and a review of the implementation of MatNet, a user involvement mechanism for maternity services. The documents were read through, relevant passages highlighted and notes made. These notes were then transferred to the field work journal where they were used to assist with the development of the analysis and the process of identifying codes. However, there were relatively few documents available to the researcher and, as such, the document review served mainly to confirm the findings on the paucity of guidance on the functioning of user involvement and the lack of detailed attention within services to the process of implementation. With the exception of a strategic policy outlining the overarching aims and principles of user involvement in mental health services, dedicated and detailed policies, guidelines and protocols were absent. A list of the documents used in this review is given in appendix 5.

In this study documents were not the sole data source but rather were used alongside interviews and field notes, against which they could be compared and assessed for subjectivity. Thus, statements made in interviews could be checked against policy documents; data found in a Performance Assessment Framework could be considered against that in the minutes of meetings; information drawn from interviews was compared with data provided by the field notes. In this way the data was triangulated. Triangulation refers to the attempt to get a 'true fix' on a situation by combining different ways of looking at it or different findings (Silverman, 1997).

This study sought to generate an explanatory theory of the processes associated with user involvement in the shaping of health and health services and, as such, there was an emphasis on the interpretation of understanding, meaning and significance. Thus, it was important to triangulate the data in order to reduce the risk of it being used in such a way as to support the researcher's understanding or contention. Of course, within qualitative research many models are incompatible with the notion of a 'true fix' on reality that can be achieved independently of the methods of looking at it. Triangulation cannot settle the trustworthiness of qualitative data but, whilst each data source will be subject to a certain level of bias, the level of uncertainty surrounding it will be reduced once the proposition can be confirmed by more than one independent data measurement process (Bowling, 2002). Triangulation of data thus reduces the level of uncertainty surrounding the findings. The issue of trustworthiness is examined in greater depth below.

Trustworthiness

Trustworthiness, which is also known as validity, concerns the interpretation of the data collected. It is defined as follows:

> "By validity, I mean truth: interpreted as the extent to which an account accurately represents the social phenomena to which it refers" (Hammersley, 1990)

Trustworthiness is an important consideration in qualitative research with its emphasis on the depth of understanding achieved and creation of theory from a series of observations. Within an interpretive approach that seeks understanding, meaning and the significance of the social world to the people who live in it rather than explanations or predictions, researchers must be concerned with the quality of their interpretations and trustworthiness of their conclusions (Silverman, 1997).

There were a number of steps taken to address trustworthiness within this study. These were checking for researcher effects and triangulation. Triangulation of the data was discussed above, while the following steps were taken to ensure that the researcher minimised her influence on the data gathered by personal interview. First, a semi-structured question structure was adopted. This ensured that a core set of data was reliably collected whilst also allowing for additional issues to be explored depending on the interests and knowledge of the respondents. Adherence to the interview schedule minimised the possibility of the researcher imposing her agenda on the interview or being unduly swayed by the interests of the respondents (Bowling, 2002). Second, the research supervisor provided regular feedback. This was designed to ensure that the interview technique used was appropriate and that the schedule was being adhered to. This feedback also helped to identify the emerging themes from the material collected.

The researcher's familiarity with, and prior knowledge of, many of the interviewees however, did appear to have an effect during some interactions. The field notes recorded a number of occasions when verbal and non-verbal communication appeared to conflict. For example, a subject would be recorded on the tape confirming that their setting had a user group and stating that this was a useful body to consult with. However, body language such as raised eyebrows, rolled eyes or grimaces suggested that the group was, or had been, problematic. In such cases the researcher's knowledge of the interviewee had a positive effect in that the non-verbal communication referred to a shared knowledge and understanding and so may not have been shown to a researcher that did not have such a shared background. This shared knowledge meant the researcher often understood where there had been difficulties or why the interviewee was not willing to articulate these. Additional questions could then be asked to draw out the information that was being

alluded to, but not articulated. An additional positive effect of the familiarity with the researcher was that many subjects had confidence in the assurances of confidentiality as past experience had demonstrated that these would be met.

However, one researcher effect with a less helpful outcome, which was also recorded in the field notes, was the tendency for some interviewees to present their experience or opinions in a form of shorthand as they assumed that the researcher was already familiar with them. On a number of occasions it was noted that they would state, "well, you know all about that…" or "it was the same as (name of project) that we worked on". Rather than describing their experience, ideas or understanding they would assume a shared experience, idea or understanding and thus, not find it necessary to articulate it fully. In such cases the researcher had to ensure that a follow-up question was asked that allowed for a fuller description and articulation.

The systematic and comprehensive collection of field notes assisted in managing these researcher effects as they helped to draw attention to what was happening and to monitor their impact. Regular supervision was also instrumental in checking for such an effect and in ensuring its minimisation.

Thus, it can be seen that these potential threats to the trustworthiness of the investigation were managed. However, there are many such threats, the most significant of which has been described as the issue of bias (Bowling, 2002). It is bias that will be considered next.

Sources of Bias

The advantage of in-depth interviews is that they have the potential to deliver a wealth of rich information that enables a detailed understanding of what people believe and why they believe as they do. However, they are costly in terms of time and as we have seen have disadvantages in relation to trustworthiness and generalisability. One further disadvantage is the risk of bias. Bias is defined as "a systematic error due to interviewers' subconscious or conscious gathering of selective data" (Last, 1995). Such bias and errors in conceptualisation can lead to systematic deviations from the true value (Last, 1995). Many sources of bias can affect social research but the principal types that affected this study were interviewer bias, response bias, sampling and selection bias and recall bias. These are discussed below.

Interviewer bias occurs when interviewers subconsciously or consciously bias respondents to answer in a certain way. This can be by appearing to hold certain values or by asking leading questions (Bowling, 2002). As previously described, regular feedback from the research supervisor was obtained in an effort to monitor and eliminate interviewer bias. Review by the research supervisor of a sample of the interview transcripts ensured that

leading questions or interviewer imposed values were identified and eliminated from subsequent interviews.

The characteristics of the interviewer can also be biasing. The results of studies on interviewer bias are often inconsistent but Cosper (1972), in a study of attitudes to alcohol, reported that more business-like interviewers were less likely to identify drinkers than interviewers who were 'friendly' and tried to gain the respondents trust. Similarly, young interviewers were found to obtain less reliable results than older interviewers and males to obtain less full responses when interviewing females than female interviewers (Webb et al, 1966). While gender may have been an issue with some respondents in this study, it is proposed that the characteristics of the interviewer did not introduce a significant element of bias into the study. All respondents were involved in the area of user involvement as was the interviewer. This introduced a similarity in interest and values that would militate against this particular source of bias or barriers between the interviewer and interviewee.

However, the familiarity with many of the respondents and the shared history that some had with the interviewer through membership of groups and committees, joint work or previous involvement in health research may have introduced a response bias. Response bias refers to the respondents' manner of responding to questions and is often referred to as 'yes saying'. Respondents desire to agree with or please the interviewer may lead to them altering their responses to give what they perceive to be the required response rather than their true reaction (Bowling, 2002). The possibility of this form of bias was reinforced by the researcher's known commitment to the principles of user involvement. Many respondents were aware of the interviewer's values and attitudes and may have amended their answers to reflect this. One indication of the possibility of response bias was the expression of some interviewees to 'help' with the study. As the researcher's views were largely known, there was a danger that subjects could interpret 'helpful' to mean 'in agreement with the researcher'. Once again, regular supervision was essential in monitoring the possibility of such bias and in ensuring that the interview style and schedule minimised this risk.

A further source of bias, sampling and selection bias is possible unless the sampling method ensures that all members of the population of interest have a calculable chance of being selected in the sample. If not, the resulting bias results in a sample that is not representative of the population of interest. If the characteristics of the sample differ from those of the population of interest then a selection bias has occurred (Bowling, 2002). While a case study approach is concerned with depth and colour gained from the analysis of social processes rather than the ability to reliably apply the analysis to other contexts or settings, it was considered important to ensure that the sampling strategy did not exclude

any individuals or viewpoints that may contribute to the study, especially if these perspectives had the potential to be different from those included.

The sampling strategy employed in this study was a combination of judgement and snowballing. Bias may be introduced by a snowballing strategy, as respondents may be more likely to identify and nominate further respondents that share their values, knowledge and experience and are thus, within their existing networks. It may be less likely that they will identify those whose attitudes and values differ from their own and who are outside of their personal networks. However, the parallel use of a judgement strategy reduced this risk by ensuring that the researcher, with assistance from the research supervisor, could introduce additional subjects whose characteristics ensured that the sample was more representative of the population of interest.

The final possible source of bias considered was recall bias. This relates to respondents' selective memories in recalling past events, experiences and behaviour (Bowling, 2002). While this may have been a source of bias, it is proposed that these possible effects were ameliorated by the relatively recent nature of the events under discussion. However, it was noted that many respondents struggled to answer a question that asked them to give an example of the impact of the policy on user involvement on practice. Many expressed a difficulty in remembering an example, although other results suggested that the actual difficulty could have been in identifying such an example.

Once the data sources were identified, trustworthiness and bias properly managed and information collection complete, the final concern of the methodology was to appropriately record and analyse the data. This issue is discussed below.

Data Analysis and Reporting

In qualitative studies data comes in the form of words, not numbers or figures. Data collected in this study included the transcribed interviews, contemporaneous and reflective field notes taken by the researcher and background and policy information gathered by the document review. As with all qualitative data, the challenge was to interpret, and thus ascribe meaning to, this raw data. As Coffey and Atkinson (1996) state:

> "This is an important stage in the analysis of the data. The move from coding to interpretation is a crucial one…Interpretation involves the transcendence of 'factual' data and cautious analysis of what is to be made of them" (Coffey & Atkinson, 1996)

The first stage of the data analysis was to ensure that the raw data was comprehensively recorded. All interviews were tape recorded and transcribed. Recording and transcription ensured the collection of both the responses to the semi-structured question schedule and verbatim off-the-cuff comments that gave additional information or amplified the findings.

In order to ensure accuracy participants were consulted on the process and opportunities provided for them to comment on the data and to check the transcripts of interviews. No factual errors were found in the data and there were no requests for amendments or amplifications.

The next stage was to analyse the transcripts using qualitative methodology and interpretative processes. In order to begin the process of narrowing the focus of the data it was first organised into themes and subsequently into initial categories that were identified from the literature review and refined using the entries in the fieldwork journal. Other categories emerged from reading the respondents' accounts and from discussions with the research supervisor. Eight themes and twenty-four categories were initially described. These eight themes were as follows:

- the philosophy and nature of user involvement
- the capacity for involvement
- facilitators of user involvement
- barriers to user involvement
- gender issues
- representation
- the impact of user involvement
- the development of user involvement

The twenty-four categories further refined these themes. The next stage was to code the data. Coding means relating sections of the data to the categories that the researcher has previously developed, or is developing on an on-going basis as the data are being collected (Bowling, 2002). As this study used an inductive approach and was exploratory in nature there was very little by way of existing studies or theories to draw on that could provide a basis for a comparative or theory testing analysis. Its interpretive approach suggested theory development through induction; that is the creation of theory from a series of observations. According to Fielding (1993), if the aim of the research is to describe the data in order to generate theory then the categories can be developed from the data. This is known as coding up.

To take one example of the general process, the first theme, the philosophy and nature of user involvement, was broken into three categories from which thirty-four codes were subsequently developed. The first category was the rationale for the development of user involvement within the setting e.g. to centre services on patients, the continuation of a historical model of practice, to comply with NHS policy. The second was the methods of user involvement used in the setting e.g. surveys, complaints procedure, service/patient forums and the third category was the uses described for user involvement within the setting e.g. to communicate plans for service change, to enhance care, to consult on service developments.

The detailed codes were developed from the initial twenty-four categories whilst reading the transcripts, through on-going reflection on the interviews and comprehensive discussions with the research supervisor. A coding framework was then described that linked these codes together typologically in the twenty-four categories. This coding framework was then tested on a small number of transcripts. Following this testing the coding framework was revised. A number of new categories and codes were identified while others were integrated or collapsed to form groupings that more appropriately described the data. The final coding framework comprised eight themes, twenty-four categories and two hundred and fourteen codes. The coding framework of themes, categories and an example of codes is given in appendix 6.

The final codes were applied to the transcripts using the ATLAS-ti computer package. All the recorded material was coded and analysed in this way. ATLAS-ti was found to be a particularly valuable tool for theory building as it had the facility to code text into different categories and to link between these codes as well as to memos and notes made by the researcher. However, it is merely a tool for organising, storing and retrieving qualitative data and as such was only one aspect of the data analysis. Other aspects such as the development of the coding framework were manually undertaken in order to ensure a high level of working familiarity with the data under consideration.

The following chapters will present the findings of the study drawn from this analysis of the data.

Summary

This chapter has outlined the research design, the process of carrying out this study and some of the practical and ethical considerations affecting the decisions taken at each stage. Some of the issues highlighted in the chapter, such as the limitations in the sampling strategy and the possibility of bias in the sample, have implications for the findings and will be returned to in chapter eleven. The findings chapters that follow outline the views of participants towards user involvement. The next chapter describes their views on the extent and nature of user involvement within the context of the three health service settings under examination. To remind the reader these are gynaecological oncology, maternity and mental health services.

Chapter 8: User Involvement in Health and Health Services in Glasgow

The following three chapters will consider the findings of this study of user involvement in health and health services. These chapters seek to build an account of the extent to which women users within maternity, gynaecological oncology and mental health services have been involved in determining their health care and in shaping the health service to their definition of needs. Furthermore, the chapters will draw conclusions leading towards the development of a model for future, systematic user involvement that has the capacity to inform decision-making about individual care as well as policy and service developments. The three chapters are organised as follows; chapter eight describes how user involvement has been understood and implemented in mental health, gynaecological oncology and maternity services in Glasgow; chapter nine discusses the character of user representation while chapter ten explores the barriers and facilitators identified as influencing the implementation of user involvement as well as proposing the lessons for a model of future engagement with the users of health services.

The first of these chapters, chapter eight, will report on managers, clinicians, strategists and users' views of the nature of the existing user involvement mechanisms within maternity, gynaecological oncology and mental health services. This chapter will make particular reference to the capacity of these mechanisms to involve users in making decisions about individual care and treatment, in examining and improving the quality of health services and in health service policy and planning processes. Three factors were identified as important to developing an understanding of the implementation of user involvement. These were the organisation of and structures for user involvement, the techniques used to provide opportunities for both individuals and user groups to participate in user involvement activity and the user agenda in treatment, service and policy processes.

The first part of this chapter will describe the findings on each of these factors in the three settings under review. Secondly, the influence of these factors on the extent and nature of user involvement in each of the three 'types' of user involvement will be discussed. A particular aspect of this analysis will be an examination of how the issues identified as important to users have been progressed within service delivery and policy planning arrangements. In doing so, this analysis will begin to explore the influence of the user perspective within a medical service structure where a clinical elite has traditionally dominated policy direction and service decision-making. Finally, this chapter will draw conclusions for the perceived influence of the user perspective in health services.

The Organisation and Structure of User Involvement in Glasgow

The first factor examined was the organisational response that mental health, maternity and gynaecological oncology services had made to the policy imperative on user involvement. Manager, clinical and user respondents from all three settings were clear that they were aware of the policy and all reported on efforts to implement it. All welcomed user involvement, describing it as integral to the culture of their organisation and consistent with their philosophy of patient-centred services. Health professionals (managers and clinicians) reported that user involvement ensured services were sensitive, inclusive and responsive to user needs and furthermore, that it helped to guide and validate the development of policy and service delivery.

> "…when I go back to the patient who is the hub of all of this, whether it is maternity services, or cancer services and it is about are we providing the right care" M1P

Mental health services appeared to have responded to this vision most thoroughly as their organisational response was more systematic and developed than that of either gynaecological oncology or maternity services. Managers, clinicians and users described an elaborate structure that had organisation-wide systems to guide and support the development of user involvement. It was reported that the Mental Health Division, which was responsible for mental health services in the city, had introduced a number of structures with dedicated policies, staff and resources for user involvement. At the apex of this structure a divisional Patient Focus Public Involvement (PFPI) group gave direction to and oversaw the implementation of the user involvement policy. This PFPI group included membership from senior management and was replicated at local level, each sector having an identified lead officer in PFPI. The Division funded the Mental Health Network, a user organisation, to provide a reliable user perspective on service and strategic planning groups while a grants scheme supported a number of smaller user involvement initiatives such as service evaluations and the production of patient information.

User involvement was reported as integral to both routine services and major re-developments of buildings and services. Within routine services each community-based service within the Division, for example local Resource Centres, had both a user and a carer's group that provided a joint forum for staff and users. Wards held community meetings to which all residents were invited and resource centres had similar groups, although it was reported that these varied in robustness across the city. An information leaflet on user involvement was available on all wards to educate users and facilitate their involvement in these and other meetings. Managers reported that they valued the issues identified by users in care plans and ward or community meetings and that these made an

essential contribution to the mechanisms for quality assurance. They described how the feedback from users was reviewed and acted upon, thus drawing upon the users experience to monitor adherence to clinical standards and guidelines.

> "… that is what the PFPI agenda is all about, it is about service improvement…
> to find out patients'… experiences and respond" M4H

> "…it is about actually making it part of something as opposed to sitting out
> there…we don't just consult when we are making a change, patient focus and
> public involvement should be an integral part of everything we are doing,"
> M8H

Thus, respondents from mental health services described a highly organised, integrated approach to user involvement, albeit one that was recognised by all groups of respondents as requiring further development. This approach was consistent with the philosophy expressed in policy documents and articulated in interviews with strategic planners in user involvement.

> "…it's really embedding the principle that this an ongoing process of dialogue
> and not just engaging when there is a big issue like closure of a hospital" S2

One factor that health professionals in mental health services proposed as influential in the development of user involvement was their history of partnership with users. In both maternity and mental health services all groups of respondents reported pride in their history of user involvement and proposed that this had given them an advantage in its further development in their settings. User representatives in maternity services reported that it had taken many years to reach the expectation that women would be involved in both their care and in shaping services, while health professionals in mental health also described how their partnership with users had benefited from many years of collaboration.

> "I have been involved in campaigning for many years… for woman to
> contribute to these sorts of things and that has happened over quite a number of
> years" U3P

> "…because we have been at it for this length of time and we have had user
> involvement since the beginning as we have grown and matured, they have
> grown and matured and our inter-relationship has grown and matured" C10H

Health professionals in maternity services thought that their history had resulted in an openness and commitment to user involvement. They felt that this gave them an enhanced understanding of the value of user involvement and a greater capacity than some sectors of the health service to adopt and proactively implement this policy.

> "I think that in maternity services we are just fortunate that a lot of user
> involvement work has been done, therefore there is a voice that maybe is not
> there and there is a body of evidence that probably isn't there for other acute
> services" M10P

However, in contrast to their reported understanding of and ability to realise the policy, these respondents could not give many examples to indicate that the maternity services had made progress in establishing user involvement, as described by policy documents. Indeed, the approach to user involvement described by respondents in maternity services was strikingly similar to that taken by the gynaecological oncology services, despite this being a relatively new concept in the cancer setting. There were no reports of dedicated policies, staff or resources to support the development of user involvement in either setting and, in comparison to mental health services, the approach taken in both appeared embryonic with little evidence of organisation or structure. Only two structures were described; these were MatNet, a network of user groups that provided user representation on the structure for local maternity service planning, the Maternity Services Liaison Committee (MSLC) and patient forums on the Managed Clinical Networks (MCNs) that oversaw planning for local cancer services. However, it was suggested that there were difficulties in securing reliable representation on both these structures and that as a result of shortfalls in funding for user involvement neither had yet met its full potential for user influence in service delivery and policy processes. In addition, respondents reported that these structures were not well integrated with other decision-making processes and, as a result, user involvement was often viewed as an adjunct to routine services. Some health professionals seemed aware of the limitations of such an approach to user involvement.

> "I think it is very informal, maybe that in itself is ok but I don't think we are
> very good formalising it and letting women know that there is a forum…yes
> the community midwife goes in, she listens and that does go back and yes
> changes happen, but that women does not know that she contributed to it" C6P

Furthermore, while all groups in both gynaecological oncology and maternity services reported a commitment to hearing the user perspective, few formal mechanisms had been established to ensure that this perspective was reliable, accountable and representative. The issue of representativeness is discussed further in chapter nine.

However, there were occasions when users had been brought in more fully and this was in instances of service redesign in both maternity and gynaecological oncology services. A number of methods, including research into women's views and user representatives on planning fora, had been successfully adopted during initiatives such as planning for the new Princess Royal Maternity Hospital or the re-design of ovarian cancer services. Health professionals described these as discrete pieces of work, not integrated with routine practice, and unlike the everyday opportunities for user involvement in that they were highly organised, staffed and resourced. The catalysts for user involvement in such projects were reported as defined aims, limited timescales and ring-fenced resources.

> "People tend to lose sight when you are providing a service day in day out…
> whereas when you have the focus of re-design they are looking at the whole of
> the journey and saying well if you speed up that part then that can surely
> improve it, then that definitely helps" C2G

Routine user involvement activity in maternity and gynaecological oncology services, however, lacked the structure, focus, profile and resources provided by re-design opportunities. Health professionals expressed concern that there was no similar routine process and that neither the systems nor resources were in place to ensure that the user perspective was utilized within on-going service and policy processes.

> "There isn't a kind of regular interface between users or other a regular
> network between users of the service and providers of the service around the
> day to day provision" M10P

It was not clear why neither of these settings had developed formal structures for user involvement in routine services nor had identified resources to support these. Health professionals and users reported that there was effective user representation on national groups charged with shaping policy and it may have been the case that this was viewed as a sufficient response to the policy. Alternatively, these settings may have been experiencing particular budgetary constraints that hindered investment or they may have lacked understanding of the implications of user involvement for the culture and systems of the NHS and hence, under-estimated the formal mechanisms that would be required to respond appropriately to these. There was certainly a very demanding policy agenda in place at the time of the study but, it could be argued that this agenda, as well as challenging fiscal, policy and organisational pressures, applied equally to mental health services which in contrast, were described as having a systematic, ordered approach in both routine services and in major service changes and developments. Clinicians proposed one possible explanation for the enhanced response of mental health services as lying in the differing nature of illness and prognosis in mental health. They considered that a unique aspect of the mental health setting was that, unlike maternity or gynaecological oncology services, users were not "cured" and discharged but rather were engaged, sometimes over a lifetime, on a maintenance basis. This led to mental health services having a greater concern with 'practice' rather than 'cure' and it is this attention to process that may be reflected in their greater investment in the structure, organisation and systems for user involvement.

Thus, it was only in mental health services that structures to organise and support user involvement, to provide a reliable user perspective and to link the outcomes to service delivery processes were reported to have been established. Furthermore, this was the only setting to identify resources to support the implementation of the policy and by

implication, to have recognised the paradigm shift in systems represented by its implementation.

> "For the first time in thousands of years they are asking people who suffer from mental ill health, that they have been caretakers for forever, for their opinion so they are asking a big change" U4H

Techniques of User Involvement

The second factor examined was the techniques for user involvement used in each of the three settings. Chapter two discussed a number of techniques for user involvement and argued that the understanding of the nature and purpose of user involvement had a major bearing on the methods adopted. Thus, the techniques employed in each setting were examined by way of exploring their understanding and implementation of user involvement. A range of qualitative and quantitative approaches was described in each setting although mental health services systematically used the greatest range. However, there were a number of techniques that were used in all three settings.

The first and the most frequently described, technique was the use of the informal face-to-face interaction between nurses and users to ensure women were actively involved in the development of their care plans. This technique was described in all three settings, but within maternity and gynaecological cancer services it was the principal method used to gather women's views of their needs and preferences.

> "I think midwives are very good at listening to women, whether they carry through after they have listened to them, but they are very good at listening to them and asking what they want and letting them know what choice is the right way for them" C7P

Health professionals reported that they viewed listening to women as routine and good practice but they also reported that this had limitations as a methodology, as not all women were articulate or confident enough to give feedback on their needs and preferences. Furthermore, while this informal technique may have been widely used, there was little to suggest that it was applied systematically or that the outcomes were utilized. It was only in mental health services that systems to review and act upon such feedback were reported.

> "I think the majority of patients would choose not to give that feedback back to the staff, that would be my experience, unless you specifically create an opportunity, say "tell me more about your experience"... but generally, there is no avenue or vehicle to then take that information to inform departments, health boards about the service and... in the past we have not done anything structured with any feedback that we have had" C2G

The other techniques discussed were formal approaches to gathering feedback. The most popular technique, used in all three settings, was the survey. Both users and health professionals reported the widespread use of this methodology. Surveys were used

systematically in mental health services to gather formal feedback every 6 weeks as part of the standards of ward management, to investigate defined aspects of local services such as the food available in resource centres and to gain feedback on sector-wide or cross-city services, for example, out-of-hours services. Surveys were also used in gynaecological oncology and maternity services but health professionals reported that these were less systematically applied and that they were irregularly implemented. However, health professionals in maternity services reported that they had ready access to a wealth of national surveys and, in particular, published social science surveys of women's perspectives. They reported that they regularly used such peer-reviewed studies as a source of user views but also noted that these may not always reflect fully the views and experiences of local women.

Perhaps as a result of the popularity of this technique within maternity services, it was in this setting that the limitations in this methodology were recognised. Concerns were reported by health professionals and users that surveys often did not include the views of women who had literacy or communication difficulties and that they failed to shed light on the reasons why women chose not to use, or were absent from, services.

> "We do have questionnaires around about segments of the service, you would maybe get a questionnaire on the parent craft…now that is all good and well for the people who have gone through because they give the questionnaire out at the very end so they ask how was the service for you but they may have started with a class of 20 and ended with a class of 15, you really want to capture the 5 who didn't come back to say why didn't you come back?" C8P

However, the most significant weakness of this technique was identified as the lack of systems to respond to the outcomes. Health professionals in gynaecological oncology and maternity services reported that, as with informal feedback, there were no systems to review and act upon the results.

> "Things like user satisfaction surveys and stuff I think are taken more notice of now but that is not true lay involvement is it, I guess it is in that you are seeking their views but it is a one-way thing, you're not feeding back what has changed as a result of it" U10P

Other formal techniques used in all three settings were suggestion boxes, research on user satisfaction and focus groups. These techniques were also sporadically applied. Focus groups were a recent innovation in gynaecological oncology services but these were felt to have limitations. Clinicians reported that efficacy was constrained as they were led by and had their agenda set by staff, were poorly funded and were an unsuitable methodology for engaging with patients who were unwell as they would be less able to attend or give continued support to a group. However, no alternative to this technique was proposed.

> "…there is no mechanism in the Health Service to provide money for focus
> groups… A focus group is great, but where are we going to have it - yes we
> can have it there, but they will charge for the room, where is the tea and coffee
> coming in, oh they will charge for that too, how are the patients to get there,
> they will have to pay for their bus fare. In order to get the patients involved,
> they need to get financial support" C1G

The final methodology that was reported as common to all three settings was the use of the complaints procedure. Whilst acknowledging that they received very few complaints, managers reported that they tracked these as a measure of user feedback and had used them to initiate developments in services. However, users questioned this as a reliable technique.

> "…many women are just happy to have a baby at the end of it that they find it
> very difficult to complain at the time and they often get so involved in new
> parenthood that although they always intended to complain, never did" U10P

A number of other formal techniques were reported in each setting. Mental health managers reported that ward meetings, meetings with user and carer groups, newsletters and written information were all regularly in use. The Mental Health Division provided speakers and information at local events in order to create opportunities for feedback on services, while public meetings and conferences were used to consult on service developments and proposals for change.

Fewer techniques were described in either gynaecological oncology or maternity services. At the time of this study cancer services were involved in a major building project for a new hospital and, in response to the demands for greater user involvement, two Patient Involvement Workers had been appointed on short-term contracts. These individuals had chosen public meetings as a technique that would both inform patients and gather feedback. Users reported that they valued this technique and argued for more discursive opportunities where they were able to raise a wide range of issues.

> "I would like to see more of that work done as a routine thing…when I asked
> the open question, what made you think you were ill in the first place, I turned
> a switch… and I think if somebody says, oh how did you get on today it would
> all come out" U6G

In maternity services, user representatives alone suggested the use of more discursive approaches describing how they would meet with women's, mother and toddler and play groups to interview women and gather a range of views and opinions.

> "…making contact with people and going out to their group is probably one of
> the best ways to engage anyone in the community" U7P

However, whilst they acknowledged the benefit of discursive approaches, health professionals in both gynaecological oncology and maternity services reported that they

remained largely dependent on just two techniques, the informal interaction with staff and user surveys, to gather feedback. In contrast, health professionals and users in mental health services all recognised the benefit of employing a variety of techniques and the need to ensure an appropriate methodology for both the issues under discussion and the individuals being engaged. All groups of respondents in mental health services stressed the need for a range of techniques and the need for creativity to ensure that individuals were given the widest possible choice of opportunities to participate in user involvement.

> "I think what we have learned in the last few years in the work that we have done is there is not just a single way to do that, it's not about coming to meetings and big events and lunches and nice hotels for everyone, but it is about finding different ways" M3H

> "…it is about being creative about how you involve people, you don't actually have to physically have a bum on a seat, it could take a phone call" U4H

The topic of involving or attempting to involve hard-to-reach groups was only raised by respondents in mental health services. Both health professionals and users proposed that more discursive techniques, that were responsive to the sensitivities of the issues under discussion, facilitated women's involvement.

> "…you have to remember that some issues that affect women might come from childhood… from all sorts of things that are hidden that they couldn't talk about in a mixed environment, they find it very difficult to talk about it…we have the most wonderful bond there that women are prepared to open up… and say what they feel" U5H

Thus, it can be seen that a restricted range of techniques were used within the three service settings and that each had associated difficulties. Each setting made extensive use of the informal interaction between users and health professionals to gather user views and each had endeavoured to find additional methodologies that suited their circumstances. For example, maternity services were able to take advantage of the high quality national surveys available to them while cancer services had tried to introduce focus groups. However, outside of mental health services, there was very little recognition of the need for a variety of techniques and an appropriate methodology for both the issues under discussion and the individuals being engaged. Furthermore, while the techniques adopted had some strengths in allowing for the expression of perceptions, attitudes and ideas, their unsystematic application and lack of formal structures to ensure that the outcomes were fed back to the relevant service processes, and acted upon, were significant weaknesses.

The User Agenda

The third factor explored was the user agenda in health and health services. Interviewees were asked to identify the issues that were important to users and to describe their

perceptions of the capacity for these issues to have influence in the decision-making structures of the health service.

In all three settings there was a remarkable level of consistency reported in the user agenda and all found it easy to describe the issues of importance to users. All three groups of respondents described a person-centred set of issues that focussed on the 'softer', less clinical, aspects of treatment and services. This person-centred agenda was reported as continuity of care, the organisation of local services, the ward/clinic environment, staff attitudes, emotional support, communication, information and informed choice. In mental health services, issues of stigma, dignity, privacy and the power of psychiatrists to determine treatment underpinned this agenda. In maternity services, the user agenda also included support with breastfeeding, a normal labour with minimal pain and as little risk as possible leading to the delivery of a healthy baby. In gynaecological oncology services, time with Consultants, travel and car parking were also described.

In each setting, health professionals agreed that this was an important agenda and there was unanimous support for it. Within maternity services in particular, users reported that managers and clinicians often shared their person-centred agenda. They described how they had advanced their agenda by forming alliances with health professionals who shared their philosophy of care. Managers agreed that there were shared values and attitudes in maternity care pointing to professional support for a social model of midwifery.

> "...there certainly is a movement within midwifery whether it be groups of midwives being supportive of homebirths… of community based midwifery units or midwife managed care or midwife birthing units where they feel they can combine the comforts of home and family and the social aspect of childbirth alongside safe care" M6P

However, despite the apparent widespread support for the person-centred agenda, user representatives reported a lack of progress. In mental health services, users felt that despite the opportunities to raise their agenda there had been little progress in advancing it and expressed regret that their aspirations were not more fully met.

> "It is sad because I have been involved since with the network since it started and it (the user agenda) hasn't changed" U4H

Health professionals agreed that progress was slow, but they and users proposed contrasting explanations for this. User representatives reported that the low priority held by their agenda was due to differences in the underpinning ideologies of health held by users and professionals. Users described their person-centred agenda as consistent with a social model of health and contrasted this with the perceived focus of services on medical model derived clinical targets and hospital-based services. In mental health services, user representatives proposed that targets reduced services to a set of quantitative objectives

such as staff: user ratios and numbers of centre users within which there was little scope for the person-centred issues of importance to users. Users in maternity services agreed, contrasting the person-centred issues that were on their agenda with the health professional's focus on hospital-based services and financial targets.

> "…each sector general manager has x amount of mental health patients…that is what they care about, it's about the bottom line, it's not about real people, I think the sooner some of the sector managers come out of their ivory towers and come down into the real world…it's not about money, it's not about having the latest gadgets in your resource centre, people don't care about that" U4H

> "…domestic abuse link midwives, the strategy for teenage pregnancies, research done by the deaf women, very local issues all focus on around social model of health and all the factors that contribute to maternity services but for me, I think there is still a major focus on hospital based provision and where are they going to get the money for x, y and z machines and who is paying for that" U7P

Users felt that it was opposition to the social model and the dominance of the medical model ideology that led to their agenda having a lower priority. Clinicians and managers, however, disagreed, reporting that the lack of progress was not ideological but pragmatic; the consequence of their need to balance the user agenda against the competing demands of other policy, organisational and political imperatives. While they supported the person-centred agenda, they also described their accountability to a target-driven, organisational agenda focussed on clinical governance, the organisation of services and finances. This organisational agenda was described as focussing on the 'hard' issues of services in contrast to the users' 'softer' person-centred agenda and all, users and health professionals, agreed that it was the organisational agenda that held the higher priority in the health service. The reasons for this higher priority were identified as relating to the political priority given to other policy drivers, such as the waiting times initiative, and the enhanced power of clinicians, which enabled them to attract greater support and resources towards their goals. The power of health professionals emerged as an issue within several areas of these findings and so is discussed more fully in chapter ten.

Health professionals proposed that the person-centred and organisational agendas were closely aligned in individual care. Within the context of the health professional: user relationship they reported that services were able to respond positively to most of the issues on the person-centred agenda. However, all three groups of respondents reported that, as a result of competing demands, the agendas were often at odds in service delivery, planning and policy processes.

> "I would say you would have a far more of a matching of agendas at that level of what is required of the individual and how you are able to provide it etc. as it

gets further up peoples' expectations of what the service can and cannot do varies widely" M7H

Health professionals reported that tensions emerged in service delivery and policy-making forums as a result of the differing priorities of managers, users and clinicians. They proposed that each group prioritised the agendas differently as a result of their varying accountability to clinical governance, financial targets or organisational policy. Furthermore, they considered that users rarely understood or recognised these differing priorities and so were unrealistic in expecting services to be able to implement a person-centred agenda without reference to targets that held a higher clinical or organisational priority.

> "…if you are a doctor and you do not have enough equipment, and the patient mentions that he needs more booklets and then you might say come on a minute, booklets are one thing, but if we can't treat you in the first place, no matter how many booklets you have, you have got to get the treatment right. So our priority would be treatment facilities and might not necessarily be patient's priorities" C1G

It was also proposed that users did not understand the constraints in resources, staffing and finances that applied to services. In all three settings, health professionals reported that there could be conflict between what users requested and what services could provide, with services only able to respond to the extent that demands stayed within established budgets, guidelines and protocols. Several health professionals in each setting described a difference between wishes and needs, whereby wishes were those elements of user preferences that were over and above their needs.

> "We have lots of requests like can we have this in the ward, we would like this, there is lots of things we have turned down… there is a fine dividing line between giving people everything that they ask for and saying well wait a minute, this is a hospital, you are here for treatment, there is still a balance to be struck" M8H

Managers in mental health services identified a particular danger that user involvement could be mis-interpreted as meaning that services would meet all user preferences and proposed that users required more information on the constraints that applied to services. This was felt to be a particular issue when the Mental Health (Care and Treatment) (Scotland) Act (2003) was used to detain individuals or compel treatment.

> "A good example of that is the Mental Health Act, knowing that they might need to be detained against their will…and then having to undergo treatment as a consequence and there is no choice there. What the patient wants is to go home, what the nurses want is for the patient to be kept safe, so there is a good example of whereby what somebody might want or wish might be quite different to what the nurse needs to provide" M8H

In all three settings, managers reported concerns that unless users were informed about the constraints that would influence their agenda then they could become frustrated at the lack of results from user involvement and the service's apparent disregard of their views.

A particular example of the conflict between the user and the organisational agenda was given in maternity services, where health professionals described how a group of users wanted to promote home births. This, they proposed was problematic, not because of a philosophical disagreement with home births, but because of service constraints.

> "…we can get down to the line of a women requesting a homebirth, all her ante-natal care would be done at her convenience and what if comes to the bit (and) you don't have a midwife who can go out on call… that is putting quite a pressure on the system" C6P

Users disagreed, arguing that it was the low priority given to the social model of midwifery that led to the restrictions on home births. They proposed that staffing and finances were elements of the ideology that services held and that their distribution and prioritisation would differ depending on whether a medical or social model of midwifery was adopted. Embracing a social model philosophy would give a higher priority to women's preference for home births and the required staffing and resources would follow. Thus, they felt that their agenda was not fundamentally incompatible with the organisational agenda but rather it was their philosophies of care that were conflicting. There was little common ground in this debate, with all groups recognising this tension but few suggestions for how it could be addressed. The advancement of a person-centred agenda within a service and policy structure dominated by a medical model understanding of health is discussed further in chapter ten.

Thus, two clear agendas emerged. The first, identified as the users' agenda although not only of interest to users, was described as a person-centred set of issues while the other was a target-driven, organisational programme. Users and managers agreed that progress on addressing the user agenda was slow, but interpreted its apparent lack of influence differently. Users felt that the two agendas were fundamentally distinct and that their underpinning ideologies of health differed significantly, but health professionals proposed that lack of progress was due to the need to manage this agenda within the context of the competing priorities of other policy, organisational and political imperatives. Tensions in the implementation of the user agenda had emerged with health professionals reporting that users did not understand the responsibilities of services and the constraints that shaped the organisational agenda.

The next sections of this chapter will explore how the reported structures, techniques and user agenda impacted on the opportunities available for users to have an influence in the

three types of user involvement described in the literature; in individual care, examining services and strategic planning.

User Involvement in Individual Care

In all three settings managers, clinicians and users reported that patient-centred care was the established philosophy of care and, as a result, there was effective user involvement in individual care and treatment. In mental health services, health professionals and users reported that user involvement in individual care and treatment was accepted as routine, good practice and that users were 'enthusiastic' participants. The facilitators for this were identified as the division-wide implementation of a patient-centred model of care called the Tidal Model (Barker, 2007), the provision of information on the expected standards of care to all users and the clinical relationship between users and staff.

> "It is expected as a standard that you should be involving patients in their own care…we have a number of educational programmes for where people are given the opportunity …to learn about their illness or their medication and how to look after themselves… that is part of the ethos, I am not just here to tell you what treatment to take, I'm here to work with you, to help you keep yourself better" C10H

All three groups of respondents from gynaecological oncology services reported that, despite user involvement being relatively new to cancer services, there was a growing interest among patients in participating in their individual care and treatment. However, they also reported that not everyone wanted this and that some women relied on health professionals to determine their care. Others, though, were active in seeking out information about their diagnosis, treatment plans, coping strategies, prognosis and what to expect from services.

> "…some women, I believe, are very happy to put themselves into health professional's care and other women, who can be very high information seekers, will want to know everything about anything and will want to take part, and will be very active in any decisions, and you have that whole spectrum in between" U1G

As suggested by Trobanski (1994), clinicians reported a number of user characteristics including confidence, knowledge of their condition and class that influenced how active patients were in their care. The time since diagnosis was also reported as a key factor, whereby at the start of their treatment women were less able to contribute owing to shock. However, once they gained some knowledge and rapport with health professionals they were more likely to participate in and shape their treatment.

> "…usually you find that people are out of control at the start, you know, that they can't even make up their mind what day they want to come for their chemotherapy…and I think that's the time where you have to kind of make

decisions for them or help them make decisions, but usually you find that once they're on the second or third treatment that they're taking over" C5G

Similarly, in maternity services, all groups of interviewees reported that users were active in their own care and treatment and that the clinical relationship between the woman and her midwife facilitated active participation. Respondents reported that the involvement of women in shared care was accepted as integral to services and that the widespread expectation that women would be involved had been built up in the years since *Changing Childbirth* (Department of Health, 1993). However, once again, clinicians and managers reported that some women did not want patient-centred care. These preferred to follow the guidance of health professionals, allowing them to determine care and treatment. A particular concern in both maternity and gynaecological oncology services was that it was educated, middle class women that were active in patient-centred care. Those from more socio-economically deprived areas were reported by managers and clinicians as less likely to participate, complying instead with the advice and guidance of health professionals.

"A lot of them, I hate to bring this down to a social class, but in many respects it does, a lot of them all they ever say is 'what do you think'?' what is the best thing?'…and they see us as being the experts in the job" C6P

The factors identified as distinguishing active participation in user involvement in all three settings and the implications of these for representation are discussed further in chapter nine.

Managers, clinicians and users in all three settings described this type of user involvement as established and routine. However, there were some suggestions that there were tensions inherent in patient-centred care and that the implementation of individual wishes and preferences could be difficult. As discussed earlier, managers and clinicians expressed reservations over the service's ability to respond to individual preferences and clinicians in maternity services reported that service provision had an impact on the capacity to offer and meet user preferences.

"…very often a midwife will encourage a woman to have an epidural for midwife stress, we are incredibly short staffed. It is an incredibly stressful job and sometimes it is easier to just power your own way through than it is to follow the woman's wishes" C6P

In common with the findings of Stapleton et al (2002), they described how competing demands, resource constraints and time pressures on health professionals led to stresses in the system and, on occasion, a situation whereby women complied with rather than chose how they wanted to give birth.

There was, therefore, considerable evidence that patient-centred care was promoted and effectively provided within these three service settings. This type of user involvement

required little additional organisation or structure as the existing clinical relationship between the user and health professional was reported as key to facilitating active participation. This relationship was described as offering the conditions within which knowledge could be shared and communication provided, and the frequent use of the interaction between users and clinicians as a technique of user involvement took advantage of this. A further facilitator was the shared person-centred agenda in patient-centred care.

However, there was also some indication that there were tensions inherent in the implementation of patient-centred care. As suggested by Nolan (1999), Hundley and Ryan (2002) and Johanson et al (2002), the constraints under which services operated appeared to place restrictions on the influence that users could have in their care plans and there was a need to attend to the characteristics of active participation in shared care.

User Involvement in Examining Services

The second type of user involvement described in the literature is the involvement of users in examining services. As discussed in chapter one, this extends the conceptualisation of user involvement from individuals shaping their own care and treatment based on personal preferences and understandings to the application of collective experience to the evaluation and development of service systems, delivery and outcomes.

> "… they should be able to ask for information to be able to control their health care to be able to understand fully…and they have a right to talk about the development and structures of the services that are being designed to serve them" S1

This would appear to be a particularly important area of user involvement if the policy is to deliver on its aim of developing a pro-active approach in the delivery, development and planning of health services. However, health professionals and users in all three settings reported that user involvement was lacking in examining services and that meetings dealing with day-to-day service delivery issues such as finance, manpower or monitoring of complaints had the poorest user representation. In gynaecological oncology services, some health professionals and users proposed that very few patients wanted to be involved in decisions about service delivery as they were 'accepting' of services. However, others from this and the other services interpreted the lack of user involvement in this level of service delivery as a weakness.

> "…these bigger items they tend to be involved in without any hassle at all, there is wide opportunities there, the difficulty comes in the middle sphere, they are involved in their own individual care and treatment but in the actual service delivery aspect, the day to day organisation of the service, there seems to be this hole of what is happening" M7H

Three factors emerged to explain the lack of user involvement in examining services and the apparent lack of user influence.

The first factor proposed was the limitations of the informal techniques used to gather feedback from women. As we have seen, the principal technique used to gather feedback on women's needs and understandings in both maternity and gynaecological oncology services was the face-to-face interaction between users and health professionals. However, some health professionals proposed that the findings from this informal method were unreliable and unscientific. Because of this they carried little weight within health service decision-making processes. This was particularly evident when the user agenda was considered against clinical needs that were supported by robust, research evidence.

> "If you go to see [___] and ask him what he wants he will say I need a Linear Accelerator. Why do you need a linear accelerator? There are books full of research showing you that linear accelerators cure people with cancer. He's got it easy. Now, if you want a patient to say I think we need better literature, more car parking spaces, something that was so intuitively right… if you want the evidence for that, in order to prioritise it, you need to have to have some means of counting or assessing it so that it then becomes a meaningful inclusion in the planning process, because you have got evidence to support it" C1G

Secondly, it was unlikely that the feedback gathered by staff using this technique could be reliably linked to service delivery processes as in all three settings clinicians reported that they (clinicians) were rarely present at service decision-making and development forums. Health professionals in both maternity and gynaecological oncology services described an informal advocacy role for midwives and Clinical Nurse Specialists (CNS) in listening to women and then representing their views in service and policy fora but there were no identified systems or resources to support this aspect of their work and very often clinical commitments took priority over attendance at service delivery or development meetings.

> "We couldn't go to their redesign thing either because it was just when they said we were to go back into the ward for day…so it meant that anything that was happening on a Wednesday and Thursday we just couldn't go because we didn't have anybody to cover us, you know, because with the chemotherapy you need, you really need two people there to check the drugs" C4G

As a result, there was a gap between the outcomes of user involvement, as known and understood by clinical staff, and the service processes that could address these. Mental health and maternity services had developed some structures but overall there was little evidence of the mechanisms required to ensure that feedback from users was systematically appraised, measured and applied. This finding was consistent with a concern expressed by Kober (1994), Fitzpatrick and White (1997) and Barnard (1998) who described the lack of systems to link the outcomes of user involvement to the mechanisms

giving control over service delivery processes as a significant impediment to user involvement in examining and improving the quality of services. In response, health professionals reported that a better avenue for linking the clinical and decision-making arenas was required and they expressed concern that user involvement opportunities were neither formalised nor integrated with the on-going operational management of services.

> "Decisions get made often much further up the ladder, that's the problem, they will get made, obviously the Consultant particularly will be involved in decisions with regard to the service and perhaps the CNS but often it's much further up with Managers who have obviously their own agendas and they have targets and things to meet" C2G

The third factor discussed was the divergence in the organisational and user agendas in service delivery. Within mental health services, managers described how their current organisational agenda was focussed on the implementation of the Mental Health (Care and Treatment) (Scotland) Act (2003), the development of the Adult Integration Model that would combine social services with health and the introduction of Community Health Partnerships. In maternity and gynaecological oncology services, factors such as the European Working Time Directive, changes to medical training, demographic factors and the Royal Colleges all contributed towards encouraging the centralisation of services leading to a prioritisation of fiscal and staffing issues. These organisational agendas, it was proposed, left little room within service processes for the user agenda.

> "…old buildings needing replaced, move toward centralisation as a result of poor real estate plus the reality of fewer doctors working less hours and trying to provide a service which is safe and with minimal risk, I think those have been the drivers and not the women" M6P

Furthermore, it was proposed that the complexity and difficulty of the agenda in service delivery and development processes created a barrier for user participation. Managers reported that it was not easy for users to get involved in service systems where issues such as staffing and finance were discussed. They described these issues as requiring knowledge, experience and expertise that would not be held by users. Users agreed with this assessment of the service agenda as complex and difficult to understand but, while they could each describe areas of the agenda that they struggled to understand, none reported that these were unmanageable. The issue of complexity was then perhaps indicative of a professional reluctance to discuss service delivery issues with users rather than a concern for users' understanding and knowledge. Indeed, one manager in mental health recognized this.

> "I think from staff point of view at these sector management meetings they are talking about finance, they are talking about manpower, about sickness levels, complaints and I think they see that as being staffing issues, it is not something they really need to get service user and carer viewpoints on" M7H

Both professional defensiveness and the barriers created by the complexity of the agenda are discussed further in chapter ten.

These three factors of methodology, links to decision-making structures and conflicting agendas appeared to converge to make user involvement in examining services difficult. Health professionals in both maternity and mental health services expressed concern at this lack of involvement in service processes. The development of participation in service delivery groups was proposed as important as this could facilitate users understanding of the health service, the constraints within which it operates and the rationale for service delivery decisions. This could, as previously discussed, assist users to understand the organisational agenda and its inter-relationship with the user agenda. However, despite their desire to enhance user representation in examining services, there were few suggestions for how to progress the development of a meaningful system for user influence in examining services.

Thus, user involvement in examining services was hindered by the limitations of the primary technique used to gather feedback; the lack of a mechanism to link the outcomes of user involvement to service delivery and development processes and the difficulties reported in advancing the user agenda within services where a complex and challenging organisational agenda was dominant. The significance of this final factor was demonstrated within mental health services where it had been reported that a range of formal techniques to gather user feedback were in use and structures to link this to service processes had been introduced. Nevertheless, respondents reported the same difficulties in establishing user involvement in examining services as both maternity and gynaecological oncology services, suggesting that the presence of users or user issues at service delivery fora was not sufficient to ensure effective user involvement.

User Involvement in Strategic Planning

The third level of user involvement under review is the involvement of users in the strategic direction of health policy and planning. This includes the participation of users in developing, interpreting and implementing policy at local and national levels. Barnes (1997a) highlighted the need for users to be involved in both local and national policy development, as the health service is shaped by policy and resource decisions taken at national policy level, as well as by the development of strategies appropriate to local circumstances and preferences. In all three settings, it was reported that users had an active role in strategic planning. However, an examination of the data revealed a different picture at national and local levels. Within all three settings, user involvement was

reported as established within national policy processes but less well defined in local policy planning.

In each setting, managers, clinicians and users reported and endorsed user involvement in national policy planning fora. All described user representation on national groups charged with shaping policy and in all settings this influence was felt to be beneficial to the policy process. Health professionals and users in maternity services, who had a particular history of user involvement in policy development, gave several examples of user influence. Managers pointed to national policy such as *Changing Childbirth* (Department of Health, 1993) that had been driven by women and to developments in maternity service delivery that they attributed to women exerting political influence, such as the movement of antenatal care from hospital to community settings. It was notable that health professionals kept mentioning *Changing Childbirth* as, although no one commented, *Changing Childbirth* was almost 15 years old by the time of this study. Few more recent examples were given but one user described the development of a national policy document on pain relief where users had worked in partnership with midwifery representatives to shape this towards women's preferences.

> "I was on one of the [ ] groups looking at pain relief in labour and felt that myself and the midwife had a very immediate effect in the initial draft report… (it) made some very strong claims that we felt couldn't be supported by the evidence and we brought that to the attention of the group and that was taken on board very quickly and very easily. The final piece of work that came out was acceptable to us" U3P

However, user involvement in local policy development and in the interpretation and implementation of national guidance was less well defined and, in each setting, differences in the interpretation of user involvement emerged. In mental health services, managers and clinicians reported that there was effective user representation in the local implementation of a key policy document, Modernising Mental Health.

> "…Modernising, we do have service user and carer representation at that and they can see where that is going and they are quite heavily involved in ensuring that all service users and carers out there are provided with that information and know what it is about have a chance to comment, have a chance to put their views forward" M5H

However, while users agreed that they had a role in Modernising Mental Health they felt that this was a 'presence' rather than being a full member of the strategic planning groups. They felt that one factor which partly explained this perception was the low number of user representatives on this and other such groups; usually only one user. As the only member who was not from the statutory sector, users could feel outnumbered or intimidated and so

less able to participate as fully as other members or to progress their person-centred agenda.

Similarly, opportunities for patients to play a role in planning local cancer services were reported. This was through the Managed Clinical Networks (MCNs) that were described as having patient forums to provide a patient perspective on developments. However, users and some managers disagreed that a patient perspective was established and instead reported that participation in MCNs required development. They reported that not all MCNs had established patient forums and that gynaecological oncology was one speciality that had experienced particular difficulty. This was thought to be as a result of the burden of ill health associated with this condition.

> "…the Managed Clinical Network level should all have patient involvement groups and I know some have and some haven't, and some are easier to have than others. Because of the nature of the illness, I mean lung cancer they actually have a lot of carers because generally speaking there is about 9 months between being diagnosed and you die, but you know those with colorectal cancer and breast cancer, they can be quite active" U6G

In maternity services, health professionals expressed confidence in the opportunities for users to exert influence in local planning as they had a structure for the interpretation and implementation of national policy. This structure, the Maternity Services Liaison Committee (MSLC), on which user representation was enshrined, was reported as providing women with a direct link to the implementation of policy and shaping of service delivery in local units. However, users felt that they exerted little influence and health professionals acknowledged that professional interests and the organisational agenda dominated MSLCs. External factors, such as the centralisation of services, were proposed as serving to limit the influence of the person-centred agenda in MSLCs. One user representative described how professional interests drove her MSLCs' agenda. She reported that, in her opinion, the MSLC was intended solely to implement strategic plans that were consistent with the organisational agenda and had been decided upon with managerial and obstetric input alone.

> "…we tried to clarify what the remit of the MSLC was because we felt that normally an MSLC is a forum for people to come together to discuss policy issues within maternity services and to have some kind of influence over what is happening in a local area... What we discovered was that in fact that wasn't the remit of our MSLC. The remit of our MSLC was specifically to push through centralisation" U3P

However, while user involvement in on-going planning fora was problematic, all groups of respondents were agreed that user influence was evident in the strategic planning for one-off, discrete projects such as the re-provisioning of the West of Scotland Cancer Centre or the development of new mental health or maternity facilities. Managers in gynaecological

oncology services reported that patients exerting political influence and campaigning publicly around gaps and shortcomings in services had prompted significant investment in cancer services in the city. As discussed earlier, this investment included the appointment of Patient Involvement Workers to ensure user involvement in the planning and design of the new facilities. Similar influence was reported for users in the re-provisioning of the new Princess Royal Maternity Hospital, while mental health managers also reported that they recognised the role of users in major service changes.

> "…for East Glasgow there is going to have to be a re-provision of the hospital…we have been much more proactive with that group because these are…the people that live in that area, that are going to be affected" M5H

It could be argued that the development of national policy could also be characterised as one-off or discrete projects, as such opportunities were often presented as relatively short-term pieces of work on a narrowly defined aspect of services. However, involvement in the on-going development of multi-faceted strategies appropriate to local circumstances and preferences was more difficult. In this respondents agreed with the proposal by authors such as Kober (1994), Barnes and Evans (1998) and Crawford et al (2002) that involving users in the long-term was challenging to the health service.

Thus, whilst the principle that users should be involved in the strategic planning of health services was accepted, it was challenging to find effective ways of involving users in the longer term rather than in discrete projects. There was clearly recognition of the value of user involvement in strategic planning and this appeared to be effectively established within national processes. However, despite a desire to involve users in local planning processes and the creation of some structures in order to facilitate their participation in groups and forums charged with the development of local policy, implementation of this was flawed. The approach to user involvement in local strategic processes were superficial with slight attention having been paid to the mechanisms required to ensure representative or meaningful participation; no indication of how such fora could manage the tensions between the person-centred and the organisational agendas and little discussion of the tensions inherent in user influence in policy-making processes.

Nevertheless, the data revealed successful user involvement within strategic planning at a national level and within discrete plans such as new building projects. Further work will be required to identify the facilitators for this and in particular, what factors have made possible this particular link between user involvement and policy development.

Summary

This chapter has described the nature of user involvement in mental health, gynaecological oncology and maternity services and examined the capacity for users in these settings to influence their health and health services. It examined three factors proposed as facilitating user involvement; the organisation and structure of user involvement, the techniques utilized and the user agenda. These factors were considered in the context of the three types of user involvement described in the literature, involvement in individual care and treatment, in examining services and in strategic planning.

Health professionals and users in each of these settings indicated an organisational awareness of the policy on user involvement as all reported that they had endeavoured to respond to this policy and that they valued a culture of partnership between the health service and users. However, the structures and organisation within each setting differed quite significantly with little evidence of a systematic approach having been developed within either maternity or gynaecological oncology services. It was only in mental health services that structures to organise and support user involvement, provide a reliable user perspective and link the outcomes of user involvement to service delivery processes had been introduced. Furthermore, in an examination of the techniques used within the three service settings, it was once again mental health services that had given greater consideration to the process of implementing user involvement. They alone recognised the need for methodologies that were appropriate to the purposes of and the people being involved. The techniques described in the settings did allow the expression of perceptions, attitudes and ideas but their unsystematic application and lack of formal structures to ensure that the outcomes were fed back to the relevant service processes and acted upon were significant weaknesses.

The third factor examined was the user agenda. In this two clear agendas emerged. The first, identified as the users' agenda, although not only of interest to users, was described by health professionals and users as a person-centred set of issues while the other was a target-driven, organisational programme. It was acknowledged that the organisational agenda held the higher priority, although the explanations for this diverged. Users attributed this to the dominant medical model ideology of services while health professionals proposed that this was due to the differential application of priorities. However, whatever the reason for the lower priority, it was clear that the user agenda exerted little influence and as a result tensions in its implementation had emerged with health professionals reporting difficulties for users in understanding the responsibilities of services and the constraints that shaped the organisational agenda.

These three factors were proposed as influencing the extent of user involvement in the three types of user involvement under review and considerable evidence emerged that these were related to the capacity for user involvement and user influence. There was differing levels of involvement in the three types of involvement under review. User involvement in individual care and treatment was described by health professionals and users as effective, routine and good practice, as was involvement in strategic planning at a national level. However, user involvement in both examining services and in strategic planning at a local level was described by all groups as poorly established and problematic. The exception to this was user involvement in discrete one-off projects such as local planning for new hospital facilities or in re-design opportunities. In these instances, factors such as the defined aims, limited timescales and ring-fenced resources were proposed as having facilitated user involvement. However, it appeared to be challenging to find ways of involving users in the long-term rather than in one-off consultations.

The management of the user agenda within service and policy processes, where a complex and challenging organisational agenda was dominant, emerged as a significant issue in the implementation of user involvement. This was compounded by the limitations of the principal technique used to gather feedback and lack of structures to ensure this feedback was appraised, measured and applied to mechanisms giving control over policy and service processes. These three factors converged to suggest that each setting had under-estimated the extent of the change that would be required in order to ensure that user involvement offered meaningful opportunities for users to influence health care. In contrast, the reliance on historical example or the superficial presence of users in service and policy processes had resulted in little scope for user influence in those spheres of health service decision-making that had the capacity to change the culture of the health service, the ways in which the NHS interacts with people and the ways in which services are delivered, as envisaged by the current policy imperative (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005).

Thus, the concept of user involvement offered significant challenges to the health service by way of the implications for its professional service culture, organisational ethos and decision-making processes. Chapter ten will examine the barriers to user involvement identified by respondents alongside the issues of the professional service culture and the organisational ethos of the health service but, before that, the next chapter will explore the views on the respondents on representation.

Chapter 9: Representation and Representativeness

Representation and representativeness are seen to be significant to the development of user involvement and the findings reported below bear out the importance of these issues. Strategists, users, managers and clinicians all spoke at length on matters of representation and the identification of user representatives for service delivery and policy processes. There was particular interest in the extent to which representatives were reliable, accountable and characteristic of the wider group of service users. Concern over these topics was common to all three settings.

This chapter will present the key issues in representation and representativeness identified by health professionals, users and strategists. These are discussed under the headings of who represents the user, the diversity of representation, particularly with regard to those identified as hard-to-reach, and whose interests does the user representative advocate. Next, the implications of these issues for users and user representatives will be discussed. Finally, this chapter will discuss the strategies proposed for widening representation and increasing diversity. It will begin by examining who was identified as representing the user perspective and how they were selected and recruited.

Who Represents the User?

The issue of who could act as the legitimate representative of other users in service and policy processes generated much interest and discussion. All groups of respondents agreed that there were two strategies for identifying user representatives in common use. The first of these was to invite individuals who were either current or past users of services to act on behalf of other users; the second was the use of an advocate or proxy, most often a user organisation but in some cases this could be carers or staff. Both of these strategies, their benefits and limitations are discussed below.

The first strategy used was the issuing of an invitation to a current or former user, who was known to services, to act as a user representative on service delivery and strategic planning groups. Health professionals in all settings reported that they often used this approach. In all three services, it was reported that individuals were encouraged to engage in user involvement as this was beneficial to health and morale. Health professionals in mental health services used the terms 'users' self-confidence' and 'self-esteem benefits', while in cancer services user involvement was reported by health professionals and users as helping patients move on from their experience of cancer and allowing them to repay those that supported them through their illness. Users equally recognised the opportunity to contribute to the service which had cared for them:

> "…they think I know this is going to be hard, but I can do this and I am glad to have that chance" U1G

No one reported advertising for representatives; instead health professionals stated that they relied heavily on their personal networks to identify representatives. These were selected based on an individual's willingness to become involved rather than on agreed selection criteria. Managers in gynaecological oncology services also reported that volunteers approached them and a similar desire to participate was identified in maternity services.

However, health professionals and users also expressed concerns with the strategy of approaching individuals already known to them. The first of these was that this strategy resulted in reliance on individuals who were not necessarily representative of the users of a service. The lack of selection criteria meant that there was little to guide health professionals on the experience, values and knowledge necessary in a representative.

> "…recently we have had patients representatives on the redesign project and it was one of our patients that I asked within our small group to be involved and I suppose it was just somebody I thought, well she talks well, she's doing well at the moment and therefore I approached her. That's how I went about that"C4G

> "…you might say, I wonder if I should phone such and such a person because I know they have an interest in this and that, it's a part of their background, they would bring a balance to the discussion, but that makes it sounds easy, quite balanced but it doesn't always work like that" M8H

Furthermore, there was concern that individuals could only tell their own story and that some may be motivated by a personal issue, or having an 'axe to grind', that was not typical of the majority's experience of services. As individuals were rarely accountable to a wider group of users, this had the potential to skew discussions towards the issues of the few.

> "The issue… has arisen in the past with representatives losing sight of the wider issues for range of patients and pursuing their more individual agendas" M7G

One example of skewing came from a maternity services user representative. She described how a user with a distressing, but atypical, experience had influenced the deliberations of her MSLC and skewed policy discussions around homebirths.

> "…we had a woman invited on to our MSLC…who had actually lost a baby. Her interpretation of her loss was that, had she been in a large centralised unit, the baby wouldn't have died… individual experiences must influence the service, but to say that all babies should be born in large centralised obstetric units because one woman had lost her baby, to us did not make any logical sense" U3P

Another concern with this strategy was the risks associated with drawing from a small pool of representatives. Managers in mental health services described user representatives as "the same willing faces" and similarly gynaecological oncology services repeatedly invited the same users. This led to fears that representatives could become over-burdened and stressed. This was of particular significance in mental health services where users were reported as being vulnerable to excessive stress. It was also reported that the issue of over-commitment was related to the symptomology of mental health and that particular care was needed to ensure that ill health did not become the unintended consequence of user involvement.

> "I look at people like [__] her brain is fried, will she slow down, will she hell, but that is part of her illness, that is all part of who she is" U4H

Over-burdening individuals was also of concern to health professionals in gynaecological cancer services where the already fragile physical and emotional health of users could be further weakened. Health professionals and users also expressed concern that user involvement could re-open old wounds causing emotional damage, with particular unease expressed for current users who may be vulnerable during discussions of issues such as palliative care. As a result, one cancer user group reported that they had an informal policy of only using volunteers in such a capacity once a period of two years had passed from their diagnosis.

> "…if they have been patients, or if they have been people who have had a diagnosis of cancer, then we say to them they need to be two years out from the diagnosis - the end of treatment basically or from a death or whatever to give them some breathing space so they can actually separate out their own emotional bit in that and be useful and not be damaged by it and you know opening the wounds all the time" U2G

As a consequence of the small pool of candidates, clinicians reported concern that some individuals were unable to leave groups or discontinue their role as a representative. The lack of alternatives meant that existing representatives could have difficulty in moving on from their experience of cancer. It could also result in representatives whose experience of services was somewhat out of date. The use of representatives who were not current service users was a concern in all three settings and is discussed further in a later section.

> "I know one of the lay reps on the Scottish Cancer Group is a carer, and her husband died nearly five years ago now, and she is stuck because she is there because of her experience as a carer. But she has met somebody new, she wants to get on in this relationship, but she can't move on because she is always getting asked about her experience" C2G

In maternity services, user representatives shared a concern that the heavy workload and difficulties of working in a hostile group that did not share the users' perspective could be stressful.

> "…you become a chameleon which I think takes its toll…always trying to adopt the right kind of language, the right kind of demeanour, the right way of saying things in a way that is maybe acceptable to those present" U3P

Despite an awareness of these risks, none of the staff respondents reported having policies or systems in place to protect individuals, although mental health managers did note that such policies were a recognised development need.

As an alternative to using individuals as user representatives, health professionals, strategists and users described the second strategy of using user groups as proxies or advocates. Managers in all three services reported that they utilized user groups in this way, as representatives drawn from groups were felt to represent a wider range of perspectives and to be accountable to a broader constituency of users. Users also endorsed this strategy.

> "Patients are not necessarily looking for a direct say but want to have a platform. Many are looking for an advocate - someone to whom they can easily and regularly relate who has a voice and can say what is wrong" U8G

In gynaecological oncology services, all groups of respondents described how national and local cancer support groups often represented users. Representatives from cancer groups thought that this was, in part, a reflection of the extensive contact they had with patients. They described how they used focus groups and research to monitor their contact with patients, families and carers to ensure that they were including different facets of the user perspective. However, they cautioned against being seen as representative of all patients as they could only represent those who used their services. Their experience, and research into membership, indicated that this rarely included those from more deprived socio-economic groups. The influence of socio-economic grouping in user involvement is discussed in a later section of this chapter.

Health professionals from maternity services reported that they had ready recourse to individuals who were members of national user organisations, such as the National Childbirth Trust (NCT), and local mutual-aid groups to act as proxies. However, they also felt there were several reasons why this was not necessarily an easy solution. First, they proposed that Glasgow traditionally had few user groups, such as the NCT, that were active and challenging to services and this limited the pool of user representatives. Second, managers reported a concern that such user groups often presented a much-polarised view of maternity services. Finally, in common with respondents from other

services, they also had concerns that such groups were middle-class in nature and, as such, did not represent the Glasgow population.

> "I think that the other thing we need to recognise is that we… work in the east end of Glasgow and… in my experience there are very few active campaigners on behalf of women in maternity services that come from the east end of Glasgow" M6P

Possibly as a result of these concerns, health professionals in maternity services reported how in recent years the MSLC in Glasgow had relied less on national groups and instead sought to formalise its local arrangements with community-based initiatives. It had established a network of local user groups and consumer organisations called MatNet to bring a wide-ranging view on women's perspectives to its meetings. The purpose of MatNet was to ensure that the needs and concerns of users and the wider community systematically informed the MSLC and thus, influenced both local and national policies and practice relating to maternity services.

> "I think the experience of the MSLC is a really good one… in terms of trying to involve them at a high level. I think the maternity network is possibly one of the best things that has happened in Glasgow in terms of maternity services" M10P

User groups were also used as proxies in mental health services. However, unlike the other two settings, managers reported that, as a result of their investment in user involvement, they had a wide range of different groups to call upon with consequent benefits for representativeness and diversity in participation. They described the use of national organisations, the Mental Health Network and a network of local user organisations and support groups. Such groups were reported as partners in services.

> "…they are advocating on behalf of service users, patients, carers - they have now been embedded in our system and they are very much partners in what we do" C11H

In addition to national and citywide user groups, mental health services also had established user forums in every ward and resource centre. However, such service-based user groups were infrequently established or maintained within the other settings. Clinicians in cancer and maternity services reported that they had found difficulties in sustaining these. In cancer groups, membership had fluctuated as a result of poor health and, as Urben (1997) has also noted, members were often looking for these groups to provide information, mutual-aid and support rather than advocacy, campaigning or input into service planning and delivery.

Where user groups are fragile or absent it has been suggested elsewhere that carers or carer groups often act as user representatives (Grande et al 1997; Small & Rhodes 2000). This

was the case in both gynaecological oncology and mental health services, where health professionals and users reported that carers had been accepted as appropriate representatives on service and policy fora.

> "…the difference with mental illness, is that it can at times rob you of your ability to make reasoned and reasonable decisions, therefore you at times have to rely more closely on carers" C10H

However, some authors, Barnes and Walker 1996; Grande et al 1997; Small and Rhodes 2000, have suggested that carers' needs and issues are not necessarily the same as users. Respondents also voiced this sentiment. An example of how carers' issues might vary from those of users was provided by a clinician in mental health who had found that there was more shared agreement between services and users than might be expected, but that this agreement was not shared by carers.

> "I have a couple of times run a workshop where I presented three different clinical case scenarios and I had a panel who talked about how they would deal with conflict issues. I had a user, a carer, a psychiatrist and an elected representative, either a MSP or a councillor… the first time the end result I was surprised, in fact the panel were all surprised, but I say it has replicated every time I have done it, in that the psychiatrist and user are of the same opinion and the carer and the elected representative are of the same opinion" C10H

As we saw in the previous chapter, health professionals were also used as proxies, particularly in gynaecological oncology and maternity services. Some clinicians reported that there were some merits in this strategy as staff could talk on behalf of some groups that would find it difficult to participate. However, there was disquiet among others at the professionals' ability to represent the user perspective and a number of health professionals reported that they were uneasy at taking on such a role, identifying their priority as being the basics of care and not feedback about service structures.

> "I have to say I'm not 100% sure that midwives should be used as a proxy for women…midwives have their own biases as well" M6P

Thus, it can be seen that both of the strategies for identifying user representation identified by Hogg (1999) were being applied in these services and that both had associated difficulties. The first was of these strategies was to invite an individual who is a current or recent user of services as the legitimate representatives of other users. The second was to use an advocate or proxy, most often a user organisation. Managers, clinicians and users all identified how the use of individuals could result in concerns over health and representativeness. As a consequence, a preference was expressed for the use of user groups as they had greater resources and links into a wider range of views. However, it was proposed that, whichever strategy was adopted, user representatives would require support to participate. The issue of support is discussed further in the next section.

> "I don't think it matters where you recruit people from providing they are
> given the support to be able to participate, I think it is unfair to expect someone
> to come in from an antenatal clinic and be able to act as spokesperson for her
> peers or her community" M6P

The identification of user representation was an issue that engendered much discussion but little resolution. Even in mental health services, where the investment in user organisations had provided more opportunities for representation, managers and clinicians expressed unease at the strategies adopted, the small numbers of active participants and the subsequent impact on representativeness and diversity in participation. Few strategies were proposed for how the issues in representation could be overcome, but those that were suggested are discussed in a later section of this chapter. The next section will discuss the concerns raised by respondents over the diversity of the user perspective.

Diversity in Representation

The issue of how representative the user is of his or her group is not new. Studies such as those by Bowling (1996) and Ham (1998) have discussed the difficulties in engaging with marginalized or 'hard to reach' groups while commentators including Steel (2005) and Beresford (2007) have identified groups such as disabled people; single parents; people in poverty; people using mental health services; people with chronic and life-limiting illnesses and conditions; black and minority ethnic users and refugees as being particularly susceptible to exclusion. Strategists, health professionals and users were aware of the risks of exclusion and reported concerns over the lack of diversity in user representation and the lack of inclusion of hard-to-reach groups. All expressed unease regarding how representative the views of user representatives were and the extent to which they were illustrative of all service users, particularly the hard-to-reach groups. They identified women from disadvantaged communities, minority ethnic communities, some faith groups, refugees and asylum seekers and disabled women as being under-represented.

> "… we are not engaging the wider community or organisations like people
> with disabilities or ethnic minority organisations to have a say in maternity
> services" U7P

The central focus of this study was the involvement of women in shaping services to their definition of need. As might be expected in gynaecological cancer and maternity services where women are the sole users of services, women were reported by health professionals and users as being actively involved in decision-making about their health and health care. However, in mental health services, where both men and women can be users, health professionals described the approach taken to user involvement as gender-neutral. Nevertheless, the need to address gender was recognised by some mental health managers and users who reported that they recognised the importance of providing involvement

opportunities in a way that was sensitive to the particular needs and issues of women. In response to this, the city-wide Mental Health Network had established a Women's Forum to support and diversify the participation of women in local services. This Forum was supported and funded by mental health services.

> "There is also support networks out there for mental health service users in the shape of mental health network… they are more pro-active at being gender based" M8H

> "…one of the remits with the Mental Health Network which [___] has tirelessly worked towards is having a dedicated women's forum, which we do now have and we work very hard as a committee, a team of dedicated women and we have a [___] from the ethnic minority project with GAMH, we have a diverse selection of women now that come regularly… and we discuss issues that are burning now for women" U5H

This issue was of particular importance to users who had taken a lead in developing the women's forum as a mechanism for encouraging women's participation.

> "I think what we found was a lot of women were not coming to our forums because our forums are mixed and a lot of ethnic minority women wouldn't come, because there were men that they didn't know…so what we did was we organised women's events. We organised one women's event and it was so vastly oversubscribed that we split it up the following year and it was still oversubscribed, so what we now have is a core of women that really want to be actively involved and have their voice heard" U4H

However, a number of barriers were identified by health professionals and users that served to exclude some groups of women. These, and their implications for women's participation, will be discussed in a later section.

It was reported by health professionals in mental health services that the characteristics of those users who were active in user involvement were typical of the general population of volunteers in that they were committed, vocal people. However, in addition a number of distinct factors emerged from the data that distinguished the perspectives represented. These were health, socio-economic status, stigma and active use of services. Each of these is discussed below.

Health

As already shown, health was seen to be a significant factor in the identification and recruitment of user representatives. However, it was also felt to be a factor in the nature of representation in both gynaecological oncology and mental health services. The physical burden of illness was seen as a major factor in gynaecological oncology services where managers reported that one of the characteristics they looked for in user representatives was a level of good health, which generally meant that patients were at a later stage of, or coping well with, their treatment. Clinicians and users both felt that many patients were so

affected by their disease that they had little time for policy or service issues while others were simply not fit enough to participate.

> "I hear this on the phones, people will phone you and they are just getting by, by the skin of their teeth, they are using every ounce of their energy, their courage, their stamina, their emotional support systems to get through the day, never mind something else" U1G

Health professionals reported that, as a result of poor health, some tumour groups were less well represented in user involvement. This included those with gynaecological cancers, as a result of the particular burden of ill health associated with this. Aggressive tumour sites, such as ovarian cancer, were reported as carrying a greater burden of ill health and a shorter prognosis than others, such as breast cancer. This, it was proposed, led to greater participation in cancer services by patients who had a better prognosis, but a corresponding lack of representation of those from tumour groups such as gynaecology.

> "…the burden of the disease from ovarian cancer… the outcome is so much worse… patients are so bunged up with that disease and coping with it that they don't have time to form pressure groups and run charity organisations and things because they are just busy surviving or should I put it, busy not dying" C1G

Although others have suggested that some people with chronic and life-limiting illnesses may be excluded because they are "too ill to talk" (Small & Rhodes, 2002), there was no reporting of this. On the contrary, health professionals and users felt that ill health should not preclude participation and users said that their experience suggested that patients wanted to be involved, even when quite ill, and especially if they thought something concrete would result.

> "I was interviewing outpatients so they were very, very ill but not extreme, they were well enough to come up to a hospital but nobody ever said they were not well enough to speak to me" U6G

Users and health professionals in mental health services also reported that health impacted on the characteristics of representatives but, in this case, it was those with the greater levels of ill health who were felt to dominate representation. Mental health services work with people with a wide range of conditions. Paradoxically, it was felt that most representatives had a history of severe and enduring mental ill health rather than mild to moderate difficulties, who might have been expected to be higher functioning and therefore more capable of managing the demands of user involvement. Both health professionals and users, however, noted that user representatives with severe and enduring mental health difficulties could not speak on behalf of those with mild to moderate conditions.

> "…that is not necessarily a group that could speak on behalf of people with
> depression who hold down jobs, and attend their GP for regular check ups and
> medication" C10H

In both gynaecological oncology and mental health services, users and health professionals

recognised the vulnerability of users to ill health and identified a responsibility to ensure

that user involvement did not represent a burden to those who were coping with the

diagnosis of cancer, the fatiguing aspects of treatment or who had a vulnerability to stress.

Within mental health services, all groups agreed that where there was a pre-existing mental

health condition, and an associated lack of robustness in mental well-being, there should be

an awareness of contributory factors and the potential health risks of excessive stress or

over-commitment. However, they also agreed that this was not a reason to exclude

individuals from user involvement and identified a need to protect the health and well-

being of individuals. User groups cautioned that such responsibility should not be

influenced by traditional paternalistic attitudes. They expressed concern that users were

sometimes excluded from active participation as a result of an overly protective attitude

adopted by some clinicians.

> "…we don't say we feel you are too unwell to participate we leave the door
> open and we will phone you in a month…but these are people who are
> seriously unwell through mental health problems, so it is an issue, it is not a
> reason to exclude people, it is maintaining dignity and respect for that
> individual" M4H

> "I think it's a hang-up from the NHS, particularly from medical and nursing
> people, who still regard people with problems as being theirs and being rather
> paternalistic about it and thinking that they have got too much to take on. You
> hear that time and again, somebody has asked a question in a clinic "there,
> there, you don't need to worry about that, let me do the worrying for you" U2G

Managers and clinicians from all settings demonstrated awareness of the threats to well-

being but no systems to manage the demands on individuals were discussed or found noted

in formal policies. In particular, despite the concerns expressed in gynaecological

oncology services over the lack of participation by those with the greater burden of ill

health, there was no discussion of how this could be addressed. The exception to this was

in mental health services where their practical experience of user involvement had led

managers to recognise that a policy statement was now required on managing ill health in

user representatives.

> "I think it can be sorted, the group could write an agreement, particularly if it is
> a group of all people with mental health problems, there would be much more
> comfort in doing something, if I become unwell then we agree what the process
> should be" M4H

Socio-Economic Status

Health professionals and users reported that those active in user involvement were largely middle class, well educated and articulate and that services were not engaging with the wider community of interest. In this, respondents sided with the views of a number of commentators (Jewkes & Murcott 1998; Hogg 1999; Bastian 2003; Coulter 2004a; Branfield & Beresford 2006). Socio-economic status was recognised as a particular factor in both maternity and gynaecological oncology services where health professionals and users stated that educated, articulate, middle class women were very highly motivated by user involvement and patient-centred care. Those from more deprived areas, however, were more likely to comply with the advice and guidance of health professionals, lacking the sense of entitlement to contribute to decision-making that was held in middle-class communities.

> "…in more deprived areas it is 'doctors and nurses know best'" M9G

Both health professionals and users in gynaecological oncology services described those who acted as representatives as overwhelmingly middle-class. They proposed that the challenge this created for representativeness was further complicated by the relationship between the epidemiology of cancer and socio-economic status. Some tumour sites, such as cervical cancer, had greater prevalence in lower socio-economic groups whereas others, including ovarian cancer, were described as 'middle-class cancers'. Thus, the tendency for middle-class representation meant that not only was a constituency of women under represented but also, potentially, some tumour groups would have less of a voice. Whilst they acknowledged that middle-class women should be represented, there was also concern over whether the issues of other groups of women were adequately expressed.

> "…if you ever went to any of the Clinical Standards Boards meetings and patients came along and stand up, they were lecturers and business men, they were articulate people, they were brilliant people, and they really gave you insight into to what it was like to be a patient, but didn't give you what it was like for some poor wife with terminal cervical cancer in Maryhill" C1G

Socio-economic status was also a factor in representation in maternity services. As discussed earlier, health professionals and users reported that groups such as the NCT were open to the criticism that they represented the views of middle class women and failed to represent the experiences of women from disadvantaged groups. Maternity service users identified a lack of funding for expenses or payment for participation as a factor in restricting the participation of those from socio-economically disadvantaged groups.

> "I think the patient forums in England they tried to set that up…but the only people that go to them are the people like retired men and white middle class women without children because they can't get their expenses paid" U10P

Some managers and clinicians proposed that women from disadvantaged communities were a largely silent group but others and users disagreed, believing that there was a large volume of articulate views. They proposed that the reason these were not expressed was that women were not given the opportunity to contribute.

> "…if you wait for the women to come to you, you are more likely to get the women who are going to be the more eloquently spoken and more politically aware, the people who would ensure that they got the service they required anyway. It is the wee wifey at the other end of the scale who is a bit 'yes doctor, no doctor, whatever you say doctor' type of thing, you want to ensure that they have a say as well" C8P

Stigma

As proposed by Oliver (1998) and Smith et al (2005), health professionals and users in both mental health and gynaecological oncology services reported the stigma of the disease as one of the factors limiting the numbers prepared to come forward as user representatives. This was a particular issue for those in mental health services where, despite the social movement for community care as well as mass media campaigns to address the stigma of mental health, health professionals still felt that it took a lot of courage to label oneself as having 'mental health difficulties'. Stigma possibly provides one explanation for the lack of involvement of people with mild to moderate difficulties, such as depression. If they were largely integrated into the community and leading a 'normal' life, they were possibly less likely to risk the negative stigma of identifying themselves as a user of mental health services and volunteer to act as a user representative.

> "…it seems to be that mental health service users, once they are out there and are being well within the community don't seem to want to be engaged" M7H

In contrast, it was felt that those with more severe and enduring conditions were less able to hide their mental health status and so were more likely to participate, as they were already identified as a mental health service user. Clinicians and managers described user representatives as 'robust' individuals, who would wear the label of 'mental health user' as a badge. Because of this, they were seen as atypical of the average mental health user.

> "…for every one person that sits on our forums and goes to one of the provider meetings are leaving another 4 or 5 at home that won't come out and say 'yes, I have a mental health problem' and 'yes I use mental health services'" M4H

There was also felt to be a stigma attached to some gynaecological cancers, with cancer of the cervix a particular example, owing to its association with sexual activity and multiple partners. This was reported by both health professionals and users as one group that was often not well represented within user involvement activity.

Active Use of Services

Health professionals and users in all three settings had concerns that many user representatives did not have active contact with services and thus, were unfamiliar with current provision and user interests. However, the reasons for this varied and depended upon the type of service they had attended.

Within gynaecological oncology services, three factors were reported to account for the lack of active contact user representatives had with services. The first, and already discussed, was the relative health status of the user, since many were too unwell to play an active role. Second, health professionals and users reported that some users would remain on service and policy groups long after their experience of cancer as a shortage of other candidates meant that they were repeatedly asked to participate. Finally, user groups identified how former patients, who had acted as user representatives, would ask to be nominated to further groups as they had found this experience empowering. Whilst there were benefits in the use of such individuals, accruing from either their good health or familiarity with service and policy processes, their experience was felt to be out of date and atypical of the views of those currently using services.

> "…really you want to have those views while they are going through treatment, but that is a terribly vulnerable time for people, but…if they are coming then to give you their views, they may not actually be typical of the service because it may have changed" U2G

A similar situation was described in mental health services where health professionals and users also reported that representatives were often unfamiliar with current service provision, particularly inpatient services. Clinicians attributed this to a unique aspect of the mental health setting where, unlike maternity or gynaecological oncology services, users were not "cured" and discharged but rather were engaged, sometimes over a lifetime, on a maintenance basis. This, it was reported, often resulted in representatives that were currently stable and maintained within the community. As with gynaecological oncology services this drew questions as to the currency of their knowledge and experience. One user representative inadvertently illustrated this in her response to a question on the current user agenda for inpatients in psychiatric hospitals.

> "I don't know you see, this is the thing I can only remember my experiences in the past which weren't good so I'm hoping, I haven't had to use inpatient services particularly for over 10 years, certainly not since I have been in Glasgow, so I can't comment" U5H

In maternity services, health professionals and users also reported a concern that the length of time since women's use of maternity services could diminish their capacity to be representative. However, unlike mental health services where users remained within

services, the use of maternity services was described by health professionals as episodic, resulting in many representatives being past rather than current users. One possible reason was proposed by both health professionals and users as the tendency for women to transfer their interest from maternity to school issues as their children grew up.

> "I was speaking to one recently and she feels that now her children are both started school that maybe she is a bit too far away from having used the maternity services to have an opinion" U9P

Managers, clinicians and users reported that it was inappropriate for women whose experience of maternity services was now some years old to represent the current users of services. This was particularly important in view of the substantial changes to services that had occurred over the past fifteen years.

> "I think it is important to have service representation that is representative of the communities who use the service and not just somebody who used the service say 30 years ago, it has to be current and appropriate to the service" C8P

One manager described her concern that the transient nature of women's participation would influence the scope for women to influence service planning. Planning for the Princess Royal Maternity Hospital, which replaced the Royal Maternity Hospital at Rottenrow, was given as a, possibly extreme, illustration of this. The Clinical Director of the Royal Maternity Hospital appointed in the 1970s was identified as the person who was going to build the new maternity hospital, but he had retired before the Princess Royal opened in 2002. Given that health service planning was a lengthy process, this manager questioned how users could remain actively involved over such a length of time.

Thus, in summary, it can be seen that there had been considerable reflection on the issue of representativeness with all groups expressing an awareness of the lack of diversity in the user perspective and identifying a number of factors to explain this. The inter-relatedness of these factors was illustrated by the difficulties in gynaecological oncology services where representation was limited by class, ill health, stigma and active use of services. Those with the lesser burden of ill health were women with cervical cancer but they were affected by stigma and largely came from the reportedly less active lower socio-economic groups. However, middle-class women, who might be expected to be more active, were limited by their greater burden of ill health. Women who were well could participate but they were subject to the criticism that they were no longer actively using services and thus, were unfamiliar with current user issues. Hence, gynaecological oncology services struggled to identify and recruit user representatives.

However, there were few suggestions for how the lack of diversity and exclusion of hard-to-reach groups could be addressed. Those strategies that were identified for widening participation are described in a later section of this chapter.

Whose Interests are Represented?

User representatives in all three settings were described by health professionals and users as acting in users' interests and as motivated by a desire to influence the issues that affected them personally, thus ensuring that others did not suffer from poor services or unsatisfactory treatment.

> "…in my experience from chatting to mums it has been later on that they have wanted to do something about it, to try and avoid other mums going through the same experience they have" U7P

Managers, users and clinicians agreed that many more users were motivated to become involved when major service changes were being considered but proposed that the motivation remained the personal dimension of services and the impact of change on them and their family.

> "I think the Queen Mothers thing that brought a lot of women's awareness to the availability of service in their area, again now that has all calmed down for the time being, it has gone back to them being more interested in their one to one, their day to day services" U9P

However, although user representatives were overwhelmingly reported as representing user interests, there were some suggestions that they could also advocate professional or managerial interests. As discussed in chapter three, Hogg and Williamson (2001) have argued that user representatives tend to support professional or managerial positions rather than users' interests, as users would define them. This contention was recognised within gynaecological oncology services where clinicians and users reported that some women were motivated to participate in service and planning groups in order to show their gratitude to the service. Health professionals and users were concerned that such gratitude could minimise criticism of services and result in user representatives being unlikely to challenge managerial and clinical interests.

> "I look back at the people that looked after my mum, and if they walked in here, I would lie on the floor and let them walk over the top of me - such is my gratitude to them, and we know from what we hear on the phone that a lot of the people are like that" U1G

Health professionals and users also suggested that 'professional users' would advocate clinical or managerial interests. As proposed by Hogg (1999), professional users are those who are perceived as different from other users, having become closely allied with and sympathetic to health professionals. In all three settings a fear was expressed that

repeatedly relying on a small number of highly competent users would result in them becoming 'professional' in their role as representatives and thus, removed from the experiences and views of the majority. In mental health services, users reported their concern that, whilst professional users may become highly regarded by health professionals, they needed to remain closely affiliated to other users.

> "…it is good that you are regarded as a colleague but don't forget that everybody else is being paid to be here, I am here because I have got something to say" U4H

Some health professionals and users reported that there was some value to professional users, as they possessed highly developed skills and knowledge that facilitated their involvement, particularly in service, planning and policy fora. However, user representatives also recognised the dilemma described in chapter three, whereby professional users may be in a position to develop knowledge but, as a result of this, they are perceived as partisan and different from other users. They discussed the difficulties they faced in trying to manage the competing demands of developing their capacity to contribute in professional fora whilst trying not to become overly sympathetic to the constraints under which services operate.

> "There is a real problem with that because there is an advantage in being aware of the system and knowing where to go and knowing how to work the system and all those sorts of things and there is a disadvantage in that you become institutionalised in a way… you shouldn't be on a committee or hold a post for more than three years so you just get into working out how to influence things and then you are meant to resign and it becomes very difficult" U10P

However, as with the issues of identifying representatives and diversifying representation no guidance was identified that could assist services or users to resolve this tension.

The Implications for User Representation

Thus, it can be seen that there were a number of issues in representation and representativeness that caused concern to managers, clinicians and users. For users though, these issues were of particular importance. As suggested by some commentators (Taylor & Lupton 1995; Hogg 1999; Hogg & Williamson 2001; Beresford 2007) they feared that when the user perspective was challenging or confrontational, a charge of lack of representativeness would be used to dismiss or diminish their argument. One user representative gave an example of this, describing how when her position challenged the clinical perspective at MSLC meetings the argument would be raised that her view was atypical of service users. As a result of the highly polarised views expressed at these meetings, clinicians had invited other users, whose views they knew to be in sympathy with their own, to join the MSLC.

> "We were accused on numerous occasions of being unrepresentative. Each
> time we brought up a issue or an argument that did not fit in with the
> committees agenda we were accused of being unrepresentative" U3P

Respondents with a role in the strategic development of user involvement also reported that the issue of representativeness could be used to challenge the policy and philosophy of user involvement.

> "…clinicians in particular, who are not sold on the idea that it is valuable to
> engage with people, will use 'representativeness' as a reason not to" S2

Neither the managers nor clinicians interviewed reported this as a concern, although some managers and users questioned why the issue of representativeness was raised in relation to users, but rarely questioned in other committee members. Some raised the parallels between the health professional's role as representative of services and the user's role as representative of users. It was felt inequitable to assume that professionals could represent a wide range of service perspectives, but users could only speak for themselves.

> "…it would be difficult to argue that any single person was representative on
> that committee and the groups of people that they represent is actually very
> small and I think it is fairly unlikely that each of those people went back to
> their bodies and talked about what had happened on the MSLC." U3P

However, despite all groups expressing a level of dissatisfaction with representation and representativeness, it was clear that there were few strategies being pursued to address the difficulties identified. One view from an interviewee, who held a strategic position in the development of the user involvement policy, confirmed the importance of this issue to health authorities but affirmed the lack of clear guidance on how the difficulties could be addressed. However, this strategist also proposed that representativeness was a 'red herring' and that there was no such thing as a 'representative' user. Thus, efforts to define and classify representativeness were a distraction from the policy's aim of engaging the users of health services in their own care and services.

> "The whole issue of representativeness comes up all the time. I'm asked about
> it often when I'm speaking to groups or to Boards, there is no official line on it,
> but my personal view is it's a red herring" S2

This was a significant view and perhaps provides an explanation for the paucity of guidance to assist services in establishing formal mechanisms that would ensure the user perspective was reliable, accountable and representative. A number of other health professionals and users also challenged the notion of a "representative" user. They argued that it would not be possible to identify an individual who could provide a representative user perspective. However, this contrasted sharply with the frequency with which the strategy of identifying individuals who were well known to services as user representatives

was used. This would suggest that the popularity of this strategy was due more to those users being perceived as a 'safe pair of hands', rather than any claim to representativeness.

> "I don't think there is such a thing as a representative patient. I think they can represent themselves and the patient perspective, but I don't think that they should say it represents patients as a whole, they are representing a view" U6G

> "If you just go and pick a patient who just happens to be a cancer patient, no hope I suppose or justification for expecting that that person is going to give you an objective judgement" C1G

As a consequence, health professionals and users reported that the solution to the difficulties associated with representation and representativeness was not the development of enhanced strategies for the identification of individuals as user representatives, but rather the widening of representation to include a greater number of views and more diverse participation. Strategies for widening representation are discussed in the following section.

Widening Representation

In all three settings it was acknowledged that further efforts were required to widen participation in user involvement and to ensure that the diversity of users was included in debates and discussions on health and health services. Managers, clinicians and users were all agreed that the NHS should take responsibility for enhancing representation.

> "I think it is our responsibility to ensure that we get a wide range of views, otherwise you just get the vocal few fighting for their areas" C10H

> "If the MSLC wants a user voice, it has to take responsibility for making it possible for users to have their say"U7P

There was also agreement that the solution to the lack of diversity was to try to bring a range of different voices, views and perspectives into user involvement. However, despite this agreement, there were very different approaches to widening representation across the three settings. As might be anticipated, given the more systematic and formal approach to user involvement adopted in mental health services, it was here that the most efforts were being made to address the issues in representation. Strategies used by mental health services to widen participation included the introduction of information resources to facilitate recruitment to service and policy groups, the development of policies and formal systems for the provision of support to user representatives and an organisational commitment to develop of a culture of openness and transparency. Representation was also an aspect of their monitoring system for user involvement and selection criteria had been established for membership of some fora. In this, health professionals and users felt that mental health services were different from other health settings and that they had taken

a lead. Health professionals reported their perception that representation was improving because of these efforts. Representation was clearly a continuing problem however, with one manager describing how recruitment to the Division's PFPI group had taken over a year.

> "…all the effort we have put PFPI steering group and the PEAK group to date it is only one small way…I think we need to be much more creative in how we do it" M4H

In contrast, while there was an equal recognition that user representation required attention in both gynaecological and maternity services, there were fewer suggestions for tactics to address this. However, two strategies were proposed by health professionals and users for widening representation in all three settings. The first was the development of techniques to provide opportunities for diverse involvement and the second was the provision of appropriate support to facilitate the engagement of a range of voices. Both of these strategies recognised the requirement for creativity, effort and resources. These are discussed below.

Techniques for Diversifying User Involvement

One aspect of the efforts to widen representation in mental health services was the enhanced range of techniques being actively applied. Managers, clinicians and users each reported that a range of techniques and approaches were needed to ensure that a range of individuals were given the widest possible range of opportunities to participate in user involvement. Mental health service users reported that they were forging relationships with other user groups as a method of widening participation. They were networking with women's groups, not simply mental health groups, in an attempt to talk to women who may not identify themselves as mental health users but nevertheless, had conditions such as depression or anxiety. The women's forum was also recommended as a strategy to facilitate women's participation and to attract users that did not come forward through more formal and non-gendered opportunities.

In contrast, a narrower range of techniques was described in both maternity and gynaecological oncology services. In maternity services, all groups reported that more proactive recruitment was required but there were few suggestions for how this could be achieved. A small number of midwives with development roles, such as in domestic abuse or with asylum seekers and refugees, had proactively sought out women's opinions by going out into the community to meet with and listen to them. The group most active in widening representation though, was users who had adopted a number of strategies. They were active in canvassing the views of women from local communities to support them in their representative role on service and policy groups and all were actively recruiting

additional representatives for such groups. Users reported that these strategies were effective in bringing into user involvement the voices of those women who were often excluded, and their experience suggested that such women could be empowered to have a voice in health and health services.

> "…we found that women were actually very articulate that they had a lot to say but did not feel comfortable going to the kind of meetings that they would have been required to go to in order to put there voices forward. They needed people to go out to them and listen to what they had to say to take that back or for health professionals to have come to them" U3P

However, only users had initiated this activity and none had received support from their MSLC in this.

Similarly, within gynaecological oncology services there appeared to be few alternative techniques for widening representation. However, managers did report on research with patients designed to gather a wide view of services. In recognition of the need to include a wide range of views, the researcher leading this work had gone out to disadvantaged communities and to public venues, such as supermarkets, to speak to those people who were thought less likely to volunteer their opinions or to participate in formal meetings. As discussed in chapter eight, cancer user groups also reported they were active in widening participation through the use of surveys and research to gather a wide range of views.

Despite the support for more pro-active engagement and the use of discursive methodologies, such as focus groups or open meetings, health professionals acknowledged that these techniques had resource implications. They reported that funding was required in order to conduct research or run focus groups that would canvass a wide range of opinion. However, as discussed in the following section, such funding was rarely available.

> "If they had funding round about that and you had an opportunity to go out and canvass the communities and talk to service users, you could talk to people at various phases in their life…you could go out there and ensure that we have representation from all walks of life" C8P

Supporting User Involvement

The second strategy for widening participation and representation was the provision of support for users engaging in user involvement. The types of support proposed included payment for attendance at meetings and for the reimbursement of expenses; the provision of childcare or respite care for those with caring responsibilities and translated materials, translators and sign language interpreters. Health professionals and users agreed that it was essential to have flexible support systems and furthermore, they agreed with the proposal by Bowl (1996), discussed in chapter two, that health professionals had a critical role in establishing, funding and maintaining these.

"If you are the one that wants…the service, then it is your responsibility" M2H

Health professionals and users all agreed with the proposal of Allsop et al (2002) that funding was required to address inequality in participation in user involvement, as the lack of practical and financial support was reported as the principal reason for the exclusion of hard-to-reach groups. All groups of respondents felt, that with the enhanced, routine provision of support in areas such as payment, expenses, adapted papers and reports, childcare, respite and the employment of sign language interpreters, greater diversity could be encouraged in user involvement. The lack of payment and expenses was reported by health professionals and users as discriminating against users who had fewer financial resources and who would require help with such costs as travel or childcare. Furthermore, some health service groups were funded to recompense users for participation while others were not. This, users reported, had the potential to lead to some forums having user representation while others might be less likely to include a user perspective.

> "…some parts of the NHS will pay, if you are involved in doing a new
> National Institute of Clinical Excellence guidelines, you get paid £200 a day,
> whereas if you go to - I was a member of a domestic violence advisory group -
> you don't get paid anything for that, sometimes you don't mind and sometimes
> you do mind" U10P

Users were especially aware of the barriers to user involvement created by the lack of payment and expenses, reporting that the NHS needed to make more effort to support user representatives with this. A particular issue for them was their perception that the NHS did not acknowledge the need for expenses such as travel or childcare. One strategic respondent, who had completed research into this issue, agreed with users' observation that there was a lack of sensitivity to the need for expenses. She reported on a national survey with user representatives in cancer services in which this had been a significant finding.

> "I think most lay reps, the barriers are mainly to do with… expenses, I haven't
> had expenses paid from my MSLC for about the past 3-5 years" U7P

In maternity services, users proposed that there was a dwindling pool of women able to attend meetings, owing to the increasing numbers returning to the workforce, and, as a result, women needed to be reimbursed for attendance during working hours. Without payment, users reported that they were encountering difficulty in providing representation on the many groups and fora they were being invited to participate in. They described this as a significant problem for them.

> "…ironically, we're in the situation now where we've worked, we've
> campaigned so hard to try and get involvement particularly around policy
> making documents, and policy making groups and we're… receiving
> invitations… to contribute to different groups, and also receiving a lot of draft

documents which we just don't have the human power to respond to, we just
don't have the resources" U3P

However, some users and managers sounded a note of caution in respect of payment for user involvement. Managers felt that this would not be appropriate for all users, especially those who were on benefits, while one user described her concern that payment may bring obligations such as regular attendance at meetings or large volumes of paperwork. In view of her mental health condition, in which excessive demands could be an issue in well-being, these obligations and the responsibilities that accompanied them were unwelcome and could potentially precipitate ill health.

> "…as soon as you put money up it is a requirement to be somewhere regularly,
> one of the things I cannot commit to is regular timing, I need to do things when
> I want to do them when I feel I able to do them. I am proactive and active at
> my time, not necessarily everybody else's" U5H

In addition to their concerns for individuals, some users reported that funding could be both a facilitator and a constraint for user organisations, fearing that groups could be compromised by their reliance on services for funding, feeling obliged to support NHS interests for fear of losing their funding if they were confrontational or challenging. Users in mental health, however, reported that they did not feel compromised by the funding arrangements they had with NHS Greater Glasgow and Clyde believing that they had a powerful role as a user group and that they could maintain that within a financial arrangement. Furthermore, they felt that mental health services needed groups like them to help fulfil their obligations in user involvement and so would be unlikely to try to influence them or restrain their independence.

> "I have learned, the more involved I have become in the higher echelons of the
> workings of Dalian House etc they would look very stupid [if they lost our
> input] and they have a lot more to lose than we have" M4H

Other forms of support, such as the provision of childcare or respite care, were noted but not discussed in detail. However, it was proposed by all groups of respondents that these were barriers of particular importance to the exclusion of women from user involvement.

As a result of the difficulties they experienced, managers, clinicians and users proposed that a key development need was the development of guidance on payment for participation and the reimbursement of expenses. Furthermore, in all three settings, health professionals and users reported that funding was an issue that required development with respondents pointing to a lack of investment in user involvement. They argued for dedicated funding and resources, rejecting the idea that user involvement would "just happen". The lack of investment contrasted sharply, it was reported, with the importance of the work and the potential contribution it could make to the future development of

services. However, the investment sought was not substantial as managers, clinicians and users all proposed that a relatively small outlay would be required to meet the costs of user involvement.

> "If the NHS want women to be involved and part of it them they have to face up to their responsibility and in the scheme of things as far as money and stuff is concerned, you are not talking loads of money" U10P

> "…we don't get the proper financial support for it and I'm not saying we need huge amounts of money but we need to have some…" M9G

Managers reported that funding was not only required to support individual participation by way of payment for attendance and expenses for travel, childcare and respite. Resources were also required in order to develop the structures for user involvement. This would include budgets for training and development activity, for staff to support and guide developments and to facilitate the development and maintenance of user groups in order for them to continue to provide a resource to services.   However, mental health services alone had established dedicated funding for user involvement. This included funding to maintain their developing structures and a grants scheme for new initiatives. It was not clear why funding was not available to provide the support required by users. Perhaps services were used to patient groups and the voluntary sector providing representation for free or perhaps, once again, there was an under-estimation of the investment of money and resources required to build robust, representative involvement.

Thus, it was clear that, despite all three settings having made efforts to widen participation and to support user representatives, representation and representativeness continued to present difficulties. In view of their suspicions that concerns around representation and representativeness would be used to undermine the very concept of user involvement, this would appear to be a crucial development need and one that requires significantly more creativity and resources than were reported as being available to services.

Summary

Thus, it can be seen that representation and representativeness were issues that generated much reflection and discussion but little resolution. The concerns of all groups of participants closely mirrored those reported in chapter three, with issues around who represents the user, how representative they are of the wider group of users and whose interests they represent all raised and discussed (Hogg 1999; Hopton & Hill 2001; Coulter 2002a; Steel 2005; Beresford 2007). There was remarkable consistency in the issues identified in the three settings. All used the same strategies to identify representatives and all described similar difficulties with these. All settings reported disquiet that the representatives on their service and policy groups were atypical and shared concerns at the

lack of diversity in representation and, in particular, the under-representation of a number of groups of users. These groups included disadvantaged communities, minority ethnic communities, some faith groups, refugees and asylum seekers and disabled women. However, women did not appear to be under-represented in service and policy processes, although a number of barriers were identified that served to restrict their full participation.

As suggested by the literature, health professionals and users proposed that those users active in putting forward their views were primarily well-educated and articulate people (Hogg 1999; Coulter 2004a; Branfield & Beresford 2006). Other characteristics of representatives identified were health, stigma and the active use of services. There had been considerable reflection on the issue of representativeness with all groups expressing an awareness of the lack of diversity in the user perspective and identifying a number of concerns associated with this. However, the difficulties in identifying and recruiting representatives were unresolved and, as a result, each setting was reliant on a small group of users that were known to them. The problems associated with this were recognised and a tension identified between services' need to identify representatives for a wide range of service and policy processes, while also exercising their duty of care towards individuals by not over-burdening them.

No guidance was identified that would assist in managing this tension and no setting reported having developed policies to facilitate them addressing the difficulties identified. As a result, all groups of respondents proposed that systematic efforts were required to ensure that the user perspective was as wide and descriptive of the experience of users as possible. However, despite the agreement that that the NHS should take responsibility for widening representation, there were few ideas for enhancing recruitment, diversity and representativeness. Those strategies that were discussed focussed on increasing the range of views collected, rather than seeking to identify an individual or user group who could be representative all users.

Thus, representation and representativeness were identified as significant issues in the development of user involvement. However, although a critical area for the progress of user involvement, representation was not the only barrier identified in the literature or by respondents as serving to limit the aims and aspirations of this policy directive. Further barriers have been described and it is the nature of these challenges to user involvement, as well as those facilitators identified by respondents, that will be examined in the next chapter.

Chapter 10: The Barriers and Facilitators to User Involvement

Chapters eight and nine have demonstrated that gynaecological oncology, maternity and mental health services had each responded to the policy on user involvement. However, they have also shown that there are complexities inherent in its implementation and that respondents had an awareness of these. It was clear from the interviews that managers, strategists, clinicians and users had reflected on the practical implementation of user involvement and that all had considered the barriers and facilitators to this. However, while all were able to report on their perceptions of barriers and facilitators, it was only in mental health services that the monitoring and evaluation structures necessary for the rigorous, systematic identification of these and determination of their significance to user involvement had been established. Nevertheless, all groups of respondents entered into considerable discussion on this issue and there was substantial agreement on the nature of the barriers encountered.

As discussed in earlier chapters, there has been some deliberation on the barriers to user involvement in the literature. Shortfalls have been identified in expertise, time and resources as well as the need for a change in the relationship between users and professionals (Harrison & Mort 1998; Levenson 2001; Oliver 2005). For many commentators these suggest a need for a shift in organisational culture rather than a simple reorganisation of financial or training shortfalls (Brown et al 2000; Anderson 2001; Foote & Plesk 2001). Strategists, health professionals and users agreed with this analysis, as the culture of the health service was frequently identified as creating barriers to user involvement.

> "It is about changing the culture, changing that relationship, the way the
> service relates to people, a much more honest, open, accountable
> communication" S2

This chapter will examine the barriers and facilitators to user involvement. As discussed in chapter three, the barriers that restrict user involvement in health and health services have been described by Pickard et al (2002) under the domains of the users' capacity to engage, the health services' capacity to engage, the professional service culture, the organisational ethos of the health service and the dynamics of the national and local political system. These domains will be used to organise the discussion of barriers and facilitators to effective user involvement that were identified by respondents. Finally, this chapter will identify the implications of these barriers for user involvement.

The first domain examined, which produced the most discussion and the greatest number of barriers, was the users' capacity to engage.   As there was significant overlap between these barriers and the factors identified as limiting the capacity of the NHS to engage these two domains will be considered together.

The Capacity for Engagement

The factors that contribute to a lack of capacity for user involvement have been identified as shortfalls in expertise, time and money (Levenson 2001; Allsop et al 2002; Oliver 2005; Branfield & Beresford 2006). All groups of respondents agreed that these were barriers, describing each as factors as limiting the capacity of users, user groups and the NHS to participate in user involvement. This was an area of considerable interest to clinicians and managers as well as user representatives, all of whom identified a number of issues. Lack of funding or payment for participation was discussed in chapter nine so this next section will examine the shortfalls in expertise and time.

Lack of Expertise

Users, clinicians and managers all reported that they lacked expertise in user involvement. The shortfalls in expertise were described as a lack of understanding of user involvement and a lack of knowledge of the decision and policy-making structures of the NHS to which the outcomes of user involvement should relate. These two areas are discussed below.

First, managers, clinicians and users identified a need for training and awareness raising programmes that would provide an understanding among users and all grades of staff as to the purpose of user involvement, its principles, methodologies and processes. They reported that many users and health professionals lacked knowledge of user involvement, its objectives and processes. A manager who was well aware of the problem commented:

> "That is one of my issues when we have some high powered conferences and they must involve users, and I really feel that you are not being respectful to the users because they have not got enough information…we know why we are there and what we are talking about, so we are able to grasp what is going on in the conference, whereas the users don't know" M2H

Managers reported a concern that a lack of knowledge of user involvement was limiting the understanding and creativity of many staff, as while some had expertise in user involvement these were a relatively small group. Many user representatives agreed with this, reporting that while many staff were supportive of the ethos of user involvement on the whole they lacked expertise.

> "It's almost as if they've been told here's a knitting pattern, can you knit this for me but they don't have the wool or they don't know how to read the pattern because they've not been trained - they don't have that training" U1G

Furthermore, health professionals reported a need for users to be better informed about the aims and methods of user involvement. They proposed that such information would assist in aligning users' expectations of the policy with those of health service staff.

However, the greatest and most urgent training need described was for an understanding of the complex and fragmented organisational and management processes of the NHS. Respondents from every group agreed with the findings of Allsop et al (2002), that a lack of knowledge of policy processes was a barrier for user involvement. In all three settings, a lack of understanding of the organisation of the NHS and its decision-making structures was repeatedly reported as a barrier and a considerable training need for both users and health professionals. In addition to creating a barrier for users, staff in maternity, gynaecological oncology and mental health services also reported that they lacked understanding of how service and policy processes operated and, as a result, they had little knowledge of how to influence them.

> "…most of the junior doctors coming through their training if you stop them
> and ask them draw the structure of the NHS and tell me how it work - not a
> chance" C10H

> "It is a bit like me going to Marks & Spencer's AGM and think that I have a
> right to have a say because I shop there, but if I don't understand how Marks &
> Spencer's works then I could be talking complete nonsense at their meeting.
> They (users) don't understand how the organisation works then how can we
> possibly, it becomes a bit useless" M5H

In mental health services, managers expressed sympathy with users in trying to understand the NHS. One manager likened this to a recent interaction with a Glasgow City Council department, an organisation with which she had previously had little contact. She described the experience as being like a detective, coming up against dead ends and blind alleys as she tried to pursue an enquiry with an unknown service. In common with other managers, she felt that the experience of users must be very difficult as they had fewer resources to assist in the negotiation of such structures.

> "I use that as an example to you because I should know how to go about this
> and I can't get a person that can have a discussion with me, so what about the
> poor user?" M3H

In maternity services, both clinicians and users reported that they lacked understanding of the drivers and decision-making processes of policy-making and service delivery. Indeed, one user representative described her difficulty in understanding where decisions were made despite a two-year involvement with the MSLC. Managers were able to describe the services' decision-making and policy processes in detail but both clinicians and users focussed on the MSLC as the principal vehicle for service and policy developments with little knowledge of other structures. Managers, however, reported that maternity services

had a complex, but uncoordinated, planning structure and that there were a number of structures in addition to the MSLC, each of which influenced maternity planning. Furthermore, steering groups were assembled when there were plans for service re-design or service re-configuration. However, except at times of change there was no one group driving strategy in relation to maternity services and no central maternity officer or maternity policy department. This, they reported, led to difficulties for users in understanding the service and policy processes.

> "…there is a committee for this and that and committees for the next thing, how midwives would influence that I don't know so given the knowledge that I have as a midwife how women as users of the service are going to influence that is going to be even harder" C8P

One consequence of user's lack of understanding of the NHS planning and decision-making structures was a concern that while they had a presence on some policy groups there were other, often unnamed, structures at more strategic levels to which they did not have access. This may have been the result of users not having access to top level meetings but, interestingly, managers and clinicians made the same observation when they also reported that they did not always know where decisions were made and their feeling that these were made 'outside' the meetings and formal structures they attended.

> "…the highest we have it the Mental Health Planning & Implementation Group (PIG) but a lot of the work for that is done somewhere else" U4H

> "I didn't understand what was going on, there is a lot of politics and a lot of deals done before you actually go into the room and I miss all that, either it goes over my head or I'm not involved" M4H

One solution proposed as militating against the reported lack of expertise was the provision of formal and informal training. Users and health professionals were described as requiring access to training on their roles and responsibilities in user involvement, methodologies for diversifying engagement, the organisation of the NHS and its planning and decision-making structures.   Managers, in particular, recognised the need for users to receive adequate training in order for them to contribute to user involvement.

> "I suppose a good bit of that has got to be down to the organisation that is requesting the input because surely if you are inviting them to represent users of your service you should give them some kind of briefing around about what they expect, what the service involves, give them some kind of education around about what it all means" M6P

A particular group that were proposed as requiring training were middle managers. These were viewed as a highly influential group in terms of translating high-level policy aspirations into practical initiatives, and so it was seen as important that they had a full understanding of user involvement.

> "…you have the Chief Exec's, and the top level saying yes we should involve patients. How much work has been done to let the management understand and the lower and lower down the line, have they ever had discussions and say we are going to involve the public because of this, this and this" M2H

Where formal training programmes for users had been introduced, such as 'Voices' in maternity services or training programmes from cancer support groups, health professionals and users reported that these had facilitated user involvement. Managers in mental health services reported that they had introduced a number of education and training opportunities such as awareness-raising events with staff, training for user representatives and joint training for the members of the Divisional PFPI group. These were described as having positive outcomes and, for users, as raising confidence and self-esteem. As a result, there was support for the development of on-going programmes of education and training.

In addition to formal training programmes, managers, clinicians and users all agreed that the health service needed to provide informal opportunities to enhance users' knowledge. They proposed that by sharing information with users and communicating fully about the history of the service and the fiscal, resource and policy restrictions they worked within, users would be better prepared for their role in service and policy fora.

> **"**I think sharing of communication is really important and keeping people fully briefed so they know exactly what is going so they know the history and sometimes the kind of barriers as well, I think you may well get someone who has this idealistic vision of how maternity services should be, but of course we are very resource driven, so I think they need to be aware of the limitations as well" C8P

Users in mental health services offered an example of informal training. They discussed how their lack of familiarity with mental health decision-making structures had often led to them accepting excessive demands for attendance at meetings and other fora. Their lack of understanding of mental health services organisationally, resulted in them not being able to judge which meetings were the most important, and so they tried to respond positively to all requests for a representative. To address this, they described how they had developed close working relationships and good networks with health professionals to help them understand and negotiate health service structures. This training took place through mentoring, personal support and sharing of knowledge and information.

> "[____] and I work closely together, I go to Modernising Mental Health meetings, implementation groups, I go to a lot of planning, through the network and primary care we sort of have a link and I report to [____] the [____] manager upstairs" U5H

Lack of Time for User Involvement

Authors such as Read and Wallcraft (1992), Poulton (1999) and Levenson (2001) have commented on the impact of staff workloads and shortages on the potential success of the implementation of user involvement, identifying a concern that involvement would feel like an added burden on an already overwhelming workload. These authors have highlighted adequate resourcing as a prerequisite to empowering users, proposing that if staffing levels are low, making it difficult for staff to spend time with service users, then it is less likely that users will end up fully informed. Health professionals and users in all three setting concurred, identifying a lack of time for user involvement. None identified difficulties in spending time with patients to discuss their care and treatment, but there were a number of issues identified in the shortages of time for user involvement in service delivery and policy planning processes.

Staffing shortages were reported by health professionals as restraining their involvement in service and policy planning groups. Health professionals described user involvement as having a lower priority within services than clinical commitments. Thus, when there were conflicting demands on limited staff resources, clinical commitments would always take precedence over staff involvement in service re-design groups. One consequence of this lack of priority was that some health professionals could be absent from meetings. Users reported that they attended meetings to discuss service and policy developments but were disappointed when key personnel were not there. Examples of this absenteeism included service delivery meetings in mental health that rarely had representation from psychiatrists and psychologists, or MSLC meetings that lacked obstetricians. Users reported that they interpreted this lack of attendance as undermining the purpose of meetings and the value of user involvement. As a result, they lacked confidence that their participation in such meetings would lead to any desired outcomes and questioned their usefulness.

> "…a lot of health administrators allow their MSLCs or the equivalents to go along happily with a few user reps getting together and maybe a nice midwife manager and a few PCT people but never insist that the actual obstetricians or paediatricians actually come and have to listen and I think that is a real weakness at a lot of MSLCs" U10P

Managers, clinicians and users also reported that there was insufficient time built into planning and service timetables for the active involvement of users. Time was required in order to provide sufficient information to users, afford a period of reflection and to enable feedback to be compiled. Sometimes decisions had to be made quickly but getting groups of users together, providing them with information and talking through the issues all took time. Users and managers described a contradiction whereby the NHS wanted planning processes to move quickly but also wanted users to be involved despite this requiring a

slower rate. One particular aspect of the lack of time for user involvement was that this constrained the diverse involvement of users. In a restricted time period, managers reported that they could not implement the more time-consuming discursive methodologies for user involvement nor consult as widely as they would have liked.

> "…the Scottish Executive, they do say they want service user and carer involvement but they hit you with timescales, you think you can't have it both ways, if you want effective users and carers involvement then you need to understand that timescales especially in mental health will be longer" M7H

> "…we tend in the acute maternity services to be very action orientated, focussing on targets and numbers and resources and something like engaging in women's groups and engaging in networking and focus groups is quite a heavy use of time and there needs to be a change in thinking on what is effective use of your time before I would see this as being well accepted" M6P

A particular difficulty regarding user involvement was related to the length of time that planning often took to come to fruition. In maternity services users' involvement was most likely to be time-limited but health professionals and users in all settings reported that the lack of apparent results was frustrating for users. While staff were used to the slow pace of change, for users adjustment to the lengthy periods involved was a learning process.

> "…it is a slow process, all these words like Rome wasn't built in a day, your not kidding when it comes to the whole aspect of health provision everything moves along like a snail" U5H

In summary, shortfalls in expertise, time and money were proposed by health professionals and users as undermining the capacity for user involvement. It has also been suggested by Anderson et al (2002) that user groups lack the capacity to engage because of poor management, unsound local infrastructure and a paucity of contacts with hard-to-reach groups. However, apart from the issue of the lack of diversity of user views, which was discussed in chapter nine, these issues were not broached as factors in the capacity of users.

This was a domain of barriers that generated much discussion, with all respondents finding it easy to describe the barriers that undermined the capacity to engage. There was much reflection, but the majority of the barriers described related to the practical difficulties experienced and there were few reports of how these had been addressed or suggestions for facilitators that could be developed. However, several commentators such as Brown et al (2000), Anderson (2001) and Foote and Plesk (2001) have argued that the implementation of the user involvement agenda would require more than simply rectifying funding or training deficits. User involvement presents a challenge to the traditional paternalistic relationship between users and health professionals and, as such, would also necessitate a redefinition of user and professional relationships. It is the nature of the barriers relating to

the professional service culture and the relationship between users and health professionals that will be considered next.

The Professional Service Culture

Authors such as Williams and Grant (1998), Coulter (1999) and McCrae et al (2002) have proposed that one of the significant changes implied by user involvement and the move towards more democratic forms of health care is a shift from the traditional professional service culture of paternalism and professional authority to a model of partnership. This shift represents a significant change to the professional service culture of the health service as it requires health professionals to accept that users are able to be involved in decision-making. This was recognised by all groups of respondents interviewed.

> "…it's tough for people, it doesn't mean they are bad people it means they have got their role as a nurse or doctor or an OT or whatever…they don't quite see people that use services as their partner, it's a big jump for folk" M3H

However, although proposed as a key factor in the development of user involvement the implications of involving users in decision-making was less discussed than the issues relating to capacity. Nevertheless, within each setting, health professionals and users reported that despite the aim of user involvement to move the health service towards a culture of partnership, professionals continued to dominate consultations, services and strategic planning forums.

> "…when you look at what those groups are actually constituted of, they are largely in the main, totally dominated by professionals, people who provide services…"C11H

The power differential between users and health professionals was proposed as responsible for the continuing dominance of professionals. Both health professionals and users reported that the traditional differences in power held by users and clinicians still existed and that partnership was not the ethos of health service interactions. Users reported that they had no power when using services, as they were dependent on them.

> "…when you are using services, you don't have any power…people that actively use services tend not to complain or rock the boat because they are afraid that the service will be withdrawn" U10H

> "I actually do think there are power differences between doctors and midwives and women… I think that you have to recognise the existence of that, I think there has been some movement towards trying to reduce that differential but it still exists" M6P

Many health professionals and users described how users could modify their participation and restrain their contributions when working on service or policy groups with clinicians, particularly those who were responsible for their care and treatment. In mental health, the

power differentials between psychiatrists and users, fear of removal of services and of compulsive re-admission to inpatient care were all given by clinicians and users as examples of issues that could make users feel reluctant to challenge health professionals or to present an opposing view. In gynaecological oncology services, both health professionals and users reported that the patient's lack of power and feelings of gratitude towards the services, even as a past patient, led to a 'halo' effect whereby they would focus on the positive aspects of services. This meant that they would not raise issues that appeared critical of services or staff. Similarly in maternity services, health professionals and users reported that users were impeded by differences in the perceived gulf between the professional and the user in terms of their differing status, authority and resources.

> "…they feel uneasy about taking part and looking at the redesign of services
> when they would have a medical oncologist or the clinical nurse specialist
> there and I have to say that I'm not comfortable with that either because I don't
> think the patients would give a honest opinion" U3G

This was particularly recognised in mental health services where all respondents reported concern at the conflict that could arise should users find themselves working alongside their past or present clinician on service or policy groups. Mental health users described how they would be inhibited in working with clinicians who held considerable power to influence their future treatment, not wishing to disturb or offend them. In such cases, it was argued that a health professional could not be both a clinician and a service representative and that users would find it difficult to be both a patient and a colleague. It was reported that one of the representatives should either stand aside or the clinician should be replaced.

> "…if they ever got into that position we would need to discuss how we deal
> with it because I don't think I could continue to be a psychiatrist and sit round
> a table as a [   ] with them and we would have to debate what was the best way
> round…I would go to one of my colleagues and say I really don't think I can
> any longer see this individual as a patient" C10H

Mental health clinicians reported that this would be easier to manage in strategic discussions because individual clinicians were not under discussion. However, users disagreed, reporting that it was the character of the relationship between user and health professional and its power differential that resulted in the impediment to their full and meaningful contribution and not the nature of the topic or service under discussion. They proposed that no matter how experienced, articulate and knowledgeable user representatives were, they would find it difficult to work alongside a health professional that had past experience of them as a patient, as well as considerable power to shape their future access to and use of services. Under such circumstances, it was difficult for them to

envisage how users could participate on the equal footing aspired to by the user involvement policy.

> "It doesn't matter how experienced you are it is still as bad, I still get the butterflies in my stomach if I have a meeting and I know my former psychiatrist or psychologist or any of the CPNs I worked with will be there…there is that overwhelming fear that they are going to take you away again if you say the wrong thing, that never goes away" U4H

One explanation for the continuing differences in power was proposed as the need for health professionals to always be in control or have the answers to patients' questions. This was in contrast to the openness to alternative views and perspectives that was required in user involvement. This explanation perhaps illustrates the extent to which the traditional professional service culture dominates the relationship between the health service and its users and the difficulties that are inherent in attempts to move this towards a culture of partnership.

> "It's this bit about the health service, and we are all in it because we want to take care of people and look after people and all the rest of it that's why we are doctors and nurses and all the other things and I think sometimes we take away peoples own responsibility as adult people out there living their lives" U2G

One consequence of the challenge to the professional service culture and the power of health professionals could be professional defensiveness. Professional defensiveness has been described as the danger of staff becoming self-protective if they feel criticised. Many health professional and user respondents reported that this was not an issue as staff were supportive of user involvement. One manager from mental health services reported on the findings of a staff survey that confirmed this.

> "I thought in the South we would have some professional defensiveness from staff and staff saying people are mentally ill so they can't get involved but when we did the survey about looking at what staff training needs were, staff were not professionally defensive at all. I was really pleased to see that" M5H

However, there were some indications that a degree of professional defensiveness could be present but concealed or unacknowledged, as some staff reported their own feelings of defensiveness when people were critical, questioning or challenging to them or their services.

> "I know I have always felt quite insulted that people think I am not talking to and listening to my patients and that there are groups that sometimes they say they can advocate better on behalf of the patient than I would" C11H

In maternity services in particular, health professionals reported this as a concern. This was perhaps a surprising admission in a service that described itself as having a substantial history of user involvement and a commitment to partnership working. However, they also

reported that defensiveness was lessening, as staff became more involved and thus more informed about the value of the user perspective on their care and services.

There remained some staff in all three settings who had reservations about user involvement for a number of reasons. Some clinicians reported reservations that user involvement would move resources to non-clinical issues, while others questioned whether the outcomes merited the investment of time and resources.

> "…you have got the doubtfulness from the clinicians as to how worthy it is - they are worried that it is going to move resources perhaps into the softer issues, rather than the level of equipment and staff" C1G

> "I felt that our ovarian cancer service was fine…and it has caused us a great deal of work for frankly very little reward at the end of the day" C2G

Furthermore, some health professionals reported that there were certain issues that should not be discussed with users present. In gynaecology oncology services, clinicians proposed that the sensitivity of some issues made it difficult for health professionals to work in partnership with users, particularly in service and policy groups. This was felt to be a reason why some were reluctant to involve users. One clinician, who reported that he found it difficult to discuss some issues openly in front of users, illustrated this with the following:

> "…ovarian cancer, it's got a poor prognosis so therefore if the consultants are talking about the poor survival rates…and they have got an ovarian cancer patient there, I think it's very difficult and I think that is why, you know, medical staff perhaps don't always like patients within their group…I don't think they feel they can speak as openly" C4G

This example was a further instance of the traditional paternalistic attitudes described in chapter nine, whereby users were sometimes excluded from active participation in user involvement as a result of an overly protective attitude adopted by some clinicians. However, despite the concern expressed over the differences in power, there were very few suggestions offered as to how this could be addressed. The first suggestion was from a user representative, who proposed that paying users for their participation in groups and meetings could help to equalise participation, as professionals were paid to attend and users were not.

> "I think the single most difficult obstacle is that it is not paid. If it was seen as something that needed to be funded in some way, and we were the only unpaid people on that committee. All the other people on that committee were on salaries" U3P

Second, some health professionals argued for enhanced peer-reviewed evidence that user involvement made a difference to both the quality of services and the subsequent care and treatment received by users. In particular they reported a need for qualitative evidence that

demonstrated the impact on the user experience and their well-being. They proposed that this would help to make user involvement more credible to health professionals.

> "…while you have a bunch of doctors who are mainly rather sceptical or doubtful about the influence of patients, then you are going to have a problem unless you can demonstrate the patient influence is itself effective in improving outcomes" C1G

As discussed earlier, education for staff in the aims, methods and benefits of user involvement was also proposed as helping to reduce levels of professional defensiveness.

There were no other suggestions and it appeared that the health service had yet to find an ideal way to meet the aspirations for a culture of partnership between users and health professionals. In common with Herd and Stalker (1994), all groups of respondents acknowledged that there were differentials in terms of power between health professionals and users but, although recognised as a development need, no solutions had yet been found and there were no reports of any guidance, strategies or development programmes to assist in progress on this issue. In this respect, the data collected bore a strong resemblance to the literature that offered little to help clarify how this new partnership in health services would be managed.

The Organisational Ethos of the Health Service

One particular feature of user involvement is that it seeks to develop debates about the role of the NHS in areas that have been previously less well accepted. This implies greater partnership with users whose 'social' understanding of health may a clash with professionals' 'scientific' ways of thinking. Although not discussed as fully as other barriers there was some recognition that, because they are not 'experts', user views were often not given the same weight or respect as those of health professionals. Strategists, managers, clinicians and users all reported that the professional domination of consultations and meetings, as well as a professionally orientated agenda, led to a lack of confidence that the user view was valued.

> "It is very difficult if you are the token patient rep in a big room filled with professional people in suits, to hold on to what you believe in. It is very difficult, and I hear how intimidated they feel, they don't know the jargon, they don't understand the terminology, they look upon these people as experts, why on earth are they there, they are not supported, they are not briefed, they are not debriefed, they go away with a lot of stuff like "I wish I hadn't said that, I must have looked so stupid" U1G

> "I think that it is important for people who are round the table doing the service planning and planning service provisions for them not to…get carried away with themselves, I think they have to remember that these people are coming from a different angle yet they still have a valuable contribution to give" C8P

Furthermore, the technical language, unfamiliar acronyms and scientific jargon used within services and at meetings were reported by all groups of interviewees as excluding users and reinforcing the differences between lay and expert knowledge. Users, in particular, reported that they found the language used in service settings a barrier. Many health professionals also reported that they recognised this barrier and proposed that clinical and managerial language excluded users and user groups from discussions at meetings and working groups.

> "…language is always a problem, I know it is written in English, but it could be in Urdu for some of the sense it makes sometimes" U4H

> "I think we perpetuate that, it is part of our vested interest if you like - if you are not talking the same language then how can you have a dialogue? We talk in a way, which we assume that everybody knows what you know, that is quite excluding" C11H

One user representative gave an example of how the user's knowledge could be less valued than that of professionals. She reported on a series of meetings where her perspective had differed from the clinically dominated view of the committee. She had noted that her contribution was either inaccurately minuted or not recorded at all. In contrast, other contributions were recorded in detail.

> "…we noticed in minutes, that often when health practitioners spoke their views and recorded quite fully and accurately, our views were often not recorded at all or recorded inaccurately which is very interesting" U3P

Health professionals reported that in their clinical practice with individuals, staff were open to discussion and negotiation on the users' person-centred agenda. However, within service and policy forums, the lack of strategies for weighting the significance and influence of the potentially very different perspectives of users and health professionals was reported as an impediment to negotiation. In circumstances where user's expressed preferences were in conflict with fiscal, clinical or political priorities, there was no guidance to assist health professionals decide which of these drivers should have priority. As illustrated by Mouton et al (1997), Lupton et al (1998) and Squires and Learmouth (2003) there was a lack of guidance to help health professionals balance the different contributions of professional and user interests, or to manage the tension between the pressure to achieve performance indicators as set by national policy and to maintain those aspects of clinical services that, are important to users but, do not feature in political priorities. In the absence of such guidance, managers reported that clinical opinion and research-based evidence remained the prime drivers in service and policy planning and that these could over ride users' views. Without mechanisms for weighting these opposing

perspectives and resolving conflict, users reported that user involvement would have little prospect of influencing services.

> "I think also there is a willingness and a wish to involve lay organisations and different views, but then I think people probably haven't thought through the implications of when there is a disagreement, particularly if the disagreement is so clearly between professional and lay views" U3P

One potential solution proposed for addressing the imbalance in the value of knowledge was, as discussed earlier, to prepare users by sharing information about services and the current fiscal, resource and policy barriers faced. It was felt this would assist users to participate more equally in debates. Users agreed that knowledge was important and had tried to strengthen their participation in user involvement by widening women's participation; bolstering evidence for their view by developing their individual knowledge and understanding of the current developments in health care and by obtaining training in their role as a representative. Such training was described as enhancing the credibility and validity of the user position.

> *"...*so the training is not necessarily about understanding the language as much as helping you to think of yourself as an equal and how to present yourself, professionally, think of yourself as a valid member without having to think oh but I am just a mum, not using that sort of term as such" U10P

Bringing users' knowledge to service and policy processes was viewed by users as a positive development. They proposed that services would benefit from a balance of different perspectives, rather than one dominant view. One user, however, had reservations about the willingness of the NHS to take responsibility for providing users with such knowledge. While accepting that it was the task of services to facilitate user involvement, she questioned the extent to which they would be prepared to search out and support an ideology challenging to the dominant one.

The importance of this barrier was recognised by a small number of users and managers who described the need for a method for weighting the different perspectives of managers, clinicians and users as a priority development need. This was proposed as helping to manage the conflict, reported in chapter eight, between the person-centred user agenda and the dominant clinical philosophy. However, there was no detail given on such a weighting system and while all expressed frustration, there were no suggestions for its progression.

The Dynamics of the Local and National Political System

Despite a considerable literature on the topic of the dynamics of the political system, respondents rarely touched on issues of local versus national policy drivers. Strategists, users and health professionals all reported that the national policy on user involvement had contributed to a change in the culture of the health service and its openness to users and

their perceptions of health and health care. They all described the policy imperative as having facilitated user involvement.

> "I have got a bigger stick now… the Scottish Executive dictates that there has to be user involvement at every level so they have it in their performance assessment framework. User involvement is number 7 but it is just as important as number 1 so whether they like it or not or want it, they have to do it" U4H

However, there was little discussion of how this policy intersected with other national and local policy imperatives. As previously discussed, some health professionals did recognise that there were a number of different policy imperatives and that these may not correspond with the preferences and priorities identified by users but, in common with other issues described in this chapter, there were no suggestions for how this barrier could be addressed.

> "…it's a political agenda I think that may well be on the forefront of the managers minds, but things like seeing the same Consultant or same doctor at the clinic is not a major issue as far as the professionals are concerned…some of those concerns, waiting times definitely, geographical difficulties I think probably not a high profile for the people in the service" C2G

Thus, there were a number of barriers identified and, although these generated much discussion, there were few suggestions for how these could be addressed, minimised or resolved. Furthermore, these discussions focused on practical difficulties associated with user involvement in service and policy processes with very little consideration of the issues of the professional service culture or the organisational ethos of the NHS. The implications of these barriers are discussed below.

The Implications of the Barriers to User Involvement

The barriers described converged to produce a culture that was professionally dominated, responsive to tight timescales, dictated by external factors and lacking both the expertise and resources for partnership with users. This culture seemed to inhibit the development of user involvement, as this would require time to ensure that users were fully informed; the provision of a range of appropriate and supported opportunities to enable them to contribute their views and a commitment to developing a new partnership within which the person-centred user agenda was valued and prioritised. The barriers were felt to be significant, as all three groups expressed a fear that user involvement would become foreshortened by a desire to comply with policy. This would entail health services ticking the box that said user involvement, rather than addressing the considerable work that appeared to be associated with developing the culture of openness, transparency and partnership that could offer benefits to users and services.

> "…like a request from clinical directors saying can a member of MatNet be involved in my 8o'clock labour ward round, no they can't, the paediatrician - can they be involved in something else, the consultant midwife - can they be involved in some sort of audit…no actually they can't because to me, that is a bit of a tick box exercise so they can tick the boxes and say well actually, we spoke to local people, well you didn't if only me and another women and a dog turn up that is not involvement" U7P

The barriers created by shortfalls in time, money and expertise; the lack of a commitment to developing a new partnership with users within which the person-centred user agenda was valued and the shortage of appropriate and supported opportunities to enable them to contribute their views, converged to produce an environment that was described by managers, users and clinicians as unsupportive of user involvement. This was particularly the case for user involvement in examining services and strategic planning. The importance of the environment was recognised by all groups who reported on how this could be intimidating for users and for some staff.

> "It's very intimidating to go along to any of the meetings where you have got a group of managers or chief execs that are there to make, decision making, and even as a nurse you are trying to represent a different aspect of what their plans include. To actually have your voice heard at these meetings can be quite intimidating" C3G

Health professionals and users identified a number of elements of how meetings were scheduled, organised and conducted as contributing to a failure to create an environment of equity in participation. First, the complexity of the agenda was reported as a barrier. A particular issue for users was the lack of control they had over the agenda and the consequent lack of preparation time they had to prepare for the anticipated discussions. They reported that this disadvantaged them in meetings. Second, the preparation required for meetings, volume of work and, as discussed earlier, papers that did not use plain English, had a lot of jargon or acronyms were also reported as difficulties.

> "There is very little acknowledgement to the kind of background work and the support that is needed in order to bring women's voices into the kinds of forums that are available at the moment" U3P

> "I feel sorry for them because the agenda is double Dutch…some of the paper work that comes out for some of these meetings is pages and pages, it is hard enough for us as professionals to read through them but what is it like for patients?" M9G

Third, the timing of meetings was seen as problematic, as most took place during working hours. This was not always convenient for users, particularly women, who could have caring responsibilities or health-related appointments during these times. Women also often had competing commitments to children, nurseries and schools during these hours.

> "… the meeting is on for hours, 2 and a half hours, they are quite lengthy and they are in the afternoon starting at 1pm…local women attending that can't stay until 3pm, they require to leave early for child care arrangements so that is a barrier in it's self" U7P

Users further reported that the professional dominance of meetings could make it difficult for them to contribute. Where other committee members or meeting participants had established effective working relationships, this could make them feel side-lined and unimportant and equally, where there were poor relationships, users could find themselves intimidated by the tone of the meeting. One user representative illustrated this, describing the reaction of users to unprofessional behaviour they witnessed.

> "...you would have one locality manager saying one thing and arguing with someone else over the table from social work and it made it really difficult. You would see all the service users sitting together, all looking at each other saying "I don't like this, want to go now" and some of them did, quite rightly, it's not very professional, they expect service users to be wholly professional and not swear and not want to have a comfort break and want them to sit there for 2 hours and not fidget or fall asleep, but they can be as unprofessional as they like" U4H

All respondents agreed that equality of membership at meetings and groups would not 'just happen' but needed to be proactively developed and maintained. As with other barriers, it was reported that the NHS should take responsibility for ensuring that users were equipped to contribute as equal partners in meetings.

> "…it is not moral or right and it's like you invite one service user to the meeting, you introduce them as a service user but you don't introduce anybody else, everybody has their papers but you haven't given the service user any paper so they are unprepared, once you have asked them for their view you thank them and they are allowed to leave the meeting and you don't remunerate them for their time" M8H

However, it was noticeable that it was only within mental health services that policies and practical measures had been put in place to meet this responsibility. This may have been as a result of their setting having a greater concern with process than the others, where outcomes were more highly valued. Alternatively, this may have been a reflection of a lack of understanding within gynaecological oncology and maternity services of the commitment required in order to construct meaningful involvement in the complex and paternalistic culture of the health service.

Few solutions to the unsupportive environment for user involvement were proposed, but one was for users to model the behaviour, confidence and approach of health professionals. By adopting a similar approach, language and demeanour, users proposed that they could reduce the differences between themselves and health professionals and thus be more effective. Health professionals agreed, reporting that where user representatives had a

professional background they were less likely to be intimidated by jargon, technical language or professional position and authority. However, as discussed in chapter nine, there was disquiet among all groups of respondents at the ability of health professionals to represent the user perspective and to remain independent of managerial or clinical interests.

> "…she wasn't frightened to sit in a room full of professional people and people at management level and say 'I don't think you are right there', she could say 'that's not what I'm hearing from patients'. She wasn't frightened to speak out on behalf of the patients so she was a good advocate for them… her background was clinical so she had a professional background but was much more up to date with what patients really wanted, and that was what worked well" C2G

A number of other actions were identified as assisting in creating an environment that would facilitate user involvement. Users described how some policy groups had established pre-meetings to facilitate attendance as well as meaningful participation. At these, users were able to work through the agenda with support workers and, usually, the Chair of the meeting. In this way they could explore the issues to be raised, identify areas of particular interest, clarify gaps in their knowledge and note the items on the agenda that they wished to contribute to. Managers, clinicians and users all identified the Chair of the meeting as a critical facilitator to a supportive environment. The Chair was thought to be important in setting an environment of openness, ensuring equality in participation, creating space within the agenda that offered a chance to build working relationships with the different personalities involved and for looking after users who were viewed as vulnerable.

> "I think the Chair makes a very big difference, who the Chair person is, and their skills in chairing groups and their skills at eliciting different views. On some committees, the Chair will make a point of asking certain people to comment if they would like to, people who have perhaps been quiet, or people that she knows find it a little bit difficult to put their views forward" U9P

Another facilitative action was the use of a 'buddy' system, whereby users attended meetings in pairs or with a support worker, rather than alone. This was reported by health professionals and users as having been successful in mental health services. Users considered that it had given them enhanced confidence to attend and participate in meetings. Mangers in both maternity and gynaecological oncology services described an interest in developing a 'buddy system'. Furthermore, it was reported that addressing the practical barriers which excluded users, enhanced participation. Users and health professionals discussed how even small changes such as modifying the language used in discussions or altering the start time of a meeting by even half an hour could make a significant difference.

"…one of the service users had a real problem getting to the meeting for 9.30am and she said at the end of the meeting, would anyone mind if we changed the meeting to 10am…it is a very simple example but I think it is about her need, in terms of , I can't get here for 9.30am, well it is ok for the rest of group, lets change the time of the meeting" M5H

Users identified a more significant development need in order to create an enhanced environment for involvement. Rather than the largely superficial changes that would facilitate attendance or presence at meetings, they proposed that there was a need to address working relationships. User representatives reported that the development of an agreement amongst attendees of a code of conduct, a set of agreed rules for behaviour, for meetings would be necessary to facilitate participation, even though it was clear that this would entail significant changes to the ways in which meetings were organised and managed. The difficulty in engendering such change was illustrated by the similarities in the barriers reported in this study and those reported in a study by the Social Services Inspectorate with the National Health Service Executive in 1994. Despite the 13 year gap, both identified styles of meetings, the language used and the complexity of the organisational systems as contributing to hindering involvement (Department of Health, 1994).

It was noticeable that the majority of solutions proposed related only to ensuring that users would be present and able to raise their agenda at service delivery and policy-making fora. However, as discussed in chapter eight, the presence of users at such meetings may not be sufficient to achieve the aims of user involvement. Whilst attendance at meetings and interactions with health professionals may be a facilitator for user involvement, this would not address the barriers arising from the professional service culture and the organisational ethos of the NHS. Nevertheless, while these barriers were identified and their significance recognised, there was little to suggest that there had been any reflection on or guidance for how to address the fundamental power differentials within the health service or the multifaceted, clinically dominated agenda within which health professionals were seeking to incorporate the user perspective.

The culture of the NHS, and in particular of its decision-making structures, appeared responsible for the lack of user involvement in the processes associated with service delivery, as described in chapter eight. In addition to the external drivers described earlier that restricted the advancement of the user's person-centred agenda, the barriers created by the complexity and fragmentation of service decision-making processes, lack of time to consult fully with users, lack of expertise on the part of both users and health professionals and the lack of guidance on how to address these barriers all converged to make involvement in service processes difficult for both users and for the health service. Where

users had been successfully involved in service development and decision-making processes, such as in service re-design, the facilitators for this were described as defined aims, identified timescales and ring-fenced resources. It was evident that none of these facilitators were identified in the discussion of user involvement in routine service delivery.

The individual relationship between the user and the health professional in involvement in individual care and treatment was described as offering the conditions within which knowledge could be shared, communication provided and negotiated decisions made. Similarly, in strategic planning, user involvement was largely within single-issue policy groups, where a user or user group could develop a relationship with the group or body convened to examine a specific aspect of health policy. In contrast, involvement in examining services was recognised by all groups as requiring that large numbers of staff and users found a system for managing their interaction within a complex agenda and multi-faceted decision-making structure. As shown from their responses, all groups of respondents acknowledged the difficulties inherent in this but, could not identify how these could be addressed. These findings illustrate the force of the culture of the NHS and, as Ham (1992) reminds us, this is difficult to change.

Summary

In summary, strategists, health professionals and users in all settings recognised that there were barriers to user involvement and all reported a number of significant areas that required development. However, although some barriers were described in each of the domains identified by Pickard et al (2002), the greatest number and most detailed discussions focussed on the users' rather than the health services' capacity to engage. This was despite the recognition by all groups that the current organisation and culture of the NHS was unsupportive of the policy imperative on user involvement. Strategists, health professionals and users proposed that user involvement required a culture of support, value and resources, but that this was not the existing environment of the health service. This was described as being professionally dominated, responsive to tight timescales dictated by external factors and lacking both the expertise and resources for partnership with users. Such a culture inhibited the development of user involvement that required time to ensure that users were fully informed, given appropriate and supported opportunities to enable them to contribute their views and in a relationship of partnership with health professionals within which their person-centred agenda was valued.

The importance of these barriers was demonstrated in their significance for issues such as representation and involvement in shaping health services to users' definition of need. It

was proposed by health professionals and users that many of the practical barriers, such as lack of funding, the exclusionary ways meetings were organised and the lack of recognition of the need for childcare or respite, were particularly relevant to women and potentially excluded them from health service decision-making processes. Furthermore, the culture of the NHS, and in particular of its decision-making structures, appeared responsible for the lack of user involvement in service delivery and local policy-making. The lack of priority for the users' person centred agenda, the barriers created by the complexity and fragmentation of service decision-making procedures, shortage of time for user involvement, paucity of expertise on the part of both users and health professionals and the lack of guidance on how to address these barriers all converged to make involvement in service and policy processes difficult for both users and the health service.

Closely associated with the identification of barriers was the recognition by health professionals and users of facilitators and development needs. However, as with the discussion of barriers, the facilitators described were of a practical nature and there was little identification of action that could address the barriers created by the professional service culture, the organisational ethos of the health service and the culture of decision-making in the NHS. This lack of action was illustrated by the similarities in the barriers reported and the findings of a 1994 study. Despite the 13 year gap, both identified styles of meetings, the language used and the complexity of the organisational systems as contributing to hindering involvement (Department of Health, 1994).

The development needs discussed by all groups of respondents revealed the depth of organisational commitment required in order to progress user involvement in health and health services. Whilst the concept of user involvement may initially appear straightforward in that it seeks to develop dialogue between users and the health services they use, an examination of these barriers revealed the complexity of this within a multi-faceted, complex health system, within which users have not traditionally been regarded as partners. Managers, clinicians and users identified the development of guidance for the health service as a pressing need. This would include advice on formal systems and processes to support user involvement; strategies for supporting equality of participation in service and policy groups and for systematically monitoring and evaluating user feedback in order to demonstrate the outcomes and value of involving users. A further development need was that of training and education for both health professionals and users. This was in recognition of the lack of understanding that currently existed in many aspects of this agenda, including the purpose of user involvement, its principles, methodologies and processes.

However, the significance of these development needs had been under-estimated as respondents were unable to offer any substantial proposals for the way forward. There was no guidance on addressing the fundamental difficulties in managing the socially constructed user agenda within the clinically dominated service culture of the NHS or on re-defining the relationship between health service users and health service professionals. The preceding discussions illustrated the significance of partnership to the meaningful implementation of user involvement and the shift in culture it represents. It could be argued that without the move to partnership then user involvement represents nothing more than a concerted attempt to ensure that users are present at treatment, service and policy discussions. However, for them to meaningfully contribute to and influence these requires a more fundamental shift in power, partnership and entitlement.

Chapter 11: Discussion

The preceding chapters have described the views of strategists, managers, clinicians and users on the implementation of the policy directive on user involvement in health and health services. They have also discussed the successes of this implementation, outlined the limitations and difficulties experienced in each of the three settings under examination and considered the implications identified for the future development of user involvement in the NHS. This chapter draws together these findings to address the aims of the study.

This study examined the scope, relevance and quality of the user involvement processes available in health services. It appeared timely and relevant as user involvement has come to form a central element of government policy on public services, and health in particular, with a series of specific policy commitments to give users a stronger voice and to involve them in the health service having been published by both the Westminster and Scottish parliaments. These seek to increase users' involvement in making decisions about their own care and treatment, in examining and improving the quality of services and in policy and planning activity (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). In doing so, this policy aspires to respond to the changing culture of personal and societal expectations of health and the health service; to build democratic participation in the difficult targeting and rationing decisions faced by health agencies and to renew public confidence in the NHS (Barnes & Evans 1998; Bury 1998; Hogg 1999a; Olzsewski & Jones 1999; McCrae et al 2002). These are ambitious aims, seeking as they do to re-define the relationship between health users and health professionals and to shape accountable and responsive services (Brooks 2001; Scottish Executive 2001; McCrae et al 2002).

The significance of user involvement is demonstrated by the expressed commitment to user participation in shaping health policy, service delivery, planning and prioritisation decisions by all major political parties. The recent change in political administration in Scotland has not reduced the drive towards user involvement but, rather, has strengthened it, following electoral commitments to address the publics' health policy and planning concerns. Indeed, it could be argued that judicious use of the commitment to listen to peoples' views and overturn unpopular local planning decisions played a role in securing electoral support. In such a political context it appears important to understand the nature of user involvement and its capacity to influence public services.

This chapter will explore the key findings of this study and the implications of these for the implementation of user involvement as envisaged by the policy directive to develop both individual care and health services in ways that are responsive to users. It will then discuss

the limitations of the methodological approach adopted by this study, before identifying those areas that would require further research. Finally, it will summarise these findings in the key features of a model for user involvement, derive conclusions and propose lessons for the further development of this significant and potentially influential policy directive.

The Aims and Structure of the Study

In order to develop a better understanding of the issues in user involvement this study explored the nature of user participation, the character of user representation and the barriers and facilitators to user involvement in three service settings: maternity, gynaecological oncology and mental health services. In doing so, it sought to explore the capacity of existing user involvement mechanisms to engage users in determining their health care and in shaping health services and policy to their definition of needs. The study explored the issues identified in three types of user involvement, by four groups of stakeholders, from three different health service settings. It was anticipated that this structure would facilitate a case study methodology of comparison, revealing those aspects that were particular to each case and those more common to a variety of contexts. Each aspect of the study's structure is discussed below.

The three types of user involvement investigated were involvement in making decisions about individual care and treatment, in examining and improving the quality of services and in strategic policy and planning activity. These three types were identified by a number of authors in this field including Charles and De Maio (1993), McIver and Brocklehurst (1999) and McCrae et al (2002). The early decision to look at these three types to explore what each could provide by way of insight into user involvement proved fruitful. Each yielded different reflections on the operation and functioning and of the concept. The strengths and weaknesses of the implementation of user involvement that this examination identified are discussed in a later section.

The three settings explored were selected on the basis that each had some level of user involvement activity. In each, users were involved in their own care and treatment, participated in examining services or played a role in strategic planning. However, the settings were also chosen for their different characteristics, which included the nature of the illness or condition treated, the focus and outcomes of treatment, the qualifications and role of staff, user prognosis and the expectations of user involvement. As a result, each setting was able to give different examples of user involvement, its understanding and implementation. Nevertheless, while respondents discussed their own situation, and often laboured the differences between themselves and other areas of the health service, there were a number of themes that were common to the three settings.

The four groups of respondents were similarly chosen to represent a number of different perspectives on user involvement. These groups were managers, clinicians, users and strategists. Each had an interest in the issues under examination, whether that was because of their role in planning, implementing or participating in user involvement. However, although they each had diverse roles and responsibilities in relation to user involvement, it was noticeable that there was a considerable degree of accordance between these groups. Their analyses of user involvement demonstrated more similarities than differences and there was significant agreement on the major themes. As illustrated in chapters eight, nine and ten, a wide range of issues were identified in the three types of user involvement, in the three settings and by each of the four groups as being relevant to the implementation and development of user involvement. What emerged were many similarities in the understanding and functioning of user involvement, but also some differences and it is these that will be discussed in this chapter.

The Health Service Response to the Policy of User Involvement

It was clear that each of the three settings had reacted positively to the policy on user involvement, all had a degree of engagement with service users and all were endeavouring to find ways to continue to develop their interaction with users. The overall response to the policy demonstrated a commitment to the principles of user involvement, a shared understanding of its aims and agreement with the philosophy of user participation in individual care and treatment, examining services and the strategic planning of health services. In all three settings, health professionals and users described their acceptance of the principles of user involvement, their comfort with the focus on the needs and interests of users and their approval for the overall aims of the policy.

The practical responses to the policy imperative included an investment of time and energy to create the conditions within which user participation could be fostered. Health professionals and users described a number of structures to organise and support user involvement and the use of a number of informal and formal methods to gather the views and preferences of individuals. The degree of organisation and investment varied between settings, with mental health services having established an elaborate and well-resourced structure and utilising a range of methodologies for gathering user feedback that were appropriate to the nature of the questions asked and the people being engaged. In contrast, both maternity and gynaecological oncology services had a much less elaborate structure, used fewer methods and had no identified funding to support their efforts.

It was not clear why the responses of these three settings varied so significantly, as all faced the same challenges in terms of fiscal, policy and organisational pressures.

However, one possible explanation could lie in the differing nature of the illness and prognosis in mental health services. A unique aspect of the mental health setting is that, unlike maternity or gynaecological oncology services, users are not "cured" and discharged but rather are engaged, sometimes over a lifetime, on a maintenance basis. This has led to mental health services having a greater concern with practice rather than cures and it is this attention to process that may be reflected in their greater investment in the structures, organisation and systems for user involvement.

Nevertheless, despite the differences in their approaches, all settings had a considerable degree of success in the implementation of user involvement and could each draw identifiable links between users' expressed needs and treatment decision-making or service developments. Health professionals and users in each setting were able to identify a sizeable degree of successful user involvement in two of the three types of user involvement that were being examined. These three types are the involvement of individuals in making decisions about their own care and treatment, involvement in examining and improving the quality of services and involvement in health service policy and planning. The reports from the three service settings showed remarkable consistency in identifying similar degrees of achievement in implementing these.

In all three settings, user involvement in individual care and treatment was established and patient-centred care was the preferred model of treatment. This type of user involvement was facilitated by the clinical relationship between the user and health professional that allowed for the sharing of information and effective communication. Furthermore, this type of engagement with users capitalised on health professionals' existing knowledge, skills and clinical priorities, requiring little in the way of additional expertise, time or resources for implementation. Tensions had emerged in the implementation of patient-centred care, as not all users wished to participate, and the constraints under which services operated placed restrictions on the influence that users could have in their care plans. However, despite these tensions, it was evident that this type of user involvement was fully accepted and constructively implemented.

Similarly, the user voice was successfully represented in national policy fora and respondents felt that user influence could be seen in the general progress of the policy and philosophy of health in recent years. There was user representation on national groups charged with shaping policy in all settings and this influence was felt to be beneficial to the policy process. Furthermore, considerable successes were reported in the active and effective participation of users in strategic planning for discrete projects such as local planning for new hospital facilities or in service re-design initiatives. In these instances factors such as the defined aims, limited timescales and ring-fenced resources had

facilitated user involvement in decision-making about policy, facilities and service development. The focussed nature of these projects, their often time-limited engagement and the additional resources provided to support user involvement had allowed users and health professionals to work in a productive partnership on a number of significant developments.

However, there was little success in user involvement in routine service examination and delivery processes and, as a result, it remained challenging to find ways of involving users in the long-term rather than in one-off consultations. All recognised the value of the application of the collective experience of users to the evaluation and development of service delivery systems, all demonstrated an awareness of the complexity and demands of this type of user involvement and each service setting had attempted to integrate users within service processes. There had been efforts to tackle the shortfalls in time, training and resources for user participation in service delivery systems but the barriers created by the complexity and fragmentation of service decision-making processes, lack of time to consult fully with users, lack of expertise on the part of both users and health professionals and the lack of guidance on how to address these barriers all converged to make involvement in examining services difficult for both users and for the health service. As a result, each setting continued to struggle to involve users effectively in examining and developing services and in the local interpretation and implementation of national policy directives. This chapter will now explore the reasons for the weakness of user involvement in examining services and what this may mean for the implementation and future development of user involvement in health.

The Key Findings of the Study

Despite the endorsement of the value of user involvement and evident success in implementing some types, it was clear that the implementation of this policy was proving more complicated and challenging than anticipated. Strategists, health professionals and users from each setting had given considerable reflection to the barriers and facilitators to user involvement and had identified a number of development needs that would assist them in taking forward their commitment to the policy. They identified a gap between the ambitious aspirations outlined in the policy documents and the actual functioning of the concept. This gap was illustrated by the weakness in the application of the user perspective to the development of a pro-active approach in the evaluation, delivery, development and planning of local health services.

Two key findings emerged as possible explanations for the limits experienced in implementation and as justifying the claim that user involvement is a complex and

demanding concept for the health service. These key findings are first, that health professionals find the development of meaningful partnership with users challenging and second, that there is little room for the users' agenda within the multifaceted and demanding organisational programme of the health service. A further key finding was that user involvement was dominated by users that were atypical and not fully representative of all those that use health services. This chapter will explore these key findings and their implications for the further development of the concept of user involvement as both a model of partnership in individual care and a pro-active and positive approach in areas of service change, policy development and planning.

The Challenge of Partnership

The examination of the history and development of the policy on user involvement demonstrated that there were a number of social, cultural and political trends that had converged to create the conditions for the increased influence of users in the health service. These trends represent a move towards more democratic forms of health care and include a drive towards more equality between lay and expert knowledge in health and a shift from the traditional professional service culture of paternalism and professional authority to a model of partnership (Barnes & Evans 1998; Scottish Association of Health Councils 1999; NHS Executive 1998; McCrae et al 2002). The subsequent aims outlined for the policy on user involvement reflect these trends aspiring as they do to build new alliances between users and health professionals (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). This study, however, revealed significant implications for the core relationship of the NHS, uncovering complexities and challenges in developing a partnership between health professionals and health users that are not explicit in the policy documents.

The issue of partnership generated much discussion with health professionals and users describing an unequal partnership between health professionals and health users and the continuing professional domination of clinical consultations, service and policy processes. Differences in the power held by professionals and users to influence decisions in treatment, service and policy processes; professional defensiveness and traditional paternalistic attitudes, whereby users were sometimes excluded from active participation in user involvement as a result of an overly protective attitude adopted by some clinicians, all contributed to the challenge of partnership. There was common concern with issues of partnership, with a high degree of overlap between the difficulties experienced by users and those encountered by the staff of the health service.

One particular feature of user involvement is that it seeks to develop debates about the role of the NHS in areas that have been previously less well accepted (Scottish Executive, 2002). This implies greater partnership with users whose 'social' understanding of health may a clash with professionals' 'scientific' ways of thinking. However, this aspect of partnership was problematic, as because users are not perceived as 'experts' their views are often not given the same weight or respect as those of health professionals. As a consequence, there was a lack of confidence that the user view was valued and a concern that the dominant medicalised construction of users as possessing less expertise has had the effect of user understanding being viewed as inferior to professional knowledge. Within this climate, the user view was relegated to the status of personal and subjective and was often regarded as secondary or inferior. Such a view of user knowledge and experience was recognised as adverse to the development of an equal partnership within which treatment, service delivery and policy decisions could be made.

This finding is shared with other authors such as Williams and Grant (1998), Coulter (1999) and McCrae et al (2002), who have proposed that the development of partnership is the most significant change implied by user involvement, and Anderson (2001) and Foote and Plesk (2001), all of whom anticipated that the success of user involvement would be highly dependent upon radical changes in the interaction between users and professionals. The success of user involvement in patient-centred care and in one-off projects, where the conditions existed for developing effective working relationships, provided evidence that partnership was a significant influence on the success, or otherwise, of user involvement. The clinical relationship between the user and the health professional in involvement in individual care and treatment was reported as offering the conditions for an equal partnership within which knowledge could be shared, communication provided and negotiated decisions made. Similarly, in strategic planning, user involvement was reported as largely within single-issue policy groups, where a user or user group could develop a working relationship with the group or body convened to examine a specific and highly focussed aspect of health policy. In contrast, involvement in examining services, where less success was reported, was described as requiring large numbers of staff and users to manage their interaction within a complex agenda and multi-faceted decision-making structure. The development of partnership working within this context was significantly more challenging.

These findings emphasise the value of the principles of patient-centred care and the need to promote collaboration between users and health professionals. On this the findings agree with the proposition of Coulter (2002c) and Pickard et al (2002) that partnership is key to the development of effective user involvement. They proposed that the failure of the flurry

of user involvement activities to have an impact can be ascribed to a fundamental flaw in the policy that has promoted involvement in committees, planning groups and policy fora at the expense of the important issue for users, which is patient-centred care and their interaction with health professionals. They suggested that the new relationship of partnership that could be developed through patient-centred care may have onward benefits for those users struggling to make their voice heard in committees, to work constructively with other, often more powerful, stakeholders and to better manage the complex health service agenda over which they have little control. This study has provided some support for this proposition. User involvement in patient-centred care and in focussed projects, where the conditions for developing strong working relationships existed, suggested that partnership was a significant influence in the success of user involvement. However, it was less clear whether there would be onward benefits as the scale of the challenge in developing partnership in service processes were significant. Even in mental health services, where there had been considerable attention paid to structures, systems, funding and methods for meaningful involvement, both users and health professionals still struggled to work constructively and to address the user agenda in service level forums.

Respondents described clearly the nature of the challenges arising from a shift in professional service culture, but were unable to identify any models available to assist them to progress this issue. In common with Herd and Stalker (1994), they acknowledged that there were power differentials in terms of funding, power and obligations between health professionals and users but, although recognised as a development need, this study was unable to identify any guidance, strategies or programmes to assist them in equalising these. Furthermore, there was recognition that a method for weighting the different perspectives of managers, clinicians and users as presented in service and policy processes was a priority development need, but there was no evidence that this was being addressed.

The lack of strategies to assist Scottish health agencies in managing these emerging tensions in user involvement appeared stark, with little to help clarify how the new partnership in health services implied by user involvement would be developed. Hence, the NHS faces a challenge in defining and developing partnership if it is to deliver on user involvement's aims of changing the ways in which the health service interacts with the people it serves.

The Advancement of the User Agenda in the NHS

The second key finding arising from this study was that the multifaceted and demanding organisational programme of the health service presented little scope for the adoption and progress of the user agenda. The users' agenda was identified by health professionals and users as a person-centred set of issues that focussed on the 'softer' elements of care and

treatment. This agenda was welcomed and endorsed by health professionals, but they contrasted this with the target-driven, organisational programme for which they were accountable. It was acknowledged that the organisational agenda held the higher priority although the explanations for this diverged. Users attributed this to the dominant medical model ideology of services while health professionals proposed that this was due to the differential application of finance, political and organisational priorities. Tensions in the implementation of the user agenda had emerged with health professionals reporting difficulties for users in understanding the responsibilities of services and the constraints that shaped the organisational agenda.

The management of the user agenda within service and policy processes, where a complex and challenging organisational agenda was dominant, emerged as a significant issue in the implementation of user involvement in service delivery and local planning processes and indeed, the organisational and user agendas diverged most significantly in these arenas. Within all services, managers described a current organisational agenda focussed on the implementation of new legislation, organisational re-configuration and political imperatives such as waiting list initiatives. These factors all contributed towards a prioritisation of fiscal and staffing issues. This organisational agenda left little room within service processes for the users' person-centred agenda that held less priority and had fewer sanctions for non-delivery. Thus, while reporting their endorsement of, and agreement with, the person-centred agenda, health professionals also reported that it was difficult to progress this in the prevailing climate of the rigorous fiscal management of public services within which funding issues overrode most other concerns.

The significance of the difficulties in addressing the user agenda was again demonstrated within mental health services where a comprehensive structure for user involvement had been developed. Links between user feedback and service processes were in place and the methods used to gather user feedback showed sensitivity to the people being engaged. In many respects these services might then be expected to have made progress in user involvement in service processes, in a way that both maternity and gynaecological oncology services had not. However, health professionals and users from mental health services reported that they faced the same difficulties in establishing user involvement in examining services. This would suggest that it was not sufficient to understand the user agenda, to feed it into service processes or even to have users in attendance at service delivery fora to present their issues. The complexity of service decision-making processes, the dominance of health professionals and the prominence of the organisational agenda all limited the potential influence of users and their agenda in service delivery and local policy

making processes. In such a context, mere knowledge of the user agenda or presence of user representatives was not sufficient to generate influence.

All groups of respondents expressed concerns around the implementation of the user agenda, demonstrating the potential for conflict in the introduction of a person-centred user perspective within a health service structure where a clinical philosophy has traditionally dominated policy direction and service decision-making. As a result, there was little scope for user influence in those spheres of health service decision-making that had the capacity to change the ways in which services are planned, developed and delivered as envisaged by the Scottish government (Scottish Executive 1997; 2001; 2002; 2004). However, the significance of this had been under-estimated as no respondents were able to offer any substantial proposals for the way forward or to address the fundamental difficulty in managing the user agenda within the clinically dominated service culture of the NHS.

Thus, in embracing user involvement repercussions can be anticipated for the professional service culture of the NHS and the nature of the relationship between health users and health professionals. Whilst the concept of user involvement may initially appear straightforward in that it seeks to develop dialogue between users and the health service, this study revealed the complexity of this within a multi-faceted, complex health system within which users have not traditionally been regarded as partners nor their agenda held any priority. The meaningful implementation of user involvement, and the shift in culture it represents, depends upon the re-definition of the relationship between health service users and health service professionals and a move to partnership, as without this user involvement offers only the opportunity for users to be present at treatment, service and policy discussions. User involvement clearly requires more than that: it needs power, partnership and entitlement.

User Involvement: Whose Voices and Whose Interests?

Matters of representation, the identification of user representatives for service delivery and policy processes and the extent to which representatives were reliable, accountable and characteristic of the wider group of service users were of considerable interest to all groups of respondents. All reported disquiet that the representatives on their service and policy groups were atypical and a number of distinct factors emerged that distinguished the users represented. These were health, socio-economic status, stigma and active use of services. It was agreed that systematic efforts were required to ensure that the user perspective was as wide and descriptive of the experience of users as possible, but there were few ideas for enhancing recruitment, diversity and representativeness. It was not clear who would speak for those from deprived communities; how those with language or communication difficulties would be involved; how those with severe health difficulties or a significant

burden of ill health would be included or how the voices of those with stigmatising or socially unacceptable conditions would gain an equal place in discussions and debates.

Those strategies for widening representation that were discussed focussed on increasing the range of views collected, rather than seeking to identify an individual or user group who could be representative all users. However, there was no guidance to assist health agencies on representation and efforts made in each service setting to identify and recruit a wide range of views were undermined by shortfalls in time, funding and expertise in discursive techniques for user involvement. As a result, there was concern at the lack of diversity in representation and, in particular, the under-representation of a number of users such as those from minority ethnic communities, some faith groups, refugees and asylum seekers, disabled women and disadvantaged communities.

A particular feature of this study was an examination of the participation of those identified as marginalised in user involvement. It chose to look at the participation of women, as the literature suggests that this is a group who are often excluded from the decision-making processes of health services. The findings demonstrated that women did have the capacity to contribute to decision-making in their individual care, to the examination and development of services and to strategic planning processes. However, there were barriers that could exclude women from participation in user involvement and many practical barriers such as lack of funding, the inconsiderate ways meetings were organised and the lack of recognition of the need for childcare or respite were particularly relevant to them. Other barriers, such as the lack of payment for expenses or the use of highly technical language, served to exclude other groups identified as hard-to-reach, including those from more deprived communities.

Of particular concern was the identification of those users active in all three types of user involvement as primarily middle-class, well-educated and articulate people. In individual care the notion of 'doctor knows best' still prevailed among those from deprived communities, while the educated and articulate were more likely to expect to play a role in their treatment decisions. Similarly, in service and policy decision-making processes, it was again middle-class users that were most likely to play a role in meetings, groups and forums. This raises some uncomfortable issues for equity in health and health services as it suggests that it is not the public who are engaged in determining the future of the health service, but rather the well-educated, middle class public. This leads to questions as to who will represent the needs, preferences and interests of other groups of health service users. If the interests of those from Glasgow's deprived communities are the same as those of the middle-class suburbs, then there is little cause for concern. However, if these do not

correspond, then the potential exists for the health service to exclude from its deliberations and planning a group of users who arguably have different needs.

The failure of the NHS to identify and engage with a diverse and representative constituency of users has profound implications for the application of equity in health and health services and represents a significant challenge for the NHS. Without action to ensure diverse participation, user involvement is likely to be partial and reflect broader social divisions and exclusions, with articulate, educated users empowered to demand treatments which others are unable to access and to shape health services to their definition of need. As a publicly funded service, the NHS will require strategies to ensure that it does not exclude the differing needs of those who lack a similar sense of entitlement to shape their health service, have communication difficulties or who simply lack the skills, resources and confidence to participate.

A Model for User Involvement

The preceding discussions can be summarised as the key features of a model for effective user involvement in health services. This model identifies the factors arising from the implementation of the policy imperative and proposed by respondents as fundamental to establishing a credible and effective paradigm that would facilitate the development of future, systematic user involvement with the capacity to inform both policy and practice. These features are proposed as the re-definition of the relationship between users and health professionals, representation, the links to service delivery and policy processes, the capacity for user involvement and funding. Each is discussed below.

Re-defining the Relationship between Users and Health Professionals

The most important feature of the model is the re-definition of the relationship between users and health professionals; from a traditional paternalistic model to one of partnership. The features required in a model of user involvement concerning the relationship between users and health professionals are as follows:

- The promotion of collaboration between users and health professionals that emphasises the principles of shared decision-making and a new relationship of partnership with users

- The development of a method for weighting the different perspectives of managers, clinicians and users

- The development of mechanisms for the management of the user agenda within a clinically and financially dominated organisational programme

Partnership is fundamental to the development of user involvement and all the other four features discussed below would also relate to the development of this new partnership.

Representation and Representativeness

The second feature of a model process concerns representation. This would include the need to identify representatives who were able to focus on broad rather than single issues, to pro-actively involve 'hard to reach' groups, and to ensure that forums for user involvement are not dominated by specific interest groups.

- The establishment of formal mechanisms to ensure that the user perspective is reliable, accountable and representative and that recognise the need for particular efforts to engage with and involve those groups viewed as 'hard to reach'

- The use of engagement mechanisms that engage a wide range of different views offering both diversity in the user perspective and support to the individuals nominated as representatives

- The need for a variety of methods that ensure an appropriate methodology for both the issues under discussion and the individuals being engaged

Underpinning activities on representation would be a principle that creativity and resources would be required to ensure that individuals were given the widest possible choice of opportunities to participate in user involvement and that these opportunities extended beyond those who traditionally have a sense of entitlement to involvement.

The Links to Service Delivery and Policy Processes

The third feature relates to those mechanisms that link the outcomes of user involvement to the decision-making structures that have control over service delivery and policy-making processes. This is the key to the development of a credible model of user involvement, one in which both users and health professionals understand how feedback from users is systematically appraised, measured and applied. In order to ensure this a model of user involvement would require:

- Reliable mechanisms linking the feedback obtained from users and the outcomes of user involvement activity to the service delivery and policy making processes of the health service

- Structures to ensure the practical integration of user involvement activity and routine practice

- Effective monitoring and recording systems to audit and report the application of user feedback and its outcomes

The Capacity for User Involvement

Fourthly, it is clear that there are several factors relating to the capacity of both users and the health service to engage in user involvement. It is proposed that a model of user involvement should encompass the following:

- The agreement of the priority of user involvement activity within the clinical commitments of health professionals and the identification of adequate time for partnership with users and participation in service and policy processes.

- The rescheduling of planning and service timetables to permit sufficient time for the active involvement of users.

- The provision of formal and informal training programmes for both users and health professionals to support and educate them in their roles and responsibilities in user involvement, methodologies for diversifying engagement, the organisation of the NHS and its planning and decision-making structures.

- The provision of appropriate support to facilitate involvement in patient-centred care as well as attendance at and participation in meetings and forums. This would include information, communication aids, practical support such as childcare, payment for participation, where appropriate, and the reimbursement of expenses

- A commitment to attend to the organisation, scheduling and conduct of service delivery and policy making meetings to ensure a capacity for participation

Funding for User Involvement

Finally and underpinning all the features of a model process, is the need to attend to the lack of investment in user involvement. A model of user involvement requires several actions regarding funding. These are as follows:

- The identification of dedicated resources to support the development and maintenance of the structures for user involvement. This would include budgets for training and development activity, for staff to support and guide developments and to facilitate the development and maintenance of user groups in order for them to continue to provide a resource to services.

- The development of guidance on payment for participation and for the reimbursement of expenses

- The provision of funding to support individual participation by way of payment for attendance and expenses for travel, childcare and respite

- The introduction of funding streams with dedicated policies, staff and resources to oversee and give direction to user involvement policy

Funding emerged as a key principle of user involvement with implications for both the organisation and management of user involvement as well as equity in participation.

Thus, it can be seen that the model process for user involvement aims to tackle the service culture of the health service, the organisation and structures of participative mechanisms as well as the practical measures required to build effective, measurable and representative participation in health and health services. The features of a model of user involvement were proposed as the re-definition of the relationship between users and health professionals, representation, the links to service delivery and policy processes, the capacity for user involvement and funding. These features are illustrative of the paradigm shift required in order to ensure that the implementation of the policy on user involvement meets the ambitious aims outlined for it and the challenges it represents to the core concepts, relationships and entitlements of the health service.

However, although each of the features of this model is important, there is a clear priority for the re-definition of the relationship between health service users and health service professionals, from a traditional paternalistic model to one of partnership. The preceding discussions illustrated the significance of this to the meaningful implementation of user involvement and the shift in culture it represents. It could be argued that without the move to partnership, the other four features represent nothing more than a concerted attempt to ensure that users are present at treatment, service and policy discussions – for them to meaningfully contribute to and influence these requires a more fundamental shift in power, partnership and entitlement. In England and Wales programmes such as Local Involvement Networks (LINks) (Department of Health, 2006) and World Class Commissioning (Department of Health, 2007) have been developed in an effort to address issues of user capacity and the re-distribution of power in user involvement in health and social care services, but Scottish health authorities do not have access to these mechanisms and there are currently no similar capacity-building initiatives in Scotland. The recent introduction of Independent Scrutiny Panels (Scottish Government, 2007) as a mechanism for independent, expert and probing scrutiny of the service proposals of health authorities is designed to provide assurance that proposals are safe, sustainable, evidence based, represent value for money and that they take appropriate account of local circumstances and the views of individuals and communities. This may offer support to health agencies in this area, but the concept of Independent Scrutiny Panels, for now, remains largely undefined and its potential unexplored.

A model of user involvement that highlights the key features for the operation of this important concept could be used in the following ways. First, as a succinct summary of a number of complex and inter-related issues in the functioning of user involvement, it

would appear to have value in providing leadership and advice for those health professionals who are struggling with the paucity of detailed guidance available to assist them in their efforts to implement the policy. The model's comprehensive description of the processes, underpinning features and key elements of the functioning of user involvement may assist them in their understanding of user involvement, its purpose, principles and procedures. A second use of the model would be in providing a framework for the development of a training resource for both health professionals and users. The value of training was repeatedly raised by respondents in this study but few training materials and resources were described. Furthermore, those resources that were identified tended to focus on the practical methodologies of user involvement rather than on the transformation in relationships and entitlements required for the successful implementation of the aims and philosophy of the concept.

A third use of the model would be the provision of assistance to those hard-pressed health professionals seeking to quantify and describe the challenges they face in ensuring the meaningful implementation of the policy. The model's description of the processes and features of the paradigm shift involved in the adoption of user involvement and its implications for the core relationships, concepts and entitlements of the NHS may assist health staff in attracting the necessary funding and guidance to ensure they can deliver on the meaningful implementation of the policy.

Fourth, it is envisaged that the model could provide a useful starting point for the production of papers describing the study and its findings. If accepted by peer-reviewed journals, these could make a contribution to the further understanding and development of this concept, its practical implementation and potential impact upon the ethos and culture of the NHS.

Finally, this model does more than simply identify the key features for consideration in the practical implementation of the policy; it also contributes to the development of an explanatory framework for user involvement. This study was based on an understanding of user involvement as underpinned by concepts of democratic accountability and citizenship (Brooks 2001; Scottish Executive 2001; McCrae et al 2002). The importance of issues of partnership, accountability and democratic participation to the respondents would appear to demonstrate their significance to any theoretical framework. They confirm the move from the ideology of individualism and consumerism to partnership as a key plank of public policy and illustrate the import of a philosophy of user involvement that derives from an understanding that users have a democratic right to involvement. Further research is required to facilitate the development of an explanatory framework that goes beyond the agenda of patient-centred care and instead describes user involvement, its

benefits and disadvantages, in relation to user experience, public expectations and the consequences for the governance of health systems.

Limitations of the Study

There are a number of limitations in the methodology and conduct of this study that should be taken into account when interpreting the findings. One constraint identified was the question of who might have taken part. This is important in reflecting on the extent to which the findings are generalisable to other areas. It has been argued that it is philosophically problematic to generalise from the particular in qualitative work (Hammersley 1992; Coffey & Atkinson 1996). In this study, it was felt that although true 'representativeness' would have been impossible to achieve and might have had little meaning, it was important to ensure that the sampling strategy did not exclude any viewpoints that may contribute to the study, especially if these perspectives had the potential to be different from those included. However, there were reasons for considering the possibility of bias in the sample.

The final sample was judged to represent national and local observations on user involvement, the perspectives of four sets of key stakeholders and the position of three distinct service settings, but it was recognised that there were number of factors that limited representativeness. The first factor lies in the selection strategy adopted. The sampling strategy employed in this study was a combination of judgement and snowballing. Bias may be introduced by a snowballing strategy, as respondents may be more likely to identify and nominate further respondents that share their values, knowledge and experience and are thus, within their existing networks. It may be less likely that they will identify those whose attitudes and values differ from their own and who are outside of their personal networks. Furthermore, those with more definite views might be more likely to agree to be interviewed, but they may also represent a more enthusiastic and possibly optimistic view of user involvement in health and health services.

This potential bias was compounded by the second factor. This was the overarching priority to recruit participants with a degree of experience in the development, application and implementation of the policy on user involvement. This yielded a sample that was, on the whole, highly committed to and supportive of the policy. However, it also influenced the outcomes of this study in that the interviewees had pre-existing knowledge of the subject and little resistance to developing their interventions in user involvement. Thus, whilst care was taken to ensure a balance of perspectives, gender, professional status and setting location, it was accepted that all participants shared, to some extent, a pre-disposition to developing their knowledge and management of user involvement. This

shared attitude to user involvement may present an explanation for the considerable overlap in the responses of the sample groups of user representatives, managers, clinicians and strategists.

A final factor that may have influenced the findings was that of the researcher's familiarity with both the subject being explored and many of the interviewees. The researcher had a shared history with some of the interviewees through membership of groups and committees, joint work or previous involvement in health research. This was reinforced by the researcher's known commitment to the principles of user involvement. As many respondents were aware of the researcher's values, they may have amended their answers to reflect this. Regular feedback from and review by the research supervisor was obtained in an effort to monitor the effect of this shared history but, nevertheless, it may have had an impact. Familiarity with the researcher may have introduced bias in the form of respondents altering their responses to give what they perceived to be the required response rather than their true reaction.

Thus, because of the way that sampling was conducted, nothing is known about those who did not take part and there would seem to be the possibility of an element of bias in the composition of the sample. Care should then be taken in interpreting the findings as these apply to a relatively well-disposed, motivated and knowledgeable group of health professionals and user representatives. Further research will be required in order to evaluate the engagement in this policy of those health professionals and users who are less familiar with the subject or who lack an active commitment to the issue.

However, whilst these limitations may have limited the generalisability of the findings to other populations, the conclusions are generalisable to theoretical propositions and as such they have value in developing an understanding of the social process of user involvement. Furthermore, in this analysis of the three case studies, the primary concern was not with their generalisability to other settings but the development of an understanding of the processes associated with each. The comparison of the three gave a degree of clarity as to those aspects that were common to a variety of contexts and, as such, provide some lessons for the future development of this key social policy.

Useful Avenues for Further Study

This study has raised a number of questions that would benefit from further investigation as an analysis of user involvement and its implementation in the intricate, multi-faceted and clinically dominated health service demonstrates a level of complexity apparently not anticipated by the policy directives. In order to take forward this investigation it is proposed that any future study should reflect the democratic participation and partnership

aspired to by the policy of user involvement. This study has demonstrated the capacity of users to contribute to the NHS and the services they use, and there is an increasing body of literature highlighting the principles of user involvement in research (Telford et al 2004; Faulkener 2004; SURGE 2005). The value of user involvement in the design, commissioning and conduct of health care research has been recognised within the NHS R&D Programme and the UK Clinical Research Collaboration and Networks (INVOLVE, 2008). Furthermore, in England and Wales the Department of Health is funding the INVOLVE programme of the National Institute for Health Research (NIHR) to promote public involvement in NHS, public health and social care research (INVOLVE, 2008). INVOLVE defines involvement in research as "an active partnership between the public and researchers in the research process rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to' or 'about' or 'for' the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research". The work of the INVOLVE project is underpinned by a belief that the active involvement of members of the public produces research that reflects the needs and views of the public, can lead to more relevant research and is more likely to produce results that can be used to improve practice in health and social care.

It is proposed that there are a number of tensions that have emerged from the implementation of user involvement that require further definition, clarification and explanation. These concern issues of partnership, influence and representation. The work of the INVOLVE project in promoting user involvement in prioritising, commissioning, conducting, applying and communicating health service research provides a number of indications for how users could be involved in future investigations arising from this study. Users' experience of engagement with the health service, and appreciation of the barriers to this, provides an unparalleled understanding of the key matters requiring the most immediate attention. This could facilitate their active participation in the prioritisation of these issues and the identification of the focus of any subsequent research. Furthermore, users and user groups could effectively assist in identifying research questions, establishing the values base of the research, commissioning, analysing, reporting and disseminating the findings. Of particular importance to the democratic approach to participation would be the adoption of participatory methodologies and processes for establishing user influence in the application of research findings and in deciding and undertaking follow up action.

The research questions arising from the tensions around the dominant culture of professional authority within the health service, the involvement of users in shaping and developing the services they use and representation are each discussed below.

The Professional Service Culture of the Health Service

The significance of partnership as a building block for user involvement was apparent. The policy documents on user involvement acknowledge collaboration as a key element and exhort health services to embrace partnership with users as the way forward for the development of a responsive, accountable and publicly endorsed NHS. However, whilst the broad principle of partnership is accepted, there is little in the way of detailed definition of the nature and practical development of this, particularly in the context of a prevailing culture that is so thoroughly dominated by a traditional service culture that assumes professional responsibility for users rather than offering them partnership.

In this context, there would appear to be an urgent need to investigate an enhanced definition of the implications for the professional service culture of health and health care arising from user involvement. The practical experience gained by health service settings, as they have begun to implement this policy, has given many an insight into the scale of the changes required if the policy is to achieve its aims of partnership and collaboration. Further exploration of these insights may not only support hard-pressed health professionals in quantifying and describing the challenges, but may also assist them in attracting the necessary funding and guidance to ensure they can deliver on the meaningful implementation of the policy.

Two pieces of guidance emerged as requiring urgent development to support health professionals in implementing this policy agenda. The first was leadership to help health agencies clarify how the new partnership in health services implied by user involvement would be developed and to manage the tensions arising from this re-defined partnership with users. The second was advice on methods for weighting the different perspectives and priorities of users, managers and clinicians, particularly in view of the differing agendas and priorities of these groups and their potential for conflict within service and policy processes. One area of health service research that may offer assistance with these is the work on patient-centred care, particularly shared decision-making, which has sought to develop the understanding, attitudes and skills of partnership within individual care and treatment. Work to extrapolate the insights of this work to the complex partnerships required in service and policy processes would appear to have the potential to offer much to the further implementation of user involvement.

User Involvement in Shaping and Developing Services

As discussed earlier, there have been varying degrees of success in the implementation of user involvement with some types, such as involvement in individual care and in national policy processes, having realized a degree of acceptance and effectiveness that other types, notably involvement in examining services, have yet to achieve. As a consequence, there is less scope for user influence in those spheres of health service decision-making that have the greatest capacity to change the ways in which services are planned, developed and delivered. This has implications for the ability of the policy to deliver on one of its central aims: to build responsive and accountable services. Involvement in shaping and developing services is, then, an area that would then require urgent attention if user involvement is not to become merely a superficial attempt to uncover the needs and preferences of users. It also needs to address how these preferences are applied to and ultimately influence health services. A detailed examination of the barriers to user involvement in the evaluation, delivery and development of routine services would be an important first step in taking forward user participation in examining services.

Furthermore, despite the frustrations and challenges experienced by health professionals and users in trying to influence service delivery processes, both groups reported that there was effective user involvement in discrete, tightly focussed planning or service re-design initiatives. Some facilitators for this were identified. It is proposed that the further exploration and detailed identification of these facilitators would not only be of benefit to an understanding of effective user involvement within the context of discrete projects, but would complement the work on involvement in routine services by helping to further clarify and define the challenges and barriers faced by user involvement in this key area of the delivery of health services.

Representation

Representation and representativeness emerged as significant issues for the user involvement agenda, with all groups of respondents expressing concerns over the atypical nature of user participation and fears for the equitable development of the health service agenda. However, although representation was the subject of much discussion and speculation, this study adds little to the deliberations within the field or the debates over whether user involvement merely panders to a middle-class agenda. Many respondents reported their fears that some groups of users were excluded from participation but, with little detail collected on those who did participate, these concerns were hard to verify.

As a first step to addressing these deliberations it would seem important to discover if the perceptions of atypical representation are accurate by conducting a rigorous examination of the nature of user participation in the three types of user involvement. If, following an

examination of participation, it does prove to be the case that some groups are less active in user involvement then there would seem to be a need to attend to the methodological issues and other factors that serve to marginalize some voices. This would be a particularly important consideration if user involvement is to deliver on its ambitious aims of re-connecting the public with the NHS and introducing democratic participation in health service processes.

Conclusions

Recent years have seen a power shift in the NHS, away from professionals and towards the users of services. User involvement now forms a central element of government policy on public services, and health in particular, with a series of specific policy commitments to give users a stronger voice in the health service having been published (Scottish Office Department of Health 1997; Scottish Executive 2000, 2001; Scottish Executive Health Department 2002; Scottish Executive 2005). These policy commitments have ambitious aims that go beyond simply identifying user views and preferences and instead aspire to use these as a catalyst for changing the culture of the health service, the ways in which the NHS interacts with people and the ways in which services are delivered (Brooks 2001; Scottish Executive 2001; McCrae et al 2002). The policy directive on user involvement in health and health services can be seen to be both the culmination of many years of development and a new concept for the NHS.   It is the consequence of the changing culture of personal and societal expectations of health and the health service that have sought to increase the influence of individuals in public services as well as a growing political imperative to address perceptions of a democratic deficit in the publicly funded NHS (Barnes & Evans 1998; Scottish Association of Health Councils 1999; NHS Executive 1998; McCrae et al 2002). As such, it is a concept which health professionals and users are both familiar with and challenged by.

This study has examined the implementation of this policy and has demonstrated that the familiarity with, and acceptance of the principles of user involvement, has resulted in many successes for this policy and an effective voice for users in some aspects of the health service. However, these far-reaching aims also present a number of challenges to the culture and professional ethos of the health service. These include the development of meaningful partnership between health professionals and health users, the adoption of the users' person-centred agenda within a complex and demanding organisational programme and the identification of a user voice that is reliable, accountable and characteristic of the wider group of service users. These are not inconsiderable issues and represent a challenge to some of the core concepts and relationships of the NHS. The scale of the development

required to address these challenges, however, emerged as largely undefined and, as yet, overlooked.

The study also uncovered the complexity, intricacy and demands of the organisational programme within the health service. In the current context of rigorous fiscal and target driven management, it has proved difficult for health professionals to implement the policy, despite their comfort with its principles and understanding of the potential benefits it could bring to health and health services. It is clear that health service settings and health professionals need support if they are to implement this ambitious policy to its greatest effect, but little was found in the way of funding, resources or guidance to provide them with the assistance they required.

It would seem important that these development needs are attended to; less user involvement develops as little more than a superficial attempt to understand user interests, falling short of these interests having an influence within the NHS. Without a shift in culture, users will continue to have little authority in the decision-making processes of the health service. Failure to address issues of partnership, the user agenda and representation could have serious consequences for equity in the NHS, with only those who have power, confidence and a sense of entitlement being able to take the opportunities for influence offered. Of greater concern, however, maybe the loss of an opportunity to bring the NHS, its future planning and the funding, staffing and training challenges it faces into the public domain, allowing all stakeholders to contribute to the difficult decisions the health service faces in times of growing demands, changing expectations, rapid technological and medical advances, but declining funding.

By seeking to involve the users of the health service in the challenging rationing and targeting decisions that face the NHS there is surely the scope for greater understanding and agreement in the difficult decisions to be made. This presents an unparalleled opportunity to shape a health service acknowledged as responsive, publicly accountable and recognisably operating for the public good.

List of References

Abbott, J., Dodd, M. & Webb, A. (1995) Different perceptions of disease severity and self-care between patients with cystic fibrosis, their close companions and physician. **Thorax.** 50, pp 704–796

Access to Health Records Act (1990) (c. 23) London, HMSO

Adam, S. (2001) Special Delivery. **NHS Magazine** August 2001

Adult Commission (1996) **What the doctor ordered.** London, HMSO

Allsop, J, Baggott, R. & Jones, K. (2002) Health consumer groups and national policy process in Henderson, S & Petersen, A (eds) **Consuming Health: the commodification of health care.** London, Routledge

American Academy of Child and Adolescent Psychiatry (2001) **Psychosis** [Internet], available from: <www.aacap.org/about/glossary/Psychos.htm> [Accessed April 2006]

Amstein, SR. (1969) A ladder of citizen partnership. **Journal of the American Planning Association**. 35 (4), pp 216-24

Anderson, W. & Florin, D. (2000) **Involving the public – one of many priorities**: a survey of public involvement in London's primary care groups and trusts. London, King's Fund

Anderson, W., Florin, D., Gillam, S & Mountford, L. (2002) **Primary care organisations and public involvement. Every Voice Counts.** London, Kings Fund

Andreassen, H., Bujnowska-Fedak, M., Chronaki, C et al (2007) European citizens' use of E-health services: A study of seven countries. **Public Health.** 7, (53) pp 1471-2458

Asher, A (1984) Neglect of the consumer in Tatchell, M (ed) **Perspectives on Health Policy**. Canberra, Public Affairs Committee and Health Economics Research Unit, Australian National University

Association of the British Pharmaceutical Industry (1999) **The expert patient—survey, October 1999** [Internet], available from <www.abpi.org.uk/publications/publication_details/expert_patient/survey.asp> [Accessed March 2007]

Avis, M., Bond, M. & Arthur, A. (1997) Questioning patient satisfaction: An empirical investigation in two outpatient clinics. **Social Science and Medicine.** 44, pp 85-92

Ayana, M., Pound, P., Lampe, F. & Ebrahim, S (2001) Improving stroke patients' care: a patient held record is not enough. **BMC Health Service Research** 1(1), [Internet] available from <http://www.biomedcentral.com/1472-6963/1/1> [Accessed March 2006]

Baggott, R. Allsop, J. & Jones, K. (2004) **Speaking for Patients and Carers: Health Consumer Groups and the Policy Process**. Basingstoke, Palgrave Macmillan,

Barker I. & Peck E. (1987) **Power in Strange Places: User Empowerment in Mental Health Services.** London, Good Practices in Mental Health

Barker, P. (2007) **The Tidal Model**. [Internet], available at http://www.tidal-model.com> [Accessed May 2008]

Barley, V., Rimmer, J.& Sanidas, M (2002) **Developing and evaluating best practice for user involvement in cancer services.** Avon, Somerset & Wiltshire Cancer Services (ASWCS). [Internet], available at http://www.aswcs.nhs.uk/userinvolvement/index.htm> [Accessed June 2006]

Barlow, J., Turner, A. & Wright, C. (2000) **A randomized controlled study of the arthritis self-management programme in the UK**. Health Education Research. 15, pp 665-680

Barlow, J., Wright, C., Sheasby, J., Turner, A & Hainsworth, J. (2002) Self-management approaches for people with chronic conditions: a review. **Patient Education and Counselling.** 48 pp 177-187

Barnard, S. (1998) Consumer involvement and inter-agency collaboration in clinical audit. **Health and Social Care in the Community.** 6(2), pp130-142

Barnes, M. (1997a) **The people's health service?** Research Paper No 2, Birmingham, NHS Confederation

Barnes, M. (1997b) From passive recipient to active citizen: participation in mental health user groups. **Journal Mental Health.** 6, pp 289-300

Barnes, M. (1999a), Researching public participation. **Local Government Studies.** 25 (4), pp60-75

Barnes, M. (1999c) Users as Citizens: Collective Action and the Local Governance of Welfare. **Social Policy & Administration**. 33, (1), pp 73–90.

Barnes, M. & Evans, M. (1998) Who wants a say in the NHS? **Health Matters**. 34, pp 6-7

Barnes, M. & Shardlow, P. (1997) From passive recipient to active citizen: Participation in mental health user groups. **Journal of Mental Health**. 6, (3), pp 289–291

Barnes, M. & Walker, A. (1996) Consumerism vs. Empowerment: a principled approach to the involvement of older service users. **Policy and Politics.** 24, (4), pp 375-393

Barnes, M. & Wistow, G. (1992) **Researching User Involvement.** Leeds, Nuffield Institute for Health Service Studies

Barnes, M. & Wistow, G. (1994) Learning to hear voices: Listening to users of mental health services. **Journal of Mental Health.** 3, pp 525-540

Barry, MJ., Cherkin, DC., Chang, Y., Fowler, FJ. & Skates, S. (1997) A Randomised Trial of a Multimedia Shared Decision-Making Program for Men Facing a Treatment Decision for Benign Prostatic Hyperplasia. **Disease Management and Clinical Outcomes,** 1, (1), pp. 5-14

Bastian, H. (1996) Raising the Standard: Practice Guidelines and Consumer Participation. **International Journal for Quality in Health Care.** 8, (5), pp 485-490

Bastian, H. (2003) Just how demanding can we get before we blow it? **British Medical Journal** 326, pp 1277-1278

Bates, E (1983) **Health Systems and Public Scrutiny: Australia, Britain and the United States**. Kent, Croom Helm

Bates, E & Linder-Peltz, S (1987) **Health Care Issues**. Sydney, Allen & Unwin

Bauman, Z. (1998). Postmodern adventures of life and death. In Scambler, G. & Higgs, P. (eds.) **Modernity, Medicine and Health. Medical Sociology towards 2000.** London, Routledge

Bekker, H., Thornton, JG., Airey, CM., Connelly, J., et al (1999) Informed decision making: an annotated bibliography and systematic review. **Health Technology Assessment**. 3, (1)

Bell, A. (2000) Involving the public: it's not just for Christmas. **British Journal of Health Care Management.** 6, (6), pp 272-3

Bell, S., Brada, M., Coombes, C., Miles, B., Morris, E., Richards, M. & Tritter, J. (1996) **Patient-Centred Cancer Services: what patients say?** Oxford, The National Cancer Alliance

Beresford, P (2007) User involvement, research and health inequalities: developing new directions. **Health and Social Care in the Community**. (10), 1111, pp 1365-2524

Berger, E., Carter, A., Casey, D. & Litchfield, L. (1996) What's happening with consumer participation? **Aust N Z J Mental Health Nurs.** 5, pp 131-135.

Bezjak, A., Ng, P., Skeel, R., et al. (2001) Oncologists' use of quality of life information: results of a survey of Eastern Cooperative Oncology Group physicians. **Quality of Life Research.** 10, pp 1–13

Bhugra, D., La Grenade, J. & Dazzan, P. (2000) Psychiatric inpatients' satisfaction with services: A pilot study. **International Journal of Psychiatry in Clinical Practice.** 4, (4), pp 327-332

Birchall, M., Richardson, A. & Lee, L. (2002) Eliciting views of patients with head and neck cancer and carers on professionally derived standards for care. **British Medical Journal.** 324 p 516

Boaden, N, Goldsmith, M, Hampton, W & Stringer, P (1982) **Public participation in local services.** London, Longman

Boardman, J., Henshaw, C. & Willmott, S. (2004) Needs for mental health treatment among general practice attenders. **The British Journal of Psychiatry**. 185, pp 318-327

Borrill, J. (2000) Developments in treatment for people with psychotic experiences. **Updates**. 2, (9), pp 1–4.

Bostock, Y. (1993) **Pregnancy, childbirth and coping with motherhood: what women want from the maternity services.** Edinburgh, The Scottish Office CRAG/SCOTMEG Secretariat

Bowl, R. (1996) Involving service users in mental health services: Social Services Departments and the National Health Service and Community Care Act 1990. **Journal of Mental Health** 5 (3) pp 287-303

Bowling, A. (1993) **What People Say About Prioritising Health Services.** London, King's Fund Centre

Bowling, A. (1996) Health care rationing: the public's debate. **British Medical Journal** 312, pp 670-674

Bowling, A. (2002) **Research Methods in Health: Investigating health and health services.** Maidenhead – Philadelphia, Open University Press

Bowling, A., Jacobson, B. & Southgate, L. (1993) Health Service Priorities: Explorations in consultation of the public and health professionals on priority setting in an inner London health district. **Social Science and Medicine** 37, (7), pp 851-857

Bradburn, J., Maher, E., Young, J. & Young, T. (1992) Community-based cancer support groups: an under-valued resource? **Clinical Oncology** 4, pp 377–380

Bradburn J. (2001) **User involvement in cancer services: Report to the National Cancer Taskforce**. Macmillan Cancer Relief, unpublished paper

Branfield, F. & Beresford, P. (2006) **Making User Involvement Work: Supporting Service User Networking and Knowledge.** York, York Publishing Services

Brearley, S. (1990) **Patient Participation: the literature**. Middlesex, Scutari Press.

British Association of Paediatric Surgeons (2006) **Guidelines** [Internet], available from: http://www.baps.org.uk/ [Accessed April 2006].

British Association of Perinatal Medicine (2006) **Guidelines** [Internet], available from: http://www.bapm.org/ [Accessed April 206].

Brock, S (1995) Narrative and medical genetics: on ethics and therapeutics. **Qualitative Health Research** 5, pp 150-168

Broderick, C. (1997) Partners for change. **Health Director** 1 pp 14-15

Brooks, F. (2001) Why user involvement in primary health care? In Gillam, S. & Brooks, F. (eds) **New Beginnings: towards patient and public involvement in primary health care**. London, King's Fund

Brotchie, J. & Wann, M. (1993) **Training for Lay Participation in Health: token voices or champions of the people?** London, Patients Association

Brown, J., Nolan, M. & Davies, S. (2000) Who's the expert? Redefining lay and professional relationships. In Nolan, M., Davies, S. & Grant, G. (Eds.) **Working with older people and their families.** Buckingham, Open University Press

Bruera, E., Sweeney, C., Calder, K., Palmer, L. & Benisch-Tolley, S. (2001) Patient preferences versus physician perceptions of treatment decisions in cancer care. **Journal of Clinical Oncology**. 19, pp 2883-2885

Bryman, A. (1989) **Research methods and organisation studies.** London, Routledge

Burgess, RG. (1984) **In the Field.** London, Routledge

Bury, M. (1998). Postmodernity and health. In Scambler, G. & Higgs, P. (eds). **Modernity, Medicine and Health. Medical Sociology towards 2000.** London, Routledge

Cabinet Office & Service First. (1998) **An introductory guide – how to consult your users.** London, Service First.

CAF (1992) **Charity Household Survey**. London, CAF

Campbell, P. (2001) The role of users in psychiatric services in service development: influence not power. **Psychiatric Bulletin.** 25, pp 87–88

Cancerlink (1998) **Directory of Cancer Self-help and Support**. London, Cancerlink

Cancer Research UK (2007) **Ovarian Cancer.** [Internet], available at http://www.cancerhelp.org.uk. [Accessed May 2007]

Chambers, R., Drinkwater, C. & Boath, E (2003) **Involving Patients and the Public; how to do it better.** Abingdon, Radcliffe Medical Press

Charles, C. & DeMaio, S. (1993) Lay participation in health care decision making: a conceptual framework. **Journal of Health Politics, Policy and Law.** 18, (4), pp 881-904

Charles, C., Redko, C., Whelan, T., Gafni, A. & Reyno, L. (1998) Doing nothing is no choice: lay constructions of treatment decision-making among women with early-stage breast cancer. **Sociology Health and Illness.** 20, pp 71-95

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

Charles, C., Gafni, A. & Whelan, T. (2004) Self reported use of shared decision-making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. **Health Expectations**. 7, pp 338–348

Charmaz, K. (1995) Grounded Theory. In Smith, JA, Harre, R & Langenhove, LV (eds) **Rethinking Methods in Psychology.** London, Sage

Cheetham, J. (1993) **Evaluating Social Work Effectiveness.** Milton Keynes, Open University Press

Chinman, MJ., Rosenheck, R., Lam, JA. & Davidson, L. (2000) Comparing consumer and non-consumer provided case management services for homeless persons with serious mental illness. **Journal of Nervous Mental Disorders** 188, pp 446-453

Chinman, MJ., Weingarten, R., Stayner, D. & Davidson, L. (2001) Chronicity reconsidered: improving person-environment fit through a consumer-run service. **Community Mental Health Journal**. 37, pp 215-229

Clark, C., Scott, E, Boydell, K. & Goering, P. (1999) Effects of client interviewers on client-reported satisfaction with mental health services **Psychiatric Services** 50, pp 961-963

Clarke, GN, Herinckx, HA., Kinney, RF., Paulson, RI., Cutler, DL., Lewis, K, et al. (2000) Psychiatric hospitalisations, arrests, emergency room visits, and homelessness of clients with serious and persistent mental illness: findings from a randomised trial of two ACT programs vs. usual care. **Mental Health Services Res.** 2, pp 155-164

Coffey, A. & Atkinson, P (1996) **Making Sense of Qualitative Data.** London, Sage

Cogan, J. (1998) The Consumer as expert: women with serious mental illness and their relationship based needs. **Psychiatric Rehabilitation Journal.** 22 (2)

Cole, A. (2001) Patient participation: movers and shakers. **Health Service Journal.** 30 August, pp 24-27

Combe, V., Delap, C. & Lenaghan, J. (1999) **Rationing and Public Involvement: what have we learned?** Summary of a draft paper presented to an Institute for Public Policy Research Seminar on 9th of June 1999. [Internet], available at http://www.ippr.org.uk/events/archive.asp?fID=199&yr=2007. [Accessed March 2005]

Conning, S., Fellowes, D. & Sheldon, H. (1997) User's views in theory and practice, **Journal of Clinical Effectiveness.** 2, (2), pp 31-34

Cook, JA., Jonikas, JA. & Razzano, L. (1995) A randomised evaluation of consumer versus non-consumer training of state mental health service providers. **Community Mental Health Journal.** 31, pp 229-238

Cooper, J. (2001) **Partnerships for successful self-management: the living with long-term illness (Lill) project report.** London, Long-term Medical Conditions Alliance.

Cooper, JM. & Clarke, A. (2001) **Expert patients: who are they? Lay-led self-management programmes: an additional resource in the management of chronic illness.** London, Long-Term Medical Conditions Alliance.

Cooper, L., Coote, A., Davies, A. & Jackson, C. (1995) **Voices Off.** London, Institute for Public Policy Research

Corke, C., Stow, P., Green, D., Agar, J. & Henry, M. (2005) How doctors discuss major interventions with high risk patients: an observational study. **British Medical Journal**. 330, p 182

Cornbleet, MA et al (2002) Patient-held records in cancer and palliative care: a randomised, prospective trial. **Palliative Medicine** 16, (3), pp 205-12.

Corney, R., Everett, H., Howells, A. & Crowther, M. (1992) The care of patients undergoing surgery for gynaecological cancer: the need for information, emotional support and counselling. **Journal of Advanced Nursing.** 17, (6), p 667

Cornwell, J. (1984) **Hard Earned Lives: Accounts of health and illness from East London**. London, Tavistock

Corry, P., Drury, C. & Pinfold, V. (2004) **Lost and Found. Voices of the Forgotten. Generation.** London, Rethink Publications

COSLA (1998) **Focusing on Citizens: a guide to approaches and methods.** Edinburgh, COSLA

Cosper, R. (1972) Interviewer effect in a survey of drinking practices. **Sociological Quarterly.** 13, pp 228-36

Coulter, A. (1997) Partnerships with patients: the pros and cons of shared clinical decision-making. **Journal of Health Services Research Policy.** 2, (2), pp 112-121

Coulter, A. (1999) Paternalism or partnership? **British Medical Journal.** 319, pp 719-720

Coulter, A. (2002a) Involving patients: representation or representativeness? **Health Expectations.** 5, (1), p1

Coulter, A. (2002b) **The autonomous patient: ending paternalism in medical care**. London: Stationery Office.

Coulter, A. (2002c) Whatever happened to shared decision-making. **Health Expectations**. 5, (3), pp 185-186

Coulter, A. (2004a) What price choice? **Health Expectations**. 7, pp 185-186

Coulter, A. (2004b)The evidence speaks for itself…but can the public? **Nursing Management**. 11, (8), pp 12-13

Coulter, A. (2005) Shared decision-making: the debate continues. **Health Expectations**. 8, pp 95–96

Coulter, A. & Magee, H. (2003) **The European Patient of the Future**. Maidenhead, Open University Press

Coulter, A. & Rozansky, D. (2004) Full engagement in health: needs to begin in primary care. **British Medical Journal.** 329, pp 1197-1198

Courcha, P. & James, S. (1999) **Patients Influencing Healthcare Project: breast cancer focus groups**. Report to Highland Health Board

Crawford, M. (2001) Involving Users in the Development of Psychiatric Services – no longer an option? **Psychiatric Bulletin.** 25, pp 84-86

Crawford, MJ., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. & Tyrer, P. (2002) Systematic view of involving patients in the planning and development of health care. **British Medical Journal.** 325, p 1263

Currell, R. (1990) The organisation of midwifery care. In Alexander, J., Levy, V. & Roche, S. (eds) **Antenatal Care**. London, MacMillan

Daly, J., Kelleher, A. & Glicksman, M. (1997) **The Public Health Researcher.** Australia, Oxford University Press

Data Protection Act (1998) (c.19). London, HMSO

Davies, S., Elizabeth, S., Hanley, B., New, B. & Sang, B. (1998) **Ordinary Wisdom. Reflections on an experiment in citizenship and health.** London, King's Fund

Davis-Smith, J. (1992) What Do We Know About Volunteering: Information from the surveys. In Hedley, R. & Davis-Smith, J. (eds) **Volunteering and Society: principles and practice.** London, Bedford Square Press

Deeble, EA. & Bhat, AV. (1991) Women attending a self-help group for anorexia nervosa and bulimia: Views on self-help and professional treatment. **British Review of Bulimia and Anorexia Nervosa.** 5, pp 23-28

Department of Health (1980) **Short Report, Second Report from the Social Services Committee Session 1979-80, Perinatal and Neonatal Mortality**. London, HMSO

Department of Health (1989) **Caring for people: Community Care in the next decade and beyond ....** London, HMSO

Department of Health (1991) **The Patients Charter**. London, HMSO

Department of Health (1992) **House of Commons Select Committee on Health's Report on Maternity Services The Winterton Report (The Maternity Services Report of the all-party Health Select Committee).** London, HMSO

Department of Health (1993) **Changing Childbirth. Report of the Expert Maternity Group (Cumberlege Report).** London, HMSO

Department of Health (1994) **Implementing Caring for People. "It's Our Lives". Community Care for People with Learning Disabilities.** London, HMSO

Department of Health (1995a) **Mental Health in England (1982 – 1992)** London, Government Statistical Service

Department of Health (1995b) **A policy framework for commissioning cancer services: A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales. Guidance for providers and purchasers of cancer services. The Calman-Hine Report.** London, HMSO

Department of Health (1996) **Maternity Services Liaison Committees, Guidelines for working effectively.** London, HMSO

Department of Health (1997) **The New NHS: Modern and Dependable.** Cm 3807. London, HMSO

Department of Health (1999a) **National service framework for mental health modern standards and service models.** London, HMSO

Department of Health (1999b) **Patient and public involvement in the new NHS.** London, HMSO

Department of Health (1999c) **Public Appointments Annual Report.** London, HMSO

Department of Health (2000) **The NHS Cancer Plan**. London, HMSO

Department of Health (2001a) **Involving Patients and the Public in Healthcare**. London, HMSO

Department of Health (2001b) **The expert patient: a new approach to chronic disease management for the 21st century.** London, HMSO

Department of Health (2004a) **Formative evaluation of the Cancer Partnership Project**. London, HMSO

Department of Health (2004b) **National Service Framework for Children and Young People**. London, HMSO

Department of Health (2006) **A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services**. London, HMSO

Department of Health (2007) **World class commissioning: vision.** London, HMSO

Department of Health and Social Services (1970) **Domiciliary, Midwifery and Maternity Bed Needs: Report of the Sub-committee, Peel Report, Standing Maternity and Midwifery Advisory Council.** London, HMSO

Department of Health and Social Services (1983) **NHS Management Inquiry.** Led by Roy Griffith. London, HMSO

Department of Health and Social Services (1999) **Mainstreaming Community Development in Northern Ireland.** Belfast, HMSO

Depression Alliance (2003) **Help and Information** [Internet], available from <www.depressionalliance.org> [Accessed January 2006].

Dick, S. & Cunningham, G. (2000) **Nothing about me, without me.** The report of practice based study of approaches to effective user involvement in individual care in one agency. Edinburgh, The Consultation and Involvement Trust Scotland

Dickens, P. (1994) **Quality and Excellence in Human Services.** Sussex, John Wiley and Sons.

Dolan, P., Crookson, R. & Ferguson, B. (1999) Effect of discussion and deliberation on the public's views of priority setting in health care: focus group study. **British Medical Journal.** 318, pp 916-919.

Donaldson, L. (2003) Expert patients usher in a new era of opportunity for the NHS. **British Medical Journal.** 326, pp 1279-1280

Donner, W. (2003) **Including gender in health planning: a guide for regional authorities.** University of Winnipeg, Prairie Women's Health Centre of Excellence

Doyal, L. (1995) **What makes women sick: gender and the political economy of health**. London, MacMillan

Doyal, L. (1998) Public participation and the moral quality of healthcare rationing. **Quality and Safety in Health Care.** 7, pp 98-102

Drewett, A. (1997) **Evaluation and Consultation. Learning the Lessons of User Involvement in Evaluation.** London, Sage

Drury, M., Yudkin, P., Harcourt, J., Fitzpatrick, R., Jones, L., Alcock, C. & Minton, M. (2000) Patients with cancer holding their own records: a randomised controlled trial. **British Medical Journal of General Practice.** 50, pp 105-110

Duff, LA., Kelson, M., Marriott, S., McIntosh, A., Brown, S., Cape, J., Marcus, N. & Traynor, M. (1996) Involving patients and users of services in quality improvement: what are the benefits? **Journal of Clinical Effectiveness.** 1, (2), pp 63-67

Eastman, N (1999) Public health psychiatry or crime prevention? Governments proposals emphasise doctors role as public protectors. **British Medical Journal.** 318, pp 549-551

Edwards, K. (1995) A preliminary study of users' and nursing students' views of the role of the mental health nurse. **Journal of Advanced Nursing**. 21, (2), pp 222–229

Edwards, A., Elwyn, G., Smith, C., Williams, S. & Thornton, H. (2001) Consumer's views of quality in the consultation and their relevance to 'shared decision-making' approaches. **Health Expectations.** 4(3), pp 151-161

Edwards, A. & Elwyn, G. (2006) Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision **Health Expectations.** 9, (4), pp 307–320

Elbourne, D., Richardson, M., Chalmers, I., Waterhouse, I. & Holt, E. (1987) The Newbury maternity care study: a randomised trial to assess a policy of women holding their own obstetric records. **British Journal of Obstetric Gynaecology.** 94, pp 612-619

Elit, LM., Levine, MN., Gafni, A., Whelan, TJ., Doig, G., Streiner, DL. & Rosen, B. (1996) Patients' preferences for therapy in advanced epithelial ovarian cancer: development, testing, and application of a bedside decision instrument. **Gynaecological Oncology.** 62, (3) pp 327-8

Elizabeth, S. (1998) Citizens' juries: outcomes of an experiment in citizenship and health. **Health Care Risk Reporter.** 4, pp 16-17

Elsdon, K., Reynolds, J. & Stewart, S. (2000) **Sharing Experience, Living and Learning: A Study of Self-Help Groups.** London, Community Matters

Elwyn, G., Edwards, A. & Kinnersley, P. (1999) Shared decision- making in primary care: the neglected half of the consultation. **British Journal of General Practice.** 49, (443), pp 477-482

Enkin, M. & Chalmers, I. (1982) **Effectiveness and Satisfaction in Antenatal Care**. London, Cambridge University Press

Entwistle, V. (1998) Lay perspectives: advantages for health research. **British Medical Journal.** 316, pp 462-466

Entwistle, V. (1999) Participation: if we want to make progress, we must speak clearly. **Health Expectations.** 2, pp 1-2

Entwistle, VA., Snowdon, AJ. & Watt, IS. (1998) Evaluating interventions to promote patient involvement in decision-making: by what criteria should effectiveness be judged. **Journal of Health Services Research Policy.** 3, (2), pp 100 -107

Evans, B. (1995) The experiences and needs of patients attending a cancer support group. **International Journal of Palliative Nursing.** 1, pp 189 -194

Evans, C. (1999) Gaining Our Voice: The Developing Pattern of Good Practice in User Involvement. **Managing Community Care.** 7, (2), pp 7-13

Evans, C. (2001) From Those Who Know: the role of service users. In Hanvey, C. & Philpot, T. (eds) **Sweet Charity: the role and workings of voluntary organisations.** Routledge, London

Evanson, E. & Whittington, D. (1997) Patient's perceptions of quality in a Northern Ireland hospital trust: a focus group study. **International Journal of Health Care Quality Assurance**. 10, (1), pp 7-19

Fallowfield, L. & Hall, A. (1994) Psychological effects of being offered choice of surgery for breast cancer. **British Medical Journal**. 309, p 448

Fallowfield, L. (2001) Participation of patients in decisions about treatment for cancer. **British Medical Journal.** 323 p 1144

Farrell, C. (1998) **The NHS, the patient and the public.** Tunbridge Wells, JMH Publishing.

Farrell, C., Levenson, R. & Snape, D. (1998) **The Patient's Charter; past and future.** London, Kings Fund

Faulkener, A (2004) **The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors.** Joseph Rowntree Foundation

Featherstone, M. & Hepworth, M. (1998). Ageing, the lifecourse and the sociology of embodiment. In Scambler, G. & Higgs, P. (eds). **Modernity, Medicine and Health. Medical Sociology towards 2000.** London, Routledge

Fellowes, D., Fallowfield, LJ., Saunders, CM. & Houghton, J. (2001) Tolerability of hormone therapies for breast cancer: how informative are documented symptomprofiles in medical notes for 'well tolerated' treatments? **Cancer Nursing**. 24, (3), pp 185-191

Felton, CJ., Stastny, P., Shern, DL., Blanch, A., Donahue, SA., Knight, E., et al. (1995) Consumers as peer specialists on intensive case management teams: impact on client outcomes. **Psychiatric Services**. 46, pp 1037-1044

Field, D., Douglas, C., Jagger, CD. & Dand, P. (1995) Terminal illness: views of patients and their lay carers. **Palliative Medicine.** 9, pp 45-54

Fielding, J. (1993) Coding and Managing Data. In Gilbert N (ed) **Researching Social Life.** London, Sage

Fisher, B. & Gilbert, D. (2001) Patient involvement and clinical effectiveness. In Gillam, S. & Brooks, F. (eds) **New Beginnings, Towards patient and public involvement in primary health care.** London, King's Fund

Fisher, B. (2001) Community development in primary care. In Gillam, S. & Brooks, F. **New Beginnings : towards patient and public involvement in primary health care.** London, Kings Fund

Fitzpatrick, R. & White, D. (1997) Public participation in the evaluation of health care. **Health and Social Care in the Community.** 5(1), pp 3-8

Fletcher, G. (2003) Building sustainable partnerships in user involvement. **The Obstetrician & Gynaecologist.** 5, pp 218–20

Flint, C. (1986) A Radical Blueprint. **Nursing Times.** 82, (1), pp 1-7

Florin, D. & Coulter, A. (2001) Partnership in the primary care consultation. In Gillam, S. & Brooks, F. (eds) **New Beginnings, Towards patient and public involvement in primary health care.** London, King's Fund

Florin, D. & Dixon, J. (2004) Public involvement in health care. **British Medical Journal.** 328, pp 159–161

Foltz, A. & Sullivan, J (1996) Reading level, learning presentation preference and desire for information among cancer patients. **Journal of Cancer Education.** 11, pp 32-38

Ford, S., Schofield, T. & Hope, T. (2003) Are patients decision-making preferences being met? **Health Expectations**. 6, pp 72–80

Foote, C. & Plsek, P. (2001) Thinking out of the box. **Health Service Journal.** 12, (April), pp. 32-33

Fox, S. (2006) **Online Health Search 2006.** [Internet], available at <www.pewinternet.org/PPF/r/156/report_display.asp> [Accessed May 2007]

Galinsky, MJ. & Schopler, JH. (1994) Negative experiences in support groups. **Social Work & Health Care.** 20, (1), pp 77-95

Gamel, C., Hengeveld, M. & Davis, B. (2000) Informational needs about the effects of gynaecological cancer on sexuality: a review of the literature. **Journal of Clinical Nursing.** 9, (5), pp 678-688

Garcia, J., Redshaw, M., Fitzsimmons, B. & Keene, J. (1998) **First Class Delivery: a national survey of women's views of maternity care.** London, Audit Commission

Garlick, W. (2003) Should drug companies be allowed to talk directly to patients? **British Medical Journal.** 326, pp 1302-1303

Gattellari, M., Butow, PN. & Tattersall, MH. (2001) Sharing decisions in cancer care. **Social Science & Medicine.** 52, pp 1865-1878

Gijsbers van Wijk, C., Van Vliet, K. & Kolk, A. (1996) Gender Perspectives and Quality of Care: Towards appropriate and adequate health care for women. **Social Science Medicine.** 43, (5) pp 707–720

GMC (1998) **Case of Wisheart JD, Dhasmana JP, Roylance J. Transcript from the Notes of T A Reed & Co.** London, General Medical Council

Goodare H (2002), User development in cancer care: Exclusion and empowerment. **Health Expectations.** 5, (1), pp 90-91

Gott, M., Stevens, T., Small, N. & Ahmedzai, S. (2000) **User Involvement in Cancer Care: Exclusion and Empowerment.** Bristol: Policy Press

Gott, M., Stevens, T., Small, N. & Ahmedzai, S. (2002) Involving users, improving services: the example of cancer. **British Journal of Clinical Governance**. 7, (2), pp 81–85

Graham, J., Broom, D. & Whittaker, A. (2000) Consulting about consulting: challenges to effective consulting about public health research. **Health Expectations.** 4 (2), pp 209-212

Grande, G., Todd, C. & Barclay, S. (1997) Support needs in the last year of life: patient and carer dilemmas. **Palliative Medicine.** 11, (3), pp 202–208

Gray, J., Lyons, P. & Melton, G. (1995) **Ethical and legal issues in AIDS research**. Baltimore, John Hopkins University Press

Greenhow, D., Howitt, AJ. & Kinnersley P (1998), Patient satisfaction with referral to hospital: relationship to expectations, involvement and information-giving in the consultation. **British Journal of General Practice.** 48, (426) pp 911-912

Griffiths, R., Gross, G., Russell, J., Thornton, C., Beumont, PJ., Schotte, D. & Touyz, SW. (1998) Perceptions of bed rest by anorexic patients. **International Journal of Eating Disorders.** 23 pp 443-447

Gummer, T. & Furney, S. (1998) The business of listening. **Health Management.** 2, 12-13

Haarni, I (2007) **"Lay" and "expert" health knowledge: from hierarchy to equality**. [Internet], available at www.uta.fi/laitokset/tsph/health/citizens/lay1.html [Accessed May 2007]

Haas, M, (1999) The relationship between expectations and satisfaction: a qualitative study of patients' experiences of surgery for gynaecological cancer. **Health Expectations** 2, pp 51-60

Ham, C. (1992) **Health Policy in Britain: The politics and organisation of the National Health Service.** London, MacMillan

Ham, C. (1998) Retracing the Oregon trail: the experience of rationing and the Oregon health plan. **British Medical Journal**. 316, pp 1965-1969

Hammersley, M. (1990) **Reading Ethnographic Research: a critical guide**. London, Longmans

Handy, J. (1990) **Occupational Stress in a Caring Profession.** Aldershot, Gower

Hansard (2000) **The official report of proceedings in the House of Commons.** [Internet], available at <www.publications.parliament.uk> [Accessed August 2007]

Harding, T. & Beresford, P. (1996) **The standards we expect. What service users and carers want from social services workers.** London, National Institute for Social Work.

Harris, B. (1989) **The Islington Mental Health Forum: A case study in how to get users involved**. London, Good Practices in Mental Health

Harris, R (1997) Consistency of patient information … is this happening? **Cancer Nursing.** 20, pp 274-276

Harrison, S. & Mort, M. (1998) Which champions, which people? Public and user involvement in health care as a technology of legitimation. **Social Policy & Administration**. 32, (1), pp. 60-70

Harrison, S. & Pollitt, C. (1994) **Controlling Health Professionals.** Buckingham, Open University Press

Hartley, JF. (1994) Case studies in organisational research. In Cassell, C. & Symon, G. (eds) **Qualitative methods in organisational research: a practical guide.** London, Sage

Hatch, S. (1984) Participation in Health. In Maxwell, R. & Weaver, N. (eds) **Public Participation in Health**. London, Kings Fund

Haynes, RB., MacDonald, H., Garg, AX. & Montague, P. (2002) **Interventions for helping patients to follow prescriptions for medications.** London, John Wiley & Sons

Hayward, K. (1998) Patient-held oncology records. **Nursing Standard.** 12, (35), pp 44-46

Health Canada in co-operation with the Schizophrenia Society of Canada (1991) **Schizophrenia: A Handbook for Families.** [Internet], available at <www.Mentalhealth.com/book/p40-sc01.html> [Accessed April 2006]

Health Management Library (2005) **Managed Clinical Networks in Scotland.** [Internet], available at <www.healthmanagementomline.co.uk> [Accessed November 2005]

Health Select Committee (2003) **Second Maternity Services Inquiry (2003) Proceedings of the Health Committee. Eighth Report**. London, House of Commons

Heginbotham, C. (1993) **Listening to local voices**. Birmingham: National Association of Health Authorities and Trusts

Henderson, C. & Laughane, R. (1999) **Patient held clinical information for people with psychotic illnesses.** London, John Wiley & Sons

Hendessi, M. (1994) **Getting better all the time? A report of a project on user and carer involvement in the NHS.** London, Greater London Association of Community Health Councils

Henman, M., Butow, PN., Brown, RF., Boyle, F. & Tattersall, MHN. (2002) Lay constructions of decision making in cancer. **Psycho-oncology**. 11, pp 295-306

Herd, D. & Stalker, K. (1996) **Involving Disabled People in Services**. Edinburgh: SWSI

Heritage, Z. (1994) **Community Participation in Primary Care.** Occasional paper 64. London, Royal College of General Practitioners

Herxheimer, A., McPherson, A., Miller, R., Shepperd, J., et al (2000) Database of patients' experiences (DIPEx): a multi-media approach to sharing experiences and information. **The Lancet**. 355, (9214), pp 1540-1543

Higgins R. (1994) Involving users in health care. **Health Services Management.** March, pp 14-15

Higginson, I., Priest, P. & McCarthy, M. (1994) Are bereaved family members a valid proxy for a patients' assessment of dying. **Social Science and Medicine.** 38, (4), pp 553–557

Higginson, I., Wade, A. & McCarthy, M. (1990) Palliative care: views of patients and their families. **British Medical Journal.** 301, pp 277–281

Hillan,E., McGuire, M. & Reid, L. (1997) **Midwives and Woman Centred Care.** University of Glasgow, Department of Nursing & Midwifery Studies. Edinburgh, The Royal College of Midwives Scottish Board

Hirschman, AO. (1970) **Exit, Voice and Loyalty: Responses to decline in firms, organisations and states.** Cambridge, Mass., Harvard University Press

Hirst, J. (2003) Charities and patient groups should declare interests. **British Medical Journal**. 326, p 1211

Hogg, C. & Williamson, C. (2001) Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees. **Health Expectations**. 4, (1) pp 2-9

Hogg, C. (1995) **Beyond the Patient's Charter.** London, Health Rights

Hogg, C. (1999a) **Patients, power and politics: from patient to citizens.** London: Sage.

Hogg, C. (1999b) Looking for a common good. **Health Matters.** 37, pp 12-13

Holman, H. & Lorig, K. (2000). Patients as partners in managing chronic illness. **British Medical Journal.** *7234*, pp 526-528

Hopton, J. & Hill, M. (2001) **Connecting Communities with the NHS. Report of the LHCC Best Practice Group.** Edinburgh, Primary Care Unit of the Scottish Executive Health Department

Horne, T., Donner, W. & Thurston, W (1999) **Invisible Women: Gender and planning in Mantitoba and Saskatchewan and models for progress.** University of Winnipeg, Prairie Women's Health Centre of Excellence

House of Commons Health Committee (1992) **Enquiry into Maternity Services.** London, House of Commons

House, J. (1988) Structures and processes of social support. **Annual Review of Sociology.** 14, pp293-318

Howells, REJ., Bradley, E., Pitts, M., Calvert, E. & Redman, CWE. (1999) Audit of the views of gynaecological cancer patients regarding follow-up. **Journal of Obstetrics and Gynaecology.** 19, (2), pp 167-168

Hundley, V. & Ryan, M. (2004) Are women's expectations and preferences for intrapartum care affected by the model of care on offer? **International Journal of Obstetrics & Gynaecology.** 111, (6), pp 550-560

Hunt, J., Stevens, T., Mitchell, N., Wilde, D. & Ahmedzai, S. (2002) How cancer service users can influence research and practice. **Nursing Times.** 98,(33), pp 32–33

Inglis, J. (2002) **SCAN Patient Involvement Report**. Edinburgh, South East Scotland Cancer Network

INVOLVE (2008) **INVOLVE Strategic Plan 2007-2011**. [Internet], available at <www.invo.org.uk/About_Us.> [Accessed May 2008]

Irvine, R (2002) Fabricating 'health' consumers in health care policies in Henderson, S & Petersen, A (eds) **Consuming Health: the commodification of health care.** London, Routledge

ISD (2006) **Cancer of the female gynaecological genital organs (ICD-10 C53-C55), Scotland: trends in incidence 2000-2004**. Edinburgh, Scottish Cancer Intelligence Unit, Information & Statistics Division, NHSScotland

Jacoby, A. & Cartwright, A. (1990) Finding out about the views and experiences of maternity-service users. In Garcia, J., Kilpatrick, R. & Richards, M. (Eds) **The Politics of Maternity Care.** Oxford, Oxford University Press

Janzen, BL. (1999) **Women, gender and health: A review of the recent literature**. University of Winnipeg, Prairie Women's Health Centre of Excellence

Jelley, D., van Zwanenberg, T. & Walker, C. (2002) Copying letters to patients; Concerns of clinicians and patients need to be addressed first. **British Medical Journal**. 325, pp 1359

Jennings, A. (1994) On being invisible in the mental health system. Special Issue: Women's mental health services. **Journal of Mental Health Administration**. 2, (4), 21, pp 374-387

Jewkes, R. & Murcott, A. (1998) Community representatives: representing the "community"? **Social Science and Medicine.** 46, pp 843-858

Johanson, R., Newburn, M. & MacFarlane, A. (2002) Has the medicalisation of childbirth gone too far? **British Medical Journal** 324 (7324), pp 892-895

Johnstone, R. (1993) Learning to Work with People: An Experience of Health Workers in Ireland. **Community Development Journal.**   28, (3), pp 252-257

Jones, J. & Jones, L. (2002) **Private Troubles and Private Issues; a community development approach to health.** Edinburgh, Community Learning Scotland

Jones, J. & Macdonald, J. (1993) Editorial Introduction. **Community Development Journal**. 28, (3), pp199-205

Jones, J., McConville, J., Mason, D., Macpherson, L., Naven, L. & McEwen, J. (1999) Attitudes towards, and utility of, an integrated medical-dental patient-held record in primary care. **British Journal of General Practice**. 49, pp 368-73

Jordan, J., Dowswell, T., Harrison, S., Lilford, J. & Mort, M. (1998) Whose priorities? Listening to users and the public. **British Medical Journal**. 316, pp 1668-1670

Jordan, L., Ellis, S. & Chambers, R (2002) Defining shared decision making and concordance: are they one and the same? **Postgraduate Medicine Journal** 78, pp 383-384

Joseph Rowntree Foundation (1997) **Involving users and carers in the care programme approach in mental health.** London, Social Care Research Findings

Kaptchuk, T. (2003) Effect of interpretive bias on research evidence. **British Medical Journal**. 326, pp 1453-1455

Karimian-Teherani, D., Micksche, M. & the National Advisory Board (2001) Caring about Women and Cancer (CAWAC): A European survey of the perspectives and experience of women with gynecological cancers: Results of the survey in Austria. **Wien Klin Wochenschr.** 113, (13–14), pp 504–50913–50914

Kelson, M. (1995) **Consumer involvement in initiative in clinical audit and outcomes**. London, College of Health

Kendall T (2000) **Schizophrenic Disorders.** National electronic library for health. [Internet], available at <www.nelmh.org/home_schizophrenic_schizophrenia.asp?c=10&fc=001&fid=263> [Accessed April 2006]

Kendrick, T., Sibbald, B. & Addington-Hall, J. (1993) General practice: distribution of mental health professionals working on site in English and Welsh general practices **British Medical Journal.** 307, pp 544-546

Kennedy, CA. (1999) **Welfare and Health: Systems in Tension**. A thesis for the degree of Doctor of Philosophy. University of Glasgow

Kicksbusch, I. & Hatch, S. (1983) **A Re-orientation in Health Care in Self-Help and Health in Europe.** Copenhagen, World Health Organisation

Kirk, S., Glendinning, C. & Burkey, Y. (1997) Involving communities in health service planning in primary care. **Health and Social Care in the Community.** 5, (6), pp 398-407

Kitchener, HC. (1999) Progress in the management of solid tumours: Gynaecological cancer. **Postgraduate Medical Journal**. 75, pp 332-338

Kitzinger, S. (1984) Experiences of Obstetric Practices in Differing Countries. In Zander, L. & Chamberlin, G. (eds) **Pregnancy Care for the 80s.** London, The Royal Society of Medicine

Klein, AR., Cnaan, RA. & Whitecraft, J. (1998) Significance of peer support with dually diagnosed clients: findings from a pilot study. **Residential Social Work Practice**. 8, pp 529-551

Klein, R. (1984) The Politics of Participation. In Maxwell, R. & Weaver, N. (eds) **Public Participation.** London, Health Kings Fund

Klein, R. (1995) **The New Politics of the NHS** (3rd edition) London, Longman

Kleinman AM & Cohen A (1993) **Mental Illness**. [Internet], available at <Mental illness@encarta@online encyclopaedia. http://encarta.msn.com> [Accessed April 2006]

Knight, A. (2003) Employing Users Who Turn Back into Patients is Difficult. **British Medical Journal.** 326, p 449

Knox, C. & McAlister, D. (1995) Policy Evaluation: Incorporating Users' Views, **Public Administration.** 73, pp 413-436.

Kober, A (1994) **Clinical audit in the therapeutic professions: connections with other forms of audit in the National Health Service.** Paper presented to the Annual British Sociological Association Conference, Leicester

Laird, A., Fawcett, J., Rait, F. & Reid, S. (2000) **Assessment of Innovative Approaches to Testing Community Opinion.** Social inclusion research programme research findings No.2. pp 1-6. Edinburgh, Scottish Executive Central Research Unit

Lamb, MA. & Sheldon, TA. (1994) The sexual adaptation of women treated for endometrial cancer. **Cancer Practitioner.** 2, (2), pp 103-13

Lang, S. & Path, R.B. (1994) **You Don't Have to Suffer.** Oxford, Oxford. University Press

Last, J. (1995) **A Dictionary of Epidemiology**. Oxford, Oxford University Press

LCTAS (2006) **Long-term Conditions Alliance Scotland: The voluntary sector's approach to self-management.** [Internet], available at <www.arthritiscare.org.uk/InyourArea/Scotland/Campaigns/LTCAS> [Accessed May 2007]

Leavitt, J. (1986) **Brought to Bed: childbearing in America, 1750-1950.** Oxford University Press

Lecouturier, J. et al (2002) Evaluation of a patient-held record for patients with cancer. **European Journal of Cancer Care (English)**. 11, (2), pp 114-121

Lenaghan, J., New, B. & Mitchell, E. (1996) Setting priorities: is there a role for citizen's juries? **British Medical Journal**. 312, pp1591-1593

Lester, H. et al (2003) A cluster randomised controlled trial of patient-held medical records for people with schizophrenia receiving shared care. **British Journal of General Practice**. 53, (488), pp 197-203

Levenson, R. (2001) **Making people's voices heard: Enabling people with long-term medical conditions to contribute to policy**. London, Long-Term Medical Conditions Alliance

Lewis, C. (1996) **Deadly Dilemma**. The Guardian: Society. 16th March 1996, p 3

Lewis, G. & Drife, J. (2004) **Confidential Enquiry into Maternal and Child Health Improving care for mothers, babies and children. Why Mothers Die 2000–2002, The Sixth Report of the Confidential Enquiries into Maternal Deaths in the United Kingdom.** London, RCOG Press

Lewison, H. (1994) **Maternity Service Liaison Committees – a forum for change**. London, National Childbirth Trust

Lewthwaite, J. & Haffenden, S. (1997) **Patients Influencing Purchasers.** A report of an action research project sponsored by The Long-Term Medical Conditions Alliance. Birmingham, The NHS Confederation

Lieberman, M.A. & Snowden, L.R. (1993) Problems in assessing prevalence and membership characteristics of self-help group participants. **Journal of Applied Behavioural Science.** 29, (2), pp 166–181

Lincoln, M. (2004) **The impact of economic rationalisation and new public management on maternity care provision: conditioning demand and limiting choices:**

the obstetricalisation of childbirth. Proceedings of the Sixth International Conference of Strategic Issues in Health Care Management. St Andrews, University of St Andrews

Lindlow, V. (1991) Towards user power. **Health Service Journal**. 102, (5285), pp 20-21

Lindow, V. (1999) Power, lies and injustice: the exclusion of service users' voices. In Parker, M. **Ethics and Community in the Health Care Professions.** London, Routledge.

Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, G., Ferrier, K. & Payne, S. (2001) Preferences of patients for patient centred approach to consultation in primary care: observational study. **British Medical Journal**. 322, pp. 908-911

Locker, D. & Dunt, D. (1978) Theoretical and methodological issues in sociological studies of consumer satisfaction with medical care. **Social Science and Medicine**. 12, (4) pp 283-92

Lomas, J (1997) Reluctant rationers: public input into health care priorities. **Journal of Health Service Resource Policy**. 2, (2), pp 103-111

London, C. & Scriven, A. (2007) **Mental health service users' perceptions of stigma: A study of community and in-patient service users in West London Mental Health NHS Trust.** Poster presented at the UKPHA annual conference Generation to generation: sustainable directions for public health. Edinburgh, 28/29 March 2007.

Lord, J., Ochocka, J., Czarny, W. & MacGillivary, H. (1998) Analysis of change within a mental health organization: a participatory process. **Psychiatric Rehabilitation Journal**. 21, pp 327-339

Lorig, K., Sobel, DS., Stewart, AL., Brown, BW., Bandura, A. & Ritter, P. (1999) Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalisation. A randomised trial. **Medical Care**. 37, pp 5-14

Lorig, K., Ritter, P., Stewart, AL., Sobel, DS., Brown, BW. & Bandura, A. et al (2001) Chronic disease self-management program: 2-year health status and health care utilisation outcomes. **Medical Care**. 39, pp 1217-1223

Luker, K., Beaver, K., Leinster, S. & Glynn Owens, R. (1996). Information needs and sources of information for women with breast cancer: a follow-up study. **Journal of Advanced Nursing.** 23, (3), p 487

Lupton, C., Peckham, S. & Taylor, P. (1998) **Managing Public Involvement in Healthcare Purchasing.** Buckingham, Open University Press.

Lyons, JS., Cook, JA., Ruth, AR., Karver, M. & Slagg, NB. (1996) Service delivery using consumer staff in a mobile crisis assessment program. **Community Mental Health Journal**. 32, pp 33-40

MacFarlane, A. (2004) Confidential Enquiries into Maternal Deaths: developments and trends from 1952 onwards. In Lewis, G, & Drife, J. (2002) **Confidential Enquiry into Maternal and Child Health: Improving care for mothers, babies and children. Why Mothers Die 2000–2002, The Sixth Report of the Confidential Enquiries into Maternal Deaths in the United Kingdom**. London, RCOG Press

Marshall, M., Lockwood, A., Bradley, C., Adams, C., Joy, C. & Fenton, C (2000) Unpublished rating scales: a major source of bias in randomised controlled trials of treatments for schizophrenia. **British Journal of Psychiatry.** 176, pp 249-252

Maternity Action (1995**) Roundabout**. 68, p 11

Maughan, K. & Clarke, C. (2001) The effect of a clinical nurse specialist in gynaecological oncology on quality of life and sexuality. **Journal of Clinical Nursing**.10, (2), pp 221-229

McCormack, C. (1993) From the Fourth to the Third World – A Common Vision of Health. **Community Development Journal**, 28, (3), pp 206-217

McCrae, M., Bruce, S. & Stewart, J. Edited by Thompson A (2002) **Patient and Public Involvement in Health Care: A Review of the Literature.** Edinburgh, University of Edinburgh, unpublished paper

McCrea, BH. & Wright, ME. (1999) Perceptions of personal control in pain relief during labour. **Journal of Advanced Nursing**. 29, (4), pp 877-84

MacDonald, L. (2002) **Consultation and public involvement in service change. Draft interim guidance for consultation**. Edinburgh, The Scottish Consumer Council

McFadyen, D. & Farrington, A. (1997) User and carer participation in the NHS, British **Journal of Health Care Management**. 3, (5), pp 260-263

McIver, S. & Brocklehurst, N. (1999) Public involvement: working for better health. **Nursing Standard**. 14, (1), pp 46-52

McIvor, S. (1991) **Obtaining Views of Users of the Health Services**. London, King's Fund

McKnight, J. (1996) **A Twenty-First Century Map for Healthy Communities and Families**. Evanston, IL: Institute for Policy Research, Northwestern University

McNamara, J. (1998) Out of order: madness is a feminist and a disability issue. In Morris, J. (1998) **Encounters with strangers: feminism and disability**. London, The Women's Press

MDF (2004) **Manic depression – bipolar disorder.** [Internet], available at http://www.mdf.org.uk/ [accessed April 2006]

Mental Health Foundation (2003) **Surviving User-led Research: Reflections on Supporting User-led Research Projects.** London, Mental Health Foundation

Mental Health Task Force User Group (1995) **Forging our futures: lighting the fire**. London, Department of Health

Mental Welfare Commission for Scotland (2006) **Our Annual report: a new year, a new law**. Edinburgh, The Stationary Office

Meredith, BL (2002) Copying letters to patients. Policy should be implemented as soon as possible. **British Medical Journal.** 325, (7360), p 388

Millet, A. (1999) Patient participation in service improvement: the initial measures project experience. **Health Expectations**. 2, pp 280-284

MIND (2003) **MIND's Policy on User Involvement.** [Internet], available at <www.mind.org> [Accessed April 2006]

MIND (2005) **MIND Information for Better Mental Health**. [Internet], available at <www.mind.org> [Accessed April 2006]

Montgomery, AA. & Fahey, T. (2001) How do patients' treatment preferences compare with those of clinicians? **Quality in Health Care.** 10, pp 139-143

Morgan, DL. & Krueger, RA. (1993) When to use focus groups and why. In Morgan, DL. (Ed) **Successful Focus Groups.** London, Sage

Morgan, DL. (1993) **Successful Focus Groups.** London: Sage

Morgan, M., Fenwick, N., McKenzie, C. & Wolfe, CD. (1998) Quality of midwifery led care: assessing the effects of different models of continuity for women's satisfaction. **Quality in Health Care.** 7, pp 77-82

MORI (2003) **Market and Opinion Research International, for Developing Patient Partnerships,** formerly the Doctor Patient Partnership, DPP Medicines and the British. [Internet], available from <www.mori.com/polls/2003/medicines.shtml> [Accessed March 2007]

Morris, J. (1995) **The Power to Change. Commissioning Health and Social Services with Disabled People.** Partnership Paper No.2. London, King's Fund Centre

Morris, J. (1998) **Encounters with strangers; feminism and disability**. London, The Women's Press

Mort, M., Harrison, S. & Dowswell, T. Public health panels in the UK: influence at the margins? In Khan (ed) **Participation Beyond the Ballot Box: European case studies in state-citizen political dialogue.** London, UCL Press

Mouton, C., Teno, J., Mor, V. & Piette, J. (1997) Communication of preferences for care among human immunodeficiency virus-infested patients: barriers to informed decisions? **Archives of Family Medicine**. 6, pp 342-347

Mullen, P. & Spurgeon, P. (2000) **Priority Setting and the Public**. Abingdon, Oxon: Radcliff Medical Press

Munn-Giddings, C. & McVicar, A (2007) Self-help groups as mutual support: What do carers value? **Health & Social Care in the Community**. 15, (1), pp 26–34

Myers F. & MacDonald C. (1996) Power to the people? Involving users and carers in needs assessment and care planning - views from the practitioner. **Health and Social Care in the Community**. 4, (2), pp 86-95

Myers, L. (2001) The NHS – a patient's perspective. **Health Expectations.** 4, (4), pp 205-208

National Cancer Alliance (1996) **Patient-centred services? What patients say**. London: NCA

National Consumer Council (2002) **Involving consumers in healthcare. Case study for the consumers project.** London, National Consumer Council

National Institute for Social Work (1993) **Building User-Centred Services**. Policy Briefing No.4. London, NISW.

National Institute of Mental Health (2005) **Anxiety Disorders**. [Internet], available at <www.nimh.nih.gov/healthinformation/anxietymenu.cfm> [Accessed April 2006]

National Service Users Association (2000) **Annual Report.** Edinburgh, The Richmond Fellowship Scotland

NCT (1994) **NCT Annual Report.**   London, National Childbirth Trust

NCT (2002) **Maternity Service Liaison Committees.** [Internet], available at <http://www.mslc.org/nat_guide/page3.html> [Accessed May 2006]

Nease, RF. & Brooks, WB. (1995) Patient desire for information and decision making in health care decisions: the autonomy preference index and the health opinion survey. **Journal of General Internal Medicine.**   10, pp 593–600

Newburn, M. (1994) Views of consumers: what are they and how can they be obtained. In Chamberlin, G. & Patel, N. (eds) **The Future of Maternity Services**. London, RCOG Press

Newton, J. (1996) Patient's involvement in medical audit in general practice. **Health and Social Care in the Community.** 4, (3), pp 142 – 149

Newton, JT. (2000) Evaluating non-professional self-help groups for people with eating disorders. **European Eating Disorders Review.** 8, pp 1-3

Newton, JT., Hartley, P. & Sturmey, P. (1993a) Treatment evaluation for eating disorders by clients with eating disorders. **Behavioural and Cognitive Psychotherapy.** 21, pp 371-374

Newton, T., Robinson, PH. & Hartley, P. (1993b) Treatment for eating disorders in the United Kingdom. Part II. Experiences of treatment: a survey of members of the Eating Disorders Association. **Eating Disorders Review.** 1, pp 10-21

NHS Centre for Reviews and Dissemination (1998) Management of Lung Cancer. **Effective Health Care.** 4, (3)

NHS Centre for Reviews and Dissemination (2000) Informing, communicating and sharing decisions with people who have cancer. **Effective Health Care.** 6, (6)

NHS Executive (1996) **Maternity Services Liaison Committees: Guidelines for Working Effectively.** Leeds, NHS Executive

NHS Executive (1998) **Patient Partnership.** London, Department of Health

NHS Executive, NHS Confederation, Institute of Health Service Management (1998) **In the public interest: Developing a strategy for public participation in the NHS.** London, NHS Executive

NHS Health Advisory Service (1997) **Voices in partnership: involving users and carers in commissioning and delivering mental health services**. London, Stationery Office

NHS Reform Act (2004) (asp 7) Edinburgh, HMSO

NLH Primary Care Answering Service (2005) **Is there any evidence that patient held records are of benefit?** [Internet], available at <http://www.clinicalanswers.nhs.uk/index.cfm?question=200> [Accessed May 2006]

Nolan, M. (1999) Antenatal Education: Past and Future Agendas. **Practising Midwife.** 2, (3), pp 24-27

Nuffield Institute for Health, University of Leeds and NHS Centre for Reviews and Dissemination (1996) The Management of Primary Breast Cancer. **Effective Health Care.** 2, (6)

Nursing & Midwifery Council (2004) **The Nursing and Midwifery Council (Fitness to Practice) Rules Order of Council: Statutory Instrument 2004 No. 1761**. London, HMSO

O'Cathain, A., Walters, SJ., Thomas, KJ. & Kirkham, M. (2002) Use of evidence based leaflets to promote informed choice in maternity care: randomised controlled trial in everyday practice. **British Medical Journal.** 324, pp 643-646

Oakley, A. (1984) The Consumer's Role: Adversary or Partner? In Zander, L. & Chamberlin, G. (eds) **Pregnancy Care for the 1980s**. London, The Royal Society of Medicine

Oakley, A. (1993) **Essays on Women, Medicine & Health.** Edinburgh, Edinburgh University Press

O'Donnell, M., Parker, G., Proberts, M., Matthews, R., Fisher, D., Johnson, B. et al. (1999) A study of client-focused case management and consumer advocacy: the community and consumer service project. **Australian and New Zealand Journal of Psychiatry.** 33, pp 684-693

Office of Public Census and Surveys (1987) **General Household Survey.** London, OPCS

Oliver, M. (1998) **The Politics of Disability.** London, MacMillan

Oliver, S (2005) **Involving consumers in research and development agenda setting for the NHS: developing an evidence based approach.** The Research Findings Register, summary number 1381. [Internet], available at www.ReFeR.nhs/ViewRecord.asp?ID=1381 [Accessed September 2007]

Olzsewski, D. & Jones, L. (1998) **Putting people in the picture**. Edinburgh, Scottish Association of Health Councils, Scottish Health Feedback

Page, L. (2003) Shaping the future of maternity services. **British Journal of Midwifery**. 11, p 3

Pagett, J. (1994) Listening to user views: an out patient user panel in Llanelli and Dinefwr NHS Trust. **CCUFLINK**. 4 p 9.

Papenek, H. (1990) To each less than she needs, from each more than she can do: allocations, entitlements and value. In Tinker, I. (ed) **Persistent Inequalities: women and world development**. Oxford, Oxford University Press

Paulson, R., Herinckx, H., Demmler, J., Clarke, G., Cutter, D. & Birecree, E. (1999) Comparing practice patterns of consumer and non-consumer mental health service providers. **Community Mental Health Journal.** 35, pp 251-269

Payne, S. (1995) The rationing of psychiatric beds: changing trends in sex ratios in admission to psychiatric hospital. **Health and Social Care in the Community**. 3, (5), pp 289-300

Peck, E. (1998) Integrity, ambiguity or duplicity? NHS consultation with the public. **Health Services Management Research**. 11, pp 201-210

Perkins, R. & Repper, J. (1998) **Dilemmas in community mental health practice: choice or control**. Abingdon, Radcliffe Medical Press

Peck, E., Gulliver, P. & Towell, D. (2002) Information, consultation or control. User involvement in mental health services in England at the turn of the century. **Journal of Mental Health**. 11, pp 441–451.

Phillips, A. (1995) **The Politics of Presence,** Oxford, Clarendon Press

Pickard, S., Marshall, M., Rogers, A., Sheaff, R., Sibbald, B. et al (2002) User involvement in clinical governance. **Health Expectations.** 5, pp 187-198

Piette, D. (1990) Community participation in formal decision-making mechanisms. **Health Promotion International**. pp 187-197

Pilgrim, D. & Rogers, A. (1999) **A Sociology of Mental Health and Illness**. Buckingham, Oxford University Press

Pilgrim, D. & Waldron, L. (1998) User involvement in mental health service development: how far can it go? **Journal of Mental Health**. 3, (1), pp 95-104

Polowczyk, D., Brutus, M., Orvieto, AA., Vidal, J. & Cipriani, D. (1993) Comparison of patient and staff surveys of consumer satisfaction. **Hospital and Community Psychiatry**. 44, pp 589-591

Popay, J. & Williams G (1994) **Researching the people's health.** London, Routledge

Pope, R., Graham, L. & Patel, S. (2001) Woman centred care. **International Journal of Nursing Studies**. 38, p2

Poulton, BC. (1999) User involvement in identifying health needs and shaping and evaluating services: is it being realised? **Journal of Advanced Nursing.** 30, (6)

Pounceby, J. (1997) **The Coming of Age Project: A study of the transition from paediatric to adult care and treatment adherence amongst young people with cystic fibrosis.** London, Department of Health/Cystic Fibrosis Trust

Priebe, S. & Slade, M. (2002) **Evidence in Mental Health Care.** London, Brumer/Routledge

Proctor, S. & Wright, G. (1998) Consumer responses to health care: women and maternity services. **International Journal of Health Care Quality Assurance**. 11, (5), pp 147-155

Public Health Agency of Canada (2002) **Family-Centred Maternity and Newborn Care: National Guidelines.** [Internet], available at <http://www.phac-aspc.gc.ca/dca-dea/publications/fcmc01_e.html> {Accessed March 2006]

Quality Network (2002) **Measuring outcomes in services for people with learning difficulties**. London, National Development Team

Ranade, W. (1995) The theory and practice of managed competition in the National Health Service. **Public Administration**. 73, pp 241-62

Rankin, J. (2005) **Mental Health in the Mainstream: A good choice for mental health**. Institute for Public Policy Research. [Internet], available at <www.ippr.org> [Accessed March 2006]

Rea, C. & Rea, D. (2000) Responding to user views of service performance. **Journal of Mental Health**. 9, (4), pp 351-363

Read J. & Wallcraft J. (1992) **Guidelines for Empowering Users of Mental Health Services**. London, COHSE MIND Publications

Ream, E. & Richardson, A (1996) The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. **European Journal of Cancer Care (Engl).** 5, (3), pp 132-138

Redfern, M (2001) **The Royal Liverpool Children's Inquiry Report**. London, Stationery Office

Reid, M. (1994) What are consumer views of maternity care? In Chamberlin, G. & Patel, N. (eds) **The Future of the Maternity Services**. London, RCOG Press

Reid, M. (1997) Consulting Consumers of the Maternity Services. In Henderson, C. & Jones, K. (eds) **Essential Midwifery.** London, Mosby

Rhodes, P. & Shaw, S. (1998) Informal care and terminal illness. **Health and Social Care in the Community.** 7, (1), pp 39-50

Richardson, A. (1983) **Participation.** London, Routledge and Kegan Paul

Robinson, D. & Henry, S. (1977) **Self-help and health: mutual aid for modern problems**. London, Martin Robinson

Richardson, A. & Bray, C. (1987) **Promoting health through participation: experience of groups for patient participation in general practice**. London, Policy Studies Institute

Richardson, A., Lee, L. & Birchall, M. (200) Learning from patients with cancer and their spouses: a focus group study. **Journal of Laryngology & Otology**. 116, pp 1028-1035

Ridley, J. & Jones, L. (2002) **User and Public Involvement in Health Services: a Literature Review**. Edinburgh, Partners in Trust

Robert, G., McLeod, H. & Ham, C. (2003) **Modernising cancer services: an evaluation of Phase I of the Cancer Services Collaborative.** Health Services Management Centre Research Report 43. Birmingham, University of Birmingham

Rodwell C.M. (1996) An analysis of the concept of empowerment. **Journal of Advanced Nursing.** 23, pp 305-313

Rogers, A., Pilgrim, D. & Lacey, R. (1993) **Experiencing Psychiatry: Users' Views of Services.** London, Macmillan/MIND

Rorty, M., Yager, J. & Rossotto, E. (1993) Why and how do women recover from bulimia nervosa? The subjective appraisals of 40 women recovered for a year or more. **International Journal of Eating Disorders.** 14, pp 249-260

Rose, D. (2001) **Users' Voices. The perspectives of mental health service users on community and hospital care.** London, The Sainsbury Centre for Mental Health.

Rose, D. (2004) **Review of the Literature; service user involvement in change management in a mental health context**. The Research Findings Register, summary number 1206. [Internet], available at <www.ReFeR.nhs/ViewRecord.asp?ID=1206> [Accessed June 2006]

Rowland, D. & Pollock, A. (2004) Choice and responsiveness for older people in the 'patient-centred' NHS. **British Medical Journal** 328, pp 4-5

Royal College of Midwives (2001) **Position Paper 4a: Woman Centred Care**. London, Royal College of Midwives

Royal College of Obstetricians and Gynaecologists (2002) **Patient involvement in enhancing service provision.** Clinical Governance Advice No 4. London, RCOG

Royal College of Obstetricians and Gynaecologists (2003) **RCOG Submission to the Maternity Services Subcommittee of the House of Commons Health Committee Second Inquiry - Inequalities in Access to Maternity Services.** London, HMSO

Royal College of Obstetricians and Gynaecologists (2006) **Guidelines in clinical governance, clinical standards and good practice.** [Internet], available from <http://www.rcog.org.uk/> [Accessed April 2006]

Royal College of Psychiatrists (2004) **Mental Health Information from the Royal College of Psychiatrists: Anxiety & Phobias.** [Internet], available from <www.rcpsych.ac.uk> [Accessed April 2006]

Royal College of Psychiatrists Faculty for the Psychiatry of Old Age (2004) **Copying Clinical Letters to Patients: Guidelines for old age psychiatrists**. [Internet], available at <http://66.102.9.104/search?q=cache:fm3LAHFZWOAJ:www.rcpsych.ac.uk/pdf/guideline sCopyingPatients.pdf+Royal+College+of+Psychiatrists+Faculty+for+the+Psychiatry+of+ Old+Age+(2004)+Copying+Clinical+Letters+to+Patients:+Guidelines+for+old+age+psyc hiatrists&hl=en&ct=clnk&cd=1&gl=uk> [Accessed June 2005]

Royal Edinburgh Hospital Patients Council, (1998) **Quality from the Users' Perspective. A Quality Assurance Framework for Hospital Services**. Edinburgh, Patients Council

Royal Pharmaceutical Society of Great Britain (1997) **From Compliance to Concordance: Achieving Shared Goals in Medicine Taking.** London, RPS

Ryan, T. (2002) Mental Health. **Research Matters.** 13

Ryan, T. & Bamber, C. (2002) A survey of policy and practice on expenses and other payments to mental health service users and carers participating in service development. **Journal of Mental Health**. 11, 635–644

Sainsbury Centre for Mental Health (2001) **Users' voices: the perspectives of mental health service users on community and hospital care.** London, Sainsbury Centre for Mental Health

SAMH (2005) **What is Mental Illness?** [Internet], available from <www.samh.org.uk> [Accessed March 2006]

Sang, B. & O'Neill, S. (2001) Patient involvement in clinical governance. **British Journal of Health Care Management.** 7, (7), pp. 278-281

Say, R. & Thompson, R (2003) The importance of patient preferences in treatment decisions: challenges for doctors. **British Medical Journal.** 327, pp 542-545

Schizophrenia.com (2005) **Schizophrenia Newsletter.** [Internet], available from <www.schizophrenia.com> [Accessed April 2006]

Schoen, C., Osborn, R., Huynh, P., Doty, M., Davis, K., Zapert, K. et al (2004) Primary care and health system performance: adults' experiences in five countries. **Health Affairs.** 10, p 1377

Scottish Association of Health Councils, Scottish Consumer Council, The Scottish Office Department of Health (1999) **Designed to Involve: public involvement in the new primary care structures.** Glasgow, Scottish Consumer Council

Scottish Cancer Registry (2007) **Cancer in Scotland NHS National Services Scotland**. Edinburgh, HMSO

Scottish Executive (1999) **Managed Clinical Networks** NHS MEL (1999) 10

Scottish Executive (2000) **Our National Health–A Plan for Action, A Plan for Change**. Edinburgh, HMSO

Scottish Executive (2001) **Patient Focus and Public Involvement**. Edinburgh, HMSO

Scottish Executive (2003) **Report of the Expert Group on Acute Maternity Services (2002)**. Edinburgh, HMSO

Scottish Executive (2005) **Delivering for Health**. Edinburgh, HMSO

Scottish Executive Central Research Unit (2001) **Public Attitudes to the NHS in Scotland.** Edinburgh, Scottish Executive Central Research Unit

Scottish Executive Health Department (2001) **A Framework for Maternity Services in Scotland.** Edinburgh, HMSO

Scottish Executive Health Department (2002) **Consultation and public involvement in service change,** NHS HDL 42. Edinburgh, Stationary Office

Scottish Executive & Communities Scotland (2005) **National Standards for Community Engagement.** Edinburgh, Scottish Executive

Scottish Government (2007) **Health Scrutiny Panels**. [Internet], available at <www.scotland.gov.uk> [Accessed May 2008]

Scottish Health Feedback, (2000) **The Public, Professionals and the Quality of Health Care, Summary Report on a Pre-consultation Exercise for a new Patient's Charter in Scotland**. Edinburgh, Scottish Health Feedback.

Scottish Office Department of Health (1997) **Designed to Care – Reviewing the National Health Service in Scotland.** Edinburgh, The Stationery Office

Scottish Office Home and Health Department (1993) **Provision of maternity services in Scotland: a policy review.** Edinburgh, The Stationery Office

Scottish Parliament Official Report (2000) **The written report of proceedings in the Scottish Parliament and its committees.** [Internet], available at <www.scottishparliament.uk> [Accessed August 2007]

Scottish Partnership Agency for Palliative and Cancer Care and National Council for Hospice and Specialist Palliative Care Services, (1998) **Patient Held Records in Palliative and Cancer Care. Practical proposition or pie in the sky?** Report of a conference, Newcastle, October 1998. [Internet], available at <http://www.palliativecarescotland.org.uk/publications/phr.htm > [Accessed May 2006]

Scriven, A. & Tucker, C. (1997) The quality and management of written information presented to women undergoing hysterectomy. **Journal of Clinical Nursing.** 6, (2), pp 107-113

Seguin, L., Therrieu, R., Champagne, F., et al. (1989) The components of women's satisfaction with maternity care. **Birth**. 16, pp 109–13

Service First, Cabinet Office, Consumer Congress & The National Consumer Council (1999) **Involving users. Improving the delivery of healthcare.** London: Service First

Shakespeare, T. (1993) Disabled peoples self organisation: a new social movement. **Disability and Society**. 8, (3), pp 249-264

Shaping Our Lives National User Network, Black User Group (West London), Ethnic Disabled Group Emerged (Manchester), Footprints and Waltham Forest Black Mental Health Service User Group (North London) & Service Users' Action Forum (Wakefield) (2003) **Shaping Our Lives: From Outset to Outcome: What People Think of the Social Care Services They Use.** York, Joseph Rowntree Foundation

Shaw, J. & Barker, M. (2004) Expert patient: dream or nightmare? **British Medical Journal**. 328, pp 723-724

Shepherd, M. (2001) Voice recognition. **Health Service Journal.** 111, (5742), pp 32-33

Sheppard, B. (2000) **A voice for older Londoners in the doctor's surgery**. London, Age Concern

Shields, N., Turnbull, D., Reid, M., Holmes, A., McGinley, M. & Smith, LN. (1998) Midwife managed vs shared care. **Midwifery**. 14, (2), pp 85-93

Silva, EL. (1990) Collaboration between providers and client-consumers in public mental health programs. **New Directions in Mental Health Services**. 46, pp 57-63.

Silverman, D. (1993) **Interpreting qualitative data**. London, Sage

Silverman, D. (1997) **Qualitative Research: Theory, method and practice**. London, Sage

Silverman, D. (2000) **Doing Qualitative Research: A practical handbook.** London, Sage

Simpson, E. & House, A. (2002) Involving Users in the Delivery and Evaluation of Mental Health Services; systematic review. **British Medical Journal.** 325, p 1265

Simpson, M., Buckman, R., Stewart, M. et al. (1991) Doctor-patient communication: the Toronto consensus statement. **British Medical Journal.** 303, pp 1385-87

Skillbeck, J., Matt, L., Page, H. & Clark, D. (1997) Nursing care for people dying from chronic obstructive airways disease. **International Journal of Palliative Nursing**. 3, (2), pp 100-106

Skelton, JR. (2005) Everything you were afraid to ask about communication skills. **British Journal of General Practice.** 55, pp 40–46

Slevin, ML., Stubbs, L., Plant, HJ., Wilson, P., Gregory, WM., Armes, PJ., et al. (1990) Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors, nurses, and general public. **British Medical Journal.** 300, pp 1458-60

Small, N. & Rhodes, P. (2000) **Too Ill to Talk? User involvement in palliative care**. London, Routledge

Smith, J (2004) **Fifth Report of the Shipman Inquiry – Safeguarding Patients: Lessons from the Past – Proposals for the Future.** London, the Stationery Office, Command Paper Cm 6394

Smith, LF. (1999) The WOMB (Women's views of birth) antenatal satisfaction questionnaire: development, dimensions, internal reliability, and validity. **British Journal of General Practice.** 49, (449), 971-975

Smith, LF. (2001) Development of a multidimensional labour satisfaction questionnaire: dimensions, validity, and internal reliability. **Quality in Health Care.** 10, (1), pp 17-22

Smith, LK., Pope, C. & Botha, L. (2005) Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis. **Lancet.** 366, pp 825-831

Smith, MK. (1984) Client involvement in psychosocial rehabilitation. **Psychosocial Rehabilitation Journal.** 8, pp 35-43

Solomon, P. & Draine, J. (1995a) One year outcome of a randomised trial of consumer case managers. **Evaluation and Program Planning.** 18, pp 117-127

Solomon, P. & Draine, J. (1995b) The efficacy of a consumer case management team: 2-year outcomes of a randomised trial. **Journal of Mental Health Administration**. 22, pp 135-146

Solomon, P. & Draine, J. (1996) Service delivery differences between consumer and non-consumer case managers in mental health. **Residential Social Work Practice** 6, pp 193-207

Spence, F. (1984) **The value of life in geriatric patients.** MSc Thesis, University of Manchester

Spencer, L., Elam, G. & Turner, R. (2000) **"It is our money anyway". Giving the public a voice in local authority spending decision.** London, Department of Environment, Transport and the Religions

Spradley, J. (1979) **The Ethnographic Interview**. New York, Holt, Rinehart and Winston

Squires, B.& Learmonth, I. (2003) Empowerment of patients-fact or fiction? **British Medical Journal.** 326, (7391), p 710

Stacey, M. (1988) **The Sociology of Health and Healing: a textbook.** London, Unwin Hyman

Stapleton, H., Kirkham, M. & Thomas, G. (2002) Qualitative study of evidence based leaflets in maternity care. **British Medical Journal.** 324, p 639

Stead, ML., Fallowfield, L., Brown, JM. & Selby, P. (2001) Communication about sexual problems and sexual concerns in ovarian cancer: qualitative study. **British Medical Journal.** 323, (7317), pp. 836-837

Steel, R. (2005) Actively involving marginalized and excluded people in research. In: L. Lowes & I. Hulatt (eds) **Involving Service Users in Health and Social Care Research.** London, Routledge

Stevenson, F., Barry, C., Britten, N., Barber, N., Bradley,C. (2000) Doctor–patient communication about drugs: the evidence for shared decision making. **Social Science & Medicine.** 50, pp 829–840

Stevenson, F. (2003) General practitioners views on shared decision making: a qualitative analysis. **Patient Education and Counseling.** 50, pp 291–293.

Strong, P. & Robinson, J. (1990) **The NHS under new management.** Milton Keynes. Open University Press

Summers, A. & McKeown, K. (1996) Local Voices: evolving a realistic strategy on public consultation. **Public Health**. 110, pp145-150

Summers, A. (2003) Involving users in the development of mental health services: a study of psychiatrists' views. **Journal of Mental Health.** 12, pp 161–174

SURGE (Service User Research Group England) (2005) **Guidance for good practice: Service user involvement in the UK Metal Health Research Network**. Mental Health Research Network

Sutherland, HJ., Llewellyn-Thomas, HA., Lockwood, GA., Tritchler, DL. & Till, JE. (1989) Cancer patients: their desire for information and participation in treatment decisions. **Journal of the Royal Society of Medicine.** 82, (5), pp 260-263

Tait, L. & Lester, H (2005) Encouraging user involvement in mental health services. **Advances in Psychiatric Treatment**. 11, pp 168-175

Tattersall, RL. (2002) The expert patient: a new approach to chronic disease management for the twenty-first century. **Clinical Medicine.** 2, pp 227–229

Taylor, M. (1995) **Unleashing the Potential.** York, Joseph Rowntree Foundation

Taylor, M. (1999) The death of midwifery? – It may be closer than you think. **AIMS Journal.** 11, (1)

Taylor, M., Hoyes, L., Lart, R. & Means, R. (1992) **User Empowerment and Community Care: Unravelling the Issues**. Bristol, Joseph Rowntree Foundation, School for Advanced Urban Studies

Taylor, P. & Lupton, C. (1995) **Consumer Involvement in Health Care Commissioning**. Report No 30. Portsmouth, Social Services Research and Information Unit, University of Portsmouth

Taylor, P. (1994) **What's in a word: Consumer Involvement Project**. Swindon, Wiltshire Health Authority

Taylor, P. (1996) Supporting Community Involvement. In Burton, P. & Harrison, L. **Identifying Local Health Needs: New Community Based Approaches.** Bristol, Policy Press

Telford, R et al (2004) What does it mean to involve consumers successfully in NHS research? A consensus study. **Health Expectations**. 7, pp 209-220

Tew, M. (1990) **Safer Childbirth: A critical history of maternity care**. London, Chapman and Hall

Thomas, R., Daly, M., Perryman, B., et al. (2000) Forewarned is forearmed: benefits of preparatory information on video cassette for patients receiving chemotherapy or

radiotherapy: A randomized controlled trial. **European Journal of Cancer.** 36, pp 1536–1543

Tinkler, A. & Quinney, D. (1998) Influence of midwife-woman relationship. **Journal of Advanced Nursing**. 28, (1), pp 30-5

Toop, L. (1998) Primary care: core values. Patient centred primary care. **British Medical Journal.** 316, pp 1882-1883

Tritter, J., Daykin, N., Barley, V., Evans, S., McNeill, J., Palmer, N., Rimmer, J., Sanidas, M. & Turton, P. (2003) **Developing and evaluating best practice in user involvement in cancer services: Final report**. Bristol, Avon, Somerset and Wiltshire Cancer Services.

Tritter, J., Daykin, N., Evans, S. & Sanidas, M. (2004) **Improving cancer services through patient involvement.** Oxford, Radcliffe Medical Press

Trnobranski, P. (1994) Nurse-patient negotiation: assumption or reality. **Journal of Advanced Nursing.** 19, pp 733-737

Twigg, J. & Aitken, K. (1994) **Carers perceived: policy and practise in informal care.** Buckingham, Open University Press

Tyler, S. (2002) Comparing the campaigning profile of maternity user groups in Europe – can be learn anything useful? **Health Expectations**. 5, (2), pp 136-147

United Kingdom Central Council for Nursing, Midwifery and Health Visiting (2004) **The NMC code of professional conduct: standards for conduct, performance and ethics.** [Internet], available at <http://www.ukcc.org.uk/> [accessed March 2006]

United Nations (1995) **The world's women 1970-1990: trends and statistics**. Social Statistics and Indicators, Series, K. no 12. New York, UN

Urben, L. (1997) Self-help groups in palliative care. **European Journal of Palliative Care.** 4, (1), pp 26-28

Vashisht, A., Domeney, CL., Handscomb, K., Smith, JR. & Bridges, JE. (2000) Patient satisfaction with the care provided at a gynaecology oncology clinic. **Journal of Obstetrics & Gynaecology.** 20, (2), pp. 183-184

Vickers, J., Rankin, P. & Appelle, C. (1993) **Politics as if Women Mattered: A Political Analysis of the National Action Committee on the Status of Women**. Toronto, University of Toronto Press

von Reusner, S. (1999) **Patients Influencing Health Care Project.** Evaluation Report. Inverness, Highland Health Board

Wallcraft, J. (2003) **On Our Own Terms: Users and Survivors of Mental Health Services Working Together for Support and Change**. London, Sainsbury Centre for Mental Health

Warner, JP., King, M., Blizard, R., McClenahan, Z. & Tang, S. (2000) Patient-held shared care records for individuals with mental illness. Randomised controlled evaluation. **British Journal of Psychiatry**. 177, pp 319-24

Warshaw, C. (1993) Domestic violence: challenge to medical practice. **Journal of Women's Health.** 2 (1), pp 73-79

Webb, EJ., Campbell, DT., Schwartz, RD. & Sechrest, L. (1966) **Unobtrusive Measures: Non-reactive research in social sciences.** Chicago Il, Rand McNally College Publishing Company

Wersch van, A. & Eccles, M. (2001) Involvement of consumers in the development of evidence based clinical guidelines: practical experiences from the North of England evidence based guideline development program. **Quality in Health Care**. 10, pp 10-16

Williams, B. (1994) Patient satisfaction: a valid concept? **Social Science and Medicine**. 1, (4), pp 509-16

Williams, B. & Grant, G. (1998) Defining 'people-centeredness': making the implicit explicit. **Health and Social Care in the Community**. 6, (2), pp 84-94

Williams, B. & Wilkinson, G. (1995) Patient satisfaction in mental health care. Evaluating an evaluative method. **British Journal of Psychiatry.** 166, pp 559-562

Williams, D. (1994) Improving the quality of service in the outpatient department at Singleton Hospital. **CCUFLINK**. 4, pp 10-12

Williams, JG., Cheung, WY., Chetwynd, N., Cohen, DR., El-Sharkawi, S. & Finlay, I. (2001) Pragmatic randomised trial to evaluate the use of patient held records for the continuing care of patients with cancer. **Quality Health Care.** 10, pp 159-65

Williams, S. & Calnan, M. (1996) The `limits' of modern medicine in late modernity. **Social Science and Medicine.** 42, (12), pp 1609–1620

Williamson, C. (1998) The rise of doctor-patient working groups. **British Medical Journal**. 317, pp 1374-1377

Williamson, C. (1999) Reflections on health care consumerism: insights from feminism. **Health Expectations.** 2, pp. 150-158

Willson, K. & Howard, J. (2000) **Missing Links: The Effects of Health Care Privatisation on Women in Manitoba and Saskatchewan.** University of Winnipeg, Prairie Women's Health Centre of Excellence

Wilson, G. (1993) Users and providers: different perspectives on community care services. **Journal of Social Policy**. 22 (4), pp 508-25

Wilson, J. (1998) Talking to the right people, **Hospital Development.** 29, (6), 10, p13

Wilson, J. (1999) Acknowledging the expertise of patients and their organizations. **British Medical Journal.** 319, pp 771-774

Wistow, G. & Barnes, M. (1993) User involvement in community care: origins, purposes and applications. **Public Administration**. 1993, pp 279-299

Wood, J. & Wilson-Barnett, J. (1999) The influence of user involvement on the learning of mental health nursing students. **Nursing Times Research**. 4, pp 257-270

Wood, J. (1984) Patient Participation in General Practice. In Maxwell, R. & Weaver, N. (eds) **Public Participation in Health**. London, Kings Fund

Woods, T. (1994) The use of ward forums in obtaining patient feedback. **CCUFLINK**. 4, pp 7-8

Wright, F. & Young, E. (1994) Focusing on client held joint health and social care records. **Journal of Inter-professional Care**. 8, pp 321-328

Yager, J., Landsverk, J. & Edelstein, CK. (1989) Help seeking and satisfaction with care in 641 women with eating disorders. I. Patterns of utilization, attributed change, and perceived efficacy of treatment. **Journal of Nervous and Mental Disease.** 177

Yin, R (2002) **Case Study Research. Design and Methods. Third Edition**. Applied social research method series Volume 5. California, Sage

Young, M. & Cullen, L. (1996) **A Good Death: Conversations with East Londoners**. London, Routledge

Zola, I. (1987) Self-help enters a new era: the politicisation of the self-help movement. **Social Policy**. 18, pp32-33

Appendices

1. Ethics Approval

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Chairman: Dr J B Neilly

Dear Kate,

<u>Proposed Submission:</u> **Consulting with health consumers: an examination of women's participation in shaping health services in Glasgow.**

I refer to your email dated 22nd April 2003, regarding the above proposed study.

Dr Neilly, Chairman of the REC, has reviewed your submission and is satisfied that there are no ethical issues involved in this staff survey project. Therefore, formal ethics review is not required.

However, please note that you should not proceed with the study on this site, or any other NGT site, until written Trust management approval – sought via the Research & Development Office – is obtained.

Yours sincerely

Sharon Macgregor

Sharon Macgregor
<u>LREC Administrator</u>

2.   Information sent to Potential Interviewees

Dear

My name is Kate Munro and I work for the Department of Public Health at Greater Glasgow NHS Board.   I am currently a PhD student at Glasgow University and my supervisor is Dr Margaret Reid.   For my study I am exploring the influence of user involvement on the development of health policy and service planning.   I am particularly interested in developing an exploratory account of women's involvement in three settings – mental health, maternity and gynaecological oncology.   I want to explore the different understandings, processes and outcomes of user involvement in these settings and to trace any identifiable links between the outcomes of involvement and the shaping and development of services.

I am planning to seek the views of a range of stakeholders in health services and will address a number of different perspectives including medical and nursing staff, academia, voluntary organisations and representatives from various patient organisations.   In order to explore the policy context and expectations I was hoping to interview you and very much hope that you will be agreeable to this.   I would be happy to meet with you at your office and would take no more than an hour of your time.   If you would be agreeable, I would like to tape record our meeting.

I have enclosed a copy of a research proposal that gives a fuller account of my study but please do not hesitate to contact me if you have any questions.   If you would be able to take part in an interview then please contact me at the above number or by e-mail so that we can agree a date and time.

I look forward to hearing from you.

Yours sincerely,

C. A. M. Munro

3. Interview Schedule: Service Settings

1. **Do you think that women want to have a say in your service?**

2. **How have you tried to involve women in the service? Can you give an example?**
   - ❖ E.g. any problems encountered in finding representatives?
   - ❖ E.g. what is viewed as a legitimate role for patients and users?

3. **How are users encouraged to have their say in your services?**
   - ❖ E.g. feedback such as questionnaires or suggestion boxes?
   - ❖ E.g. patient information about medical conditions or services?
   - ❖ E.g. user forums?

4. **Can users get involved in discussions about service planning or delivery?**
   - ❖ E.g. where are decisions made about the development and delivery of services and are users represented on these?

5. **Do you think users are able to contribute to the development and delivery of services?**
   - ❖ E.g. can you give an example of user feedback shaping services or policy decisions?

6. **Is user involvement monitored or evaluated?**

7. **What issues do you think are important to users in this setting?**
   - ❖ E.g. issues that are repeatedly identified in feedback or other ways?
   - ❖ E.g. issues that differ from medical, nursing or management priorities?

8. **Are there any difficulties in having a user perspective on services?**
   - ❖ E.g. barriers to effective involvement or ways to improve their contribution?

4.   Interview Schedule: Strategic Health Service Overview

1.   **Why have users involved in planning and developing health services?**
   ❖ Rationale

2.   **What benefits do you expect from involving users?**
   ❖ Philosophy and understanding

3.   **How will representatives be chosen?**
   ❖ Legitimacy

4.   **How will they be involved?**
   ❖ Role and responsibility

5.   **What issues do you think users can make a particular contribution to?**

6.   **How will their contribution be acted on?**
   ❖ Links to decision-making and policy fora

7.   **How will their contribution be weighted against those from a medical, nursing or management perspective?**

8.   **How will disagreements be addressed?**

9.   **Are the contributions made on behalf of users monitored or evaluated?**

10.   **Do you anticipate any difficulties or tensions in having a user perspective?**

11.   **If so, what would improve their contribution to service planning and policy-making?**

5.   List of Documents in Document Review

Author	Description	Date
Mental Health Services		
Greater Glasgow Health Board	Mental Health Strategy: Modernising Mental Health Services consultation paper	Nov 1999
Greater Glasgow Primary Care NHS Trust	Involving People information pack	Aug 2000
Greater Glasgow Primary Care NHS Trust	Guidelines for Improving Patient and Public Information	2001
Greater Glasgow Primary Care NHS Trust	Public Involvement Policy	2001
Mental Health Network (Greater Glasgow)	Women's Forum: report of the first meeting	April 2001
NHS Greater Glasgow Mental Health Services	Patient Focus Public Involvement information leaflet	Feb 2005
Mental Health Network (Greater Glasgow)	Women's Forum: minutes	2005–06
Maternity Services		
Greater Glasgow NHS Board	Maternity Services – Consulting with Users and the Community: Proposal for the Maternity Services Liaison Committee	May 2002
Greater Glasgow NHS Board	Maternity Services – Consulting with Users and the Community: Report on Developing User Representation for the Maternity Services Liaison Committee	Feb 2003
Greater Glasgow NHS Board	Greater Glasgow's Maternity Services: A Users Perspective on the Proposed Changes	Oct 2003
Greater Glasgow NHS Board	MatNet – Involving Users in Maternity Services in NHS Greater Glasgow: A Review of the Structure and Work of MatNet	June 2006
Gynaecological Oncology Services		
North Glasgow and Forth Valley Designed Health Care Initiative	The Re-design of Ovarian Cancer Services Across Central Scotland Information Updates	2002-2003
National Cancer Plan	Cancer Networks: A Focus on Gynaecological Cancer Conference Proceedings	June 2003
Greater Glasgow NHS Board	Talking to Women: Action Planning in Gynaecology with Women from Minority Ethnic Communities	June 2004
TakTent	TakTent Newsletter	Summer 2004

NHS Greater Glasgow and Clyde
NHS Greater Glasgow and Clyde Performance Assessment Framework 2005/2006

6. Coding Framework

Theme	Category	Codes
The Philosophy and Nature of User Involvement	Methods	Actively seeking views
		Advocate
		Complaints procedure
		Distribution of information on services
		Evaluation
		Health Council
		Lack of formal mechanisms
		Listening to patients
		Multiple approaches
		Patient forum
		Public meeting
		Service wide structures
		Service/patient for a
		Shared care
		Suggestion box
		Surveys
		Treatment information
		Unsuccessful methods
	Rationale	Bridge to NHS for users
		Centres service on patients
		Historical model
		Patient desire in service
		Patient desire in treatment
		Policy compliance
		Public expectation
		Service desire in service
		Service desire in treatment
		Tick box
	Uses	Communication of plans etc
		Enhanced care
		Enhanced decision-making
		Information provision
		Policy consultation
		Service consultation
The Capacity for Involvement	Links to decision-making fora	
	Management of agenda	
	NHS issues	
Facilitators of User Involvement	Communication	
	Culture	
	Education	
	Meetings	
	Support	
Barriers to User Involvement	Communication	
	Culture	
	Education	
	Meetings	
	Support	
	Systems	
Representation	Representation	
	Representativeness	
	Roles	

The Impact of User Involvement	Outcomes Tensions arising
Development of User Involvement	Development
Gender Issues	Gender