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PATIENT AND PUBLIC INVOLVEMENT IN PRIMARY CARE GROUPS

A CASE STUDY

BY

VERNA FEE

**A THESIS SUBMITTED FOR THE DEGREE OF DOCTOR OF
PHILOSOPHY IN THE SCHOOL OF APPLIED SOCIAL SCIENCES,
UNIVERSITY OF DURHAM**

APRIL 2007

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A CASE STUDY

VERNA FEE

PhD, 2006

ABSTRACT

The focus of this thesis is patient and public involvement in the UK National Health Service (NHS) following the White Paper, *The New NHS: Modern, Dependable* (DoH 1997). It offers a critical analysis of the delivery of the promises made in the White Paper, with particular reference to a detailed case study of one Primary Care Group (PCG) during the period 1999 – 2002. The study is set in the policy context of profound organisational and structural change in the UK NHS, which has included an increasing emphasis on developing mechanisms for involving patients and the wider public.

The case study is based on observation of several key structures and processes within the PCG and in-depth interviews with key stakeholders – medical and nursing practitioners, PCG managers, members of partner organisations, the lay member of the Board and community representatives. Using a theoretical framework that draws on Lukes' analysis of power, the study explores how the roles of patients and members of the public were perceived and constructed, the effectiveness of involvement and some of the main issues and challenges.

The study revealed immature structures and processes, confusion over the why, how and when of involvement activities, tensions between centrally driven targets and local control and relatively little understanding of how acknowledging and addressing existing power relationships is fundamental to developing meaningful involvement. The thesis concludes that attempts to develop patient and public involvement in isolation from theoretical and philosophical issues undermine the impact that traditional and historical patterns of power and control can have on current and future developments in respect of policy and practice. In particular, creating the conditions necessary to enable all stakeholders to identify, articulate, negotiate and argue for their perceived needs will require ideological as well as structural and organisational change.

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I owe a debt of gratitude to my family for their patience, tolerance and practical support during what must have seemed an interminable process. A special thank you is owed to Peter who has had much to put up with during completion of the thesis but has suffered it without complaint or comment.

INTRODUCTION

This thesis is about the role of patients and members of the public in the UK National Health Service (NHS). The role of patients and members of the public in health and health care services planning and decision-making has changed significantly since the establishment of the NHS. The modernisation agenda of New Labour in 1997 was intended to build on the New Public Management policies of the previous Conservative government by extending the role of patients as consumers to encompass democratic renewal and the collective rights and responsibilities of members of the wider public. In the “modernised” health service, patients and members of the public were promised a much greater say in planning and decision-making than previously held in the NHS. In delivering this agenda, local NHS bodies called Primary Care Groups were seen as the vehicle for achieving devolved decision-making and moving away from the centralised command and control model of planning for which the NHS has frequently been criticised.

RATIONALE FOR THE RESEARCH

The emphasis placed on the role of patients and the wider public in the UK NHS reforms of 1997 built on earlier reforms aimed at transforming the NHS from a service frequently criticised for a democratic deficit into a modern and dependable service “built around the needs of people not institutions” (*The New NHS - Modern, Dependable*, DoH, 1997:5). When the NHS was founded in 1948, the emphasis was on professionals identifying, planning and delivering health care. The principles underpinning the *New NHS*, announced in the 1997 reforms, were intended to turn this around by developing partnerships between patients, the wider community, and professionals.

A key element of delivering this “New NHS” was the establishment of bodies called Primary Care Groups (PCGs) that would over time develop into independent Primary Care Trusts. Primary Care Groups were formed around relatively small populations and involved those responsible for delivering primary care services. Managed by a governing body made up of health care professionals, social

services, health authority and lay representation, they were predominantly led by General Practitioners.

General Practitioners (GPs) have traditionally worked within a legal and contractual framework that recognised members of their constituencies only when they became patients. The framework did not include definitions of, or responsibilities to, members of the wider community until they became a user of a health service. With the introduction of PCGs, a legislative framework was put in place that extended this and referred to working with and responding to the perceived needs of communities and individuals, not just when they became patients but in wider planning arrangements. Primary Care Groups would produce Primary Care Investment Plans that made reference to residents not just patients. In addition, they were required to demonstrate clear arrangements for involving patients and the wider public in their planning and were accountable for this to their local health authority through an annual accountability agreement.

The establishment of PCGs introduced significant changes for those involved in delivering primary care. Primary Care Groups, the 1997 reforms claimed, recognised that, for the majority of people, the most contact they had with the NHS was through a primary care professional. These professionals were deemed to be best placed to understand the needs of patients and to identify how to make local services more responsive. In addition, a health service that not only treated people when they were ill but worked with others to improve health and reduce health inequalities was promised. Key to achieving this was the involvement of patients and members of the public in decisions regarding not only their own individual care but also the way in which services were planned and delivered.

Primary care was changing, but were primary care professionals attuned to or prepared for these changes? Those responsible for delivering the change at PCG level, in particular GPs came with no real history of involving the wider public. There was little evidence of any involvement in GP services, for example, except for individual-doctor patient interaction (Lupton et al, 1998:105-107) and yet if the partnerships advocated in the New NHS were to become a reality, the engagement of GPs in the patient and public involvement agenda would be crucial. As Anderson (2001:30-43) suggests, without this engagement there was the potential for professionals to sign up to an involvement agenda but manipulate the process

simply to legitimise their own decisions. Patients and members of the public would remain observers without any real access to, or influence over, decision-making.

THE AIMS OF THE RESEARCH

The research is based on a case study of how one PCG responded to an agenda that emphasised the need to develop the role of patients and members of the public. The aim of the research was to formulate an understanding of how members of the PCG governing body had defined their role and responsibilities, both collectively and individually, and how this complemented or conflicted with their construction of the role of patients and the wider public. In addition, the study aimed to identify context-specific and wider issues that would or could influence the role of patients and members of the wider public in the work of the Primary Care Group.

The main research questions to be explored were as follows:

1. How did members of the governing body of the PCG define individual and collective roles and responsibilities?
2. How did the key stakeholders construct the role of patients and the public and subsequent decisions regarding whom, how and when?
3. What were the aspirations of the key stakeholders in terms of the role that patients and the wider public could, or should, have?
4. What factors were perceived as influencing the development of the role of patients and members of the wider public?
5. What structures and processes were in place and how did these facilitate or constrain aspirations?
6. Were aspirations for involving patients and the wider public incorporated into planning processes and, if so, how?

In answering these questions, the study explores the perceptions, aspirations and intentions towards patient and public involvement as expressed by PCG Board members and a sample of local people involved with the Primary Care Group. The study also examines the structures and processes in operation within and out with the PCG and identifies how these helped or hindered the inclusion of a patient and public perspective in planning and decision-making.

In many respects, the research was opportunistic in that it was made possible through my own role as a Community Involvement and Partnerships Development Officer with the PCG being studied. The advantage of my role as an “insider” was in the support made available to me in terms of access to key players and documents and also in the contribution the findings would make to development of the role of patients and the public locally. It also presented some challenges that will be discussed more fully in subsequent chapters.

DESCRIPTION OF THE CASE STUDY PRIMARY CARE GROUP

The subject of this case study is one PCG, as it existed from April 1999 until March 2002. Established in April 1999, this was one of the smaller PCGs with a population of approximately 85,000. The PCG incorporated fifteen General Practices, one third of which were single handed General Practitioners. Prior to the establishment of the PCGs, a number of the larger group practices had been fund holders and a Primary Care Commissioning Group had been established to provide the opportunity for non-fund holding practices to contribute to decisions surrounding the commissioning of particular services.

The PCG covered a semi-rural area that has significant areas of disadvantage particularly in terms of ill health (Index of Multiple Deprivation 2001). Organisationally, the PCG was situated in an area that included local authorities at both county and district level. The geographical boundaries of the PCG were co-terminus with those of the Local District Council while the County Council was responsible for delivering social care services.

THE STRUCTURE OF THE THESIS

The thesis is structured around the following themes:

1. A brief overview of some of the changes occurring in the NHS since its introduction in 1948 and the subsequent implications for the role of patients and members of the public.
2. Current and previous debate surrounding issues of power and empowerment and the importance of this in terms of developing models of

engaging with patients and the wider public, particularly in relation to consumerist and democratic approaches.

3. The research methodology employed in this study.
4. Discussion and analysis of the data obtained.
5. Conclusions arrived at based on the research findings.

Chapter one briefly discusses the major changes that have taken place in the NHS since its inception in 1948 up to and including the introduction of the *New NHS* in 1997. Discussion is included on the public health agenda and in particular the impact that this has had on the role of patients and the wider public. The chapter also explores the history of engaging with patients and the public in the UK NHS and how various policy and guidance has been responded to.

Chapter two discusses the nature of “involvement” and examines this within the context of power and influence. In particular, the chapter examines Lukes’ three dimensions of power and Alford’s structural theory of power in health care policy and how these might be applied to the policy and decision-making in the UK NHS. The various roles assigned to patients and members of the public, particularly in relation to consumerism and democracy, and their development in the context of power in the NHS are also examined. In addition, the extent to which intentions in respect of developing the role of patients and the public are susceptible not only to the aspirations and commitment of those who have the responsibility to develop the role but also the wider power relationships that exist is explored.

Chapter three describes the study in terms of research design, methodology and methods. This chapter also discusses the strengths and weaknesses, advantages and disadvantages of the methodology in the context of this study and more generally.

Chapter four is the first of three data analysis chapters and draws on data obtained by observing PCG processes in action. The existing structures and processes and how these had helped or hindered the development of the role of patients and members of the public are discussed. Specific examples of how local people had been included in planning and decision-making processes are examined.

This chapter also discusses how those involved in the study had interpreted key roles and responsibilities and explores issues surrounding the composition of PCG Boards in general and more specifically in relation to the PCG in this study.

Chapter five introduces the themes of intent, implementation and impact in respect of the role of patients and the public. The chapter discusses the purpose of and aspirations for engaging with local people in relation to PCG planning and decision-making and explores perceptions of how these could be achieved in terms of the model adopted and the methods introduced. The chapter concludes with an examination of how the contribution of local people and the subsequent impact that this could, or should, make had been interpreted.

Chapter six explores the issue of accountability in the context of how promises of increased accountability to patients and members of the public had been interpreted locally. In particular, what changes had been introduced at a local level that would ensure that accountability to local communities was embraced as a priority.

Chapter Seven identifies the key findings of the study in relation to models, methods and outcomes of engaging with local people and how the structures, processes and relationships evident within the PCG influenced these. The chapter ends with reflections on the research, a discussion of the changes that have taken place since the study specifically in relation to the transformation from PCGs to Primary Care Trusts and the implications for future policy and practice.

CHAPTER ONE

CHANGE IN THE NHS

INTRODUCTION

This chapter discusses the major structural and policy changes in the NHS since its inception in 1948 up to and including the introduction of the *New NHS* in 1997. The impact of “New Public Management” policies introduced by a Conservative government during the early 1980’s is explored and compared with the concept of “modernisation” announced by the Labour government in 1997. The changing emphasis in terms of the priority given to primary care services provided by general practitioners and their teams compared with hospital and specialist services is examined and discussion on parallel developments in the public health agenda introduced. In particular, the chapter examines the impact of these changes on the emphasis given to, and the subsequent opportunities made available for, patients and members of the public to contribute to planning and decision-making in the NHS. The chapter ends with an exploration of how NHS bodies have responded, in practical terms, to expectations surrounding the inclusion of a patient and public perspective inherent in successive policy and reform.

A CHANGING NHS

Since it was established in 1948, the NHS has been subject to successive changes in organisational structure, policy and reform. A shift in emphasis from hospital and specialist services in favour of developing primary care-led services is evident along with varying degrees of importance that have been given to the public health agenda. The debate on health improvement and addressing health inequalities has moved from focusing on issues such as the eradication of widespread poverty and squalor to promoting health education and encouraging responsible citizens.

Many of these changes, particularly those introduced by a Conservative government in the mid-1980s, referred to the role of patients and members of the public as “consumers” in the context of developing health services. In contrast, the acknowledgement that people are not merely passive recipients of health services

but are actually producers of health and that the empowerment of local people is key to improving health has become more popular within the public health movement over recent years. The Labour Government's *New NHS* introduced in 1997 indicated an attempt to combine these two concepts by reinforcing the rights that should be afforded to those who use health services with the development of an approach to health and health care that acknowledged both the responsibilities of patients and members of the public but also their rights as citizens to be involved in decisions that affect them.

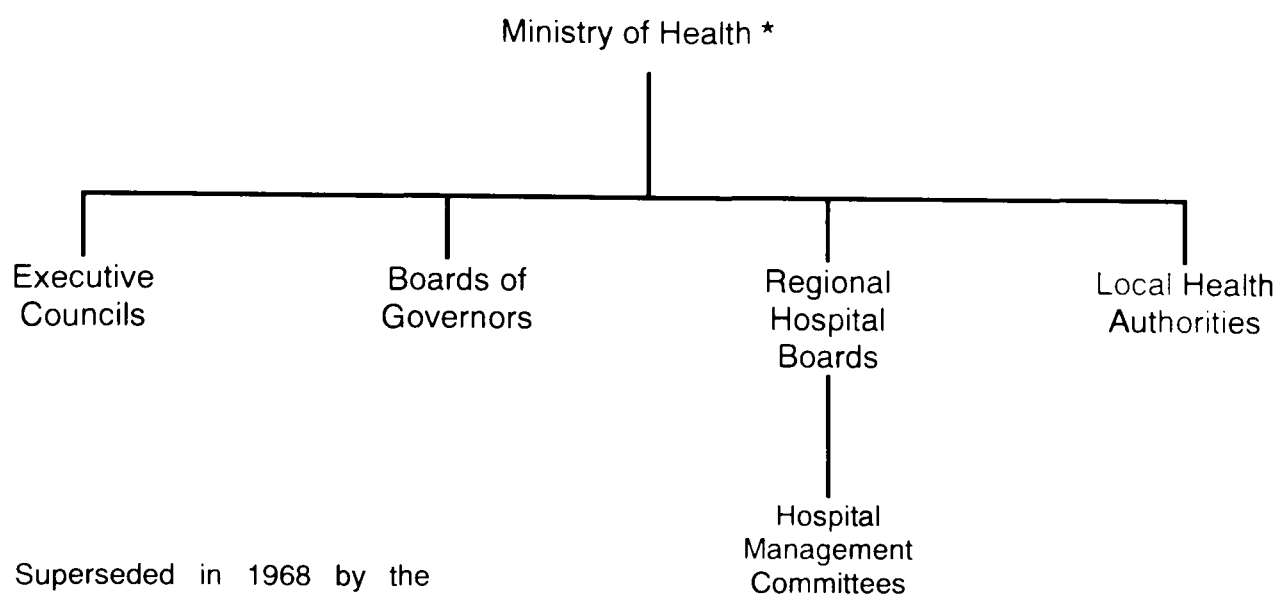
Until 1974, the inclusion of a patient and public perspective was almost exclusively centred around lay and local authority representation on various NHS bodies. In 1974 this changed with the introduction of Community Health Councils that were intended to be mechanisms for safeguarding public interests in the NHS. The introduction of general management practice in the NHS, and the subsequent separation of purchasing and providing functions, also included an attempt to instil a more business like approach to patients by viewing them as consumers of services with the same rights, such as choice, information and redress, in relation to health services that they would expect in any other service they would use. In 1997 the *New NHS* extended this by promising patients and members of the public new powers and influence, not only when they used health services but also over the way in which services were planned and delivered.

The NHS 1948 - 1989

When the NHS was established in 1948 it consisted of three separate but parallel structures (Leathard, 2000):

- General practitioners, dentists, pharmacists and optometrists whose contracts were administered by Executive Councils.
- Local Authorities with responsibility for a range of personal and public health services such as maternity, health visiting, child welfare, health education, preventative and health promotion services.
- Regional hospital boards and local hospital management committees administering hospital services, consultants and specialist services

Fig 1.1: The Structure of the NHS 1948 – 1974 (Source: Ham 1999)

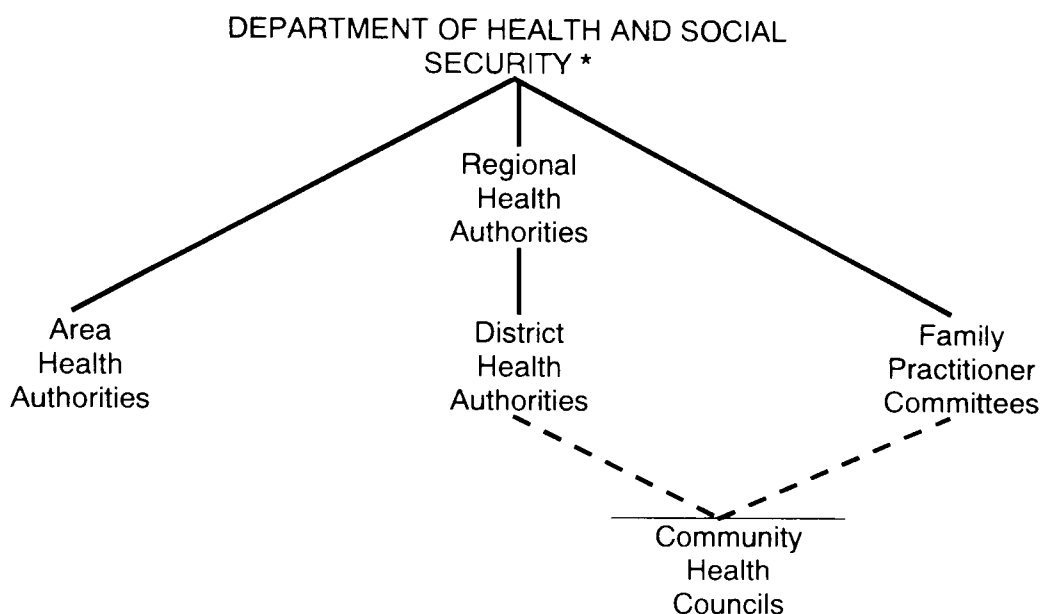


* Superseded in 1968 by the Department of Health and Social Security

This tripartite structure (Fig 1.1), although frequently criticised for being fragmented and uncoordinated, continued largely unchanged for more than twenty-five years. In 1974 major organisational change was introduced in an attempt to unify health services by bringing them all together at area health authority level, ensure better coordination between health authorities and local authority related services and increase efficiency by providing better management and reducing duplication (Leathard, 2000:24-42).

Regional health authorities replaced regional hospital boards and were given responsibility for all regional planning and prioritisation while area health authorities were established to develop services jointly with local authorities. Most area health authorities were split into districts administered by district management teams and although local authorities retained an environmental health function, all community health services were transferred to the NHS (Fig 1.2).

Fig 1.2 The Structure of the NHS 1974 – 1982 (Source: Ham, 1999)



Although the 1974 reorganisation had been intended to unify services, the prevailing structure was soon criticised for introducing too many tiers and encouraging excessive bureaucracy, duplication and waste (Baggott, 1998:86-104). Equally, absolute unification had not been achieved as the independent contractor status of primary care service providers such as general practitioners and dentists had been retained. The administration of these independent contractors, previously the domain of executive councils, became the responsibility of family practitioner committees. Family practitioner committees were, like their predecessors, administrative rather than management bodies and independent contractors continued to enjoy their traditional level of autonomy.

Grounded in the principle of consensus management, introducing a range of perspectives into the decision-making arena and giving clinicians a key management role, the 1974 arrangements were considered to have resulted in delayed and fragmented decision-making (Ham, 1999:4-26).

In 1979 *Patients First* (DHSS 1979) recommended the removal of one tier of management thereby reducing bureaucracy, duplication and waste and establishing a less hierarchical structure than the command and control model seen as resulting from the 1974 reforms (Leathard, 2000:43-58) This new structure merged area health authorities with district management teams and renamed them district health authorities. The resulting structure was intended to simplify structures and introduce decentralised, local decision-making around smaller populations.

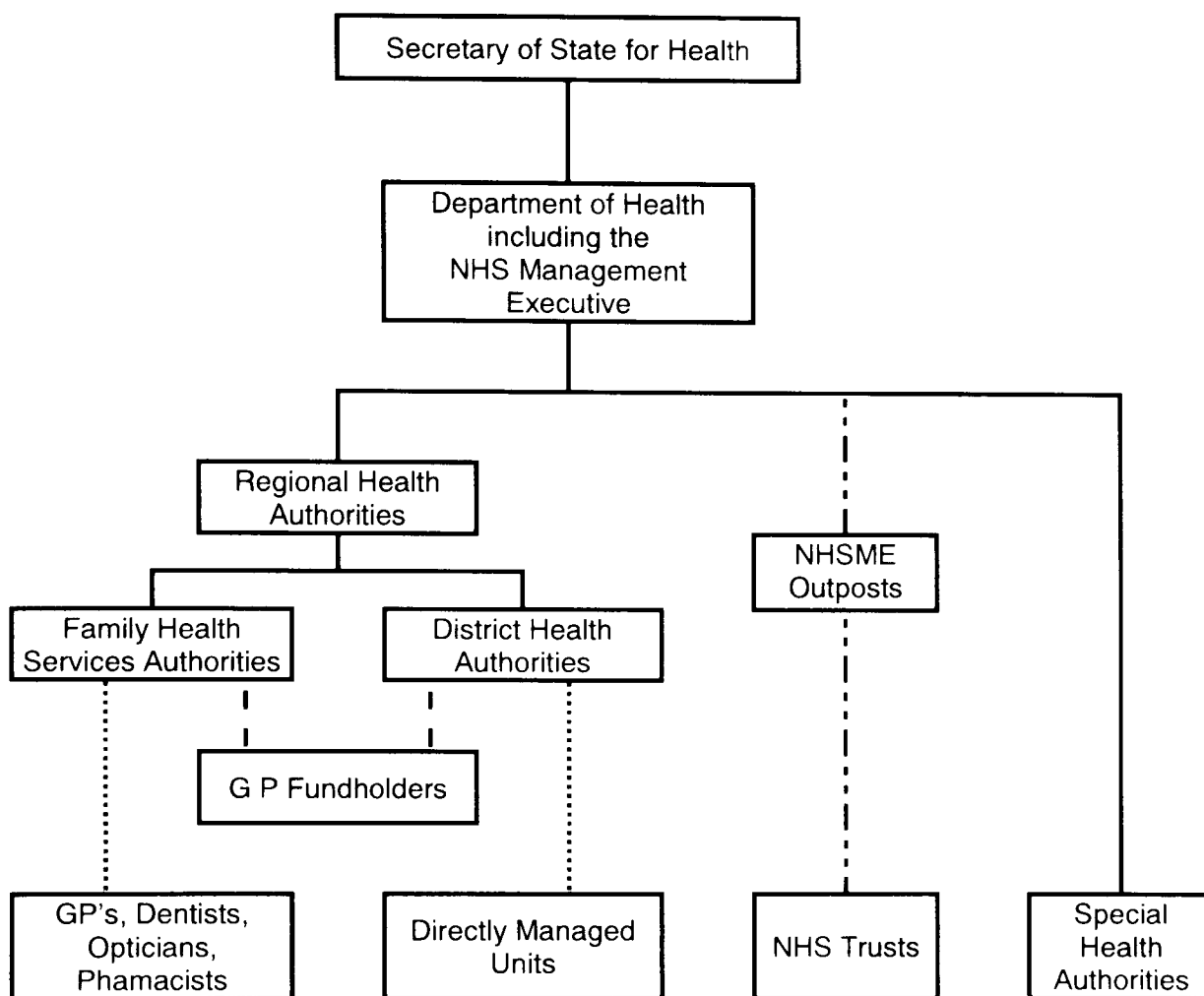
In reality, as Webster (2002:140-207) argues, the reorganisation was more fine-tuning than major shake up and the new arrangements differed little from those introduced in 1974. The changes did however result in a much greater emphasis on devolved decision-making and provided the opportunity for decisions to be made at a local community level. However, although structural simplification had been achieved, the removal of one tier of management had resulted, in many cases, in the loss of co-terminosity with local authorities and a subsequent weakening of the links between locally elected representatives and the NHS (Leathard, 2000:43-58). In addition, the integration of GPs had still not been achieved as the boundaries and financial arrangements of family practitioner committees continued to be independent of district health authorities.

The NHS 1989 - 1997

In 1989 the White Paper *Working for Patients* introduced the separation of the purchasing and providing functions within the NHS. Speaking of the need to extend patient choice, delegate more responsibility to a local level and secure best value, the proposals were described as putting the needs of patients first. The main proposals of the White Paper were to introduce medical audit, GP fund holding, an expansion of privatised initiatives and a slimming down of the membership of family practitioner committees and regional and district health authorities. In addition, the separation of the purchasing and providing function introduced self-governing NHS Trusts that would provide the major proportion of secondary health care and generate income from securing contracts with purchasers. The separation of the two functions was intended to create conditions for competition between NHS hospitals and other service providers. The resulting structure is shown in Figure 1.3.

While health authorities would retain a purchasing function, NHS Trusts were established as the main providers of secondary and community health services. These Trusts were self-governing and expected to compete with one another and with private health care providers for contracts and the subsequent funds these would attract. The separation of the purchaser and provider function to create self-governing NHS Trusts along with the introduction of GP fund holding were considered to be incentives that would improve quality and reduce inefficiency.

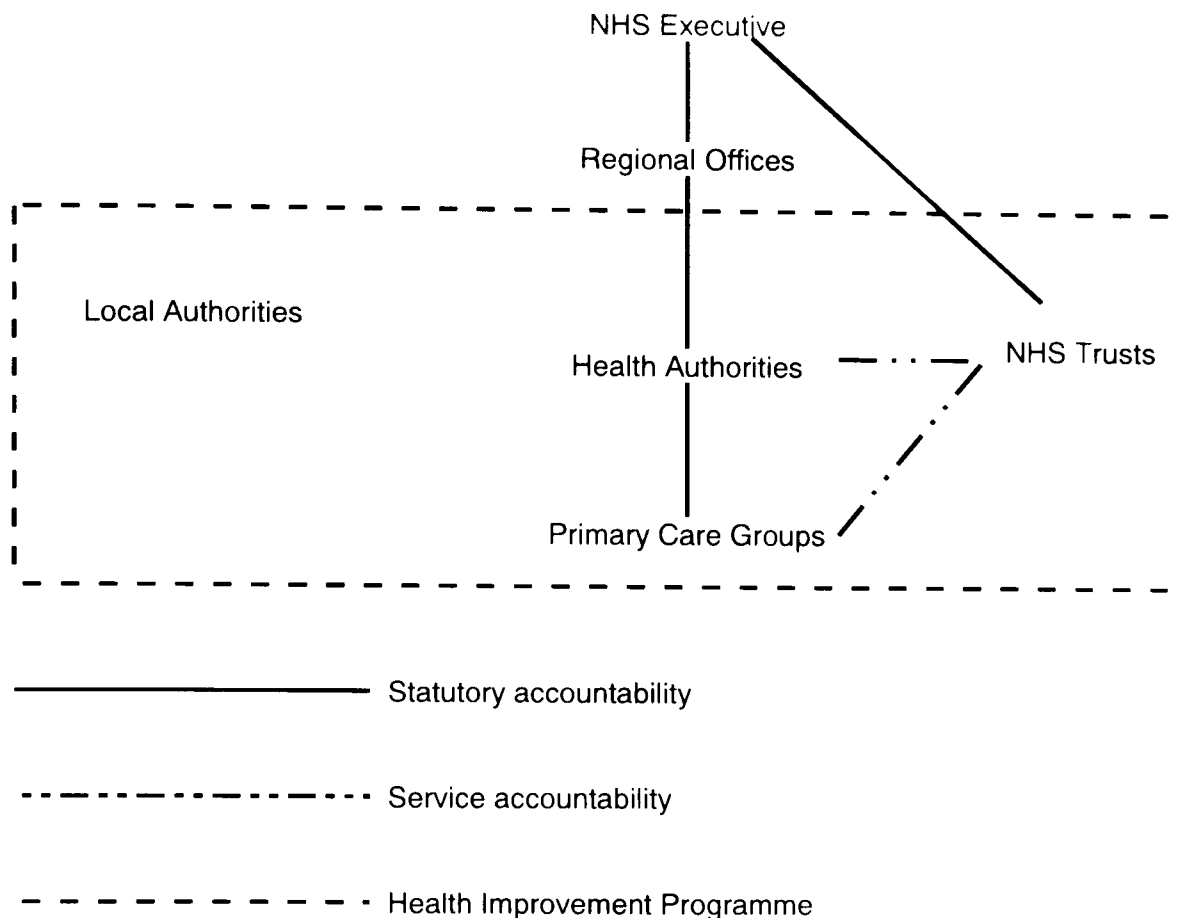
Fig 1.3 The Structure of the NHS in England 1991 – 1996 (Source: Ham, 1999)



1997 - The New NHS

The *New NHS* (DoH, 1997) promised reforms that would deliver an NHS shaped by the views of those who use it. Announcing the reforms, the Labour Government described a ten-year plan that was expected to improve clinical effectiveness and governance; increase openness and accountability in a service that had frequently been accused of presenting a democratic deficit and build partnerships with those who used services. Central to achieving these aims was the introduction of Primary Care Groups. Managed by Boards predominantly made up of GPs, PCGs built on initiatives introduced during the late 1980s and 1990s to allow more local influence to be exerted over the planning and delivering of services particularly in the context of primary care. The new reforms represented a significant slimming down of the structure of the NHS (Figure 1.4).

Fig 1.4 The Structure of the “New NHS”



Source: Secretary of State for Health (1997)

Wilkin (1999:6) describes the organisational change required to deliver the reforms included in the New NHS as the biggest since 1948. Seen as a means of removing the divisiveness of internal markets that had resulted in fragmented decision-making, bureaucracy, inequity and inequality, the Labour government referred to retaining the most effective elements of the internal market model of health care introduced in 1991. The separation of the purchasing and providing functions would be built on by retaining self-governing NHS Trusts, developing the purchasing role of GPs from individual fund holding practices to locality based models of service commissioning and introducing a patient-focused approach to health care.

In the *New NHS* it is clear that, as Webster (2002:208-252) suggests, although the reforms heralded the end of GP fund holding, they had resulted not so much in the abolition of fund holding but rather in it becoming universal. While individual GP practices would no longer have their own budgets, the financial resources for the whole of a designated population would be devolved to and managed by bodies predominantly made up of General Practitioners.

Describing decisions regarding the purchasing and provision of health care as being best made by those closest to their populations, the establishment of PCGs was seen as the corner stone of the new reforms (Anderson, 2001:28-42). Primary Care Groups typically served populations that ranged from 46,000 to 257,000 patients, included all GP practices in a given constituency and were formed, in the main, around geographical boundaries co-terminus with those of local authorities. Although still a sub-committee of their local health authority, PCGs would be managed by a governing body made up of GPs, nurses, health authority, social services and lay representation. Primary Care Group chairs were invariably GPs and relatively small management teams supported the work of the governing body (Ham, 1999:51-71)

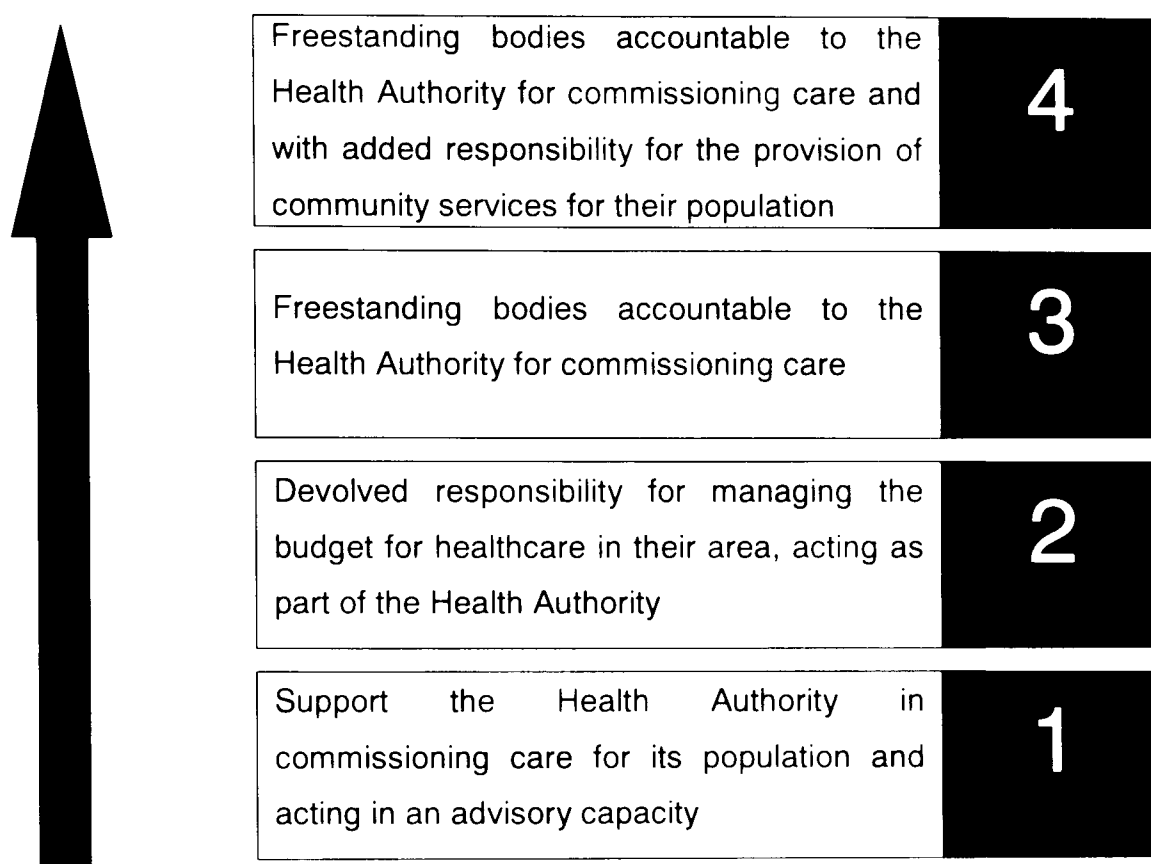
Membership of PCGs was a requirement for all GPs but flexibility was possible in the degree of responsibility they wished to assume. Primary Care Groups could enter at one of four levels (Figure 1.5) and were expected to undertake the following functions:

1. Improving the health of their community by:
 - Addressing the health needs of the population;
 - Promoting the health of the population;
 - Working with other organisations to deliver effective and appropriate care.

2. Developing primary and community health services through:
 - The introduction of clinical governance that would develop high quality primary and community services;
 - Professional development, education and training;
 - Investing in improving primary care services.

3. The commissioning of secondary care services by:
 - Over time taking on responsibility for commissioning the majority of hospital services;
 - Developing appropriate mechanisms and structures to commission services;
 - Seeking long-term investment in care by developing NHS service agreements.

Fig 1.5 Levels of Primary Care Groups (Source: DoH, 1997)



The *New NHS* was underpinned by several key themes:

- The renewal of the NHS as a genuinely national service that would provide fair access to prompt, high quality services wherever people lived;
- Delivery of services to be a matter of local responsibility and local doctors and nurses key to driving change because they were in the best position to know what patients needed;
- Closer partnership working within the NHS that would break down the organisational barriers created by the internal market reforms and closer working with local authorities that would ensure that the needs of the patient would be at the centre of the care process;
- Increased efficiency and less bureaucracy would be achieved through more robust performance management arrangements and a focus on quality so that excellence would be guaranteed to all patients.

The promise of the Labour Government was an NHS rebuilt as a public service that was accountable to patients, open to the public and shaped by their views (DoH, 1997:11).

PRIORITISING PRIMARY CARE

The key role given to primary care, and GPs in particular, announced in the *New NHS* further developed a trend evident in the NHS since the 1980s. In contrast to the early days of the NHS where the emphasis was on hospital and specialist services, by mid 1980 the focus had shifted in favour of expanding the role that primary care could play. Secondary care services were seen as contributing to the spiralling costs of health care by continuing to receive the largest amount of resources. The development of specialist areas of health care had continued to grow, perpetuating the emphasis given to treating ill health rather than attempting to stem the flow of resources into treatment by addressing the causes of illness and investing in preventative and health promoting initiatives (Leathard, 2000:59-74).

Two distinct features were evident however in the move to a primary care-led NHS. Firstly, the gate-keeping role of GPs - people could only access specialist health and hospital services either through a GP or accident and emergency services. The role of GPs in limiting access to more expensive secondary care services was therefore crucial if the spiralling costs of a national health service were to be brought back into control. Secondly, the rising costs associated with primary care services such as the cost of prescriptions, dental and optometry services, introduced in earlier reforms, might in themselves have been seen as a way of preventing people from seeking health care in the first place.

Two years prior to the concept of GP fund holding being introduced, *Promoting Better Health* (DHSS, 1987) had introduced new contractual arrangements for GPs and dentists that included targets and incentive payments for health checks, immunisation and screening procedures. General Practitioners were encouraged to develop health promotion and minor surgery services and additional payments were offered to those practising in disadvantaged areas. Other incentives were made available in respect of payments for improvements to premises and for employment of additional staff. The reforms also included simplified procedures for patients wishing to change GPs and placed a responsibility on GP practices to produce annual reports and information leaflets for patients.

Leathard (2000:75-91) argues that *Promoting Better Health* reflected the government's intention to make the provision of health care more accountable to the public. The main objectives were to improve value for money, give patients a

wider choice in accessing high quality health care and continue the theme of making services more responsive to the consumer.

In the wider context, the introduction of fund holding in *Working for Patients* (DoH, 1989) would allow GPs the freedom to purchase services tailored to their own patients rather than refer them to those purchased on mass by the Health Authority. This patient focused approach to purchasing was intended not only to foster provision of better services for patients but also to influence the wider pattern of hospital and community health services provided.

GP fund holding however was available only to relatively large GP practices, although those not able to enter into fund holding arrangements were given indicative prescribing budgets. What had started as a marginal activity continued to grow and by 1995 total purchasing projects were being established that brought together groups of GP fund holding practices to purchase services on a larger scale than individual practices could (Lupton et al, 1998:79-92).

Fund holding appeared to provide real opportunities to focus on local needs as funding was allocated to commission services directly related to the size and characteristics of the district served by the fund holding practices. In addition, with financial incentives being offered to GPs for reaching targets in respect of immunisation, vaccination, screening and routine monitoring of older patients health status, a more balanced approach to prevention and health promotion was made possible (ibid).

Despite the opportunities, a number of questions remain surrounding the effectiveness of GP fund holding. As the Audit Commission (1996) pointed out, there was little evidence that fund holding had eliminated variation of services particularly in respect of what services were provided and how. Fund holding had in many respects served only to highlight inconsistencies in availability of services. The ability of those GPs in fund holding practices to purchase particular services on behalf of their own patients compared with the limitations faced by non-fund holding practices might be perceived as resulting in more variations in access if not quality of services.

The move towards a primary care-led NHS although announced as a means of becoming more responsive to patients might, in reality, have simply have been a

holdall for a variety of other issues (Webster, 2002:178-179). While offering token inducements to improve the information made available to patients, simplifying complaints procedures and making it easier to change GPs satisfied the consumerist agenda, by incorporating primary care teams into *Health of the Nation* (DoH, 1992) strategies the vacuum left by the collapse of the public health speciality could also be addressed. In addition, as noted earlier, by focusing on the gate-keeping role of GPs, demand on the more expensive hospital services could be restricted by providing alternative forms of care and support.

Primary Care Groups, introduced in the 1997 reforms, were seen as a demonstration of the Labour government's commitment to further developing a primary care-led NHS (Anderson, 2001:29-42). With the introduction of governing bodies made up primarily of GPs, not only was primary care changing but the role of those delivering primary care services was also being expanded. Family doctors and nurses were, in theory, given the opportunity to shape local services on the basis that they delivered, or referred patients on to, most health services and therefore had a better understanding of need (DoH, 1997). Combining a primary care-led health service that was predominantly shaped by GPs with an increased commitment to the engagement of local people in decision-making was in many ways a contradiction – while openness and public involvement were seen as a key feature of the “modernised” NHS, decisions about the use of resources would still be made by those who treated patients.

General Practitioners have traditionally been seen as proxies for their patients (Lupton et al, 1998:93-108); the challenge for PCGs would be to move beyond this proxy role and develop the shared decision-making promised by in the *New NHS*. Equally, the position of GPs in the context of their governing responsibilities was somewhat ambiguous given their role as providers of care to patients in their own individual practices while taking on the purchasing of services for the wider population.

General Practitioners have long enjoyed the autonomy associated with independent contractors status and yet, as members of PCGs, would have to develop a sense of collective responsibility. In respect of engaging with patients and the public there has been little to suggest that GPs have developed this aspect except at the level of individual doctor and patient interaction (Hogg, 1999:84-110).

MANAGEMENT AND MODERNISATION

During the 1980s and 1990s, a Conservative government intent on transforming public services into businesses introduced a series of wide-ranging reforms that have been categorised under the broad heading of the “New Public Management” (Clarke et al, 2000). In the NHS, the main thrust of the reforms was focused on improving management practice and viewing patients as consumers and not simply passive recipients of services.

The *Griffiths Report* published in 1983 suggested that the NHS, with its focus on consensus management arrangements, was suffering from a lack of leadership and direction. Consensus management was blamed for the absence of clear lines of management responsibilities and what it had gained in bringing a range of perspectives into decision-making, was lost in terms of blurred responsibilities, delayed, and in some cases avoidance of, decision-making (Baggott, 1998:132-159). Bringing together people from a diversity of backgrounds, as in NHS Boards, had resulted in no one having superior status and everyone having the power of veto over decisions. Griffiths was also critical of a perceived failure to address the needs of the consumer in health services and urged the evaluation of performance from the patients’ perspective and not solely in terms of organisational needs. Ultimately, the *Griffiths Report* was the catalyst for attempts at introducing consumerism into the NHS.

The overall aim of the *Griffiths Report* was to transform the NHS into a managed rather than an administered service (Leathard, 2000:59-74). General Managers were appointed at all levels to provide leadership, facilitate change and cost improvement, motivate staff and develop a more dynamic approach to management. In reality, the reforms had laid the foundations for the introduction of an NHS internal market (Ham, 1998:27-50).

Far from improving quality, Lupton et al (1998:93-108) argue that the model was flawed in that it resulted in self-governing NHS Trusts acting in the interests of the organisation rather than the patient. A preoccupation on securing contracts and a market share of business favoured quantity rather than quality and the experience of patients. In addition, those commissioning services were perceived as settling for ineffective but comfortable purchasing that concentrated on balancing the books and preserving institutions rather than pursuing health gain or quality of service

(Enthoven, 1999:3-4). An added complication was the difficulty of engaging clinicians in a process that placed decisions regarding resource allocation in the hands of non-clinical managers (Strong and Robinson, 1990:32).

The internal market conditions introduced in *Working for Patients* (1989) were intended to be a means of promoting greater choice and service improvements for patients. Whether the competition between the internal markets of the NHS could be equated with consumer choice, however, is arguable. Patient choice remained limited and governed by the contractual arrangements between purchasers and providers. For example, while fund holding GPs had some scope to act on behalf of their own practice populations, there were only limited options for non-fund holding practices to take advantage of this. Equally, other policy initiatives in many respects complicated the internal market. The imposition of centralised standards and rights introduced in *The Patients Charter* (DOH, 1992) and the universal nature of *Health of the Nation* strategies (DOH, 1992) appeared to contradict the decentralisation and local enterprise inherent in the internal market (Baggott, 1998:108-209). Ultimately, as Klein (1995:238) argues, the emphasis on consumerism in the NHS had not been in response to demand from patients and members of the public but rather another example of a top down directive.

Notwithstanding the complexity of reconciling the market mechanisms of private sector management practice within the NHS, GP fund holding became central to the development of a primary care-led NHS. General Practitioners were deemed to be closer to patients and could identify needs more effectively therefore promoting a more responsive service on behalf of their patients.

In 1997 the *New NHS* (DoH, 1997) promised reforms that would increase efficiency and reduce bureaucracy. The internal market system of the Conservative Government was described as having driven up administrative costs and diverted resources away from improving patient services; the new system it was suggested would focus on cost efficiency. (DoH, 1997:14). Equally, with so many players in the previous system, bureaucracy, it was argued, had spiralled. By placing combined clinical and financial responsibility in the hands of PCGs, who would have the freedom to use resources to the benefit of patients, efficiency would be increased. Management costs in the NHS would be capped and a national schedule of reference costs developed that would itemise the cost of individual

treatments, be used as a benchmark for NHS Trust costs and provide both a lever and a tool to address inefficiency.

In addition, incentives and sanctions would be introduced that rewarded health authorities that performed well with additional cash resources and allow PCGs to use savings to improve services for patients. Where performance was not deemed to be up to standard, freedom to manage could be withdrawn from PCGs who themselves would be able to withdraw contracts from providers who did not meet required standards. If all else failed, the NHS Executive could intervene where performance continued to be substandard.

Although quality and efficiency were described as inseparable, the difficulties faced by PCGs were not inconsiderable. In particular, managing some of the inherent contradictions between the drive for cost efficiency while achieving a plethora of national targets and priorities that came as part of the parcel of reforms was likely to require significant capacity. While resources had allegedly been allocated to take account of the population characteristics, the scientific way in which this was calculated might not necessarily take account of locally perceived need. In addition, the proportion of management costs available to PCGs was calculated as a percentage of their annual budget. Although those PCGs with smaller populations would have the same responsibilities, the amount of financial resources available with which to develop the capacity to undertake the responsibilities would be smaller than those with relatively larger populations. Passing the responsibility on to bodies predominantly led by GPs might be seen as yet another way of capitalising on the traditional role of GPs as gatekeepers to more expensive secondary care and specialist services (Baggott, 1998:210-227). Rather than increasing cost efficiency the outcome might simply be a reduction in the level of resources invested.

The 1997 reforms were an amalgamation of the previous Conservative government's "managerialism" and New Labour's "modernisation" (Newman 2000:45-60). The Labour government had pledged to keep what had worked in previous NHS reforms but rid the system of those elements deemed to have created variations in quality and access to services. The basis on which the decision had been made regarding which elements to keep and which to discard is not clear. A perceived lack of reliable information on where success had been achieved, and whether this had been the result of the organisational model or

simply the enthusiasm of individuals, made it impossible to establish which elements of the internal market had been effective (Enthoven, 1999). Whether the reforms were in fact based on evidence of what had worked, or whether many of the elements were considered too costly and difficult to dismantle, both politically and administratively, is difficult to say.

The significant role that GPs would play in the planning and delivery of health and health care in the “modernised” NHS was intended to retain the most effective elements of GP fund holding while removing the perceived variations in quality and access resulting from it. Notwithstanding these variations, there was very little evidence to suggest that GPs were in fact the best placed to know the needs of patients other than those in their own practices. Practice fund holding and the total purchasing projects of 1995 were seen mainly to have focused on addressing purchasing at an operational level with little evidence to suggest that consideration had been given to the development of a more strategic population based purchasing role (Audit Commission, 1996).

The drive for increased efficiency might in many ways also be deemed counter productive in respect of ensuring the engagement of patients and members of the public explicit in the *New NHS* in order to shape services around their, rather than organisational, needs. While there is clear evidence that cultural issues have often been an obstacle to the NHS engaging with patients and members of the public, Brooks (2001:1-13) puts forward the view that a lack of organisational capacity is as often the major issue. Balancing national targets, cost-efficiency exercises and growing into their new roles might all be seen as having a negative impact in terms of ensuring the engagement of local people that the *New NHS* had promised.

The Labour government's modernisation agenda continued the theme of cost containment evident in the New Public Management policies of the Conservative government (Newman, 2000:45-60). A focus on performance was retained and, although decentralised decision-making, flexibility and innovation were promised, central control was maintained. Standardised performance through the introduction of National Service Frameworks and tighter regulation procedures were somewhat at odds with the notion of the local decision-making promised in the *New NHS*.

In terms of the role that patients and members of the public would play, the difference between the “management” policies of conservatism and new Labour's

“modernisation” agenda were significant. New Public Management policies were, amongst other things, intended to make public services more accountable to those who used them and introduced the concept of patients as consumers. The Labour Government’s modernisation of public services went much further calling for more public participation in decision-making and extended this beyond the “patient as consumer” model to include all citizens and communities. If this approach were to work however, a number of issues would need to be resolved. In particular, the issue of who was to participate, at what level and on whose terms would necessitate much greater clarification (Newman, 2000:45-60). In addition, as Poole (2000:102-121) argues, evidence of unstable power relationships, a failure to acknowledge the unequal distribution of power and the sheer diversity of the stakeholders involved, challenged the “modernisation” concepts of patients and the wider public as partners. The public health agenda had been attempting to resolve some of these issues.

THE NHS AND PUBLIC HEALTH

Definitions of health range from fairly minimal descriptions of the absence of illness and the prevention of disease to the broader definition provided by the World Health Organisation (1985) that describes health as a state of complete physical, mental and social well-being and not simply the absence of disease (Lupton et al, 1998). These definitions can be further broken down to include Stacey’s (1977) dimensions of collective or individual concepts of health, functional fitness or welfare and preventative or curative. Individual concepts of health are associated with functional fitness or curative approaches and relate to finding specific cures for illnesses in order to make individuals fit for work. The collective approach to health is based on addressing the causes of illness to be found in environmental, economic and social conditions in which people live. The third of Stacey’s dimensions of health relates to the concept of welfare that focuses on the importance of relieving pain and providing care.

In Baggot’s (1998) opinion these different concepts can be viewed as either negative or positive definitions of health. The broad definition offered by the World Health Organisation and Stacey’s collective, preventative concept of health are considered positive definitions in that they emphasise health as an asset and incorporate mental and social well-being as well as physical aspects. Concepts of health that focus on the absence of specific illness, disease or disorders and

subsequently on diagnosing and treating ill health are felt to be negative concepts of health. These two approaches to health can also be described as medical models of health and social models of health. While medical models have traditionally been given the most priority in the NHS in that the largest proportion of resources has been directed at investment in hospitals and primary health care, the public health agenda has attempted to encompass social models of health that address the wider determinants of health such as social, economic and environmental conditions.

Public health has a somewhat chequered history in the UK National Health Service. In the early years of the NHS, health policy at a national level was increasingly concerned with developing health services and as a result there were health services but no health policy (Klein, 1980: 416-429). A decline in the role of public health services combined with the recognition that an expansion of health services on its own would not alleviate growing levels of illness, eventually led to renewed attention being given to health promotion and ill health prevention.

During the 1970s, health education was seen as the answer to these problems and the responsibility for this given to community health services. Education and health messages directed at changing behaviour were intended to create responsible patients and reduce the prevalence of illness and the subsequent demand on health services. This, combined with more efficient management of health services, appeared to be the foundation for health policy during the 1980's and 1990's.

The 1974 reorganisation of the health service had resulted in significant changes to the way in which public health issues were addressed. The problems traditionally associated with poor public health – particularly poverty and squalor – had allegedly been eradicated and existing problems were considered to be the result of individual lifestyles and illnesses such as cancer, heart disease and stroke caused by irresponsible acts such as smoking, poor nutritional habits and generally unfit lifestyles (Williams and Popay, 1994:99).

What the health education approach failed to take account of was the effect that wider socio-economic factors could have on the health of local communities. An increasing prevalence of chronic illness was soon linked with prevailing conditions such as unemployment, poor housing, high welfare benefit dependency and limited access to recreational and leisure opportunities. In addressing these factors, a new

public health movement emerged that encompassed not only these wider determinants of health but also the need to take a collaborative approach to public health and an acknowledgement that the active participation of individuals and communities was a key ingredient in addressing those inequalities caused by factors other than individual lifestyle (Ong, 1993:65-82).

The World Health Organisation *Health for All* (1981) philosophy developed these ideas into a framework that emphasised an understanding of health needs within a political context shaped by social and economic factors (Ong, 1993:65-82). Health is multi-dimensional, it was argued, and the involvement of people in determining the services and input required from organisations was seen as crucial to developing a successful interface between the different factors that affect health.

During the 1980s and 1990s, the public health movement encompassed three particular elements (Williams and Popay, 1994:99-112):

- A focus on the physical and social environment and the role this plays in health;
- An acknowledgement of the need to encourage collaboration of the different sectors that could influence the environment in which people live;
- An acknowledgement of the need to encourage the active participation of individuals and communities.

In taking account of these aspects of health, new methods of addressing health improvement and inequalities were needed. Emphasis was subsequently given to the need to empower individuals and communities, not only to identify factors that affected health but also to be a part of the potential solutions. By strengthening the relative position of local people in terms of the ability to influence the way in which services were shaped and delivered a number of the wider determinants of health could be addressed (Health Development Agency, 2000).

To a large degree, public health initiatives appeared to be developing separately but in parallel with the changes taking place elsewhere in the NHS. While local authorities were found to be enthusiastically engaging with community-led initiatives and the commitment this required to the principles of equity, participation and an

holistic approach to health, the response from most NHS organisations continued to focus on delivering health messages and educating people (Hogg, 1999:50-63).

Changes to primary care services announced in the white paper *Promoting Better Health* (1987) gave a clear indication that more attention was to be given to health promotion and ill health prevention. The traditional influence of secondary and specialist services was being challenged by the purchasing role of health authorities and GPs and consequently, more attention was being given to public health and the role of primary care in respect of this (Ham, 1998:152-175).

Although the public health movement was actively encouraging a much broader approach to health improvement and health inequalities, Ham (1999:203-217) argues that a medical model of health with its focus on ill health was still being given priority, particularly by clinicians. *Our Healthier Nation* (DoH, 1998) and the World Health Organisation's *Health for All* strategies (WHO, 1981), in contrast, were focused on the premise that it was only people themselves that would achieve health and the engagement and full participation of communities were essential if health improvement was to become a reality.

The *New NHS* (DoH, 1997) gave a clear indication that health improvement was to be prioritised. In addition, policies such as *Our Healthier Nation* (1998) and the *Acheson Report* (1998) were focused on health improvement and addressing health inequalities and supported the need for the collaboration and partnership working identified in the *New NHS*. Changes necessary in the NHS were seen to be twofold; improving and developing primary and secondary health care services while also addressing inequalities in health, health promotion and ill health prevention. In particular, health authorities and PCGs were given an explicit role in respect of improving the health of the population and not just developing health services.

The needs of individual practices and their patients had in the past driven primary care; with the responsibilities in respect of health improvement and addressing inequalities explicit in the *New NHS*, GPs would require a much broader knowledge of health and health needs than was available through engagement with their own patients. Given that GPs were considered to have no real track record of engaging with patients and the wider public and were felt not to adequately communicate with even their own patients (Lupton et al, 1998:93-108), the capacity and commitment

to engage with and adequately reflect the needs of the wider population must have been in doubt.

The inclusion of health improvement and addressing health inequalities in the list of responsibilities was an additional factor in respect of the capacity of PCGs to fulfil the promises of the *New NHS*. In respect of the public health agenda, a focus on consumerism and the rights of individual patients had in many respects served to limit the interest in developing models of engaging with the wider population. If the problems surrounding health improvement and health inequalities were to be addressed then patients and members of the public had to be central to decision-making about their own lives, the way in which services were organised and managed and the policies that affected health and the wider determinants of health (Bradshaw, 1994:46-55).

This debate between medical and social models of health is in many ways parallel to the discussion between consumerism and citizenship. While the consumerist emphasis of *Working for Patients* reflected the position of patients simply as users of services, the public health agenda was embracing a more democratic approach where people were viewed not only as recipients of health services but also partners in health care and, ultimately, producers of health.

Primary Care Groups were, in many respects, well placed to take health improvement and health inequalities seriously by developing collaborative health needs assessment processes in relation to populations much smaller than those of health authorities. In addition, in respect of health services, PCGs had far greater opportunities to develop population-based models of purchasing rather than the patient based models of their GP fund holding predecessors.

Despite these new organisational arrangements, the emphasis on health improvement inherent in *Our Healthier Nation* (DOH, 1998) and the joint working that was advocated, just how effectively NHS structures, focusing largely on ill health, could respond to this renewed interest in the public health agenda was questionable.

THE ROLE OF PATIENTS AND MEMBERS OF THE PUBLIC IN THE NHS

Until the 1974 reorganisation, local people had little opportunity to influence or contribute to decisions surrounding health and health care planning. In 1974 Community Health Councils were established to represent the views of the consumer and to monitor health services. Financed by area health authorities they remained independent bodies with representation from local authorities, regional health authorities and voluntary organisations. Community Health Council members had the right to visit NHS premises at any time, had to be consulted about any proposed closure or substantial variation in service and asked to advise on the impact of proposed plans.

Announcing the 1997 reforms, the Labour government emphasised the importance of building partnerships with patients and the public. The success of any partnership approach however is likely to be evident in terms of whether people were allowed to speak for themselves or continued to have others speak on their behalf. The ascendancy of patient and public involvement, in theory, should have been assured by successive policy and reform. The reality, however, depends on whether the role of patients and members of the public is integrated into the mainstream of NHS organisations or whether the theory and philosophy underpinning it remain isolated from management and decision-making structures and processes (Ong, 1993:65-82).

The constant state of change that has characterised the NHS since its inception appears to have resulted in a lack of attention being given to developing and transmitting a clear vision of the contribution that patients and the wider public could make to planning and decision-making. References to effectiveness, efficiency, quality, audit, regulation and consumerism in the NHS are for many dominated by questionable assumptions (Hogg, 1999:110-138).

That patients are consumers assumes that they have choice, information and the rights to redress. In addition, while in a consumerist society it is the customer's response to products that determines their sustainability, in health care demand is often created by professional and commercial interests with the development of new techniques, medicines and general advances in health care (ibid). Similarly, the development of health policies and services that put the patient first require a strengthening of their position in relation to professionals and managers.

Continuing to stress the role of local doctors and nurses in determining need and solutions it might be argued undermines this.

Despite this, policy initiatives of the 1980s and 1990s appear to have stimulated interest in methods of engaging with patients and the wider public. This interest, Baggott (1998:248-269) argues, is attributed to a number of factors; a general feeling that a democratic deficit existed in the NHS, an increasing recognition that services should be more responsive to the needs and requirements of those who use them and, much later, an acknowledgement that health could only be improved if people themselves were involved in determining and addressing the factors that constrained good health.

The Democratic Deficit

In the early days of the NHS, the inclusion of a patient and public perspective was generally focused around the representative role of lay and local authority members of NHS Boards. While the Secretary of State appointed members of regional health authorities, members of area health authorities were partly appointed by regional health authorities, partly by local authorities, universities, professional nominees and members of non-medical and nursing staff. The inclusion of local authority members offered at least a degree of local input and the opportunity for local accountability – local people could vote for their local councillors although not in respect of their membership of NHS bodies.

With the introduction of *Working for Patients* and NHS internal market systems, the composition of NHS Trust Boards included managers and non-executive directors selected not for their representation of local communities or organisations, but for their personal contributions (Ham, 1998:27-50). Local authority members lost their right to representation on district health authorities and all non-executive members of NHS Trust Boards were appointed by the Secretary of State. Local representation became increasingly limited as the emphasis moved to a more business like approach. With the introduction of these non-executive members of NHS Boards, *Working for Patients* had virtually eliminated local authority representation.

Community Health Councils were seen as a way of addressing this lack of local representation and were given the responsibility of representing public views, monitoring local services, keeping the public informed and assisting patients with individual complaints and concerns. Introduced in an attempt to improve patient representation and accountability in the NHS, concern was expressed that these bodies were under resourced relative to their workload, had no clear statutory role in relation to working with general practitioners or local authorities and therefore had limited powers in respect of these aspects of health services (Moon and Lupton, 1995:335-346). In addition, although deemed a good idea at the time, Hogg (1999:90) argues that they were an example of “back of an envelope planning” that lacked any proper thought or direction in respect of what they would do, how they would do it or how they would be accountable.

The membership of Community Health Councils was made up of local authority, voluntary organisation and regional health authority representation. As statutory bodies they had the right to visit hospitals, have access to information, attend health authority meetings and be consulted on changes and substantial variations in services. The paucity of guidance on how the rights of Community Health Councils would operate however led to frequent disputes about their interpretation. Criticism was levelled over a perceived lack of consistency in the nature and standards of the work undertaken and the way in which it was carried out. Additional difficulties were caused for Community Health Councils by the lack of an agreed definition of “substantial variation” and this allowed Health Authorities the luxury of determining which of their decisions were substantial enough to be consulted on (Hogg, 1999:90).

Although Community Health Councils were retained with the introduction of *Working for Patients*, they would no longer have an automatic right to representation on health authorities. While the internal market had posed a threat to the retention of Community Health Councils the need to reassure the public and a recognition of their potential in terms of monitoring services and identifying need appeared to have ensured their survival. Their position however began to be eroded and their already limited powers reduced still further. Consultation was seen as inadequate in that it was often initiated after decisions had been made or that the information presented was difficult to understand and insufficient on which to make informed comments (Leathard, 2000:59-74).

In addition, the purchaser provider split meant that NHS Trusts, who made many of the decisions regarding closure or service variations, were under no obligation to consult with Community Health Councils. The power to inspect NHS premises was also diluted by having to negotiate inspection visits to the private nursing and residential homes that had replaced the long stay hospitals that they had statutory visiting and monitoring rights over and the difficulties of monitoring and inspecting rehabilitation services that were increasingly being provided in patients' homes (Hogg, 1999:84-110).

A further complication was the introduction of general management practice that had diminished the influence of health authority board members and led to deterioration in the relationship with Community Health Councils. As a result, how, when and the way in which consultation was undertaken appeared to depend on the enthusiasm that individual managers had for complying with the process.

Increasingly, questions surrounding the independence of Community Health Councils were also being asked. For many, Community Health Councils were viewed as part of the NHS establishment rather than an independent voice (Baggott, 1998:248-269). Additionally, the lack of mechanisms that enabled the wider public to elect members meant they were yet another example where members were appointed or nominated to act on behalf of local people (Leathard, 2000:59-74).

The introduction of general management in the Griffiths reforms led not only to a decline in the influence of health authority members but also a deterioration in the relationship with Community Health Councils (ibid). Griffiths had made only limited reference to the public representation role typically assigned to members of regional and district health authorities and Community Health Councils. The failure to acknowledge this was evident, as noted earlier, in the way in which members were subsequently selected, not for their representation, but for the personal contribution they could make.

It is also clear that *Working for Patients* had provided a focus to experiment with new ways of securing patient and public views in terms of responding to their needs and preferences and there was a danger that Community Health Councils would be bypassed or replaced by these new methods (Baggott, 1998:248-269). While defending the value of their role, Community Health Councils themselves admitted

that they were no substitute for collective decision-making based on the wider involvement of local people (Hutton, 2000:35). Despite criticism, they remained largely unscathed by successive NHS reorganisations until they were abolished in 2003, by which time various policy initiatives had already contributed to a weakening of their role.

Responsive Services

The *Griffiths Report* had urged NHS organisations to pay more attention to the needs of the consumer, advocating that quality and customer satisfaction should come first and that efficiency would emerge as a by-product of effective services. With responsiveness to those who use services being hailed as the key to an organisation's success, the new management practices of the 1980s and 1990s had introduced the concept of consumerism into the NHS (Nettleton, 1998:130-145).

Following the lead from Griffiths, who had been critical of the NHS failure to develop a customer orientation, *Working for Patients* was seen as a means of encouraging greater attention to finding out the needs and preferences of patients and using this to develop more responsive services (Ham, 1998:35-50). In response, the *Patients Charter* (DoH, 1991) was designed as a way of setting out a range of rights and standards that patients could expect to receive.

The *Patient's Charter* introduced in 1992 was deemed to be an attempt to redress the balance of power in favour of health service users. The charter set out rights and standards that could be expected by those using NHS services but was criticised almost immediately over a the lack of clarity and the ensuing difficulties of measuring the rights and standards it included (Baggott, 1998:248-269). While it was relatively easy to measure standards such as waiting times, measuring the success of respecting patient privacy for example, was more difficult to measure. Although official statistics testified to the success of the Charter, patient views often contradicted this. Rights were often not upheld and standards not met and, by using national averages, poor performance in some localities could be hidden amongst high performers. Equally, while professionals welcomed the *Patients Charter* this was on condition that it did not impose excessive and unrealistic demands on service providers and that it reflected "professionally" defined good practice and reinforced self-regulation of standards (ibid).

The *Patient's Charter* appeared to have only varying impact on improving the responsiveness and quality of services but it had opened up to greater scrutiny comparative data on health service performance, complying to a degree, with one of its key themes of providing better information.

While *Working for Patients* had followed the consumerist rhetoric of Griffiths in as much as patients were to be viewed in the same way as consumers purchasing any other product, *Local Voices* (NHSME, 1992) was intended to place patients and members of the public central to the NHS agenda in terms of measuring and assessing the health needs of communities (Lupton et al, 1998:93-108). The emphasis, however, appeared to remain on identifying key priorities for health care rather than a broader assessment of need in relation to health improvement and health inequalities.

There were clearly difficulties in promoting the democratic rights of people in an organisation such as the NHS where, as Hogg (1999:84) points out, there was no real tradition of this. Policy and reforms such as *Working for Patients* and *Local Voices*, served to highlight the need to find out the views of local people in order to ensure that services were appropriate and acceptable. New methods of engaging with people began to be used but, while many and varied, in general tended to be those that still did not allow local people to define the issues to be debated or the aims and objectives of the exercise. Consultation, public meetings, focus groups and surveys began to be used regularly as a means of engaging with local people and more sophisticated methods such as citizens' juries were being tested. What is not evident is that the use of these various methods had been defined by and linked to any agreed aims, objectives and outcomes.

At one end of the spectrum, data collection tools such as surveys, focus groups and interviews, although useful, as Brooks (2001:1-13) argues, do not really constitute engagement with local people. At the other end of the spectrum, community development approaches being introduced into the public health arena promoted the empowerment of local people to both identify needs and problems and also be part of the solution (Health Development Agency, 2000). Although new methods were being employed in the NHS, a key question was whether these were serious attempts to engage with patients and members of the wider public or were simply a means of providing evidence of the engagement encouraged by various policy and reform.

Engaging Patients and the Public

Focusing on methods of engagement, combined with a lack of clarity on the aims, objectives and outcomes, appears to have caused considerable difficulty for NHS bodies. Many of these difficulties might be attributed to the continuing tension between professionals, managers and lay people and, in particular, issues surrounding the local and central distribution of power inherent in the NHS (Lupton et al, 1998:126-139). Despite this, the changes in the membership of NHS Boards, from representatives to non-executives, the subsequent weakening of formal accountability and the increasingly restricted role of Community Health Councils, introduced by the purchaser and provider split, stimulated attempts to improve both accountability and consumerism (ibid).

Developing a consumerist approach to health care while ensuring local and national accountability requires not only the use of multiple methods but also a clear understanding of the broader framework in which they are undertaken. Such a framework would, of necessity, need to recognise the interplay between consumerist and democratic, and individual and collective approaches (see Chapter Two for a discussion of consumerist and democratic approaches). The relatively ad hoc “pick and mix” approach, described by Lupton et al (1998:134) as characterising the NHS, did little to address these issues.

While the policy environment was favourable to incorporating patient and public perspectives, mechanisms and processes to secure this appeared to depend on local initiative and support. As a result there was diversity and inconsistency in the arrangements established at a local level with various methods being used but no real evidence of their being developed in relation to outcomes or goals or their relative strengths or weaknesses in relation to these (Baggott, 1998:248-269).

Structured questionnaires and patient satisfaction surveys became a regular occurrence and, in organisational terms, the strength of these methods was the relatively low cost involved and the potential for large numbers of people to be targeted. The weakness of these methods was the considerable time and methodological expertise that design and analysis requires. As a method of engaging with patients and members of the public, local people are rarely involved in setting the focus and design of the questions, the wording of the questions can affect the response and, being organisationally led, they can be used simply to

support issues rather than improve responsiveness (Hart, 1996). In addition, a self-selecting majority can submerge the views of minority groups given that surveys and questionnaires often fail to reach marginalized or vulnerable people (Baggott, 1998:248-269).

The use of more qualitative techniques such as semi-structured interviews and focus groups was also becoming more popular in the NHS. In terms of engaging with patients and local people, these methods can enable the emergence of the patient and public agenda and priorities rather than responding only to questions set by professionals. Although fashionable, the success of these particular methods from a patient and public perspective depends on how appropriately they are used. The construction of questions and the way in which focus groups are managed is a skilled craft particularly if issues of bias are to be handled effectively (Brooks, 2001:1-13). The somewhat ad hoc way in which this method is often used can, in many instances, be detrimental to capturing the potentially rich source of information that might be achieved. Equally, methods that are concerned with this type of qualitative data are more costly and time consuming from the organisation's point of view, in respect of data collection and analysis, and also require more time and commitment from patients and members of the public than completion of a survey for example.

While the use of focus groups, special interest groups and a range of voluntary and community organisations is considered a valid way of eliciting views and opinions, given that many people will not join groups or attend meetings, Baggott (1998:248-269) considers there to be little evidence of the extent to which they accurately reflect those they attempt to represent.

User representation is typically applied to initiatives that seek to include local people in mechanisms to inform decision-making. One of the major flaws in this particular method is the assumption that people approach issues from a single perspective that can be neatly packaged and incorporated into planning. In reality, there are a multitude of diverse views that cannot be captured and are thus compromised if representation is not sufficiently robust to ensure the range of perspectives is given attention (Fuller and Petch, 1995).

More recently, Citizens' Juries have been used as a less biased means of enabling local people to contribute to decisions on health and health care. Citizens' Juries are based on the assumption that, given time and information, lay people can make

complex decisions on issues that affect them (Hogg, 1999:99). Exercises of this nature typically involve up to fifteen members of the public hearing evidence from expert witnesses, taking part in discussions and finally reaching a consensus on the issue being debated. While described as less biased, the selection of participants is at the discretion of the organisers as is the issue to be discussed, the evidence presented and, crucially, whether any account will be paid to the final outcome (Brooks, 2001:1-13).

Consultation exercises have generally been linked to public meetings and traditionally used as a means to discuss or inform people of pre-determined plans. In the NHS, consultation appears to have developed a specific meaning linked with Community Health Councils and referring to the right to be consulted about closures or substantial variations of use or development of service (Hogg, 1999:84-110). Section 11 of the *Health and Social Care Act* (2001) retains the statutory duty of NHS bodies in respect of closures or variations although the role of the Community Health Council in formal consultation was passed on to local authorities via health overview and scrutiny panels. Further clarification on what constituted a “substantial variation” appears to have been overlooked.

Consultation, while inviting discussion, in reality was often an exercise in validating decisions that had already been made (Brooks, 2001:1-13). The outcomes of consultation usually appear to be associated with the need to attract public support for specific plans or to justify or explain professional and organisational decisions. These exercises invariably fail to reach the majority of the population and there is often no clear link between the opinions expressed during consultation and decision-making processes.

Whether the ultimate aim is consultation or data collection there is a fundamental issue surrounding how knowledge is constructed. If organisations are in control of how these activities are formulated then local people will continue to be passive recipients of information. It is only by involving patients and the public in determining the issues to be explored or consulted on, that knowledge can be constructed using a variety of perspectives and not just those determined by NHS bodies (Ibid).

While the introduction of new mechanisms for involvement in the NHS is welcomed, the way in which they are managed has the potential to attract further criticism. The

relatively small numbers of people involved, the risk that organisations would direct the agenda or influence the level and nature of the information presented questions how neutral any methods can be. At best they can be seen as enlightened exercises that encourage stronger bonds between the public and NHS organisations that are unlikely to achieve the inclusion of a collective perspective that only truly democratic processes can provide (Hutton, 2000:32-37).

Community Development

During the 1980's and 1990's, public health and health promotion movements within the NHS attempted to move away from traditional top-down approaches to engaging with people. Community development became popular as an indication of commitment to empowering both individuals and communities (Hogg, 1999:105-106). Unlike traditional approaches to health education associated with public health and health promotion, community development did not see people as contributing to health problems because of attitudes to lifestyle for example, but rather acknowledged and sought to empower local people to address those aspects inherent in the environment in which they live that contribute to health.

In 1992 *Local Voices* placed an emphasis on collaborative health needs assessment and provided the opportunity for more collective methods of engagement but the question of how this would be undertaken was still not resolved (Lupton et al, 1998:93-108). Traditional approaches to health needs assessment typically relied on a combination of health statistics and health economy data. This approach, to an extent, perpetuates medical models of health that focus on need as perceived by professionals rather than acknowledging people, and the environment in which they live, as producers of health and therefore central to the process. If the engagement of local people was to be more than a genuflection to central directives, a move away from this somewhat traditional reliance on epidemiology was essential (Popay and Williams, 1994:99-112). It was against this background that community development, with its emphasis on participation and empowerment, was being developed in response to health needs assessment and the subsequent improvement in health that this could achieve.

Community development, as described by Community Development Exchange (2002:1-2), is about "building active and sustainable communities based on social justice and mutual respect". In addition, it is about changing power structures to

remove the barriers that prevent people from participating in the issues that affect their lives.

Community development on its own, however, in many respects, is insufficient to address health improvement. One of the biggest obstacles to engaging with social as well as medical models of health appears to be the reluctance of professionals to accept that experiential and non-scientific knowledge is as valid and as necessary as the more objective data derived from clinical and statistical evidence. The bottom up approach of community development needs to be matched by top down endeavours to address the reliance on scientific knowledge and data inherent in medical models of health. While it is unrealistic to claim one is more valid than the other, a balanced approach to health improvement would acknowledge that the experiential knowledge of communities complements and enhances the empirical data favoured by clinicians.

Although there is evidence of more community development based participatory approaches to health need assessment, there appears to have been no consistent process for testing and evaluating these. There is little evidence of either the process or the outcome of these activities being co-ordinated or evaluated. The apparent lack of attention given to developmental processes had perhaps led to simply exchanging traditional consultation methods for alternatives that retained an ad hoc approach that *Local Voices* had criticised. Health needs assessment was still, in most cases, a one-off exercise not intended to foster long-term partnerships but seen rather as a single transaction between organisations and local people (Popay and Williams, 1994:99-112).

Community Development and associated methods such as rapid appraisal and participative action research are rooted in giving people control over their lives and building the capacity of local people to identify local need and contribute to solutions. These methods are not deemed to be simply a means to an end, that is a way of gathering local views, but rather that they result in people taking control of their lives by giving them the skills, knowledge and confidence to take collective action.

While there appears to be little doubt that these methods have the most potential for bringing about real change at a local level, providing tangible action while shaping the process of resource allocation, there is still uncertainty over capacity

within the NHS to engage with them (Humphris and Ong, 1994:59-80). In practical terms, these methods are time and resource intensive. In addition, the challenge of understanding the diversity of unmet need and demand and the contradictions between the needs expressed by different groups of people while complying with a centrally defined agenda and priorities has the potential to result in less rather than more localised engagement.

Considerable concern has been expressed in relation to community development approaches because of their perceived emphasis on raising political consciousness rather than delivering objective information on the health and health needs of communities. Describing them as time consuming and failing to produce tangible results, professionals have often been seen as reluctant to engage with initiatives grounded in community development principles (Ong, 1993:65-82). Equally, focusing on communities requires relatively small-scale activities the results of which cannot be generalised thus constraining the influence that outcomes can have on wider policy formulation.

The impact of community development can be twofold; firstly, it has the potential to empower communities by providing information and secondly, it can validate information already held within communities (Humphris and Ong, 1994:59-80). The exchange of information is a fundamental principle in any form of engagement but requires changes to the way in which qualitative information is viewed by professionals and clinicians. The qualitative nature of the information gathered by community development methods is often felt to be at odds with and offending the positivistic cannons of quantitative data that health professionals and clinicians have traditionally used in decision-making and resource allocation (Ibid).

While research by the Health Development Agency (2000) demonstrates the value of the participative methods fundamental to community development in engaging with and addressing the health inequalities agenda, concerns are still evident. In particular, the extent to which marginalized and vulnerable groups have participated in the past and the realities of achieving this have been questioned. Additionally, while involvement of this nature is aimed at the empowerment of local people, health improvement and addressing inequalities continues to be defined by a pre-determined agenda. The public health agenda is still centrally driven and focused around specific issues considered to be priorities such as smoking, diet, exercise

and sexual health. In addition, the drive is invariably linked with cost efficiency and effectiveness in relation to the future cost of providing health care.

Further limitations are imposed in terms of the variety of factors that are simply beyond the domain of local people and are a result of national policy (Hogg, 1999:110-138). Equally, definitions of “community” and “participation” are open to interpretation and the way they are viewed by those involved might not always be the same resulting in inconsistencies.

In practice, it is difficult for community development approaches to address the complex relationships between communities, clinicians and managers that are at the heart of decision-making processes (Croft and Beresford, 1990). At its simplest, community development is about enabling people to redefine health and health needs in order to influence planners and policy makers. The sheer size and complexity of the NHS, however, requires formalised relationships that locate the process within an agreed and acknowledged framework.

With such an array of methods available to engage with patients and the public, a test of the validity of those used is likely to be whether they have achieved a mutually agreed outcome. In this respect, there is general consensus that it is clarity over the ultimate purpose of engaging with patients and members of the public that will shape decisions over whom, what and when and subsequently influence outcomes (Hickey and Kipping, 1998:83-88). It is perhaps this clarity that has been absent from successive policy and reform that has sought to strengthen the role of patients and the public in the UK National Health Service.

CONCLUSION

This chapter has discussed how successive reorganisation of the NHS has resulted in a shift of emphasis from hospital and specialist services to the promotion of primary care-led services. Equally, the introduction of general management during the 1980s was seen as an attempt to move the NHS from an administered service to a managed service and invest more power over decision-making and resource allocation to managers and a subsequent reduction in the traditional levels of power enjoyed by clinicians. At the same time, successive policy and reform has attempted to put the role of patients and the public involvement more explicitly on the NHS agenda.

How successful these attempts at change within the NHS have been has been widely debated. The introduction of general management for example, has been argued as having only variable impact at a local level; while some managers were considered to have gained influence in relation to clinicians others felt the impact had been minimal (Harrison, 1994). In addition, despite attempts to introduce structural simplification and decentralised decision-making in a move away from administrative unification and centralised planning, upward accountability was retained. Structural and organisational change in the NHS, as Leathard (2000:129-172) suggests, appears to have been aimed more at finding effective ways of pursuing national priorities at a local level rather than real devolution of power and influence.

While an interest in engaging with patients and members of the public has continued to be evident, this appears to be on the terms set by NHS bodies and concerns over the use of particular methods is still evident (Baggott, 1998:248-269). Added to concerns over the methods employed, there are doubts over the impact that these have had on policy and services. Little evidence exists to demonstrate that different methods have been set within a framework that recognises different outcomes and goals particularly in respect of the consumerist and democratic agenda (Lupton et al, 1998:44-61).

Fundamentally, if control over the models adopted, the methods employed, the issues discussed and the attention paid to the outcome is retained by those bodies responsible for initiating them, increasing the diversity and sophistication of the methods used will not necessarily result in more local involvement in decision-making. The issue of control then is likely to be at the root of patient and public involvement; more specifically, who holds it, how is it exercised and in whose interests it is used. The following chapter discusses these issues in the context of power in the UK NHS and the subsequent impact this might have on developing the role of patients and the public.

CHAPTER TWO

CONSUMERISM, DEMOCRACY AND POWER

INTRODUCTION

Although this study is primarily a case study of how one PCG had responded to national imperatives relating to the involvement of patients and members of the public, of necessity this must take account of and be placed within a wider context. While the *New NHS* promised more power and influence this has tended to be packaged as “patient and public involvement” and although ensuring that the role of patients and members of the public remains on the NHS agenda, a consequence of this has been a continued interest in methods of engaging with patients and members of the public. This interest in methods has led to a focus on activity rather than addressing some of the fundamental issues evident in the imbalance of power that has been an inherent feature in the NHS. Promises of more power and influence would suggest an acceptance that there are asymmetrical power relationships between those who make decisions in the NHS and those on whose behalf they are made. If these relationships are to be addressed a better understanding is required of the nature of involvement as well as an acknowledgement of the various ways in which power can be mobilised.

This chapter begins with a discussion on the nature of involvement and the role of patients and members of the public in the context of the UK NHS. The chapter then discusses theories of power and how these might be, or have been, applied to the NHS. In particular, Lukes' three dimensions of power are examined in relation to how power is distributed, the different ways in which it can be mobilised and the various interests that are served by prevailing structures and processes in the NHS. The chapter also discusses Alford's analysis of health care politics in the 1970's, how this has been applied in the UK NHS and the extent to which it is still relevant today. The chapter goes on to discuss the extent to which issues of power and influence are evident in the ways in which the role of patients and members of the public has been constructed. The role of patients, as users of health services, as well as issues of citizenship in the context of the role of members of the wider public are examined and the differences and similarities between them explored. The chapter ends with a discussion on the extent to which attempts to secure a more

equitable balance of power for patients and the public have been successful and the implications this will have for the development of patient and public involvement.

THE NATURE OF INVOLVEMENT

The Labour government gave a clear indication that a key theme of modernising health services would be the involvement of patients and members of the public (DoH, 1998:23) but references included in policy documents encompassed a wide range of objectives. A weakness of this all-encompassing approach is that it fails to draw attention to differences in the nature and level of involvement required to achieve different objectives or to formulate bridges between them.

Anderson (2000), for example, identifies six main objectives in relation to patient and public involvement all of which are underpinned by different assumptions:

1. Informing decision-making;
2. Improving access to and appropriate use of services;
3. Monitoring and improving standards and performance;
4. Educating people about their health;
5. Empowering people to take control over their health and health care;
6. Encouraging openness and accountability.

Failing to recognise the different purposes and outcomes of “involvement” has resulted in the term being used interchangeably with terms such as “consultation” and “participation”. A number of studies (for example, Lupton et al, 1998; Hogg, 1999; Ong, 1993) indicate that this lack of attention to the interpretation of “involvement” often results in a failure to develop mechanisms that are owned by the very people that organisations are attempting to engage with.

Consultation has been a statutory duty of NHS bodies since the establishment of Community Health Councils in 1974, but this has often been considered a tokenistic exercise as plans were invariably presented after decisions had been made. Most dictionary definitions of “involvement” describe it in terms of “being included” or “being a part of”. The Institute of Healthcare Management (2000:5) goes further and describes “involvement” as a process where organisations sit down with the community and plan services together. Despite these definitions, it has been argued that “involvement” still indicates a relatively passive role and some

commentators prefer the term “participation” as this implies a more active role (Arnstein, 1969). In addition, although the *New NHS* promised more power and influence for patients and members and the public, Lupton et al (1998:44-61) argue that it is frequently those who already hold power that allow involvement in the first place. In this and subsequent chapters, the term “involvement” is used for the purpose of consistency and because this is the term used in the *New NHS* and related policy documents.

In practical terms, as Emmel and Conn (2004:1) point out, a lack of clarity over the different ways in which involvement is interpreted often results in the term being used loosely to describe any activity that includes local or lay people and this lack of clarity is particularly evident when comparing the characteristics of shared decision-making with activities that simply seek to include people in pre-determined issues (Table. 2.1).

Table 2.1 Features of Involvement (adapted from Emmel and Conn, 2004:10)	
Organisationally driven activities	Shared decision-making
<ul style="list-style-type: none"> ○ Achieves a set objective with targets pre-determined by those initiating the exercise ○ May coincide with the perceived needs of local people ○ Generally linked to improving efficiency and delivery of services ○ Involvement used as a management tool ○ Static, passive, top-down and controlled ○ Temporary, involvement in specific tasks and abandoned when these are complete and targets achieved ○ Does not lead to local people directly controlling or influencing resources 	<ul style="list-style-type: none"> ○ Involvement is seen as a process that builds community confidence and capacity ○ Unpredictable, not quantified, responding to locally perceived need and changing circumstance ○ Local people directly involved in devising solutions to perceived need ○ Dynamic involvement that is led by local people and communities ○ Long term and seeks to enhance awareness and increase self confidence, while targets might be set, these are not seen as the end product but as a part of an on-going process ○ Brings about change in existing organisational arrangements and local community control of resources and validates local community understanding of need

While some of the objectives identified above might be satisfied by the inclusion of lay people in organisationally driven activities, others imply a much more active role as I shall now discuss.

Objectives of Involvement

1. Informing decision-making

Involvement as a means of informing decision-making can be both organisationally and community oriented depending on whether local views are taken account of in final decisions. If the aim is to establish legitimacy for pre-determined priorities or to reduce or prevent local opposition to change rather than establish community needs then it is likely that only limited opportunities will be presented. However, this does little to encourage the development of a framework capable of acknowledging the rights of people to take part in decision-making while recognising and taking account of the full diversity of interests within local communities (Anderson, 2001:29-42).

2. Improving access to and appropriate use of services

Similarly, an emphasis on improving access to and appropriate use of services is invariably perceived as being organisationally driven and linked to cost efficiency and effectiveness. Elements of equity and demand management however can unearth issues of conflict not only in terms of balancing the needs of some groups with those of others but also in balancing the perceived needs of local people against professional perceptions of need (Lupton et al, 1998:44-61). Involvement in these terms would necessitate clarity over the level of influence available, the basis on which decisions will be made and processes that enable patients and the public to voice their interests.

3. Monitoring and improving standards and performance

While attempts to focus on quality and standards might be related to meeting the expectations of those using services, they can also be organisationally driven when combined with the need to meet organisational targets and priorities. Clinical governance, for example, is the framework included in the *New NHS* for ensuring consistency and quality of standards and yet there is still little evidence of the

inclusion of patients or local people in this (Gillam, 2001:17-27). In addition, measures such as medical audit, used to regulate clinical and medical standards and increase quality and consistency, can be obstacles to patient and public involvement because they can result in even less acceptance of what patients think is valuable in health care (Allsop, 1995).

4. Education and empowerment

Educating people about their health is often associated with the provision of information to encourage responsible patients. Although set against a pre-determined public health agenda, more recently this approach has been underpinned by recognition of the role that people have in maintaining their own health (Anderson, 2001:29-42). The empowerment of people is more radical than simply providing health education and is about enabling people to identify and address their own health needs rather than imposing professional solutions (Ibid). While health education has typically been concerned with educating the public in lifestyle issues related to health, empowerment is rooted in community development and enabling people to take control of their lives rather than necessarily complying with the public health agenda.

5. Encouraging openness and accountability

Encouraging and increasing openness and accountability is based on the premise that people have the right to know which decisions are being made, the basis on which they are made and also that those who are making them on behalf of others should be answerable for them (Hogg, 1999:175-187).

These very different perspectives on the purpose of involvement reflect the distinction between the needs of the organisation and the needs of local people but also the difference between operational and service delivery issues and the more strategic issues of policy and decision-making (Lupton et al, 1998:93-108). Equally they draw out issues surrounding the differences between various models of involvement and this is central to the debate on how the perceived power imbalance that exists in the NHS can be addressed. Although not mutually exclusive, the issue of maintaining public credibility and legitimacy for decisions whilst complying with imperatives driving the identification of need will need to be resolved.

Distinguishing between objectives such as the organisational requirement to know the needs and preferences of those who use services, a long term commitment associated with sharing decision-making with local people, enabling people to take control over their own lives or simply including lay people in issues intended to achieve a particular outcome determined by professionals is a key factor in developing a framework for involvement (Emmel and Conn, 2004:1-10). Unless the different objectives of engaging with local people are acknowledged and understood then the purpose becomes obscured and the models adopted are likely to result in false expectations and understanding of what can be achieved.

Differences in the way in which patient and public involvement is operationalised in terms of the different groups that need to be involved is also an issue in the context of operational and service delivery issues and those concerned with broader policy and decision-making. The role of the patient as a user of health and health care services can be clearly linked to operational issues and knowledge of how health services are received in order to make them more responsive. On the other hand, there is a much broader role for members of the public in terms of policy and decision-making on a wider scale, in particular, determining collective and publicly perceived need and agreeing mutually acceptable solutions. In responding to arguments for this collective approach, the emphasis in the NHS has typically focused on collecting and analysing health statistics rather than developing mechanisms that facilitate information sharing between patients, members of the public, managers and professionals. A major obstacle to this shared approach appears to be that patient and public perceptions of need often challenge those of professionals and are not considered as relevant as evidence based on clinical need and statistical data.

In recent years, the debate over the role of patients and the public has moved from viewing patients as consumers using the services of market driven organisations to an acknowledgement of issues of citizenship and accountability in the wider public sense (Brooks, 2001:1-13). Referring to both the rights of those who use health services and the rights of members of the public as citizens, the 1997 reforms appeared to suggest that it was no longer acceptable for one to be ignored at the expense of the other; health service organisations must take account of and develop strategies for both paradigms. Just how realistic this was given the separate and distinct assumptions that underpin each of these models and the very

different strategies for implementation that each would subsequently require is perhaps questionable. I will now outline briefly what is meant by “consumerist” and “democratic” approaches to patient and public involvement in the NHS.

Consumerism in the NHS

Consumerism in the NHS was part of a parcel of reforms introduced by a Conservative government, which came to power in 1979, intent on making health services business oriented, better managed and more efficient. Rooted in the market relationships of the private sector, consumerism focuses on the importance of organisations knowing the preferences of their customers in order to enhance and increase market share (Lupton et al, 1998:44-61). Although consumerism emphasises the rights of those who use services to information, access, choice and redress, it might also be described a management tool, because the control over who, when and how consumer views are included in planning and decision-making invariably remains with organisations.

From an organisational perspective, a fundamental aspect of consumerism is establishing the preferences of those who use services and identifying potential changes that the future might bring in terms of patterns of need and demand. With the philosophical core of the model being choice – consumers choose whether, where and how to use services - an understanding of people and their social and cultural characteristics forms the basis on which the consumerist approach is built. Ong, (1993:65-82) argues that in this respect, health care is not essentially different from other services.

The NHS can be described as providing a diverse range of services, many of which are not urgent and therefore potential choice can be exercised about whether to use them or not (Ibid). It can also be argued that people have choices in respect of health as demonstrated by lifestyle choices in relation to smoking, diet and physical activity, for example, and much depends on the relative priority given to health over lifestyle. The counter argument however, is that less voluntary aspects of lifestyle such as economic, environmental and social circumstance can and do impact on the ability to stay well (Blaxter, 1990). From this point of view, consumerist principles of choice cannot be reconciled with health and health services unless people have a means of redress if these wider determinants are not compatible with their perceived health needs.

In respect of access to health services, there are few opportunities for people to directly access services except through a GP or accident and emergency services. Despite an increase in availability of private health care in recent years, most people still choose to use NHS services (Hogg, 1999:1-49). Equally, an inherent weakness in relation to consumerist rights in respect of health services is that the issues of whether individuals are eligible for or have the resources to use services are not addressed. Subsequent debate over choice of which services to use, or indeed whether to use them or not then becomes meaningless (Lupton et al, 1998:44-61).

A further issue in terms of developing a consumerist approach to health and health services is access to information. NHS organisations have frequently been criticised for their reluctance, or in some cases inability, to impart appropriate information (Stacey, 1994:85-97). Those who hold information are invariably those who purchase or deliver services and within the health and health care context this has tended to favour clinical and managerial knowledge rather than the issues of process and outcome that are often more important to those using services (Ong, 1993:65-82). While health policy over the past twenty years has emphasised the need for relevant information to be made available so that choice can be made, this requires a fundamental shift, not only in terms of the nature of the information given but also the related issue of defining the consumer. Nettleton (1998:130-145), for example, argues that the consumerism inherent in *Working for Patients* (DoH, 1989) was misleading in that health authorities and GPs continued to act as third party buyers -services were still not purchased by those who used them.

As well as maintaining the previous Conservative government's focus on consumerism, the *New NHS* also referred to the need to balance the rights of consumerism with the democratic responsibilities inherent in collectivist models of universally available health care. Consumerist models, it is argued are unlikely to achieve this and alternative models that provide mechanisms for effective participation and ensure professional accountability are more appropriate (Winkler, 1987:1-8).

Democracy and the NHS

In democratic models of involvement, the emphasis is on equity and empowerment. People are seen as citizens with rights to use public services but also the

responsibility to contribute to and participate in society. The principles that underpin a democratic approach are firstly, that the participation of people should be encouraged because of the benefits it can bring in terms of maintaining a healthy society by enabling people to fulfil their responsibilities as citizens. Secondly, it is argued that the full diversity of interests inherent in society should be represented in the political process (Lupton et al, 1998:44-61).

Democratic models of involvement are fundamentally different to consumerist models in a number of respects. Firstly, while consumerism tends to view involvement as a series of separate and discreet episodes related to specific services or products, democracy is seen as a more developmental process that requires collective action and broadens both the perspectives and capacity of those involved. Secondly, democratic models are seen as enabling people as citizens to bring a variety of roles and experiences to the process rather than the more limited role associated with consumerist models (Lupton et al, 1998:44-61). From a philosophical point of view, democratic involvement in health and health care draws heavily on social justice ideology that necessitates a fundamental redistribution of power and the empowerment of communities. The ultimate aim is to enable people to define health and health needs from their own perspective not only to encourage community-led solutions, but also to identify patterns of services needed and action to address inequalities (Ong, 1993:65-82). Within this paradigm, there are clear links to the community development approach discussed in the previous chapter.

The World Health Organisation's *Health for All* philosophy (World Health Organisation, 1981) recognised the various dimensions of health and the importance of understanding health within the context of existing social and economic factors. Implicit in *Health for All* was the involvement of communities in determining the input of organisations necessary to address the different factors that influence health and well being. The empowerment of communities was seen as central and a change in the relationship between communities, managers and clinicians essential (Ong, 1989:505-507).

A democratic model of involvement would acknowledge people as producers of, and partners in, health and not simply passive recipients of services. As a result, a more sophisticated understanding and acknowledgement of existing inequities in respect of power and control is seen as essential if the core concerns of communities are to be addressed (Brooks, 2001:5-11). Recognising equity based

on need rather than uniformity across different groups, democratic models encompass mechanisms for direct participation, localised activity and decentralisation of services. If health care is ultimately aimed at giving people equal opportunities to achieve optimal health, resources may have to be distributed unequally (Townsend, 1992).

The differences between consumerist and democratic models are in many ways reflected in the differences between health service and health improvement models of planning. A health service model, where planning is primarily about improving the quality of defined health services, holds relatively few opportunities for local people to be involved in a democratic sense. Health improvement, where there is the potential to work in partnership not only with local people but also with other organisations to address the broader issues involved in determining health, is considered to have far more potential in terms of engaging with democratic models of involvement (Callaghan and Wistow, 2002:8). In this respect, it is not only clarity over the approach to involvement that it is a significant factor but also the priority given to either health service improvement or health improvement.

The consumerism inherent in *Working for Patients* had served, in many respects, to create an emphasis on market-based models of involvement, driven by the organisational need to know how those who used services viewed them. The introduction of *Local Voices* in 1992 however, advocated a widening of involvement to encompass alternative approaches. With an emphasis on health needs assessment and identifying key priorities of health and health care, *Local Voices* made explicit reference to information giving, dialogue, consultation and participation in decision-making. Involvement was not to be seen as a series of one-off consultation exercises but rather the development of more robust models of local involvement that were co-ordinated across purchasers and providers. The dilemma of how to develop models that encompass consumer driven operational issues as well as the more strategic issues of policy was however still apparent (Lupton et al, 1998:93-108).

While operational concerns to know what people think of services often result in activities such as consultation exercises and service monitoring, they invariably take place within a centrally defined framework that promotes the rhetoric of the market place at the expense of popular democratic participation (ibid). A continued emphasis on the individual consumer would seem to encourage involvement to be

developed around mechanisms such as surveys, focus groups and consultation exercises rather than involvement of the wider public through representative mechanisms.

Consumerism versus Democracy

Consumerist models of involvement, particularly when they are linked to health service improvement, can be effectively developed through mechanisms such as consultation and involve limited transfers of power. Democratic models of involvement are considered to require a much more fundamental shift of power that addresses accountability and devolved decision-making (Callaghan and Wistow, 2002:8). While there is a need to clarify whether involvement is about educating people in respect of their own health, validating the decisions that are made on their behalf or improving local accountability and promoting democracy, there is also a need to examine whether the prevailing commitment, structures and processes are amenable to the various shifts in power and influence that particular intentions will necessitate.

The role and legitimacy of public, or citizen, involvement is often less clear than that of individual patient or service user involvement. Although it implies a much wider role in terms of the devolved and shared decision-making characteristic of democratic models of involvement, at a local level there is no democratic accountability in respect of health and health services (Hogg, 1999:175-187). Control in respect of determining health policy that affects society as a whole remains at a national level and while local people can exercise their democratic rights to vote governments in and out of power, there are no opportunities to pick and choose and vote for individual policies.

While the role of individual patients and service users is somewhat clearer in terms of consumerism, a number of weaknesses are still apparent. Individual patients exercising their rights as consumers implies a much narrower role that focuses more on personal and self-interest and securing the best service for themselves (Callaghan and Wistow, 2002:11). The mechanisms available to secure this in a consumerist model rely, to a greater or lesser degree, on the availability of options if services do not meet their personal needs or preferences. In the market-based systems of the business sector, exit, voice and loyalty are the most frequently used mechanisms to influence services. Consumers can stop using a service or express

their dissatisfaction by complaining in order to affect change, equally even if dissatisfied they may continue to use a service because there is no alternative, alternative options are inconvenient or they are members of vulnerable groups not able to articulate their dissatisfaction (Lupton et al, 1998:44-61). The degree of influence that can be achieved by not using a service or product (exit) or expressing dissatisfaction (voice) will be directly related to the factors that hold people to a particular service or product (loyalty) and ultimately the opportunities available to exercise choice. In the case of health services, the option to exit is restricted, as opportunities for choice remain relatively few. In addition, in the managed markets of the NHS the service user is rarely the direct purchaser of a service and their voice is therefore compromised (Lupton et al, 1998:44-61).

In terms of influencing decisions, the evidence suggests that while willing to engage with involvement by providing information, seeking local views and consulting on proposals, NHS professionals are still reluctant to enter into shared, or devolved decision-making (Callaghan and Wistow, 2002:4-9). This reluctance is often attributed to the difficulties that managers and clinicians have in acknowledging the validity of local knowledge and experience and subsequently that it can and should be assimilated into planning processes to produce better health and health care (Stacey, 1994:85-97). Similarly, and perhaps more importantly, attempts to transpose patient and public perspectives into professional frameworks can undermine the legitimacy of what counts as evidence of need. When people use their knowledge to say the way things are done is wrong and we want them changed, professionals are uncomfortable and have difficulty in perceiving this as valuable data that can and should be used to influence decisions (ibid).

These different and often competing claims to legitimacy need to be resolved if involvement is to be developed as an integral part of planning within health service organisations. While an expansion of the role of patients and the public has been a consistent theme in changing policy and reform in the NHS, Ong (1993:65-82) suggests that it appears to have been developed as a separate and distinct priority isolated from policy and decision-making processes. Against a background of centrally defined targets, priority setting and performance management arrangements, there is little evidence of attention having been given to the wider issues of power and influence. In particular, health policy has done little to address the relative levels of power held by patients, members of the public, managers and clinicians and the way in which these shape the opportunities for involvement and

are subsequently reflected in the methods used as involvement mechanisms. I shall now discuss involvement in the context of these issues of power and influence.

THE NATURE OF POWER

Power is a complex concept that is widely contested and although various theories of power have been applied to policy and decision-making in the UK NHS it has been argued that none appear to capture the total picture (Ham, 1999:215). This failure is perhaps precisely because of the complexities involved. If the *New NHS* promises of more power and influence for patients and members of the public were to be realised, a fundamental issue would be an understanding of who holds power, how it is mobilised and in whose interests it is used.

Theories of power tell us that there are a variety of ways in which power can be mobilised. The use of power does not always involve overt and observable action but can also be exercised in ways that are covert and latent. In addition, power can be exercised through the action of individuals or groups or determined by the structural arrangements and relationships that exist. Moreover, amidst arguments that our actions are always shaped by structural systems of control, the extent to which freedom of choice can ever be exercised in relationships that are not equal is questioned. It is also argued that power does not necessarily involve conflict, domination and the imposition of wills and interests but can be an essential and desirable component of all highly organised societies. In this sense, power can be perceived as consensual and legitimised by those who invest power in others to act for the benefit of a collective and does not necessarily involve domination and compliance but is an ubiquitous part of any society that has a structural, hierarchical basis.

Lukes (1974) identifies three dimensions of power:

1. In a one-dimensional model of power, there is a plurality of interests, each group knows and can articulate their interests in open and transparent processes. Although resources are distributed widely among many different groups and they may vary in the level of power they can exercise, there is no single group that holds and exercises power but rather a multiplicity of

competing groups none of which are dominant. This multiplicity serves to ensure that democracy is maintained through competition between the various interests (Haugaard, 2002:5-7).

2. In a two-dimensional model of power, while particular groups might know their own interests, their ability to secure them is constrained by those who hold greater levels of power. In particular, agendas can be controlled and power exercised by a variety of means that might include inaction as well as overt and covert action.
3. In Lukes' three-dimensional model, power is not only mobilised by the actions or inaction of individuals or groups but also by the prevailing cultural processes and social structures. These invisible structural and cultural influences serve to limit not only the ability of those without power to articulate their interests but also to undermine their ability to recognise them in the first place.

One Dimensional Power

In a one-dimensional, or pluralist, theory of power the development of health services and health policy would be the result of the interplay between different interest groups. As there is no dominant interest, the distribution of power would be analysed in relation to individual issues by examining the different interests present and how these are incorporated into decisions; decisions are often the result of compromise between the different interests involved. Despite potential differences, alliances can and would be formed but these would change over time leading to fragmentation and a diffusion of power that ensures no group remains dominant (Ham, 1999:203-217). Power, in other words, is not stable and will change over time and in relation to particular issues under debate.

Equally, although different groups might be perceived as having different and unequal levels of resources, in a one-dimensional view of power there is a difference between power and power resources (Dahl, 1968:405-415). While power is about prevailing in decision-making, the existence of power resources, such as information, knowledge and expertise, only indicate potential power that may or may not be mobilised. Although power and power resources can be used together to influence specific outcomes, individually they cannot be used to

exercise generalised power nor can they combine to constitute a power elite. While power resources might be distributed unequally, it cannot be assumed that they are necessarily activated (ibid). Crucially, power can also be held by reputation and in this case it is not necessary to exercise power because behaviour is influenced simply by the belief that particular groups or individuals hold power.

One-dimensional theories of power might be criticised as being too simplistic because they tend to concentrate on the exercise of power rather than the source (Haurgaard, 2002). Power is seen as participation in decision-making and is analysed only in relation to important, concrete decisions. Subsequently, being concerned with the study of key rather than routine decisions no account is taken of the fact that power might be, and often is, exercised by confining the scope of the decision-making to relatively safe issues (ibid). In addition, there are no objective criteria for distinguishing between important and unimportant decisions. If predominant interests were challenged, for example, would this constitute an important issue?

One-dimensional power is relatively weak in explaining several issues in respect of policy and decision-making in the NHS. Firstly, the somewhat disproportionate influence that the medical profession is able to bring to bear among the various interests that exist in relation to health and health care. The medical profession, managers, civil servants, politicians and patients and members of the public all have different and potentially conflicting interests but, importantly, there are distinct differences in the way in which they are integrated into policy and decision-making processes at both a national and local level.

Consumer groups, in many cases voluntary sector organisations, represent a variety of special interests, are consulted on a regular basis and are part of an extensive network of advisory bodies that assist government departments in the development of policy and offer advice and expertise. The medical profession is also able to offer specialist knowledge, information and expertise but, crucially, they are a key producer group in relation to implementing policy. Managers are often concerned with cost control, financial balance, quality improvement and performance management. Politicians and civil servants are, among other things, interested in efficiency, equity and public support. While consumer groups can offer information and expertise, the medical profession has a much more significant role in terms of cooperating with policy implementation and politicians and managers

rely heavily on this. Subsequently the sanctions that can be brought to bear by the medical profession and their representative bodies enable them to exert far more influence than consumer groups (Ham, 1999:203-217).

The second issue that one-dimensional power does not fully explain is the continued focus on medical models of health that emphasise the diagnosis, prognosis and treatment of illness and disease rather than broader definitions. If the medical profession is only one interest among many, a continued focus on medical models of health would be a reflection that agreement had been reached on the meaning of health and the way in which services should be provided. If expressed preferences were the only reliable way of identifying interests, the strong support shown for the medical profession would be seen as demonstrating that genuine consensus had been reached. There is an alternative argument that this is not necessarily the case because more powerful groups can and do manipulate the preferences of other less powerful interests and this will be discussed further in the context of two-dimensional theories of power.

Thirdly, one-dimensional theories do not fully explain how issues are brought to the policy and decision-making arena in the first place. Public consultation, for example, has been a statutory obligation for NHS organisations since 1974 when Community Health Councils were introduced and yet there is evidence that plans were, in the main, presented too late for patients and members of the public to influence them (Hogg, 1999:84-110). Equally, *Working for Patients*, was introduced without consulting organisations such as the British Medical Association and in the face of strong opposition from the medical profession. A number of these weaknesses are more fully explained in a two-dimensional theory of power.

Two-Dimensional Power

Critics of one-dimensional theories of power (for example Bachrach and Baratz, 1962) argue that it is too focused on decision-making and that it is not enough to simply study overt decision-making but that studying what is not brought into the decision-making arena is equally, if not more, important if power is to be analysed. One-dimensional power is considered weak because it begins by studying issues rather than the values and biases that are built into political systems. In a two-dimensional model, power is used to limit the scope of the political process and prevent issues from reaching the decision-making arena. The extent to which

issues are excluded from the agenda, information withheld. decisions left to perceived experts that are known to favour a particular outcome and the use of bureaucracy and red tape to exclude issues and groups is a key aspect of two-dimensional theories of power (Haaguard, 2002:26-29). Specifically, the extent to which dominant values prevail, the way in which the status quo is preserved and how this prevents anything other than safe issues being brought to the table for decisions are issues that one-dimensional theories of power neglect.

Bachrach and Baratz (1962) argue that the distinction between important and unimportant decisions cannot be made unless the dominant values that tend to favour the vested interests of some groups relative to others are analysed. In particular, who gains and who loses by the existing biases and dominant values, the dynamics of non-decision making and how the status quo oriented persons and groups influence values and limit the scope of actual decision-making are not examined.

In the UK NHS, for example, the most influential concept of health continues to be based on what Stacey (1977) describes as an individual, curative and functional fitness model. Two-dimensional theories of power tell us that this is important, firstly because it justifies and maintains the prominent position of the medical profession and secondly, because it shapes subsequent patterns of investment in health and health services. While this concept emphasises specific individual causes of illness and searches for specific individual cures, there is also a collective concept that is concerned with prevention and seeks causes of illness within environmental, social and economic systems (Ibid). In the collective concept of health, addressing the wider determinants of health is a key issue.

While medical models of health serve the medical profession because they legitimise their control over health services and successfully maintain definitions of illness and disease, the interests of the population might be just as well, or even better, served by improving health and preventing illness by investing in social models of health that emphasise wider determinants rather than medical models that focus on illness and disease. Although policy in recent years has acknowledged this (e.g. The Health of the Nation, 1992, Our Healthier Nation, 1998) this appears to have fallen short of what is required to address a number of key issues. The key areas identified – coronary heart disease and stroke, cancer, mental illness, HIV and aids and accidents – reflect government concerns and do not go far enough to address some of the major causes of ill health such as

poverty, environmental and social issues. Policies for prevention remained focused on individual behaviour and locked into the structures and culture of the NHS that continued to be dominated by medical definitions of health (Allsop, 1995:232).

More explicitly in relation to addressing the relative position of patients and members of the public, although Stacey's collective concept of health might be more highly valued and opportunities might be made available to voice this, there is only limited evidence that this would make a significant difference to the decisions made. While giving the appearance of power, activities aimed at including the voice of patients and members of the public are often used simply to distract attention away from more contentious issues (Lupton et al, 1998:44-61). Despite more power and influence being promised to patients and members of the public, by channelling interest into a fairly limited agenda, potential areas of conflict can be avoided and mechanisms intended to develop the role of patients and the public then become a means of control that prevent challenges to the status quo. It is this aspect of control that Lukes' three-dimensional theory seeks to explain.

Three Dimensional Power

Lukes (2004) considers a two-dimensional explanation of power weak in that it associates power with actual, observable conflict but fails to acknowledge that manipulation and authority may not involve conflict. Power is not just exercised by getting others to do things they don't want to do but is also about influencing, shaping or determining their very wants thereby securing compliance by controlling thoughts and desires.

Although two-dimensional power incorporates control over the agenda and the ways in which potential issues are kept out of the political process, it is still too committed to the study of actual behaviour (Lukes, 1974: 21-42). While decisions are choices consciously or intentionally made by individuals or groups, biases can be mobilised and reinforced in ways that are not consciously chosen or the intended result of particular choices. In a three dimensional explanation of power, the domination of the defenders of the status quo are so secure that they are not aware of any potential challenges to their position and therefore of any alternatives to the existing processes (ibid). The bias of the system is not only maintained by individuals or groups but also by the prevailing socially structured and culturally patterned behaviour of groups and practices.

Theories of power that are linked to the structural relationships in society do not have a basis in concrete policies or the people they involve and nor are they limited to open conflict or politics. The three dimensional model of power rejects the notion that simply because no conflicts are uncovered, no interests have been harmed. In Lukes' (2004) view, the most supreme and insidious exercise of power is to prevent people from having grievances by shaping their perceptions and preferences in such a way that they cannot see alternatives. To assume that the absence of conflict is the same as consensus is to disregard the possibility of false or manipulated consensus. Power can equally be used by those who administer populations as a controlling mechanism in that people are shaped by the prevailing patterns of culture and social groups that they belong to.

In this sense, power can be used by a range of institutions such as governments, employers, schools, parents and, important in this study, the medical profession to socialise individuals and orient them to roles and practice. This type of control however is seen as positive rather than repressive because it is intended to ensure that individuals conform to the norms of society (Foucault, 1987). While repression is negative in that it constrains and prohibits the way in which people might think and act, this concept of power is arguably positive because it normalises people to act and think in a way that conforms to society. In this way, while some have the power to dominate others it is in a productive way. This power is not the result simply of a structural society but rather structural relationships. While structures remain constant, relationships within and between structures change and individuals are the product of these changes. Wherever there are social relationships, there will be an asymmetrical balance of power that results in this level of domination and insubordination (ibid).

This view of power also emphasises the relationship between knowledge and power and the impact that the claims of "expert" knowledge can have on shaping the way in which people think and act. Power in this sense is productive rather than oppressive in that it shapes people and allows power to operate through them, normalising them to render them capable of and willing to conform to the norms of society. What appears normal and natural is in fact produced by the relationships that exist in some underlying structure. From this perspective, there are no autonomous, rational or moral actions; there is no liberation from power because people are moulded into conformity. Individuals are socialised and oriented into

roles and practice that are culturally and socially given and while believing themselves to be free of power – making their own choices and pursuing their own interests - they are in fact acting as their own overseers in complying with patterns of normative control that are the results of the relationships within a structural society (Lukes, 2005).

Unlike Foucault's (1987) model of power with its focus on systems of thought and how these can be manipulated, Bourdieu's (1984) view of power, although similar, relates to a cultural model where the emphasis is on action rather than structures or relationships. In this concept of power, it is acquired patterns of thought, behaviour and preferences that are the link between social structures and social actions. This concept moves beyond a definition of power that involves conflict and consent or coercion and submission and is disguised, or rendered invisible, by naturalising class, conventional or position-based visions of the world. The result is that our visions of the world are shaped by acquired patterns of thought, behaviour and preferences - what Bourdieu calls "habitus" – in a way that is resistant to articulation, critical reflection or conscious manipulation (Lukes, 2005).

Power in these circumstances is not a deliberate attempt to dominate or constrain and as a result it is more effective – people are unaware of it being exercised and see their situation as natural, value it and fail to recognise the source of their desires and beliefs (ibid). The thoughts, behaviour and preferences are learned and embodied in people and this reproduces hierarchies of social positions.

Our knowledge of the world is shaped by past life experience and this determines our future and instils a particular order into our lives. Although this concept of power is similar to Marxist theories of power, in that it is class related, it is wider and more fragmented taking account of both economic and status factors. The dominated class use past experience to shape their future expectations and by accepting the preordained order of things this becomes a self-fulfilling prophecy. Equally, trying to achieve a higher social class reinforces the value of the dominant class because individuals perceive this as more desirable than their own status.

The NHS and Three-dimensional Power

While Lukes' work is, as he himself admits, based on a very radical, and somewhat negative view of power, the theories of Foucault and Bourdieu imply that differential

levels of power are necessary and desirable if order is to be maintained in highly organised societies. In many respects, public services such as the NHS rely on this order not only to ensure the equity and universality that underpins them but also to contain costs and retain public credibility. However, while the NHS and other public services might be seen as a symbol that the government cares for the welfare of its citizens (Hogg, 1999: 158), there are a number of interests evident that lead to questions surrounding the purpose of the NHS, the significance of the continued dominance of the medical profession and assumptions about the benevolent motives underlying state intervention in the provision of health (Ham, 1999).

A number of commentators (For example, Klein, 1980; Harrison and Pollitt, 1994) question how the public or collective interest is represented in health and health services. Klein (1980) suggests that the identification of health needs and society's response to these is in the hands of a very powerful group – the medical profession. Although in theory, the public good might be defined by the state, it is the medical expert that operationalises it. Harrison and Pollitt support this view arguing that the service delivered by the NHS is the aggregate outcome of individual doctors' decisions rather than the result of decisions made by politicians, policy makers, planners or managers (Harrison and Pollitt, 1994:35). One outcome of this is that medical models of health continue to prevail and this medicalisation of health as well as illness turns people into “patients” and threatens their autonomy by introducing compliance (Hogg, 1999:86).

Since its inception the NHS has, in many respects, been based on paternalism and compliance because Doctors can treat illness but patients must comply with treatment. This compliance is most prevalent in medical models of health where it is the price that people pay for the treatment of ill health – doctors know what is best for their patients and if patients do not comply they forfeit the right to have treatment. This is further extended in debate about whether people should be given treatment if they do not comply with advice about lifestyle issues, for example should people who smoke or are overweight be given treatment for related illnesses.

Similarly, while the introduction of patients as consumers of health and health care was seen as a means of achieving a more equitable distribution of power and influence, this can also be used as a means of control. By encouraging patients who are armed with information from a variety of sources to focus on their own

personal interests and values this can distract from issues of democratic accountability and collective involvement (ibid).

From a Marxist perspective capitalism is at the heart of power and as the economically dominant class is also politically dominant, the state will always act in the interests of capitalism. Economic and political interests have mutually dependent needs and this creates a shared agenda that produces a power elite and class divisions (Haugaard, 2002). Although it might appear that the welfare of the work force is of prime importance, this is only a result of the way in which workers contribute to maintaining capitalist interests.

In respect of health and healthcare, for example, ensuring that people remain healthy, from a Marxist perspective, is aimed at ensuring that they are economically active and so the focus is on diagnosis and treatment of ill health with health services acting on behalf of a powerful elite. One example of this would be in relation to provision of services for those considered less likely to be able to contribute to economic interests, such as older people or those with mental ill health where services have traditionally been perceived as being less of a priority than other areas.

In this sense, the dominant concept of health does not reflect the power of the medical profession but rather the interests of capitalism. The diagnosis and treatment of individuals masks the real causes of ill health that lie in the economic and social systems of capitalism (Ham, 1999). The prevailing concept of health therefore reflects divisions in class and although doctors are powerful, they are merely acting on behalf of the state by administering health services on behalf of a more powerful group. This capitalist argument however still does not explain fully the traditional emphasis on medical models of health nor does it explain the developments that have taken place and the higher priority that has recently been given to relatively neglected aspects of health care such as mental health, learning disability and older people. The continued dominance of medical models of health, for example, is not necessarily the result of class conflict but more likely to be a reflection that the medical profession, rather than capitalists' interests, dominates and these interests are protected by ensuring that medical definitions are accepted (Alford, 1975).

POWER IN THE NHS

Alford's (1975) analysis of health care politics, although undertaken more than thirty years ago, is still very influential in understanding how power is distributed and mobilised in the UK NHS. In Alford's view (1975), it is structures, rather than particular groups, that are powerful with social, economic and political institutions preserving the status quo. These structures are made up of dominant (professional monopolists), challenging (corporate rationalisers) and repressed (community population) interests. The dominant interests, those of the medical profession, are only activated when they are challenged. Concerned with cost control, as spending on health increases, the corporate rationalisers increasingly challenge the dominant medical professionals (Baggott, 1998). The interests of patients and members of the public remain suppressed because the communities they represent lack coherence and a power base.

While patient and consumer groups may organise to articulate their own interests, this simply represents a struggle between and within their own structure in much the same way that there is competition between and within the medical profession. These are internal struggles however that do nothing to challenge existing structures and so the dominant interests continue to prevail. When patient and community groups mobilise, they tend to conflict with each other and with professionals over a variety of issues such as funding, priorities and control. This conflict between the various groups leads to fragmentation and a diffusion of any power that might be exercised by working in harmony resulting in a classic case of the veto group process leading to stalemate. Equally, while the corporate rationalisers might use a variety of tools to challenge the professional monopolists, the role they have in implementing policy often results in a dilution of measures intended to challenge the status and autonomy they enjoy.

Alford's theory of power in health care politics tells us that any challenges to the power of the medical profession would result only in shifts within existing structures rather than changes to the relative position of medical, managerial and community interests. In examining whether this is the case, I shall now discuss the basis on which these perceived dominant interests are constituted, discuss how they have been challenged in recent years and the impact these challenges have had on the involvement of patients and members of the public.

The Power of the Medical Profession

The power of the medical profession is, in the main, attributed to four key factors – the social composition of the profession, the autonomy and self-regulation enjoyed by the profession, the way in which the profession is politically organised and the medical knowledge that members of the profession hold. Traditionally, those entering the medical profession have come from middle class backgrounds and it has therefore been considered, to a large extent, a socially exclusive profession (Baggott, 1998). There is however evidence that this is changing in as much as it is no longer impossible for those from a working class background to break into the profession. In terms of self-regulation and autonomy, doctors are perceived as having superior status because, to a large extent, they are the only health care professionals that do not work under medical direction and instruction. Other health professionals have far less autonomy and are also weaker in relation to their political organisation and leverage.

The organisational strength of the medical profession is evident in the number of groups that represent this field of work, how well they are organised and how they complement, rather than work in conflict, with each other. The General Medical Council (GMC) is the body responsible for regulating the medical profession, maintaining a register of doctors, ensuring the fitness of doctors to practice and investigating complaints about doctors – the GMC can suspend or remove doctors from the register. With clinical and non-clinical members, the GMC is perceived as an established and effective pressure group that has political clout.

The British Medical Association (BMA) has a long and established reputation as an effective pressure group and is the main representative organisation for British doctors (Baggott 1998). Although focusing on the pay and conditions for doctors, the BMA also campaigns on issues of public health and has campaigned on issues such as smoking and road safety. The BMA is regularly consulted by the government of the day on a range of health policies.

The Royal Colleges claim to be non-political and are responsible for the accreditation and training of specialists. Although the Royal Colleges operate with a much lower profile than the GMC or the BMA, they are still consulted by the government on a wide range of health issues. The combination of the GMC, BMA and the Royal Colleges and their integration into policy making serves to give the medical profession a very strong power base (ibid).

It is, however the traditional focus on illness and disease, rather than the wider determinants of good health, that is seen as providing the legitimacy on which the dominance of the medical profession is maintained and reflects the control that the medical profession continues to have over expertise and knowledge (Ham, 1999). The medical profession is perceived as being steeped in bio-medical models of health focusing on biological changes that can be defined, measured and isolated. Not concerned with the patient as a whole, bio-medical models are directed at dysfunction of tissue and organs and might be described as a negative perspective of health in that it defines health as the absence of disease rather than the possession of healthy attributes (Baggott, 1998).

Challenging the Dominant Interests

In relation to Alford's repressed community interests, there has been significant growth in the number of voluntary and community groups seeking to lobby for and represent the interests of various patient and service user groups. In contrast to the highly organised way in which medical profession is represented however, these groups are fragmented and often in competition with each other. This lack of co-ordination can be attributed to a number of factors. Firstly, these groups do not generally work well together because of their very specific and different interests, aims and objectives. For example, while some focus entirely on lobbying and campaigning others are concerned with self-help. Secondly, voluntary organisations that operate at a national level are more likely to be integrated into national policy and decision-making processes and yet, at this level, these organisations often lack grass roots membership (Hogg, 1999). Thirdly, competition for funding can lead to division and, more importantly, this can further the interests of those who are providing the funding by false alliances being formed. Considerable strengthening and co-ordinating of these groups will be necessary if they are to pose a serious risk to existing relationships of power and influence.

There is however, some evidence to suggest that relationships in the policy and decision-making arena are not always stable and that there have been challenges to professional dominance in NHS during certain periods of change (Ham, 1999:203-217). Specifically, the introduction of *Working for Patients* was carried out in the face of strong opposition from the medical profession and its representative groups, the introduction of general management, an increasing

emphasis on audit and regulation and the phasing out of pay beds in the NHS were all strongly opposed by the medical (Baggott 1998: 26-52).

The introduction of general management practice in the NHS was not intended to be just about organisational change; it was also a reflection of a conservative government's acknowledgement that cultural change would be necessary (Baggot, 1998: 158-159). If managerialist values were to be adopted, they would have to infiltrate the mind-set of the medical profession. The recommendations in the *Griffiths report* (DHSS, 1983) attempted not only to shift the balance of power between managers and clinicians but also to encourage doctors to become more involved in management and subsequently increase control over the activities of the medical profession (Ham, 1999).

An increased emphasis on medical audit and regulation has also been used as a means of challenging the autonomy of the medical profession. Various reforms have forced individual clinicians, the GMC and the Royal Colleges to focus more closely on issues of appraisal, revalidation and disciplinary procedures. Medical audit, introduced in *Working for Patients*, was seen as a means of regulating clinical and medical standards, increasing quality and consistency of practice and ensuring patient safety.

New Labour's modernisation agenda included even tighter regulation and audit procedures. New forms of regulation requiring doctors to take part in clinical audit, and work within guidelines set by a National Institute of Clinical Excellence along with the establishment of a Commission for Health Improvement to examine clinical performance and the publication of comparative data on clinical outcomes were all intended to highlight variations in performance and open them up to public scrutiny. In addition, these central regulatory bodies would be responsible for evaluating the clinical and cost effectiveness of new and existing treatments and technologies, analysing evidence-based practice and turning it into policy where deemed appropriate. As Webster (2002:247) points out, however, a number of interests impinge on this work. As well as clinical interests, political and economical interests are also evident and it remains to be seen whether the impartiality of decisions can be maintained or whether it becomes more of an exercise in cost control and a blocking device rather than a means of improving quality and ensuring consistency of standards.

Whether these challenges had seriously threatened the power of the medical profession is questionable. There is little evidence to suggest that managerialism had challenged the medical profession given that “the primary determinant of the pattern of the health services is still, just as before *Griffiths*, what doctors choose to do” (Harrison, 1988:23). The structural monopoly of the medical profession had remained unchanged.

Although *Working for Patients* had resulted in the implementation of changes that were neither the product of political consensus nor the outcome of bargaining between the government and key interests groups (Ham, 1999: 47-49), the effect had simply been to change relationships within the medical profession rather than between doctors, managers and patients or the wider public. The creation of GP fund holders and the purchasing power this involved, along with the purchasing role of health authorities, did result in changing the relationships between GPs and hospital doctors and the relative levels of influence held, but had little effect on relationships outside the medical profession. More importantly, with the introduction of GP-Led commissioning bodies, rather than limiting the power of the medical profession, although increasingly subject to the ethos and discipline of management, they were becoming even more powerful (North, 1995). Despite laying the foundations that would counter the dominance of the medical profession, there was little evidence to suggest that this had resulted in any long-term changes in the balance of power between doctors and managers (Harrison et al, 1992) and this supports Alford's (1975) arguments that transfers of power remain within rather than between existing structures.

The introduction of medical audit was also disappointing because its implementation was hampered by the difficulties presented by differences in medical practice that offered valid alternative solutions for individual patients (Leathard, 2000). In addition, Allsop (1995) suggests that medical audit had resulted in even less acceptance of patients' evaluations of health status or even of what patients thought was valuable in health care.

In relation to challenging the continued emphasis on medical models of health, in the 1997 reforms, the labour government built on the *Health of the Nation* initiative by launching a public health strategy. *Our Healthier Nation* (1998) looked beyond health and illness in the narrowest sense and recommended addressing issues such as welfare rights, housing, community safety, economic and environmental

factors (Hogg, 1999). Accepting these issues as important in health has enormous financial and political implications and, as has already been discussed, governments rely heavily on the medical profession to implement policy. Whether PCGs, predominantly made up of GPs who have no real track record in engaging with these wider health issues, but would be expected to take responsibility for priority setting at a local level, would prioritise health improvement and the wider determinants of health above health services is questionable.

Addressing these wider determinants requires significant time and energy and if power is devolved to a local level there is little guarantee that medical models of health will not continue to prevail and this investment not be seen as a priority. This, as Ham (1999:96) suggests, is the paradox of an NHS where doctors and local NHS bodies play a major role in resource allocation because of the political costs involved in explicit priority setting at a national level. Subsequently a way needs to be found to diffuse blame and avoid accountability and, in many respects, structural and organisational change that has sought to delegate power to a more local level might simply be seen as a means of passing on the blame for unpopular decisions.

Patient and Public Power

Various policy and national guidance over the past thirty years or so has served to ensure that the role of patients and members of the public has remained on the NHS agenda. Since the early days of the UK NHS, when patients were afforded little or no opportunity to take part in decisions regarding their own treatment or policy and decision-making in general, there have been a number of developments that have been seen as attempts to secure a more balanced approach to the asymmetrical power relationships that have traditionally existed between policy makers, professionals and patients and members of the public. Examining these attempts in the context of the various explanations of power however highlights that many of them, as in two-dimensional theories of power, while giving the appearance of increased levels of power and influence simply preserve the status quo.

Despite the consumerist agenda of *Working for Patients*, for example, there is still evidence to suggest that the balance of knowledge, expertise and status favours professionals over those who use services and this is a powerful constraint in terms

of developing consumerist models based on access to information, choice and redress (Baggott, 1998:248-269). In addition, attempts to introduce market models of consumerism are considered by some as too narrow to be applied to health care with too much emphasis on customer relations and not enough on reducing the disparities in levels of power between those who use and those who purchase or provide services (Winkler, 1987:1-8). In respect of developing patient and public involvement in the NHS, the consumerist model has been described as too crude and adversarial (Lupton et al, 1991:559-568). Rather than establishing rights and standards that can be difficult to enforce and might undermine relationships, as in *The Patients Charter* for example, it is more important to develop trusting, supportive partnerships between professionals, patients and the public

A Fundamental flaw of consumerism was that the internal market conditions created by *Working for Patients*, as Webster (2002:182-207) points out, were neither internal nor a market in anything other than a restricted sense. To describe the market as internal was at odds with the concept of maximising the contribution that independent sector providers could make to the NHS while the market analogy was inaccurate in that the consumer was still not able to exercise choice given, as noted above, GP fund holders and health authorities continued to act as surrogates. Patients could not really influence where resources were invested as decisions regarding resource allocation continued to be largely driven by medical professionals. The only way in which patients could influence the market and exercise any kind of choice lay in exercises such as changing GPs and making formal complaints, neither of which were deemed likely to result in anything other than marginal influence being exerted (ibid).

Promises that *Working for Patients* would give the NHS back to the people were also diluted by the gradual reduction of local authority and lay representatives on NHS Boards and the failure to acknowledge that this might reduce rather than extend the potential for local choice and participation (Leathard, 2000:110-128). Under *Working for Patients*, the boards of regional health authorities and district health authorities were slimmed down to five executive and up to five non-executive members appointed by the Secretary of State for their individual skills. Local authorities no longer had the right to appoint members to the district health authorities. The introduction of general management practice had effectively served to sever the links between democratically elected local authority representatives and the NHS. In addition, the changes in board membership of

NHS bodies had resulted in a perceived weakening of the Community Health Council function that was felt to be counter to the notion of greater patient and public representation (ibid).

In addressing these issues, a key theme of *Working for Patients* had been to devolve decision-making to a local level thus bringing patients and the public closer to those delivering and purchasing services and providing more opportunities for local influence. In reality the emphasis continued to be on structural issues with little evidence to suggest that the traditional proxy role assumed by clinicians and managers had changed (Lupton et al, 1998:44-61). Decisions were still being made on behalf of, rather than by, patients and local populations.

The introduction of *Local Voices* (DoH, 1992) attempted to address this by advising that mechanisms had to be set up to enable the views of local people to be heard. Despite this, it has been suggested that it is not obvious that what was heard was actually used to inform subsequent decisions (Nettleton, 1998:143). Decision-making at a local level still appeared to be concerned with internal processes rather than the inclusion of patients and the wider public. Although espousing the principles of patient choice and accountability, the main impact, supporting Alford's (1975) theory, was to shift influence within the NHS. Health Authorities and GPs, as direct purchasers of services, could exert more influence over those involved in delivering secondary care services, for example, and so became a countervailing power to established NHS Trusts (Ham, 1998:27-50). While, to a degree, the separation of purchasing and providing had succeeded in reorienting purchasers to patients and populations, the shift in influence was more to do with changes within and between the relationships of professionals and managers.

Although district health authorities had to consult widely on their plans, there was no prescribed framework for this. Similarly, GPs had only to discuss their plans with health authorities. While reiterating the need for services that were more responsive to the needs of patients, there was no concrete guidance on the need for direct dialogue with patients, but rather an assumption that this would be ensured by market mechanisms associated with a consumerist approach (Lupton et al, 1998:93-108). In addition, competition within an internal market for many was not really a viable solution to securing best value and the application of free market mechanisms that ensure the survival of the strongest were hardly appropriate in health care (ibid). With demand for health care rising, the possibility of

organisations capable of delivering services going out of business could not be seen as a solution to achieving value for money, given the additional capacity this would require from those who continued to operate.

Suggesting that the introduction of market type mechanisms in the NHS would force services to respond to demand was perhaps over ambitious. In reality, the constraints faced by both purchasers and providers in making the system run smoothly and limiting the adverse affects of patient flow uncertainty were more likely to limit rather than enhance patient choice (Bartlett and Harrison, 1993:91).

The modernisation agenda of the Labour government continued the theme of consumerism in the NHS explicitly speaking of patients and the public as consumers and urging NHS organisations to respond to the needs of those who use their services. Responsiveness to patients and placing them at the centre of care processes was described as one of the key areas of modernising the NHS:

Successful services thrive on their ability to respond to the individual needs of their customers. We live in a consumer age and services have to be tailor-made not mass-produced, geared to the needs of the users not the convenience of the producers (DoH, 2000:26).

This responsiveness however was only narrowly defined and continued to be centrally driven (Ong, 2000:12-15). Responding to patients and members of the public, of necessity, should focus on combining patient and public perceptions with those of clinicians and managers rather than seeking compliance with centrally defined policy documents and guidance. While many national targets and priorities will almost certainly be of importance to patients and the public at a local level, what is not certain is how much priority they would be given against other aspects of health and health care.

The emphasis on setting national targets and priorities inherent in the *New NHS* might be argued as being counter productive in that it fails to take account of or provide the scope to address contextual and local understanding of factors that impact on the relative importance of priorities as perceived by patients and members of the public. Issues surrounding health improvement, particularly in relation to the wider determinants of health, appear to have been relatively neglected in the NHS (Hawker, 1999:283-291) and this in many ways supports

perceptions that priority continues to be given to medical models of health that emphasise specific, individual causes of illness and the search for treatment and cures (Ham, 1998:203-217). It is this prevailing concept of medical models of health that has posed questions over whether democratic involvement can be achieved particularly in the definition of issues and resource allocation.

Arguments that lifestyle and environmental factors have a central role to play in relation to health challenge the medical model because they imply a reduction in the role of clinicians. Although subsequent policy and reforms have attempted to redress the balance of power held by clinicians, Harrison (1988:123) has argued that only limited success can ever be achieved because GPs still refer patients to consultants and consultants still decide how many patients to see, how to diagnose and what treatment to offer. As a result, the focus of involvement has remained on consultation exercises that have been criticised for maintaining the interests of communities in a repressed position so as not to challenge clinicians (Ham, 1998:203-217).

The 1997 reforms followed by publication of the *NHS Plan* (DoH, 2000) outlined clear expectations that for the first time patients would have a real say in the NHS with new powers and more influence over the way the NHS works. As in earlier policy and reforms, however, the changes appeared to be focused on structures and process rather than a fundamental shift of power as referred to in *Shifting the Balance of Power* (DoH, 2000). The establishment of PCGs was explicitly aimed at empowering local doctors and nurses in respect of decision-making about resources (DoH, 1997) although it might be suggested that this would also enable them to control the level and nature of the involvement of local people particularly as PCGs were to be predominantly led by GPs, professionals that are perceived to have no real history of involving patients or the wider public (Klein and New, 1998, Barnes, 1997).

While there is evidence to suggest that efforts have been made to extend the role of local people in the NHS, the adoption of increasingly managerialist approaches and the power struggles between clinicians and managers that have dominated the various changes within the NHS appear to be at odds with the structures and processes necessary for democratic forms of involvement to flourish (Stacey, 1994:86-97).

Although the 1997 reforms and the establishment of PCGs imply a commitment to locally devolved decision-making, this might be argued as being primarily concerned with enabling local doctors and nurses to influence decision-making rather than local people. As in previous organisational change, the effects appear to have been more structural than process driven and thus likely to rely on commitment at a local level if meaningful involvement of patients and the public is to be addressed. I shall now discuss some of the fundamental issues that will need to be addressed if a more symmetrical balance of power is to be achieved for patients and the public.

ADDRESSING THE BALANCE OF POWER

Arnstein's Ladder of Participation (1969:216-224) implies that involvement (or participation as Arnstein prefers to call it) is an incremental process that at worst is an exercise in manipulation but at best can result in the empowerment of local people. Based on various levels of activity, the steps on Arnstein's ladder relate to where power and influence are held (Table 2.2). At the lower levels of Arnstein's ladder local people are included in processes for therapeutic reasons that encourage a feel good factor without any of the power sharing associated with democratic models. Applying this model to the NHS, the inclusion of patients and members of the public is subject to the influence of wider power relations and cannot move to the higher levels associated with partnership, delegated power and citizen control unless there is a commitment to the developmental process necessary to renegotiate power distribution.

Table 2.2 Arnstein's Ladder of Participation (Source: Arnstein, 1969)

8	Citizen Control}	Degrees of Citizen Power
7	Delegated Power}	
6	Partnership}	
5	Placation}	Degrees of Tokenisms
4	Consultation}	
3	Informing}	
2	Therapy}	Non-participation
1	Manipulation}	

The lower rungs of Arnstein's "ladder" can be aligned with two-dimensional theories of power as they are largely concerned with information giving that makes

people feel involved, but without transferring any of the power and control evident in the higher rungs. Information giving, consultation and placation, which are described as offering a very limited role for people within a much wider area of decision-making, are all seen as degrees of tokenism. It is only possible to achieve meaningful participation of local people through the development of partnership, delegated power and citizen control.

Even at the lower levels, however, it might be argued that empowerment can be an outcome if they are seen as the first step in a developmental process that leads to long-term change (Lupton et al, 1998:44-61). Additionally, even if relatively limited opportunities are available to contribute a patient and public perspective, this can serve to raise the profile of the issues that concern local people and might still be deemed empowering to a greater or lesser degree (Ibid).

While Arnstein's ladder advocates an incremental approach, the Institute of Healthcare Management's continuum of involvement (2000:5) suggests that different relationships will need to be developed and tailored to specific circumstances. Ranging from information giving at one end to partnership at the other, the continuum includes communication, consultation, involvement and participation. This approach acknowledges that in certain situations there may be few opportunities for control or influence with patients and members of the public receiving information but nothing more than that. In different circumstances, when planning a particular service for example, there are opportunities for the group of people who use the service to jointly plan how it is to be developed.

The philosophical core of Arnstein's model is that developmental processes are necessary to facilitate a more equal distribution of power and influence between professionals and local people. Given the complexity of the NHS however, The Institute of Healthcare Management (2000) advocates a spectrum of opportunities that enable people to become involved at whatever level they wish. Despite the devolved decision-making introduced by the *New NHS*, the centralist nature of the NHS is likely to mean that there will still be top down targets and priorities to be met that will only allow a certain, if any, degree of influence to be exerted by local communities. While there is little opportunity to fundamentally change or renegotiate the priorities included in the *NHS Plan* (2000), for example, there is scope for local people to contribute to the detail of how they will be implemented. At the other end of the spectrum, there are opportunities for NHS bodies to engage

with communities to identify and support action on locally perceived need and potential solutions in relation to addressing health inequalities and health improvement as in the community development initiatives discussed in the previous chapter. The critical issue is to be absolutely clear about the degree of influence available and how this might be exercised.

The relatively unplanned, ad hoc way in which involvement has typically been approached in the NHS might indicate an absence of any commitment to the long-term, developmental processes necessary to address issues of power and control. If involvement is undertaken as a means of responding to particular policy requirements or providing evidence to satisfy compliance with national directives, this can perpetuate the notion that professionals are ultimately in control over the level at which they pitch their initiatives (Stacey, 1994:85-97). Simply presenting NHS bodies with a menu of options for involvement will do little to address this.

While professionals have been challenged in the past, by managerial interests and more recently by the interests of patients and members of the public (Callaghan and Wistow, 2002), these challenges appear to have failed to overturn the professional monopoly and domination of the NHS. The professional control over knowledge, training, recruitment and claims to autonomy over work have continued to provide a power base for the medical profession. Simply including local people in activities determined and led by organisations fails to address either the issues of information, choice or redress associated with the development of the patient as a consumer or the wider issues involved in facilitating democratic processes. It is only by defining involvement in broader terms and including strategies that enable local people to set the agenda, with professionals acting as facilitators, that real change can be affected in relation to community driven objectives.

If the rhetoric of involvement is to become a reality a fundamental rethink is required of the relationship between those who make decisions and those on whose behalf they are made. Democracy does not necessarily mean that everyone should decide everything but that the power to make decisions is given by people who are confident that their views will be sought and taken account of (Handy, 1988:65-81).

While community development and related models have been seen as attempts to introduce a more democratic approach to involvement, they have also been

described as oversimplifying the process of decision-making and not addressing the complex relationships between managers, clinicians, patients and members of the public (Croft and Beresford, 1990). Health organisations are still considered more likely to offer involvement at an operational level in respect of service development rather than in wider strategic or structural issues (Callaghan and Wistow, 2002). Ultimately, without the establishment of a more formalised relationship with patients and members of the public and more localised accountability mechanisms it is unlikely that the current climate will change.

In developing strategies for involvement, a fundamental requirement is that the value of an individual's contribution is clarified, agreed and made explicit (Popay, 1994:88-97). Specifically, if there is not a mutually agreed purpose of involvement and an understanding and acknowledgment of the knowledge base and the different levels of expertise that people come with then the shared decision-making inherent in democratic models is unlikely to be achieved. The continued dominance and relative autonomy of the medical profession and the multiple and often contradictory pressure on managers to achieve top-down targets and priorities are all factors that might result in sacrificing the involvement of those whose interests they are supposed to be serving.

The *New NHS Modern, Dependable* (DoH, 1997) appears to have retained the central command and control nature of the NHS characterised by nationally defined targets, priorities and performance management that might be argued as providing little opportunity for those managing at a local level to influence. This top down agenda might also suggest that upward accountability continued to be a priority with accountability to the hierarchy of the NHS as strong as ever. Consequently, that these reforms could renew public confidence in the NHS and introduce a more democratic approach to health and health care planning has been strongly contested (Hogg, Lupton et al, Ong).

The introduction of PCGs is considered to demonstrate the political and organisational support necessary to develop a local focus for the planning, development and monitoring of services (Lupton et al, 1998:126-139). Primary Care Groups provided the opportunity to concentrate on relatively small populations and develop robust models of engagement based around natural geographical, if not special interest, communities. That moving the purchasing of health and health care services to local bodies driven by GPs would bring it closer to communities

however has never really been proven. In respect of fund holding, for example, while GPs appeared to be able to reflect the needs of individual patients and patterns of illness within their practice there was no real evidence to suggest that they had engaged with the needs of the wider communities or addressed inequalities in accessing services (Audit Commission, 1996). Equally, the increasing emphasis being placed on primary care and in particular the notion that local doctors and nurses are best placed to understand their patient's needs and identify ways of making services more responsive might be seen as perpetuating the concept of professionals as agents of patients and questioning the level of input that local patients and members of the public could or should have.

That concern is still being expressed over the relative position of patients and members of the public is perhaps a reflection of the power struggles that have been an inherent feature in the UK NHS since its inception more than fifty years ago. The tension between centralised administration to ensure national equity and improved efficiency and the democratic accountability and responsiveness promised by local control is a constant theme and is set against the contradiction between political and professional power (Lupton et al: 4, 1998). There is an inherent contradiction between the values of localism, differentiation and responsiveness that the current emphasis on locally devolved power presumes and those evident in a universally available service such as the NHS and this has served to confound rather than support structural and organisational change (Klein, 1983).

The National Health Service in 1948 was founded on the collectivist principles of equity, equality and access to provision of services irrespective of the ability to pay. While the aim was to provide universally available, comprehensive services that were free at the point of delivery and underpinned by values of rationality (of financing), efficiency and national equity, it is the very nature of these values that are considered to have bedevilled the history of the NHS (Klein, 1983). The centralist nature of the NHS continues to compete with local values and there is still a perception that there is a relatively low level of consumer choice or the information necessary to exercise it (Klein, 1983). In addition, from a democratic point of view, there is still little evidence of anything other than only limited opportunities for collective or wider community engagement in decision-making in health care and health more generally (Leathard, 2000:163-171).

Further, attempts to introduce a consumerist approach to health and health services can result in fragmentation and diffusion of patient and public interests by creating a mass of individual service users each seeking to maximise their personal resources and freedom to choose (Lupton et al, 1998). Equally, while greater emphasis has been given to prevention and health improvement, this has still tended to focus on issues that relate to the lifestyle of individuals rather than wider social or environmental issues and does not really threaten medical models of health as it is still based on a concept of health related to the behaviour and lifestyle of individuals (Stacey, 1977).

CONCLUSION

Theories of power tell us that it can be mobilised in a variety of ways, that might be covert as well as overt, and that it can be used to serve a number of different interests as well as to preserve the status quo. In the NHS, while there is evidence of each of Lukes' three dimensions of power none appear to capture policy and decision-making in its entirety. Although Alford's analysis of policy making in the NHS is more than thirty years old, there is still evidence to support his argument that a structuralist model of power exists that constrains anything other than changes in power within rather than between the medical profession, managers, patients and the public.

While there is some evidence that the power of the medical profession can be, and has been, challenged it is still not clear whether these attempts have been in the interests of achieving a more equitable level of power for patients and the public or whether they continue to be attempts to curb the power of the medical profession per se. The *NHS Plan* (DoH, 2000:88) explicitly refers to patients having more influence over the way in which the NHS works but if this rhetoric is to become a reality a fundamental rethink is required of the relationship between those who make decisions and those on whose behalf they are made. Specifically, addressing issues of power and control to enable patient and public influence to be exercised is likely to require more than structural and organisational change.

The role that the medical profession has in relation to implementing policy is likely to be a key factor in relation to whether the power and influence promised to patients and members of the public is realised. The way in which this is interpreted and operationalised will be an essential component to understanding how

achievable a more balanced distribution of power really is. The exercise of power is not always overt and a result of action, it can also be covert and mobilised by omission. Those who are perceived as holding expert power, such as the medical profession, are not always aware that they are exercising power by withholding information, disregarding and devaluing the contribution that lay people can make and controlling the way in which patients and members of the public are allowed or enabled to contribute.

Policies that seek to address the balance of power and influence between professionals and the people they serve are merely rhetoric if they are not matched with structures, processes and the commitment that facilitate this. Although there is evidence of attempts to shift the balance of power, as demonstrated by previous shifts from clinicians to managers, from hospital and specialist services to primary care and the introduction of more locally devolved power, the sheer size and intricacy of the NHS might simply militate against the empowerment of patients and members of the public. If there continues to be an emphasis on achieving top-down targets and priorities, the upward accountability that this entails will ensure that involvement remains at the margins (Ranson and Stewart, 1989:5-24). In addition, if medical models of health continue to prevail, the interests of the medical profession are likely to remain in pole position.

It is perhaps not so much the absence of clear definitions of consultation, involvement and participation that result in the disillusionment of patients and the wider public but rather the lack of clarity over expected outcomes. If more balanced relationships are to be developed, a clear understanding and agreement on the aims and objectives of activities that include patients and the public are essential. Without this, devolution of power to a local level will only succeed in replicating the tensions apparent at a national level. In the following chapters I shall examine issues surrounding patient and public involvement, at a PCG level, particularly in relation to the source of power, how it is mobilised and whose interests it serves.

CHAPTER THREE

METHODOLOGY

INTRODUCTION

The purpose of this chapter is to describe the research design of the study and discuss the methodology and research methods used. The chapter also discusses the relative merits of each facet of the research methodology in the context of this study and the strengths and weaknesses of the methods used.

Having worked as a practitioner in the field of community involvement for a number of years, several in the NHS, issues surrounding patient and public involvement were of significant interest to me, not only from an operational perspective but also in the policy context. When the PCG in this study was established I was employed as a Community Involvement and Partnerships Development Officer with responsibilities for facilitating the development of the patient and public involvement requirements of the *New NHS*. The post I held was a legacy from the predecessor to the PCG, the health authority locality team, and I was particularly interested in how the newly established PCG would perceive and adapt to the new responsibilities particularly in respect of patient and public involvement. In addition, as new bodies, there was the opportunity to influence local policy and practice.

The choice of research topic and selection of the case in this study therefore owes much to what Reimer (1977:474) describes as opportunistic research. Opportunistic research strategies, as Reimer describes them, use the researcher's first hand knowledge and familiarity with situations to generate research ideas. In such circumstances, the researcher knows rather than knows about their area of study – they are insiders. As will be discussed later, being an “insider” has both advantages and disadvantages.

THE AIM OF THE STUDY

This study was designed primarily to explore the issue of patient and public involvement from the perspective of one PCG and is essentially a case study of

how involvement was constructed and responded to. The aim of the study was to capture an understanding of how PCG Board members had defined their role and responsibilities, collectively and individually, in general terms and more specifically in the context of patient and public involvement. Further, the study aimed to identify factors that would either help or hinder the development of involvement. The inclusion of the PCG Community Reference Group members in the study was designed to explore patient and public perspectives of these same issues and compare them with those of PCG Board.

The key research questions were as follows:

1. How had individual and collective roles and responsibilities been interpreted?
2. How had patient and public involvement had been constructed in terms of the purpose of involvement and subsequent decisions regarding whom, how and when people should or could be involved?
3. What were the aspirations for involvement?
4. What factors were deemed to influence the development of involvement?
5. What structure and processes had been adopted to facilitate involvement and how these facilitated or constrained involvement?
6. How had aspirations for involvement been transformed into reality and incorporated into planning processes?

DESCRIPTION OF THE STUDY

The particular features of the research are that it is a single case study using a qualitative methodology and undertaken by a practitioner researcher.

Data was gathered using a combination of semi-structured interviews, participant and non-participant observation, examination of local and national policy documents, minutes from local meetings and relevant literature on studies of involvement. The research was undertaken over a five-year period and included five main phases some of which were undertaken concurrently (Appendix 1). These phases comprised a study of the relevant literature concerned with patient and public involvement in the NHS, a series of semi-structured interviews, participant and non-participant observation, analysing the data collected and writing up the findings of the study.

Various documents were referred to during the study to clarify points, examine guidance and compare local policy and practice. In addition, throughout the study, relevant literature and studies of involvement were used to identify and explore current and previous thinking on the subject and to compare data from this study with the findings from similar or related studies.

METHODOLOGICAL CHOICE

The spectrum of methodological choice ranges from controlled experiments at one end through surveys using quantitative analysis to qualitative analysis of data obtained by unstructured methods of data collection at the other end. The decision to be made is at what end of the spectrum a particular study is best located. While there has been much debate, particularly within the health and health care sectors, on the use of quantitative versus qualitative methodologies and their respective merits, Daly and McDonald (1992:1-11) argue that it is not the particular methodology used that is to be debated but rather the rigour with which the research is undertaken that is the more important question. The definition of "rigour", however, is itself open to interpretation. When a given problem is studied, different approaches will ask different questions, collect different data and use different forms of analysis (*ibid*). This does not necessarily make the research any the less rigorous but requires an acknowledgement that the criteria used to test rigour within one methodology cannot be transferred to another with fundamentally different epistemological assumptions.

Silverman (2000:75-86) argues that to focus on either an objective or a subjective view of the world is likely to deflect attention away from the phenomena under examination. Such debates allude to false polarities and ignore the fact that the social world is neither simply objective nor subjective but consists of a set of practices that researchers need to describe. One of these practices is distinguishing reality from illusion or thought from fact and it is precisely these practices and routines, which constitute the phenomena that social research should address (Silverman, 1992:176-188).

It is an examination of these practices that provide the primary focus of this research and on which the decision to use a qualitative methodology is based. Daly and McDonald (1992:209-216) question whether we actually choose research or if it chosen for us by the questions to be answered. The randomised control trial offers

the potential to compare different groups and control variables associated with given phenomena in order to test pre-specified hypotheses. Surveys, on the other hand, demonstrate their value by their ability to measure identified variables, where control is not required, to develop further hypotheses and to involve large numbers of respondents. If, however, the aim is to learn about what is happening in a given setting, exploring the subtleties of interaction and the nuances of complex situations, a methodology is required that allows direct observation and the recording of whatever data are relevant to understand what is happening, then only a field study using qualitative data analysis will do (ibid).

The case study in itself is not a methodological choice but a choice of what is to be studied, the value of which relies on how well the study is focused and the fit between the questions to be addressed and the case or cases to be studied (Hakim, 2000:59-75). As practitioner research is often focused on our own practice or those around us, the key research questions were designed as a result of examining existing literature on patient and public involvement and identifying key themes. From this perspective, the fit between the questions to be asked and the focus of the case study were, to a large extent, assured.

The research in this study is rooted in the view expressed by Carr and Kemis (1986) that social situations typically involve competing values and complex interactions between different people who are acting on the basis of different understandings. Patient and public involvement, as subsequent chapters will demonstrate, is also characterised by complex and often competing values. Further complexity was likely to be evident given that PCGs were new bodies bringing together a diversity of people with different backgrounds and experience. As a result, the potentially different perspectives that would be evident would need to be negotiated if involvement was to be developed in a coherent manner.

QUALITATIVE RESEARCH

One of the strengths of qualitative research is that its rich data can offer the opportunity to change focus as the on-going analysis suggests. Such changes reflect the subtle interplay between theory, concepts and data (Silverman, 2000:75-86). Patient and public involvement is multi-dimensional and as a result, there are various perspectives from which it can be examined. This study is concerned with patient and public involvement in the context of one PCG and how those with the

responsibility of developing the role of patients had responded to the task. The study particularly explores how the understanding and interpretation of patient and public involvement was reflected in subsequent action. A qualitative approach to the research was selected because, particularly when used in relation to case studies, it is considered to be uniquely qualified to examine how well a procedure or policy works in practice because it alone looks at practice in situ (Silverman, 2000).

Much qualitative research is based on an holistic view that social phenomena, human dilemmas and the nature of cases are situational and influenced by happenings of many kinds (Lincoln and Guba 2000:163-185). Many researchers consider there to be little value in the search for cause and instead focus on the coincidence of events, while some are seen as purposive, others are situational and many of them are inter-related (Stake, 2000:435-448). As a result, enquiry designs that seek data describing the diverse operations of the case are favoured. It is the very diverse nature of PCGs and their membership that governs the research methodology of this study.

Relevant studies have already established that there is an acknowledged plurality of voices among patients, communities and members of the wider public. That there might also be such plurality within the make up of PCGs was a key theme to be explored. Examining how a plurality of attitudes, meanings and interpretations influences and relates to public and patient involvement was an issue of particular interest. In addition, the question of how the views and perceptions of those involved were influenced by the context and the environment in which they exist was explored.

Hakim (2000:34-45) describes qualitative research as being concerned with the individual's own accounts of their attitudes, motivations and behaviour. It offers richly descriptive reports of perceptions, beliefs, views and feelings as well as the meanings and interpretations given to events and situations. Qualitative research can capture how these are put together, more or less coherently and consciously, into frameworks that make sense of experiences and highlight the motivations that connect attitudes and behaviour. Equally, such studies can provide an insight into how conflicting attitudes and motivations are resolved and particular choices made.

The debate of qualitative versus quantitative research focuses to a large extent on the nature of qualitative data. Qualitative data have been variously described as,

among other things, unreliable, imprecise and subjective. Champions of qualitative methodologies argue that quantitative data often ignores the social and cultural constructions in the variables that they seek to measure (Silverman 2000).

The main strengths and weaknesses of this study are characteristic of those evident in the qualitative versus quantitative debate. The study depends to a greater or lesser extent on the personal interpretations and values of the researcher. The issue of values and interpretation are of importance when attempting to demonstrate the reliability of the researcher. While the aim of quantitative research is to be value free, Barnes (1993) points out that it is unrealistic to expect social research to be completely value free and for the researcher to have no interest in how these values can be best applied in practice.

Qualitative research was considered to be the best option of researching the particular questions embedded in this study and many of the weaknesses attributed to qualitative research are the very strength of this study in terms of providing a rich picture of the phenomena in its natural setting. The challenge, as Silverman (2000) sees it is to produce strong, persuasive arguments that support the findings.

In this study, in common with most qualitative research, people are the central unit of account. It is not about particular individuals per se, however, but rather the various patterns or clusters of attitudes, interpretations and related behaviour that make or contribute to the systems and processes in operation.

PRACTITIONER RESEARCH

As noted earlier, I conducted this research as an “insider” and in this respect the research could be described as “practitioner research”. Fuller and Petch (1995:5) argue that, for many, the term practitioner research has become synonymous with action research and that action research itself has almost come to be known as any research that is conducted in real life situations. With the traditional action research cycle of enquiry, intervention and evaluation, to assume an automatic association between practitioner research and action research is perhaps to minimise the contribution that practitioner research can make to the wider research agenda.

While practitioner research is described as combining intellectual enquiry with the tough minded realities of life (Fuller and Petch, 1995:3-6) it is not necessarily

involved with problem solving but rather contributing to a developing body of research by conducting enquiry from within. Enquiry is not undertaken simply to provide solutions to problems but to understand them more fully.

The term practitioner research in this study is used to identify the researcher as an individual who not only knows but also works in the field and has first hand experience of the phenomena being studied.

Practitioner research does not imply the use of any special or particular methodologies or research methods that would not or could not be used by an external researcher. The core elements are the same as those employed by any researcher; the application of research skills in formulating research questions, the collection and analysis of data in ways that address these questions, interpreting the findings and reporting the results (Fuller and Petch, 1995). As in all research studies, it seeks a better understanding of the phenomena under examination. The nature of this type of research, however, allows it to contribute to a body of research by producing small but significant studies that focus on the concerns of practitioners whilst also taking account of and setting the study within the wider context.

In the context of this study, practitioner research was used to add to existing studies by focusing on a context specific, real life situation. The study focuses specifically on those identified as key players in one PCG and attempts to develop an understanding of how the issue of patient and public involvement was made sense of in a local context and how or if it was susceptible to wider influences.

The Nature of Practitioner Research

Although practitioner research is not intended to imply particular methodologies or methods, a number of characteristics are evident in this type of research more than in any other. Essentially, the main differences are the relationship between the researcher and the researched and the values and experiences that the researcher brings to the study.

Roseneil (1993:180-182) argues that no researcher comes to research without existing values and experience. This view is perhaps more pronounced in practitioner research where these values and experiences are a direct result of

being a part of the phenomena being studied. The critical question is whether to attempt to cast aside these pre-existing values and remain neutral and unbiased or to use them to generate concepts and theory. The separation of personal experience in this study would have been counter-productive. It is precisely because of the personal experience of working with the PCG that this study was undertaken and the research questions generated.

The issues raised in the existing body of literature on the subject were no less present in the PCG in this study. As a practitioner, however, there seemed to be a fundamental need to understand better how these issues were made sense of at a micro level and within a given context. Debate over who, why and how to involve local people, from a practitioner point of view, appeared to be secondary to an understanding of where those individuals deemed “responsible” for its development saw themselves in relation to this responsibility. Without such understanding, involvement, itself a complex issue, might be developed in an ad hoc fashion separated from more pressing organisational issues.

Although this PCG had a strategy and an action plan for developing public and patient involvement, as a practitioner, I was acutely aware that these had been devised in isolation from other PCG planning processes and that there appeared to be an expectation that it was my responsibility to implement them. This study is not therefore concerned with involvement per se but how it was being made sense of by a particular group of people, at one time and in one place. In other words, it was my own personal experience and position within the organisation that shaped the formulation of the research questions and presented the opportunity for the study.

The second main difference in practitioner research is the relationship between the researcher and the researched. Although not to be confused with action research, practitioner research, because of already existing relationships can result in the collaboration and participation of colleagues in ways that external research cannot. This relationship can have both strengths and weaknesses. Participants in the research might provide answers and accounts that they think are socially and politically correct or acceptable to the researcher. Similarly, colleagues might be reluctant to risk disclosing a negative view or a lack of understanding of patient and public involvement, particularly to the person in the organisation who has the job of developing it.

To overcome these potential weaknesses, researchers are urged to avoid questions that are not capable of being validated. Fuller and Petch (1995:9-12), however argue that it is practitioner research, where colleagues can be observed on a daily basis and where discrepancies between accounts and action can be identified, that this validation can most easily be achieved. In addition, questions were framed in this study in such a way to allow probing and exploration of answers that could be perceived as being intended to please.

There must still be a certain level of doubt over whether it is possible to validate answers in response to questions about attitudes. By their very nature, these answers are capable of being interpreted in different ways by different people at different times. The advantage of practitioner research is that accounts can be checked for coherence with practice. All participants in this study were fully aware of the researcher's position and that answers that indicated a contradiction between current practice and the views expressed would be further explored. In this respect, the relationships that exist in practitioner research can be a strength in that they assume a level of trust between researcher and researched that acts as a built in truth check and subsequently a form of triangulation (Roseneil, 1993:189-192).

Challenges of Practitioner Research

The challenge of practitioner research is to minimise the weaknesses by capitalising on the inherent strengths. Existing relationships, as noted above, can act as a disadvantage as well as an advantage; although the interest and participation of colleagues can be easier to achieve, there is a danger that they will tell you what you want to hear rather than present a true picture. Conversely, knowing respondents can offer validation. In reality, the focus of the research questions in this study was intended to go beyond superficial attitudes towards patient and public involvement and explore the understanding of additional elements that would or could have an impact; perceptions of roles, responsibilities, accountability and power were also explored.

This issue is also linked to the ability to distinguish between presenting and underlying problems. Examples were evident in existing research of barriers to and methods of involvement and this was important in identifying problems such as the lack of capacity and resources in developing involvement. Practitioner knowledge goes further in identifying fundamental problems that transcend these practical

problems and can ask, for example, if additional resources were available would prevailing attitudes and constructs of public and patient involvement have been significantly different? Enquiring from the inside allowed an examination, at a micro level, of the significance of involvement and its interpretation as well as the effects on people at a local level. It then became possible to compare this with macro level policy imperatives, the centrally driven agenda and top-down priorities and to pose the question of how this affected PCGs with their local focus.

While day-to-day experience gives a higher degree of insight into and knowledge of the real problems, practitioners must be able to distinguish the researchable from the non-researchable; being too close to the phenomenon to see the significance of everyday incidents and processes often results in the loss of the wider picture. Relying on the taken for granted conceptual and linguistic apparatus is insufficient and must be operationalised into the terms required of research studies (Fuller and Petch, 1995). While this view is at odds with Roseneil (1993:189-192) who argues that there is a shared language and experience that avoids meaningless questions and allows probing of sensitive areas with greater ease, this issue was particularly important in this study where part of the focus was on the complexity of interpreting and defining patient and public involvement. More attention was given to deconstructing the jargon and taken for granted terms, phrases, expressions and words into neutral terminology to which research participants could apply their own meaning. It was only when this had been established that deeper examination was possible.

Practitioner research can be challenging both in terms of selecting the case to be studied and sampling within the case. While, in access terms this is often easier for practitioner researchers who tend to have access to situations that external researchers do not, care is needed to select samples that are relevant and of interest rather than simply those that are easily accessible. In this study, although not claimed to represent PCGs in general, the case to be studied was representative as far as any could be said to be representative, of these new bodies. This PCG had to comply with the same core membership of the governing body and the responsibilities laid down in government guidance, they were also under the same imperative in terms of centrally driven priorities. In addition, although not commissioned by the PCG, the study was fully supported by Board members and the only access denied was to the confidential part of board meetings.

Knowledge and experience of the structures, mechanisms and hierarchical arrangements that were in place meant that sampling within the case, knowing which areas would be interesting to focus on and would add an extra dimension to the debate on involvement, was far easier. External researchers often have to spend time orienting themselves to an organisation before these decisions can be made. Notwithstanding this, the fieldwork highlighted areas that, even as a practitioner fully involved in the organisation, had not been fully understood prior to the research.

One of the disadvantages of the additional knowledge that practitioners bring to research is the difficulty of drawing boundaries around the research. While all researchers continually define, refine and confirm definitions of what is important and what makes sense, practitioner researchers have access to vast amounts of unsolicited data as a consequence of their presence in the research setting on a day-to-day basis. Decisions have to be made in respect of which data will contribute to answering the research questions in order to avoid sacrificing data analysis in favour of data collection. How much to observe, record and analyse was a major challenge in the early stages of this study. It was difficult not to be drawn to and interested in separate events that although linked to patient and public involvement were not related to the key research questions. A conscious decision had to be made to focus only on data derived directly from the research framework.

The question of the validity of practitioner research, not dissimilar to the debate surrounding qualitative research, is one that appears to dominate discussion on the relative merits of this type of study. Replication is often not possible because of the perspective from which the practitioner approaches the study. Personal experience shapes not only the research questions but also the interpretation as individual accounts are checked against actual practice. In this study observation would not be repeatable because the PCG had ceased to exist by the time the study had been completed, structures and processes had changed and different people were involved. In addition, the accounts related by participants were all the more meaningful because of references to events that both the researcher and the participants had experienced. These shared experiences would not be replicable and the accounts open to different interpretation by another researcher. However, as Roseneil argues (1993:189-192) it is because of and not despite the

researcher's personal involvement that a high level of validity can be claimed; that these findings were evident at that particular time and in that particular context.

Crucially perhaps, practitioner research can bring to the surface issues surrounding the researcher's own practice. As practitioners we are urged to reflect on our actions and, as part of a learning process, adjust them accordingly. In this study, the research process unearthed questions about my own role within the organisation and while reflection allows us to confront questions about our own everyday practice, develop and move on, it does not always take account of the context in which we are working. It is only through reflexive practice that we become aware of how the ideas and concepts present in the environment that we work in have constructed our role and subsequent practice (Dalrymple and Burke, 1995:10).

Practitioner researchers must be aware of their role not only as observers but also participants. In analysing the way in which my own role had been constructed within the PCG, questions were posed not dissimilar to those often associated with the process of involvement. One particular question was whether the work was intended to empower patients and members of the public by ensuring they were treated equally in decision-making processes and their contributions were taken account of, or whether it was more to do with providing the illusion of involvement by allowing selective access to planning processes that provided evidence that would comply with national guidance. The answer, as in patient and public involvement, is likely to lie in prevailing power relations and the control that organisations retain not only over the level of involvement that is allowed, but also the way in which they allow officers such as myself to facilitate its development.

As discussed in the previous chapter, power in the NHS has been subject to much debate. In particular, where power is held and the way in which it is exercised. The tension between clinical and managerial interests is well documented, as is the view that community interests remain repressed because of the continued dominance of the medical profession and the managers that challenge this power (Alford, 1975). PCG governing bodies included a mixture of clinical, managerial and lay members, a key issue in terms of my own practice would be how, or if, agreement had been reached on the way in which involvement would be pursued and subsequently my role within this.

CASE STUDIES

Stake (2000:435-448) suggests that the design of a case study should be undertaken with a view to optimising the understanding of the case in question rather than to generalise beyond. All that can be said about the single case is not the same as can be said of all cases and the purpose of the case study is not to represent the world but to represent that particular case. The value of case study research is especially relevant to practice and policy in that it is an extension of real life experience rather than abstract theory. This view is particularly true of this study where the intention is not to generalise about PCGs or patient and public involvement but to explore the issue within a given context.

As discussed earlier, the case study in itself is not a methodological choice but rather a choice of what is to be studied. A spectrum of case studies exist that ranges from simple descriptive accounts to achieving experimental isolation of selected social factors (Hakim, 2000:59-75). Along the spectrum there is a range of possibilities that combine exploratory work, description and the testing out of ideas in varying combinations. The case study is described as the social equivalent of the spotlight or microscope (ibid). While the choice of the case to study is often opportunistic, particularly in practitioner research, attention to the design of the research is considered essential if the necessary fit between the case and the research questions is to be achieved.

Case studies can be focused on single or multiple cases and the research design can range from descriptive studies that explore issues where relatively little research has been undertaken or to illustrate patterns or variables thought to be typical, representative or average through to experiments aimed at achieving isolation of selected factors or processes within a real-life context in order to test prevailing explanations or hypotheses. Selective case studies are often undertaken once a body of research has accumulated and particular aspects can be studied to refine knowledge (Hakim, 2000:59-75).

Although this study was essentially opportunistic in that an interest in the subject and access to the case was already established, to a large extent it falls within the selective case study category. A body of research already existed and the study of one particular PCG in relation to patient and public involvement was intended to

provide a much more detailed account of the constructs that existed and the processes at work in a specific given context.

Stake (2000:163-185) argues that case studies differ in relation to whether they are intrinsic or instrumental. The intrinsic case study seeks a better understanding of the particular case being studied, not because it is representative of other cases or that it illustrates a particular phenomenon, but because it is of interest in itself. Instrumental case studies, on the other hand, provide an insight into an issue or redraw a generalisation; the case itself is of secondary interest simply facilitating an understanding of something else.

In reality, it is difficult to draw a line between the two and distinguish where intrinsic interest ends and instrumental interest begins. The study of involvement within a given case, as in this study, actually cuts across the two categories. An intrinsic interest is evident not only because of the researcher's role as a practitioner within the case in question but also because of the contribution the study could make to the overall understanding of issues surrounding involvement.

The Nature of a “Case”

There is often a tendency in case studies to ignore the need for specificity and boundaries because, as Stake (2000:163-185) points out, certain features will be within the case but others will be outside. It is often difficult to distinguish where the case ends and the environment around it begins. Hammersley and Atkinson (1995:45-53) also argue that it is important to distinguish between the case and the setting. While a setting is a named context in which a phenomenon occurs that might be studied from a number of different angles, a case is that phenomenon seen from one particular angle. Both agree, however, that the case may go beyond defined boundaries and that it may be necessary to go outside to collect information.

It is therefore necessary to acknowledge that this study is only one way of studying involvement and is seen from one perspective among many. There will be multiple perspectives on patient and public involvement, the complex nature of the issue as demonstrated by existing research is evidence of this. Equally, there can be no doubt about the difficulties in drawing boundaries around the “case” given the practitioner involvement. Primary Care Groups were not isolated bodies that could

be separated from existing NHS policy, guidance and priorities. Thus, these wider contextual issues had to be explored in terms of how far they had influenced the perceptions and actions of key players in the PCG. As well, the diverse nature of the people involved and the different roles they played alongside their involvement in the formal PCG structures and processes were all factors that might impinge on but were outside the case being studied. While exploring these additional factors would no doubt have added an extra dimension, for practical reasons, mainly time and capacity, the decision was made to restrict the research to those times and those events relating purely to the PCG context.

The value of a case study is dependent on how well the case is focused (Hakim, 2000:59-75). This applies not only to selection of the case itself but also to questions about what is to be observed and when, who to talk to and what to ask as well as what to record and how. Not everything about a case can be understood, decisions must be made about how much needs to be understood and what is relevant to answering the research questions. While each case is singular, each has sub-sections that are complex and at best can only be sampled (Stake, 2000:435-448). When identifying what is relevant and what is not relevant to the focus of the research; Hammersley and Atkinson (1995:45-53) advocate a focus on three particular dimensions - time, people and context.

Time, People and Context

There are two elements of time to this particular study. The first is the period over which the fieldwork was carried out and the second, those aspects of PCG 'time' selected for observation. The fieldwork was carried out between September 1999 and March 2002. Established in April 1999, by January 2002 the PCG had applied for and been successful in achieving independent Primary Care Trust status from April 2002. This, then, was a critical period for observation; independent trust status would result in entirely different organizational arrangements. Would the experience of patient and public involvement, along with the knowledge and understanding gained as a PCG be reflected in the planning for Primary Care Trust status? Equally, how would these impending changes influence existing arrangements for public and patient involvement?

The second element of time relates to those aspects of the PCG that were specifically selected for observation. The processes selected related to those times when the main players came together to 'act' as the governing body of the PCG as opposed to going about their everyday activities. Primary Care Groups were intended to bring together a very diverse range of people working at a local level and create a corporate identity; doctors, nurses, ancillary staff of GP practices, therapists and social services representatives name were all included.

Whether or not PCGs were successful in creating a corporate identity is in itself a research subject. Notwithstanding this, they were to be managed by a Board that reflected this diversity and drawn from the constituent members of the PCG. Each of the Board members had a 'day job' and PCG work was an extra curricular activity. How Board members interacted with each other and the relationships that had developed was considered an important element of the study in relation to whether there was a cohesive view of involvement, a collective understanding of roles and responsibilities, an even distribution of decision- making power within the PCG and how this was 'acted out' or demonstrated.

Board meetings were selected for observation because they alone brought together all Board members and they were, to all intents and purpose, public meetings. The Quality sub-group had been established to take on responsibilities for clinical governance and this was felt to be a key area for observation in terms of patient and public involvement given its emphasis on patient experience, safety and standards. In addition, the group had expressed a commitment to include patient and public representation and was in the early stages of developing this.

The Community Reference Group was one of the PCG mechanisms for involvement. Group membership was made up entirely of local people who were therefore actual or potential patients. This group was selected for observation in order to compare the perspective of the professionally led working groups with that of a community dominated group and to examine how or if the views expressed by the Board were demonstrated in the relationship with the Community Reference Group.

When identifying which people to focus on, the decision was made to concentrate on those identified as having a key role in managing, driving, monitoring or being

accountable for the work of the PCG. Members of the PCG Board were expected to take on the mantle of PCG governance and it is how they responded to and made sense of this role in general, and patient and public involvement in particular and the attitudes, values, beliefs and behaviour attached to this that provides the basis for the research. Attention was also given to the influence that might have been exerted by other players and an attempt has been made to explore this aspect by including reference to it during interviews and taking account of and noting specific instances observed during meetings. In an attempt to present a more rounded picture, the public and patient perspective was explored to a limited degree by including members of the PCG Community Reference Group.

The inclusion of Community Reference Group members was perhaps a less robust element of the study. The numbers involved were too small to be considered representative and indeed were not intended to allow generalization. This, however, does not mean that their contribution to the study was not valuable but rather that the relatively small numbers involved meant that only a snapshot was possible in terms of how members of the public who had been involved with, and recognised by, the PCG as mechanism for public and patient involvement, viewed their own position and that of the wider patient and public population.

Cases can be complex entities operating within a number of contexts (Stake, 2000:435-448) and within any setting, a number of different contexts may be evident that display different behaviour. Clarity over the context in which the case is being studied is essential if boundaries are to be drawn and specificity achieved. The issue of context relates not just to physical location but also to social constructions and the actors involved in the setting (Hammersley and Atkinson, 1995:45-53). For the purpose of this study, the primary concern was those considered key players within the PCG and their acting role within this context. The context identified was therefore restricted to that which identified them as PCG actors. Board meetings were particularly relevant in relation to context as it became clear during the study that this was almost the only setting in which all of the Board members came together

The Validity of Case Studies

Changes in the context, environment and organisation of specific cases mean attempts to replicate case studies are extremely difficult if not impossible. In

addition, case studies can rarely make claims of generalisation because people will see and interpret things differently. As noted earlier, it would be impossible to replicate this particular study given the changes occurring at the end of the study.

Small single cases studies make extrapolation to other contexts difficult, relying not only on comparable circumstances but also the ability to use the same samples within the case. In this study, the time element was crucial for a number of reasons. Attitudes might have changed as levels of experience and understanding increased, new structures and processes were introduced, different people became involved and significantly different levels of power were devolved.

The validity of the case study, however, lies in the opportunity to gather first hand information about processes in a naturally occurring setting. Equally, concerns over relatively small and single, case studies and the small samples involved can be answered in the trade off that exists between the depth and breadth of the data collected. The smallness of the sample involved in this case is justified on the basis that PCGs, particularly the governing bodies, themselves were small and that increasing the sample by drawing in larger numbers of participants would have extended the breadth of data collected but would not necessarily have resulted in achieving sufficient depth to answer the key questions.

There is a need to be clear about why data is being collected, what purpose will it serve and how it contributes to the questions being asked. Case studies typically use multiple methods of data collection and there is the risk of simply aggregating data thereby sacrificing depth for breadth (Silverman, 2000:98-99). The challenge is to balance the time spent on data collection with reflection on the significance of the data. Conversely, the use of multiple methods can achieve a more rounded picture, comparing attitudes with action for example, and contribute to the validity of the findings by acting as a means of triangulation. In managing this aspect of the study, it was difficult to discipline the collection of data and restrict it to only those areas already discussed.

As a practitioner, there is a constant involvement in the day-to-day activities of the organisation and the subsequent danger of attempting to record anything and everything. Continually referring back to the research questions was an essential element of staying within the boundaries of the study.

The tension between attempting to generalise and focusing on the particular features of the case being studied is an issue particularly evident in case studies (Stake, 2000:435-448). As Stake argues, it is essential to be clear over the intention not to generalise but to add to or refine existing theory. This study of public and patient involvement within a specific context was not intended to generalise but to develop the issues evident in this Primary Care Group.

The validity of case studies is perhaps in the recognition that the question why often cannot be answered or asked directly but involves a variety of factors that identify links or choices between apparently unrelated matters (Hakim, 2000:59-75). Case studies can identify problems and associated factors in situ rather than abstract correlations between variables. While the challenges of patient and public involvement in a global sense are well documented, this study is an account of the subject in action at a micro level.

The validity of this study is considered to be the development of the themes and issues evident in one PCG, although they have been interpreted with reference to the broader context of patient and public involvement. Existing studies and literature on involvement were crucial when formulating the research questions and also when analysing the data. Notwithstanding the need to demonstrate rigour within the research, in claiming validity for this study, the ultimate intention was not to represent the world but to represent one particular Primary Care Group.

THE RESEARCH METHODS

The particular research methods used in the study were semi-structured interviews and participant and non-participant observation. Interviews were used to obtain individual accounts of attitudes, motivation, experience, views and perceptions. Participant observation was used to gather data on how, or indeed if, these individual accounts were translated into action.

Interviews

Although asking questions and getting answers is a much harder task than it may first seem, interviewing is still considered the most common and one of the most powerful ways in which we try to understand our fellow human beings (Denzin and Lincoln, 2000:645-669). The spoken or written word is seen to include certain

ambiguities no matter how carefully the questions are worded or the answers recorded. Interviews are not simply neutral tools of information gathering but interactions whose value relies on developing negotiated, contextually based results.

Increasingly, qualitative researchers are acknowledging that the focus of interviews is no longer the traditional “what” questions but also the “how”. While the question “what?” tends to be about the everyday activities of life, “how?” is concerned with defining the constructs involved in producing order in these everyday activities (ibid)). In studying patient and public involvement within the context of the PCG, it was the question “how” that was the primary focus of the study - how had the PCG made sense of this issue and constructed it accordingly? Simply focusing on the everyday activities would perhaps have resulted in an almost superficial enquiry that failed to take account of how these actions had come to be negotiated, on what basis they were taking place and what factors had influenced them.

While there is a wide range of interview designs and uses, most fall into one of three categories; structured, semi-structured or unstructured. Structured interviewing aims to capture precise data that can be coded in order to explain behaviour within pre-established categories. Unstructured interviews, on the other hand, seek to examine the complexities of behaviour without any preconceived ideas that may limit the enquiry. Semi-structured interviews fall somewhere between these two categories and the degree to which they lean more to one or the other is led by the themes that guide the interviewer.

In structured interviews, the interviewer is as far as possible neutral, asking the same pre-set questions, in the same manner and often recording the answers in accordance with an already established coding scheme. If a structured interview had been selected for this study, it is questionable whether any useful contribution could have been made. The whole issue of public and patient involvement has suffered in the past from being developed in a vacuum separated from the organisational context (Ong, 1993). If structured questions had been used this might have resulted in obtaining a limited set of responses, and would have precluded the opportunity to explore this in the depth made possible by unstructured or semi-structured interviews that create the rich picture and thick description that are described as characteristics of a good case study (Stake, 2000:435-448).



From a practical point of view, there are a number of factors that researchers must take account of when selecting interviews as a research method. In asking and answering questions, there must be an understanding of the language and culture of those being interviewed. Without this, interpretation becomes almost impossible and findings difficult to validate. At its simplest level, this was noted in the early interviews in a question aimed at perceptions of who sets the PCG agenda. Although the word "agenda" was intended to convey the overall work of the PCG, the first two respondents appeared to take it literally to mean the written agenda for Board meetings and the term was subsequently replaced. Within the arena of involvement, there is a multitude of terms and phrases that are used interchangeably; "consultation", "involvement" and "participation" are classic examples of terms that have each been demonstrated as meaning different things to different people and are often used interchangeably to convey the same meaning.

In interviewing, just as in practitioner research it is necessary to be aware of the everyday, taken for granted jargon and to attempt to use terms that are as descriptive and explicit as possible. It is also the case, however, that the interviewer must be able to understand and tune in to or seek to clarify the taken for granted language and experience of the respondent.

Other factors that were taken into account when designing the interviews in this study were access to the setting, identifying the respondents, gaining trust and establishing rapport. It is in addressing these issues that the strength of practitioner research is best demonstrated. By already being a member of the setting under scrutiny, having established relationships and access to multiple sources of data that help to identify informants appropriate to answering the research questions, these practicalities proved not to be a problem. Notwithstanding this, the importance of the relationship and rapport between researcher and researched should not be underestimated. If the aim is to understand how people make sense of particular situations then it is crucial to be able to see the situation from their viewpoint and not to impose on them the interviewer's own preconceptions.

Participant and Non-participant Observation

Observation is seen as one of the cornerstones of ethnography (Ong, 1993:430). It is characterised by the immersion of the researcher into the system under scrutiny. It allows the researcher to understand the internal systems and relationships both within the system and with those outside the system.

Understanding these internal systems and dynamics was an important element in conceptualising the perceptions of the key players within the PCG in relation to involvement issues, if these players were expected to be the main drivers of change in terms of involving the public and patients. Equally, observation is often the only way to examine differences between statements of intent and operational implementation. Public and patient involvement has often been a victim of this in the past when, faced with varying priorities, the issue becomes secondary and undertaken in a somewhat shallow and superficial manner. As was pointed out by one participant in this study “they couldn't shelve clinical governance like that”.

Hammersley and Atkinson (1995) argue that everyone is an observer and knowledge is acquired by simply participating in the social world. The issue of validity, however, is often more present in observational studies than in many other research methods. Data collection might be regarded as unreliable because different observers may see and record different things and because of this, the collection of data from different sources that can either corroborate or support findings is an issue that often needs to be addressed.

The use of semi-structured interviews as well as participant observation and documentary analysis was intended to provide such triangulation in this study. Hart and Bond (1995) suggest that combining techniques in an informed manner offers the opportunity to compensate for the limitations of one with the contributions from another, and to take bearings on the problem under investigation in different ways and from a number of perspectives. Observation and interviews were used in this study as they provided not only a means of triangulation but also the opportunity to compare what people said with what they actually did.

Observation is often discounted by positivists who see accounts produced as a result of this method as subjective and at best in need of explanation. Hammersley and Atkinson (1995), however, argue the case for naturalism where this type of

knowledge is seen as constituting the social world. The common sense accounts achieved as a result of observation, particularly participant observation, should be appreciated and described not exposed to critical scrutiny in terms of their validity.

In their broadest sense, statements made by individuals might simply be described as personal accounts of intentions and are more powerful when linked to data on action (Ferlie et al, 1996). In attempting to conceptualise patient and public involvement from the perspective of PCG Board and Community Reference Group members, an understanding of the existing systems and dynamics was therefore as important as the views of the individuals themselves. As Ong (1993:430) states, observation is the only way to examine the differences between statements of intent and the ways in which these are put into action.

Data Analysis

Strauss and Corbin argue (1990) that qualitative data should not be subjected to interpretation but rather it is the researcher's task to gather and present data in such a way that it speaks for itself. An alternative view is that many studies are not reflexive enough about interpreting data, choosing to claim that data speak for themselves and that the researcher is neutral, unbiased and invisible (Denzin and Lincoln 2000). Although the argument for allowing the case to speak for itself is strong, it is by no means certain that this would tell the full story or tell it in a way that reflects the subtleties and complexities of the stories told within the case.

Researchers invariably enter into studies with their own ideas of what will be important or interesting, never more so than in practitioner research. The exact nature of these events, attitudes or relationships is discovered in an almost evolutionary way that continues throughout the study. As Stake points out (2000:435-448) more will be pursued than is volunteered but less will be reported than is learned. What is produced is the researcher's dressing of the story not the case's own story. If this is acknowledged, then it is only by demonstrating a robust data analysis process that credibility can be achieved.

Qualitative studies provide data in the form of words, often unstructured, rather than statistics and the challenge is to transform these words into data analysis. Denzin and Lincoln (2000) suggest that many researchers are not reflexive enough about interpreting unstructured data. Many researchers make no reference to the often

problematic and contradictory nature of their data or to what has been left out and why, claiming that the researcher is unbiased, neutral and invisible. The key to overcoming this somewhat naïve view is in the process of data analysis.

Coffey and Atkinson (1996:10-11) describe analysis as a pervasive activity that takes place throughout the life of a research project. It is considered neither sensible nor effective to leave analysis until the fieldwork is ended and all the data gathered in. In many respects, the analysis in this study began even before fieldwork and data collection was embarked upon. That the research was undertaken at all was directly related to comparing the issues highlighted in the relevant literature and studies of patient and public involvement with personal experience as a practitioner. It was these very issues that were used as a reference when identifying themes and the subsequent coding of data.

The extensive amount of data generated by a study is daunting, consisting, among other things, of field notes, transcripts, local and national documents. Yet the way in which data is recorded and stored can be a crucial element during the analysis stage of a research project. As suggested by Miles and Huberman (2001:122), keeping systematic field notes that recorded what people, situations or events were involved, what the main themes were and what new ideas or speculations were suggested helped significantly to identify what aspects should be given further attention. Silverman (2001:140) points out; the recording of data is a means to an end with the quality of the recording being directly related to the quality of the analysis.

The data recorded in this study consisted of transcripts of tape-recorded interviews, notes from observation and a fieldwork diary that recorded both personal experiences and issues and events occurring that were seen as outside but potentially linking to the study. All of the data, including the transcripts from interviews, were recorded in text form.

Coding is at the heart of text analysis, forcing the researcher to make judgments about the meanings of blocks of text and identifying significant categories and concepts. This is in itself, however, is only useful if it is designed in relation to a particular approach to analysis. Although not grounded theory in the purest sense, the intention of this study was to understand better public and patient involvement as perceived and experienced within the PCG. Based on the premise described by

Corbin and Strauss (1990) that not everything had been explored, at least not in that particular place or time it was the development of the categories and constructs that emerged from the stories that the particular people involved told at that particular time and within that given context that formed a framework for the data analysis in this study.

The framework used included identification of the emerging themes, coding these into different categories, establishing patterns and clusters that could be compared to or contrasted with the themes evident in the relevant literature and similar studies while also developing the case's own themes.

Having first identified themes, the coding process is about reducing a vast amount of text into meaningful units of analysis (Hobbs and May, 1993:202). Coding however is only one element of analysis; the next step is to move from this to interpretation and the transcendence of factual data and cautious analysis of what is to be made of them (Coffey and Atkinson, 1996:46). While coding provided the initial focus of the analysis, it was by examining how these were linked together and identifying new issues that the particular features of the study were developed. The interpretation of the data was intentionally focused on its use as a proxy for experience and how this challenged or supported some of the assumptions in literature relating to PCGs and their role in public and patient involvement. The ever-present caution, however, applies no less to this analysis than any other; phenomena can be viewed from many perspectives and will be interpreted by different people in different ways. This analysis is the story of involvement told from the perspective of one practitioner researcher.

THE RESEARCH PROCESS

Originally, it had been intended to undertake a preliminary survey of all PCG members to establish baseline information on local understanding in relation to the role and responsibilities of the PCG and patient and public involvement. The survey (Appendix 2) was relatively short and it was originally intended to use the results to identify themes for more in-depth exploration. Survey forms were sent out to all the one hundred members of staff in the fifteen GP practices that formed the PCG. A first reminder was sent six weeks after the survey had been sent out and a further reminder six weeks later. Despite this, only twelve responses were received. The disappointing response to the survey led to this element of the

research being discontinued and the decision made to aim for depth, rather than breadth, and focus on interviewing and observing key players and processes.

Interviews

A series of semi-structured interviews were carried out over a period of twelve months with all board members and a number of co-opted board members and Community Reference Group members. A total of twenty-nine interviews were carried out that encompassed fifteen board members and fourteen Community Reference Group members. All interviews were tape recorded with the consent of those interviewed, transcribed and read back to each respondent to check for accuracy. Follow up questions were used to clarify points or build on emerging themes. Each interview lasted on average two hours.

Those identified for inclusion in the study were first approached and asked if they would consider participating, the nature of the study and the context in which the findings would be used were also explained. An assurance of anonymity was given within the constraints possible. Identifying the research as a case study of would necessarily make general identification of the people involved possible. To overcome this, it was agreed with all participants that particularly sensitive information would only be used with the consent of the person disclosing it. Equally, it was agreed that participants were free to request that certain information should not be used and this would be honoured. Having discussed these issues, the following people agreed to be interviewed:

- Five general practitioners.
- Two nurse representatives.
- One Lay member.
- One Health Authority non-executive member.
- One Social Services representative.
- One Chief Executive.
- Four co-opted board members.
- Fourteen Community Reference Group members.

There were ten co-opted Board members during the period of the study. The constitution of the PCG made provision for co-opted members but did not specify

numbers and stated “co-opted members do not have the right to vote but may take part in the meeting at the discretion of the Chairman”. Only five co-opted members were identified as regularly attending Board meetings and these included three paid officers of the PCG – the deputy chief executive, the finance manager and myself as community and partnerships officer. Given the relatively low numbers attending, only four co-opted members were interviewed: the Community Health Council and District Council Representatives the PCG finance manager and a GP practice manager. These were selected to obtain comparative views, that is, community health council compared with lay member perceptions, the views of partner agencies in the case of social services and local authority and the views of representatives from the managerial group.

Fourteen members of the PCG Community Reference Group were interviewed and asked the same questions as members of the PCG Board but from the public perspective, this was not to provide a representative sample but to obtain a snapshot of views from a relatively small number of people with knowledge of and involved with PCG structures and processes.

The framework for the interview schedule (Appendix 3) was designed to incorporate the key questions described above and allow exploration of a number of key themes. The themes identified arose from a variety of sources:

1. Personal experience – as a practitioner with several years experience of working in the NHS I was well aware of the complexity of and cultural and operational issues surrounding patient and public involvement.
2. New policy and reform – the “New NHS” policy and reforms had built on the continuing twin themes in the NHS of devolving power to primary care and developing a more robust approach to patient and public involvement. Just how prepared new Primary Care Groups were to implement the expectations placed on them appeared to be a relatively unexplored issue.
3. Guidance on involvement – a plethora of guidance in relation to why and how to involve patients and members of the public was being introduced as part of the induction process for PCGs. Whether this guidance had or could influence policy and practice at a local level and if so how, seemed to be very relevant to exploring patient and public involvement within a local context.

Observation

Access to meetings to undertake participant and non-participant observation was fully supported by members of the groups concerned and all were aware that meetings were being observed and the context in which material would be used. As in the interviews, it was agreed that material that would clearly identify people in relation to sensitive information was excluded. Observation was used primarily to compare how actual behaviour compared with the responses given during interviews but also to identify and explore issues in relation to management structures that could influence involvement. These included the format and content of meetings and 'softer issues' such as interaction, contribution and facilitation.

The PCG had instituted a sub and reference group structure to assist with work. The membership of the groups was multi-disciplinary, although primary care oriented, in that the majority of members were either clinicians or managers in the PCG. The Quality Sub-Group was concerned with clinical governance, quality, and development of best practice, standards and policy. The Community Reference Group was made up entirely of lay members and had been established as a means of including some degree of patient and public perspective in planning processes. These two groups, along with the PCG Board, were chosen as the focus for observation.

The Quality Group was selected because of its emphasis on clinical governance and the clear links this had with improving patient experience as demonstrated by its inclusion in the quality standards framework (Appendix 4). The Community Reference Group was an obvious choice given that it had been included as part of the PCG structure specifically as a vehicle for involvement. PCG board meetings were public meetings and described in PCG guidance as a means of encouraging open, transparent processes that enabled local people to see the basis on which decisions had been made. It was considered important therefore to observe how or if these meetings did encourage the development of open and transparent processes.

As a co-opted member of the PCG board I was present in my professional capacity at all meetings and this enabled participant observation. Similarly, I was the facilitator of the Community Reference Group and consequently a participant

observer. Although not a member of the Quality Group, my attendance as a non-participant was agreed under the conditions outlined above.

Observation took place during six meetings of each group. All of the groups met monthly and three meetings of each group were observed over a three-month period between January and March 2001 and then again between January and March 2002. Including an interval between the meetings observed allowed a comparison to be made and the identification of any changes that had taken place during the intervening twelve months.

Notes were made during and after meetings and minutes of each of the meetings were referred to for clarification or confirmation of my own notes in respect of decisions made or actions agreed.

Analysing the Data

Data analysis drew on interview transcripts, observation notes from meetings, supporting field notes, local documents such as minutes from meetings and relevant literature on and studies of involvement in the context of the NHS. Data collection and analysis were undertaken concurrently and a system of identifying emerging themes was used to reduce the vast amount of data collected into manageable proportions. These broad themes were further broken down into different categories and refined further by identifying clusters of related data and the differences or similarities that linked them. Using this method allowed the study's own themes to emerge while providing a framework for comparison with the themes identified by similar or related studies.

ETHICAL CONSIDERATIONS

All research involves ethical considerations. Issues around informed consent, confidentiality and anonymity are strongly debated. Informed consent is intended to ensure that participants in research are fully aware of and understand the nature of the research, what its purpose is and the possible consequences of participating. Participants are then able to give agreement based on full and open information. Although codes of ethics oppose any deviation from this, there has been discussion over how the strict application of this may constrain or restrict a great deal of innocuous and unproblematic research (Denzin and Lincoln, 2000:138-141). In

addition, it is argued that exceptions are possible where knowledge gained is clearly valuable to society. Decisions as to whether knowledge is valuable are of course subjective but, as Weber points out, all research is contaminated by the values of the researcher (Quoted in Silverman, 2000:200).

Two of the most obvious situations where the principle of informed consent may be relaxed are covert observation, where access to settings would be impossible if full information was disclosed, and situations where the behaviour of participants might be artificial and would therefore invalidate the research as a direct result of knowing they were being observed. Notwithstanding this, from an ethical point of view, deliberate misrepresentation is still regarded as unjustified, unnecessary in practical terms and not in the best interest of social research as an academic pursuit (Bulmer, 2000:139).

Privacy, confidentiality and anonymity are crucial ethical considerations and it can be difficult to distinguish between these in practice. Privacy and confidentiality are about safeguarding the identity of research participants and locations to prevent unwanted exposure. Personal information is protected and hidden behind a shield of anonymity. Despite this, identities and locations are often identifiable by the very characteristics that the research unearths or reports and it is important that the researcher and the participants are aware of this. Adhering to codes of ethics should be based on the premise that no one deserves to be embarrassed as a result of research but within this, it is evident that value judgments might be made. What appears to be neutral on paper can be conflicting in practice and what researchers see as innocent, participants may see as misleading (Denzin and Lincoln, 2000:138-141).

A further consideration is how far does or should the researcher go in ignoring evidence of malpractice, for example. Practitioner research in particular, because of its scrutiny of the researcher's "own" people and practice can highlight elements of policy, practice and activity that have previously not been identified. The question here is how to strike a balance between obligations to colleagues, assurances of anonymity and loyalty to the organization and wider social and professional responsibilities.

Ethical considerations should be addressed at the beginning of a study and not left until or unless they become an issue. Asking the questions what is the purpose of

the research, which individuals or organizations might be interested in it or affected by it and what are the implications for those involved given the proposed framework for the research helped to focus the ethical considerations of this particular study.

All participants were informed of the nature and reason for the research. Namely that it was primarily an academic piece of work but that there could be benefits in terms of the findings contributing to local policy and practice. Confidentiality and anonymity although appearing to be relatively straightforward were potentially more complex. Although both had been assured, because of the small numbers involved, it would have been easy to identify participants by attributing quotes for instance. For example, as there were only two nurses involved, anything attributed to a nurse would have proved impossible to anonymise effectively. While retaining the anonymity of the location was initially not considered to be a problem, naming the location automatically reveals the identity of those involved in relation to Board members, given the high profile of PCGs within the local, at least, health sector. Ultimately, agreement was reached with participants that they would have a veto over information that they did not wish to be included.

The study was not intended to be about blame or recrimination, nor was it about individuals' views of each other but about their own attitudes, views and perception of public and patient involvement and their role in this. If information was offered with a request for strict confidentiality, this was respected and not included.

Dealing with instances of unethical or poor practice is fraught with difficulty because of the different values held by different people and the often subjective nature of the issues involved when considering the ethics of research. No such examples were noticed during the fieldwork and so the issue of how to manage this did not arise. This of course is my subjective view and does not and cannot rule out the possibility that an external researcher or other colleagues would view certain practice in a different way.

When research involves public organizations, it is suggested that decisions have to be made on what if any parts should not be exposed (Denzin and Lincoln, 2000:138-141). Increased public and patient involvement is almost a counter argument to this, based on the drive to increase transparency, openness and accountability. Nevertheless, the Chief Executive of the PCG pointed out, when interviewed, that not releasing particularly sensitive information, or choosing the right time to release

it, can avoid raising public anxiety unnecessarily. Whether this might be seen as justification for not engaging fully with involvement or whether it is a genuine concern for public interest is open to debate. Despite being public bodies, PCGs, in common with many other public organizations retained the right to a confidential part of otherwise public Board meetings. Access to this part of meetings was not made available to me for observation. Participants in all other meetings subject to observation were fully aware of being under scrutiny and raised no objections.

In opening themselves up to scrutiny, people and organizations risk embarrassment, loss of credibility and self-esteem and, in extreme cases, potential loss of employment. The overall responsibility of researchers is to recognize and uphold the duty that they have to research subjects and to research itself in terms of both safeguarding the privacy of participants and retaining the integrity of the research community.

CHAPTER FOUR

STRUCTURES, PROCESSES, ROLES AND RESPONSIBILITIES

INTRODUCTION

Primary Care Groups have been described as the cornerstone of the 1997 health care reforms (Anderson, 2001:29) and as such would have a significant role in shaping the development of the Government's patient and public involvement agenda. However, as previous NHS reforms have demonstrated, organisational and structural change does not necessarily facilitate a development of the role of patients and the wider public. If promises of greater power and influence for local people were to be achieved they would have to be underpinned by structures and processes that enabled it to happen.

Although various reorganisations have attempted to streamline structures, the NHS remains a hierarchical organisation that continues to impose centrally driven targets and priorities. Devolution of power and responsibility to a local level has invariably related to processes within the NHS and appears to have had only limited impact on releasing the potential to develop the role of patients and the public in terms of decision-making. While decentralisation and devolved budgets have the potential to facilitate a more even distribution of power and influence, whether PCGs were able and willing to realise this potential would rely on whether local structures and processes were designed to aid the transformation or simply reinforce traditional levels of influence while providing the illusion of involvement.

This chapter discusses the structures and processes put in place by the PCG in this study and how they had helped or hindered the development of involvement. Specific examples of involvement that were observed during the study are examined and conclusions drawn in relation to the factors that had contributed to outcomes. Primary Care Groups had been allowed significant flexibility in how they organised themselves to deliver the Government's agenda, this chapter explores the extent to which structures and processes had been shaped by perceptions surrounding roles and responsibilities of PCG Board Members.

The chapter draws on data from participant and non-participant observation of meetings, interviews with PCG Board and co-opted members and members of the PCG Community Reference Group, reference to key local and national documents, minutes and agendas of local meetings and personal reflection on how the structures were operating.

As a co-opted member of the PCG Board and facilitator of the Community Reference Group, I was routinely present at these meetings. Agreement was given for me to attend Quality Sub-Group meetings as an observer for the purpose of the study. During the study, six meetings of each group were selected for examination, three consecutive meetings at the beginning of the study and three consecutive meetings twelve months later. The decision to allow a lapse in time between the meetings studied was primarily intended to establish what, if any, developments or change had occurred during the intervening period.

During meetings, notes were taken on the content of the agenda, how discussions were introduced, the contributions of members, decision-making processes and dynamics during meetings. In addition, the role of each element of the structure and the relationships that existed were also explored. Data from interviews were referred to and taken account of when comparing what had been said with what was happening in reality.

PRIMARY CARE GROUPS – THE CORNERSTONE OF THE NEW NHS

If PCGs were indeed the cornerstone of the *New NHS*, they would have a significant role in shaping the development of the Government's patient and public involvement agenda. There is however, little concrete evidence to suggest that structural and organisational change is sufficient to facilitate a change in traditional patterns of power and influence in the NHS. Whether locally devolved decision-making results in more opportunities for local people to influence decisions or whether the medical profession continues to dominate is still questionable. Baggott (1998: 158-159) argues that while delegating decision-making to a more local level might indicate greater potential for local people to influence decisions this potential might be difficult to realise because it is at this level that the medical profession is most powerful.

In respect of affording patients and members of the public more power and influence, simply introducing new NHS bodies such as PCGs would not necessarily challenge the perceived power traditionally held by the medical profession. In many respects, the devolution of power implicit in the introduction of these new bodies simply reinforces the importance of the medical profession.

While national targets and priorities can be used to influence decisions made by NHS bodies, the advisory and often-ambiguous nature of policy and guidance leaves scope for local interpretation (Ham, 1999: 174-175). The “New NHS Modern, Dependable” (DoH, 1997) had pledged to bring health and health service planning closer to communities and afford greater opportunities for, and commitment to, patient and public involvement. Given the flexibility that PCGs were to be allowed in terms of how they organised themselves to achieve these aims (DoH, 1997:32), the success of *New NHS* policies was likely to depend on how it would be interpreted by those given the responsibility for its implementation, particularly given the diverse membership of the governing bodies (the Boards) of Primary Care Groups.

The Labour Government had pledged that the structures introduced by the *New NHS* would be open and transparent and that the membership of PCGs would ensure the representation of a diversity of interests. While, on the one hand, these arrangements might facilitate democratic decision-making processes there are, as discussed in chapter two, a number of ways in which interests can be manipulated, repressed or simply ignored. If structures and processes are not rooted in enabling the involvement of patients and the wider public this raises questions about how involvement has been interpreted. In particular, is local involvement simply a means of allowing local people to see what decisions were being made rather than enabling them to be a part of the process, is it intended to be a way of encouraging people to take responsibility for their own health and use health services responsibly or is it to allow people to assert their right as citizens to be part of decision-making processes that might affect them. What appears to be a relatively neglected issue is that whatever the reason, certain principles must underpin structures and processes.

At a basic level, the value of an individual’s contribution needs to be clarified, agreed and made explicit (Popay, 1994:84-97). In addition, if there is not an understanding and acknowledgment of the knowledge base and the different levels

of expertise that people come with, it is unlikely that shared decision-making will be achieved. Very different views of this were evident among Board members in this study; while one member was clear that involvement should mean that everyone's contribution was valued and accepted on an equal level, irrespective of the knowledge and experience they bring, others were concerned that the 'person on the street' had no knowledge of the technical aspects of decision-making, were more likely to make emotional decisions and should therefore not be involved.

Although the views of some of those interviewed reflected the need for negotiated outcomes and, occasionally compromise, the structures and processes in place appeared to contradict this. Ultimately, it is where the power lies to facilitate negotiation and compromise that will shape how this is achieved. As discussed previously, establishing how power is being exercised is a complex process because it can be manifest in a number of ways. In this study, by examining existing structures and processes, it was evident that the relationships being developed had major implications for patient and public involvement. As well as the structure and processes themselves, underlying issues such as the content, timing and dynamics of meetings related to the various components of the PCG structure were also identified as factors that would help or hinder involvement. Perhaps more importantly, it was clear that the structures and processes had been determined without the involvement of the very people that they were intended to include.

STRUCTURES AND PROCESSES

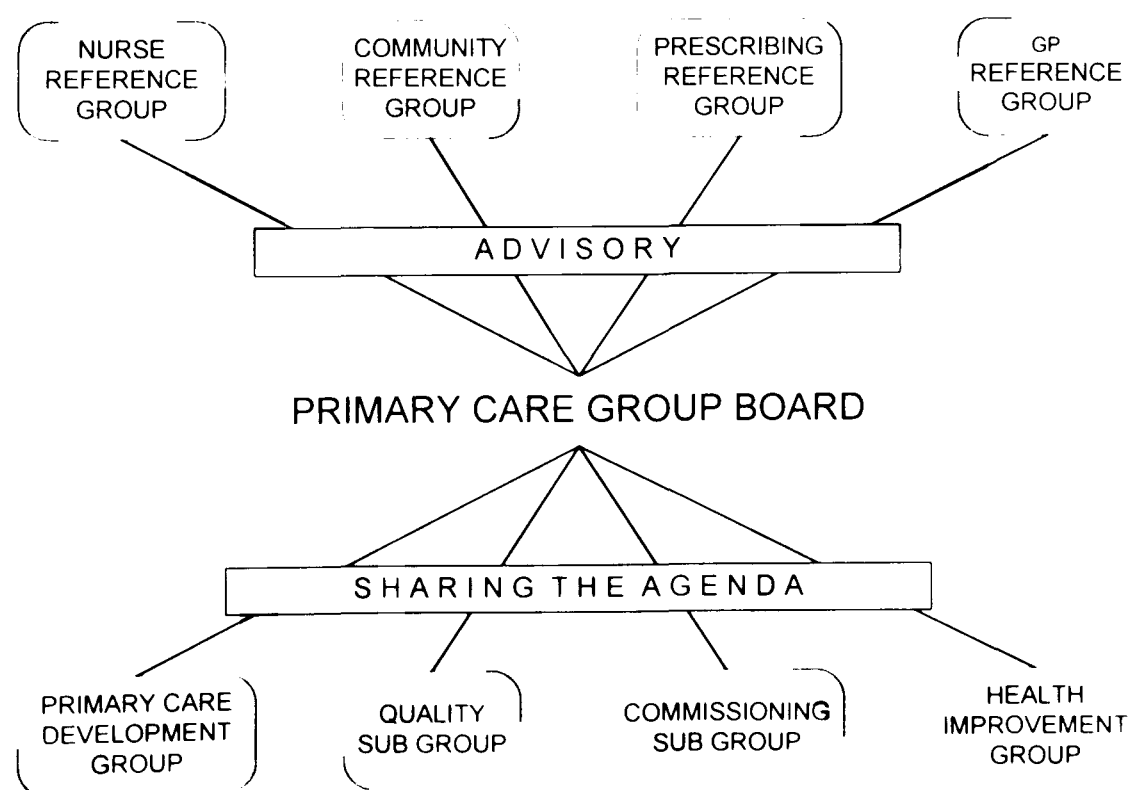
The NHS is a complex organisation that is made up of many separate and distinct parts and this in itself creates difficulties in terms of involving patients and members of the public, particularly in terms of identifying where decisions are actually being made. Equally, the various stakeholders in the NHS and the relative levels of influence they are able to exercise have been widely debated. Different stakeholders bring different perspectives and have different roles in relation to both developing and implementing policy. There is evidence that the sanctions that can be brought to bear by different stakeholders are invariably related to their role in the implementation of national policy and as such different groups might be regarded as relatively more important and afforded more attention. Governments rely heavily on producer groups such as the medical profession to implement health policy at a local level and because of this they are perceived as being very powerful players

(Ham, 1999). A key issue in relation to patient and public involvement is therefore how, or if, the structures and processes in place enable the various stakeholders to voice their needs and opinions and have them taken account of or indeed allowed to identify and articulate them in the first place.

Primary Care Groups were urged to develop open and transparent processes that allowed stakeholders to see the basis on which decisions were made and, while recognising the need to protect confidential business where necessary, there had to be public access to meetings that required, at a minimum, Board meetings to be held in public. There was also an expectation that the structure would be capable of delivering the prescribed tasks of the PCG while promoting the wider involvement of staff, patients and members of the public (HSC 1998/139, NHS Executive, 1998:8-30).

Primary Care Group Boards were the governing body of PCGs and, although expected to demonstrate joint governance and act corporately, how they operated was left to local discretion (ibid). A structure of sub and reference groups (Figure 4.1) had been established by the PCG in this study in an attempt to reflect national guidance on developing capacity and providing an opportunity for the involvement of a range of stakeholders.

Fig 4.1 Primary Care Group Structure



The sub-groups included in the PCG structure were labelled as “sharing the agenda” and, when interviewed, one Board member had described them as a means of involving a range of people in making recommendations to the Board. Another member had described them as “the working bits, making sure the right information goes into the Board so that the Board can make the right decisions”. A very clear distinction was expressed between the reference groups and the sub-groups. Reference groups were seen as a means of gauging reaction to, rather than contributing to the identification of issues.

Taking account of the functions of the PCG, the sub groups were organised around five main themes; primary care development, clinical governance, commissioning services and health improvement. The reference groups were initially organised around nursing, community involvement and general practice issues with a prescribing reference group added later. When interviewed only a few Board members had referred either to the existence of these groups, their terms of reference or their links with the Board and associated planning and decision-making mechanisms.

For the purpose of this study, three aspects of the PCG structure were selected for examination, the Community Reference Group, the Quality Sub-Group and PCG Board meetings. In selecting these particular groups, consideration was given to the various roles assigned to them in the PCG structure. The Quality Sub-Group was one of a number of groups focused on specific responsibilities of the PCG and described as “sharing the agenda”. In contrast, the Community Reference Group was established, along with a Nurse Reference Group and a GP Reference Group, to act in an advisory capacity. According to the structure, sub and reference groups would feed into the work of the Board.

The Quality Sub-Group

The Quality Sub-Group was given the remit of developing PCG capacity in relation to complying with clinical governance responsibilities. A GP Board member chaired the group and membership included GPs, district nurses, GP practice nurses, GP practice managers, the PCG Lay Board member and the Primary Care Development Centre Manager. The group had been keen to add additional lay membership and two members of the Community Reference Group had joined the group in the early stages of the study.

Introduced as a system to ensure continuous improvement and consistently high standards of care, clinical governance was intended to improve the professional development and accountability of NHS organisations (Gillam, 2001:22). Despite patient and public involvement being considered a critical element of clinical governance, Wilkin et al (2000) take the view that there has been little evidence of this being included in relevant processes. The inclusion of lay members in the work of the Quality Group was seen as an attempt to address this issue. The Quality Group had actively sought patient and public membership and had chosen to pursue this through the Community Reference Group. Despite this, there was no evidence that the purpose of including patient and public membership had been explored and agreed and, as a result, little understanding of the role these lay members would have.

Two Community Reference Group members had agreed to attend meetings, take issues back to their wider membership and feed the results into subsequent Quality Group meetings. When discussing the role of lay members, the main issue for the group was whether patient and public members would be observers or participants and the implications for confidentiality this would have. While the Chair of the group admitted that, although there were terms of reference that included guidance on confidentiality, no one could remember where these were or what they contained. Despite this, the group decided that the Community Reference Group members would be invited to attend as full participants with the same responsibilities in relation to confidentiality and the same right to contribute at meetings as other members.

The nature of this involvement raises two particular issues. Firstly, when recruiting lay membership, if there is a lack of clarity surrounding roles and responsibilities, there is likely to be a similar lack of understanding surrounding expectations of the outcome of the involvement. Little consideration had been given to whether representation would be related to the specific interests of the individuals involved or as a proxy for the wider community. The lack of attention paid to this aspect often results in lay members being recruited not for the particular characteristics they bring as individuals but simply because they are not health professionals (Hogg, 1999:100-102).

Secondly, the conditions attached to lay membership, whilst giving the appearance of involvement, can actually prove to be frustrating and ineffective. Complying with confidentiality for example, might leave individuals feeling isolated and unable to seek advice or information from anyone outside of meetings. This issue was particularly evident in the Quality Group given that the lay members were, in theory, representatives of the Community Reference Group and as such should have been reporting back on the content of meetings.

While indicating a commitment to equality, this might have placed the two Community Reference Group members in an ambiguous position. Being bound by confidentiality might well have constrained them from discussing issues at meetings of their own group therefore limiting the opportunity to introduce a wider perspective.

The Community Reference Group

The Community Reference Group had been included in the PCG structure as a means of establishing a patient and public perspective. That the Group had been included in the structure was an indication that involvement had been given consideration and a level of commitment. When first established, members had been recruited by inviting representation from all local voluntary and community groups in the area. As the group progressed, a number of individuals not associated with other groups or organisations but hearing about the group through word of mouth began to attend meetings. Despite the early recruitment drive, membership never got beyond a relatively small number with approximately twenty-five people attending regularly. The group was attended and supported by myself and the PCG Lay Board member attended meetings on a regular basis

The Community Reference Group had a number of characteristics similar to those of Community Health Councils. There were no lines of accountability for members and it could be argued that members were not necessarily typical of patients and members of the wider public. When interviewed, a number of Board members had referred to the dangers of involving the same people all of the time and the constraints this might have in terms of achieving a balanced view of need. Despite this, if it was considered necessary to include a patient or broader public perspective in issues it was the Community Reference Group that was referred to. In developing a mechanism such as the Community Reference Group, the PCG

might be criticised for relying on individuals and groups with whom they felt comfortable. Equally, there was the potential for those involved to develop into an elitist group that failed to take account of the wider population.

That the Community Reference Group had been established by the PCG, and given a pre-defined role, supports the view of Hogg (1999) who points out that while consultation has been an aspect that has been given increasing attention in the NHS, this has been mainly to an agenda set by organisations on the terms they decide. Equally, the reliance on the Community Reference Group raised a significant issue in relation to the impact that the involvement of relatively small numbers of people can have. Using the Community Reference Group as a ready-made forum for consultation or when lay people were needed to attend other PCG meetings could have encouraged exclusivity rather than inclusion and diverted attention away from attempting to seek the views of the wider community (Emmel and Conn 2004b: 7). The Community Reference Group therefore might be seen as a contradiction in terms.

During the time of the study the role of the Community Reference Group remained static and consequently might be seen as a lost opportunity. This group could have provided a platform from which to launch a developmental process that would embed involvement in the work of the PCG. If, as user movements often argue, involvement should be a progressive process made up of different steps that allow individuals to develop their ability and willingness to contribute over time (Lupton et al, 1998:44-46), the Community Reference Group could have provided the first step. The lack of development in both the scope and range of work undertaken implies that the PCG while maintaining the presence of a Community Reference Group had not considered its potential in the context of long-term development.

The PCG Board

In contrast to the business style management boards introduced by *Working for Patients*, membership of PCG Boards was not centred around executive and non-executive membership but was made up of clinical, managerial and lay representatives that were expected to adopt corporate decision-making processes and assume corporate responsibility. While *Working for Patients* had removed direct representation of producer groups and consumer interests from NHS boards (Klein, 1990), the composition and nature of PCG Boards was not unlike previous

consensus management arrangements. Primary Care Group boards were expected, at a minimum, to include not less than four but not more than seven General Practitioners (GPs), one or two community nurses, one social services member, one health authority non-executive member, one lay member and a Chief Executive.

One of the similarities between PCG boards and consensus management arrangements was the diversity of backgrounds, experience and knowledge that members came with. Equally, there was the expectation that neither individual members nor groups would have superior status suggesting that the power of veto over decisions would, in theory, be available to all members. It was, however, these kind of arrangements that the *Griffiths Report* (DHSS, 1983) had been so critical of because they were perceived as resulting in the blurring of responsibilities, delayed decision making and avoidance of difficult decisions. Webster (2002:140-207) however, argues that clinicians were far more comfortable with consensus management arrangements because it afforded the opportunity to retain their influence over health and health care decisions. The medical profession had not particularly welcomed the introduction of general management, as this might have meant a relinquishing of the authority they had previously held. In many respects, the establishment of PCGs had once again placed the medical profession centre stage.

The PCG in this study had chosen to take advantage of the maximum number of GP board members allowed but had only succeeded in recruiting six. This number was subsequently reduced to five as one of the GPs resigned in the year preceding transition to Primary Care Trust status. The Board had also chosen to co-opt a further ten members made up of a range of people from other NHS organisations, the local district council and the local Community Health Council.

Board meetings were held in public as distinct from being public meetings and during the time of the study, no protocols were in place to allow members of the public to ask questions or make comments and so they attended only as observers. Similarly, no formal procedures were in place to allow members of the public to contact relevant individuals to ask questions or seek additional information prior to meetings. For members of the public, involvement at board level was therefore restricted to observing rather than taking part in, contributing to or sharing decision-making. If involvement were to become a reality, opportunities other than

attendance at board meetings would have been needed to enable local people to influence decisions rather than simply observe them being made.

The role of the Board with regard to driving the strategic direction of the PCG might be seen as a key aspect in terms of developing patient and public involvement. If the Board was assuming a strategic role, there might have been an expectation of a degree of monitoring at this level, in terms of how the patient and public perspective had been integrated into planning processes. If the role were more closely aligned to the rubber-stamping of decisions made elsewhere then opportunities to ensure involvement had been incorporated would most likely be more limited and dependent upon the stage at which proposals were when presented to the Board.

The distinction between these different roles is often blurred and to assume that a Board is either concerned purely with strategic issues or, at the opposite end of the spectrum, simply endorsing decisions made elsewhere is perhaps too simplistic. What is as important is the degree of influence that can be exerted by Board members when issues are presented and the role of the sub and reference groups was a key factor in this.

The role of the sub and reference groups

Both the Chief Executive and the Chair of the PCG gave clear accounts of the role and relationship of the sub and reference groups when interviewed. The sub-groups were described as a way whereby the PCG engaged with and involved a wider range of people in the process of making recommendations to the Board. The ultimate purpose of these groups was seen as the integration of individuals and groups into decision-making processes and also sharing the extensive PCG agenda. In contrast, reference groups were referred to as being established primarily to engage with different groups in order to gauge reaction to rather than necessarily generate proposals for PCG decisions. It had also been suggested by the Chief Executive and the Chair that the sub-groups were the mechanism for undertaking the business of the PCG, while the Board would take on a strategic role.

A number of issues were evident surrounding the impact that the framework of sub and reference groups might have, not only in terms of involving patients and the wider public but also the involvement of Board members themselves. Few people

had mentioned the existence of the groups and their relationship with or input into the business of the Board and this raises questions about Board members' awareness of the significance of the wider planning processes and how the role of the Board was perceived in relation to decision-making. A number of different views were evident in relation to this. On the one hand, some members felt that not enough information was given to enable informed discussion while others had taken the view that too much debate took place at Board level that should have been undertaken in other arenas. One board member, for example, had suggested that:

The Board got very embroiled in some very detailed discussion at Board level and really that should have been done in the background.

Guidance for PCGs had recognised the difficulties of bringing together people from different backgrounds with varied experience of working at Board level but appears to have offered little support for overcoming them. Acknowledging that securing ownership and responsibilities for decisions reached would be reflected in how Boards operated, how functions were carried out and how stakeholders were involved (HSC 1998/139, DoH 1998), there was little reference to developing the skills that would be needed to act corporately.

A further issue is how the various functions of the PCG were reflected in the structure. Primary Care Groups were given a very clear role in relation to both health service improvement and health improvement; the functions delegated to them included developing primary care, commissioning health services from relevant NHS Trusts, integrating primary and community health services and promoting the health of the local population and addressing health inequalities. Such a wide ranging agenda would require a shift in roles for those previously involved only in delivering primary care services. Equally, developing mechanisms for patient and public involvement might depend on how "primary care" was defined. This research did not specifically explore whether Board members had taken account of this and embraced a wider role by developing the partnership working associated with addressing the wider determinants of health or whether a somewhat limited definition had been retained. The structure that the PCG had introduced, however, suggested that there was relatively more emphasis on delivering health services rather than addressing health in its widest sense.

The sub groups were heavily weighted in favour of health services with four out of the five groups focusing on clinical governance, commissioning services from NHS Trusts, prescribing and the development of primary care services particularly general practice and community nursing. The remaining sub group was the only group concerned with inter-agency working, health promotion and health inequalities. The reference groups also had an emphasis on “professional” views including nurses, GPs and pharmacists; only one was concerned with community input. A few Board members had recognised this continued focus on clinical models of health and the need to take a more balanced approach. One Board member had commented:

For me, this is how I perceive it, the perception is that primary care is GP led and the drive will come from them. So there is inevitably a drive that it becomes a medically oriented process and not an integrated process across different professions and different services. I think that is always a risk within many organisations, particularly the NHS, that however local you become in your decision-making and your determination it will inevitably become a medically oriented focus. That is something that has to be culturally changed.

The emphasis on health services suggested by the PCG structure and this explicit reference to the need for cultural change implies that not all PCG Board members had engaged with a wider definition of primary care, particularly in relation to health versus health services, and the subsequent opportunities for the community development models of involvement discussed in earlier chapters.

Finally, and in the context of this research perhaps most importantly, only one reference group had been established to “ensure stakeholder involvement” (PCG Chair) from local communities and this in an advisory capacity rather than sharing the agenda. Equally, only two of the sub-groups, the health improvement and clinical governance groups, had lay representation. This representation had been drawn from the community reference group but when the group asked for representation on the nurse reference group, for example, the response had been that this group was concerned with nursing issues and lay membership was inappropriate. The subject of lay membership on each of the remaining sub-groups had never been discussed.

PCG Processes

Despite having a structure that described sub and reference groups as sharing the agenda or acting in an advisory capacity there was no evidence of any formal procedures that acknowledged the work of these groups, particularly the Community Reference Group. Although the minutes of all the sub and reference groups were included in Board papers they were described on the agenda as routine reports, allocated ten minutes for discussion and presented “for information”. If all of the groups had met during the month, this meant that the minutes from eight separate meetings were available. The relatively short time allowed for discussion of these minutes, suggests an expectation that any debate would be minimal. Equally, although individual Board members had been nominated to provide a link with each of the sub and reference groups no verbal report was ever asked for or offered.

In practice, discussion on issues recorded in these minutes was rarely generated and the time allocation never used in full. In addition, if the Community Reference Group had been involved with the work of these groups it was not overtly reflected in or referred to in reports or recommendations. While there were some references at Board meetings to passing specific pieces of work to the sub or reference groups to carry out or asking them to comment on particular issues there was no evidence to suggest follow up procedures.

Given the apparent lack of attention at board meetings in respect of issues included in the minutes of the sub and reference groups it is questionable how the work of these groups, particularly the reference groups who were there in an advisory capacity, was taken account of and reflected in board level decisions.

A significant number of additional items on Board meeting agendas that were described as “for information” or “reports to be received” suggested that, as might be expected, a great deal of PCG business was being undertaken outside of board meetings. A key question was how, or if, a patient and public perspective had been included in shaping this work.

Despite the implication that planning and decision-making was taking place at various levels, particularly within the sub and reference groups, it is difficult to say whether associated minutes or reports had been read prior to Board meetings and

members had no questions or comments on their content or whether, with so many other items to be discussed, they had simply assumed that items for information did not require debate.

While the structure established by the PCG appeared to represent opportunities for involvement at a range of levels how the work of the sub and reference groups was organised, prioritised and co-ordinated was a significant factor in how it was facilitated. Equally, the role of the Board in determining how involvement was integrated into the structure was crucial if there was to be a strategic approach taken to its development. Additionally, a number of underlying issues were identified that were shaping opportunities for the involvement of patients and members of the wider public. In particular, the organisation, content and dynamics of meetings were all factors that affected the ability of local people to take part in PCG processes.

The Organisation of Meetings

Specific to the involvement of patients and members of the public, a member of the Community Reference Group had pointed out that there were a number of indirect ways to exclude people from meetings. The PCG structure did not appear to be underpinned by formal policies that facilitated or encouraged involvement. There was an absence of any guidance relating to timing and location of meetings, physical access to venues where meetings were being held and payment for expenses such as travel and caring responsibilities.

Although Community Reference Group members were paid travelling expenses; no provision was made for the cost of any care involved while members were engaged in PCG business. All PCG Board and Sub-Group meetings were held during the day and this would exclude those not able to attend because of work or care commitments. Only the Community Reference Group remained flexible and alternated the time of meetings to accommodate those not able to attend at specific times of the day. Although the venue for Board meetings alternated between two locations, given the semi-rural nature of the location of this PCG, those living in the most rurally isolated areas of the district might still have experienced difficulty in travelling to meetings.

Additionally, there was little to suggest that the PCG had managed to encourage the involvement of those whom the NHS has traditionally found it hard to engage with. Mental health, learning disability, physical disability and black and minority ethnic groups were poorly represented at any level of the PCG and the lack of representation from these groups might have been attributed to the absence of policies that took account of advocacy, cultural or language needs.

In addition to these very practical issues, issues of organisational capacity might equally have frustrated aspirations for involvement. Board and Community Reference Group members all referred to the practicalities of being involved in PCG work in relation to time and effort. This time and effort appeared to apply not only to the practicalities of being involved such as the time to attend meetings but also the cost to an individual in respect of acquiring and assimilating the information necessary to contribute at meetings. Community Reference Group members had commented on how much harder they had to work to acquire a level of understanding that would allow them to contribute to discussions.

The time involved in contributing to the work of the PCG was an issue for both Community Reference Group members and Board members. A number of Board members had described the length of Board meetings as a matter of concern. Lasting on average four hours, up to five if as was often the case it had been preceded by a PCG Board seminar, the length of meetings was perhaps not conducive to informed decision-making, as one member had pointed out during interview:

When you've got a Board meeting that's going on from two till six then maybe you've got a lunchtime seminar before that, you can be sitting in the same seat for five hours at a time and you can't tell me, with all the will in the world, that people's concentration is going to be there. You're lucky if your concentration's going to be there for two thirds of that time.

Although Board meetings were indisputably long and offered little opportunity for patients and members of the public to contribute, both the Quality and Community Reference Groups were mechanisms that actively encouraged and to some degree, facilitated involvement. Despite this, the time consuming nature of being involved in PCG work for both members of the PCG and patients and members of the wider

public in many respects might be seen as a means of indirect, and not necessarily deliberate, exclusion.

This PCG was relatively small and various members of the Board were also active in a number of the Sub and Reference Groups. The Lay member of the Board for example attended both the Quality and Community Reference Groups; a GP Board member was also chair of the Quality Group. The time involved in preparing and attending these meetings might therefore be significant. In respect of the Community Reference Group, it was to this group that attention was turned whenever involvement was felt to be required and this placed additional demands on the time of members outside the regular meetings.

The capacity necessary to attend meetings would also have an impact on the issue of information. The agenda, minutes and any associated reports or papers for Board meetings were supposed to be sent out at least seven days prior to meetings. In reality, papers were often received on the Friday or Saturday before a meeting on the following Tuesday thereby significantly reducing the time available to become familiar with the content. With an average of 13 agenda items that included 31 sub headings it might be reasonable to question whether all relevant information, reports and papers could be read and fully assimilated prior to meetings.

While certain Board members had remarked during interview that there was often not enough information available on which to base informed decisions, there might also be an argument that it was not just the lack of information, but also the lack of time available in which to assimilate that which was available.

The Quality Group although covering a significant number of items conducted meetings in a different manner. The same issues appeared on the agenda at a series of meetings having been discussed and amended several times before final agreement. This appeared to have the advantage of avoiding the need for issues to be resolved in one long drawn out discussion.

Notwithstanding the volume of information involved in contributing to the business of meetings it was apparent that the level of attention given to the information presented and the way in which specific aspects of work were engaged in was also an issue.

The Content of Meetings

The tension between the need to develop and commission health services while improving health and addressing inequalities was evident in the way in which the PCG had framed its responsibilities and the relative priority given to specific aspects of work. Primary Care Groups had been given the task of improving health and addressing health inequalities as well as improving health services and yet there was little evidence of this being taken account of at Board level.

The content of Board and Quality Group meetings had a much greater emphasis on health service issues than other aspects of PCG work such as health improvement or addressing inequalities. On the few occasions that issues relating to wider health issues, for example partnership working with other agencies, appeared on the agenda, this was usually presented for information and discussion only entered into by certain members, in particular the Lay and Health Authority members, the Chair and the Chief Executive.

During the Board meetings observed for this study two thirds of the items discussed were directly related to clinical or health service issues. Each item on the agenda was given a time allocation that meant business would be concluded in two hours. Discussions, however, were rarely contained within the time allotted particularly when they related to primary care development or the commissioning of secondary care services. An item relating to the commissioning of physiotherapy services, for example, was allocated ten minutes but was debated for more than twenty-five. In contrast, discussion surrounding a proposal to host a Community Health Conference was concluded in less than half the time allotted. Although this might be seen to reflect the relative importance attached to the various elements of PCG work, it might also be a reflection of the way in which the particular priorities of the PCG had been shaped. With a majority of Board members being GPs, it is perhaps not unreasonable to expect that their interests would largely be concerned with primary care. Given that the majority of national targets and priorities were also related to the improvement of primary and secondary care services this emphasis was not entirely unexpected.

As the Quality Group was the PCG mechanism for taking forward clinical governance issues it was also not surprising that these meetings were focused on

health service improvement. The *New NHS* (DoH, 1997:82) had described clinical governance as the means of assuring and improving clinical standards. Members of the group had admitted that their work was almost entirely focused on clinical issues within a relatively narrow definition of clinical governance. Despite this, during early Quality Group meetings the clinically oriented members of the group were the strongest advocates of including patient and public members as equals and, more importantly, offering to provide additional support to allow them to contribute fully and therefore potentially to influence discussions. In addition, the commitment to include patient and public representation at meetings was extended to combining issues from a patient and public perspective with the clinical perspective demanded by the clinical governance agenda.

Given the emphasis on health service issues, Board and Quality Group meetings were often characterised by the inclusion of technical words, phrases and abbreviations. Sustaining the involvement of patients and members of the public not initiated into the language used by clinicians and managers as part of their everyday work requires processes that take account of this. In respect of the content of meetings, much will depend on the way information is presented, paying attention to the language used and acknowledging the different levels of knowledge and understanding of those present (Lupton et al, 1998:123).

In the early meetings following attendance of Community Reference Group representatives at Quality Group meetings, there was evidence of attempts being made to reduce the use of technical language and to explain it where it was impossible to avoid its use. Equally, issues such as policy development and proposals for service improvement were presented at a relatively early stage in their development when it was still possible to include amendments as a result of any comments or views expressed at meetings. For example, the development of a policy for adverse incident reporting was revised and brought back to meetings no less than three times as a result of discussion at meetings.

In addition, all members of the Quality Group admitted that the agenda was largely clinically driven and that Community Reference Group members might need additional support to enable them to take part in meetings in an informed way. All members of the group agreed to offer mentoring and to meet with community representatives prior to meetings so that any issues needing clarification or explanation could be discussed.

There was little evidence of similar mechanisms at Board level and incidents were observed where not only members of the public might have struggled to understand discussions but Board members themselves were having difficulty. One particular example during a Board meeting related to a discussion about “Micturating Cystograms”. The GP members present debated the issue for almost thirty minutes before the lay and health authority members asked for an explanation of the terms being used and the purpose of the discussion. In the event, it was explained that the term was used to describe a diagnostic test for urinary infections and the debate was around the advantages and disadvantages of referring patients for these tests.

In this instance, the use of clinical terms without first determining the understanding of those present had clearly served to constrain the ability to contribute to the discussion. With certain Board members struggling to understand a very clinically focussed discussion it is not unrealistic to assume that similar difficulties would be experienced by patients and members of the public.

The *New NHS* promises of open and transparent processes was somewhat diluted by the lack of opportunity for local people to question or clarify issues at Board meetings and the absence of very fundamental protocols surrounding issues of language and the use of jargon and technical terms. If people aren't able to understand the nature of the discussions taking place then it is not unrealistic to assume they will have difficulty in understanding the basis on which decisions are being made.

The need to educate and raise awareness of those people wishing to be involved was mentioned by many of those interviewed, yet little appeared to have been done, in relation to the content of Board meetings, to either simplify or reduce the use of jargon. While this might have been because members of the public were only observers at this level, questions surrounding the effectiveness of using Board meetings held in public as a mechanism to encourage openness and transparency of decision-making remain. If people were to be allowed to see the basis on which decisions were made then understanding the substance of discussions that were taking place was fundamental if it was not to be perceived as an exercise aimed at satisfying national guidance. As one member of the Community Reference Group had pointed out:

Open Board meetings are a gesture; there are other ways of excluding people who are thought to be a nuisance.

Additionally, there was little evidence to suggest that these clinically dominated discussions had taken account of the need to capture the experience of people in respect of how they receive services. This somewhat one-sided approach might imply that people could only take part if they were prepared to be educated in the way of the professionals and not acknowledged as experts in how services were received. This approach severely limits the level of influence that might be possible.

Agreement on the nature of information given or exchanged is perhaps dependent on the way in which involvement is constructed. The lack of appropriate information is at best an obstacle and at worst a disincentive to become involved. While “professional” knowledge tends to be taught, codified, systemised and generalised, “people” knowledge is often experiential, informal and mostly unwritten (Stacey, 1994:84-97). The characteristics of people knowledge often militate against it being taken seriously because it offends against positivistic canons by including the subjective along with the objective. It is because of this that patient and public knowledge is often undervalued and only by overcoming this reluctance to combine the two that the value of involvement can be realised. That the PCG was able to control the nature and level of information that was available or taken account could be considered a further obstacle to involvement.

There was little evidence to suggest that reports presented to the Board included reference to any wider issues raised by patient and public members of the sub or reference groups. Specifically, none of the reports made reference to the inclusion of the Community Reference Group perspective although when, or if, an issue was seen as requiring a patient and public perspective, it was the Community Reference Group that was referred to as the appropriate vehicle for consultation. Similarly, if reference had been made to the need for a patient and public perspective, there was no evidence of this being followed up in terms providing information on the outcome of the exercise.

Meeting Dynamics

Bringing together people from different backgrounds to form the governing bodies of PCGs was intended to introduce a wider variety of perspectives into planning and developing health and healthcare. The success of this, however, was likely to rely on how effective individuals were in terms of ensuring alternative or complementary perspectives were introduced or indeed whether there was an interest in including them. A number of Board members referred to the traditional inequality in status between GPs and nurses and the nurse members themselves indicated that they still felt able to exert only a certain level of influence.

Although there was no evidence to suggest any deliberate attempts to stifle debate, it was apparent that during Board meetings members only contributed to those discussions directly relating to their particular interest. The nurse members, for instance, only participated when an issue explicitly included a nursing perspective; such as a review of health visiting that was being undertaken during the time of the study. Similarly, the GPs contributed mainly to those items perceived as having a direct impact on either the service they provided or would refer patients to. Only the lay and health authority members, the Chair and Chief Executive generated discussion on issues not directly related to provision or commissioning of health services.

Rather than stimulating wider debate, Board members still appeared to focus on their own particular areas of interest and expertise. The somewhat limited participation of certain members, in particular the nurse members and the social services member, suggested that the inclusion of a wider perspective into decision-making had not been secured. This link between a member's background and their contributions during discussion was not as evident among Quality Group members during observation at the earlier meetings. In meetings of this group, all members appeared to contribute equally to debate and this was particularly evident in respect of patient and public membership

It was evident that individual interests had shaped contributions at Community Reference Group meetings. For example, one member was also involved in the Patient Council associated with the local Acute Hospital while another was a member of the Community Health Council. These members often brought issues raised at meetings of these other bodies such as the difficulties in relocating the

local hospice or concerns over services in the newly opened general hospital. Compared with these wider issues those raised by other members were more often associated with their own experience, or that related by their various contacts, of using or being involved in services.

A particular example of how group dynamics were shaped by changes in membership was observed during observation at later Quality Group meetings. When first established, the Quality Group had a membership of eleven excluding the two Community Reference Group members. This membership was made up primarily of GPs, practice and district nurses and GP practice managers. Towards the end of the study membership had increased to seventeen largely as a result of including more managers. As the PCG had developed, a number of new appointments to management posts had been made and increasingly these managers were undertaking work on behalf of the Board and the Sub-Groups. While work had previously been undertaken by members of the group who were, in the main, front line practitioners carrying out tasks additional to their usual work load, work was increasingly being undertaken by managers and meetings were focused in endorsing proposals and recommendations. Having previously been a very task focused group, taking on the role of endorsing pre-determined recommendations appeared to become less appealing to a number of those involved and their attendance and involvement became less frequent and consistent.

Additionally, prior to the inclusion of managers, Quality Group meetings had presented as encouraging balanced contributions from all members with the clinicians in particular being concerned with ensuring that Community Reference Group members were able to understand and take part in the business of meetings. Equally, the group had expressed a commitment to identifying and acting on locally perceived need. As membership changed so did the dynamics of meetings. They became more formal with the agenda focusing on the presentation of recommendations that were in final rather than early stages of development. One of the Community Reference Group members actually noted that it had become harder to contribute at meetings since the membership had changed.

INVOLVEMENT IN ACTION

Examination of structures and processes can identify various factors that have implications for involving patients and members of the public but these are best demonstrated by discussing actual examples of involvement activities. It was evident that the PCG had at least attempted to address the issue of involvement - consultation exercises, the inclusion of patient and public representation in the PCG structure, the relationship with the Community Health Council, the role of the lay Board member and my own role as Community Development and Partnerships Officer were all examples of this. However, as the following examples highlight little attention seems to have been paid to negotiating and agreeing outcomes in respect of involvement and as a result there were inconsistencies in what was achieved. While there appeared to be the beginnings of an infrastructure for involvement, there also appeared to be only limited attention being given to learning from and developing this and as such, activities might be viewed simply as a means of complying with national guidance rather than a commitment to integrating them into decision-making processes.

Involvement in action – example one

The issue of access to GP appointments had been discussed at Community Reference Group meetings on a number of occasions. That this was a priority area in the *NHS Plan* was perhaps not coincidental. Nevertheless, the Quality Group had expressed enthusiasm for working with the Community Reference Group to identify the nature and scale of the problem. It had been agreed to survey GP practices and patients and the Community Reference Group was asked to advise on the way in which the patient survey would be framed and how it would be distributed.

Community Reference Group and Quality Group members worked together to develop both the content of the survey and the method of distribution. Having agreed that the method would be face-to-face interviews and that patients might be encouraged to respond to a request from the Reference Group rather than their own practice staff, members went so far as to offer their own time outside of meetings to facilitate this. The timing of this piece of work was considered crucial in order to capture a broad range of views and it was decided to wait until the end of the summer and begin the survey in October. As October came and went the

group were increasingly keen to know when the survey would be undertaken and, asking for an update on progress, were told that the PCG had become involved in a national pilot scheme to address GP access issues and that it would no longer be necessary to continue with the work.

During the period between the Community Reference Group and the Quality Group agreeing to undertake work on this issue and the proposed start of the survey, the PCG had been given the opportunity to participate in a national pilot. The Community Reference Group had neither been informed of, nor involved in, the decision to take part in the pilot scheme nor given the opportunity to comment on or contribute to the work involved. It was clear that either account had not been taken of the work undertaken by the two groups or that those concerned with developing the pilot locally had been unaware of its existence. In either context, consideration appeared not to have been given to involving patients and the public in the initiative.

The apparent lack of co-ordination within the PCG suggested a degree of dislocation in the structure and somewhat fragmented planning processes. This had clearly constrained local involvement in this instance and made it difficult, if not impossible, to contribute and subsequently influence decisions given that people were not aware of how or where they were being made. By the time information was made available on the pilot project, several discussions and a plan of action had already been agreed between the Community Reference Group and the Quality Group. To inform the group that this work was being dropped in favour of taking part in a national initiative, particularly when it was so far advanced, without their involvement might at best be seen as an oversight, at worst a devaluing of the role that the Community Reference Group could play.

In this particular example, while the final outcome in respect of improving access to GP appointments might have been the same irrespective of the process, the outcome from the point of view of involving the Community Reference Group had been thwarted.

While the absence of a co-ordinated approach to involvement was a significant factor in this example, in many respects, the input of the Community Reference Group was also overshadowed by what Lupton (1998:123-125) describes as the predominance of the experts and the power imbalance created by different levels of importance being attached to different perspectives. That decisions had been

made without reference to the Quality and Community Reference Groups suggests that control over the level of involvement available was still beyond the scope of the very structure intended to foster the inclusion of a wider range of stakeholders. The following example describes how these different levels of power were also evident on a much larger scale.

Involvement in action – example two

Towards the end of 2001, a major review of acute hospital services was announced in response to the need to deliver the national agenda on waiting list targets for inpatient and out patient treatment. Significantly, while the local health authority had responsibility for this, an external consultant, who was also a consultant surgeon and an advisor to the Department of Health, had been brought in to oversee the review. An outcome of the review was to recommend that the two local Acute Hospital Trusts merged to achieve extra efficiency and create additional capacity. Public meetings were organised across the whole of the county to consult on these recommendations. The merger would have major implications for local people, the main concern being the access difficulties that would ensue if people had to travel further for treatment. The local public meeting was poorly attended although the issue of access was raised by the few who did attend.

At the Board meeting following the public meeting, the need to take account of the views of local patients was reinforced by the lay member who referred to public meetings disadvantaging the most vulnerable groups of people and advocated additional consultation being undertaken by the PCG. The use of the word “consultation” in this context is used advisedly and based on the discussions surrounding the review in question. Although there was agreement among Board members that some patients might be disadvantaged not only by using public meetings as the sole means of consultation but also by potential access problems if plans to merge the two Trusts went ahead, the general view was that decisions would be clinically driven and not necessarily compatible with patient views.

When the final recommendations were published, the report made clear that decisions had in fact been based primarily on clinical need but had taken account of a range of good ideas from local staff and others (Acute Services Review, County Durham and Darlington, February 2002). The report contained an appendix

outlining the staff and others involved in the consultation. Public meetings were not referred to in any great detail except to say that a range of local visits had been undertaken, but 194 named individuals were included as having had the opportunity to voice their opinions. Of the 194 named individuals, 178 were doctors, nurses, therapists or health service managers, five names had no designation beside them and 11 were described as patient representatives.

Discussing the position of the Board in relation to the review and the suggestion that more local consultation be undertaken, one Board member remarked that this would be an exercise aimed at keeping people informed about progress rather than raising false expectations about the influence that consultation could have. Summing up, the same Board member commented:

Consultation or communication, there is a difference. Don't kid people they are being consulted when decisions have already been made.

The review was acknowledged as having been undertaken primarily on the basis of clinical need and achieving the capacity to deliver on national waiting list targets and, although not stated explicitly, irrespective of the impact, in practical terms, this might have on the perceived access difficulties expressed by patients. Influencing the proposed merger of the two Acute Trusts involved was perceived as being beyond the influence of the PCG as implied by the statements reflecting that any involvement would at best be an information giving exercise. The outcome in this case exemplifies the limited influence that could be exerted by patients and members of the public but also the reluctance of the PCG to challenge either the outcomes or the process on behalf of their constituent populations.

Involvement in action – example three

At one of the Quality Group meetings during the latter stages of the study, a draft consent to examination and treatment policy was presented and generated lengthy discussion particularly from the Community Reference Group members. Concerns were expressed regarding the document not being patient friendly because of the inclusion of technical terms and questions were asked about the use of phrases such as "informed" consent and "sufficient information" and how these would be defined and applied in relation to ensuring patient understanding and awareness not only of the treatment or examination they were being offered but the implications of actually giving their consent. The overall view of the Community

Reference Group members was that the document appeared to be aimed at protecting professionals rather than patients.

The rights or wrongs of these arguments were not pursued in this study but significantly, these concerns were neither included in the minutes of the meeting nor recorded when the policy was presented to the PCG Board for approval. More importantly, there was no evidence that the policy had been altered to take account of these comments.

Assumptions about the value of contributions can in itself be detrimental to involving patients and members of the public. As Hyatt (1992:21) points out, you can't give people power, they have to take it. If people are frustrated by processes that lack clarity over the value and worth of their contributions and if demonstrable outcomes are not evident then it is not unrealistic to suggest that they will opt out of the process. The lack of attention paid to the views of the Community Reference Group members is perhaps another example where management processes had confounded involvement by failing to negotiate and agree a collective understanding of and commitment to enabling the patient and public perspective to be included.

Involvement in action – example four

During the time of the study, the local Acute Trust had decided to reduce the opening hours of the local minor injuries unit. The Community Reference Group had raised the issue of access to the minor injuries unit on a number of occasions and had been reassured that a review of the service was imminent and that when it was undertaken there would be public input. When the proposal to reduce opening hours prior to this review was brought to the PCG Board meeting for approval, the Acute Trust representative presenting the report was very clear that the statutory duty to consult had been discharged by securing the agreement of the Community Health Council. Despite reminders from the lay Board member of the reassurances given to the Community Reference Group, the Acute Trust was adamant that no further consultation or public involvement exercises would be undertaken on the proposals. Ultimately, the decision of the Board was that they had would support the decision and took the line that a review of this service would still be undertaken and that the involvement of the Community Reference Group would remain a priority.

The dilemma for the PCG had been whether to support the recommendations of the Acute Trust and perpetuate the traditional approach to involvement that reliance on CHCs indicated or to delay approval until wider local consultation could be undertaken. Despite the recommendation of the lay member of the Board that more local involvement should be undertaken, the final decision had been to approve the proposals without further consultation at that time.

This example poses questions surrounding the role of the PCG in justifying or defending decisions that they had not consulted on or involved local people in and the potential loss of confidence in the PCG given their promise to the Community Reference Group. There are equally, questions surrounding the value attached to the intervention of the lay Board member and the relationship between the Community Reference Group and the Community Health Council. How perceptions surrounding roles and responsibilities, and the importance attached to these had shaped involvement was very evident in this study.

Failure to agree on the ultimate purpose of involvement often results in decisions regarding the nature of involvement being made in an arbitrary fashion (Anderson, 2001:36–42). Examples of involvement during this study implied that these decisions were in many ways being made in an ad hoc manner with little evidence to suggest that they had been tailored to agreed outcomes. Specifically, how the role of the lay board member had been interpreted, the relationship with the CHC and attempts at consultation and involvement were co-ordinated or integrated into planning and decision-making was not clear. In addition, questions were raised in terms of how the context in which the PCG had framed involvement had shaped the way in which those with key roles responded or were allowed to respond to the issue of involvement. A key element of the introduction of PCGs was that they would facilitate the inclusion of a range of managerial, lay and professional perspectives. Most importantly, PCGs were urged to act corporately and ensure that no individuals or groups of individuals dominated proceedings (HSC 1998/139, DoH 1998). The very diverse membership of PCG Boards however, might be seen as leaving them susceptible to being driven by majority interests.

DEVELOPING A CORPORATE IDENTITY

The government had made it clear that PCGs were intended to ensure a diversity of interests were represented on PCG Boards; that there would be active social services support in developing joint approaches to health and social care; that there would be public accountability and public confidence in the governing arrangements and that the Board would be large enough to include a range of skills, knowledge and experience but not so large as to be unworkable (ibid). Yet despite this, there was also the intention to ensure that family doctors and nurses would be in the lead. Lay membership on the Board was intended to foster local opportunities for public involvement and scrutiny of strategic and operational decisions rather than as a mechanism for representing patient and public interests. Recognising that joint governance would be a new experience for many of those involved as Board members, very clear guidance was given about the expectation that PCG Boards would share governing responsibilities and secure joint ownership of decisions reached (HSC 1998/139, DoH 1998:8-14).

In many respects, bringing together such a diverse group of people was not without risk. The experience of NHS Boards prior to 1990 had demonstrated the difficulties in reaching consensus decisions when a variety of perspectives were present. Until changes were made that introduced non-executive rather than lay members, Board members were seen as focusing on a representation role often associated with lay membership. The introduction of non-executive Board members rather than the traditional lay membership was seen as an attempt to move away from rubber-stamping and approving decisions made elsewhere and to encourage the development of a corporate identity and Board ownership of decision-making (Ferlie et al, 1996).

To an extent, PCG Board membership reflected this representational role by bringing together a variety of people each with a different perspective. The challenge was to capture this diversity and channel it into positive action. Notwithstanding the difficulties in achieving a corporate identity, the richness of debate that diversity could bring was the opportunity for PCGs to add texture to decision-making and develop an holistic model of health and health care planning. Achieving this would require setting aside the assumptions that often accompany different roles.

The existence of different interests is very evident in relation to health and health services, the issue is perhaps not so much about the existence of different interests but whether there is the opportunity for these to be expressed and represented and whether the introduction of PCGs had done anything to address this. The contribution that the medical profession makes in relation to policy implementation has been a major theme in the NHS. It is not surprising therefore that GP ownership of the PCG agenda was seen as crucial, and might account for the majority of board places being given to them. Securing this ownership however, would involve GPs in general, not just PCG Board members, recognising and understanding the wider context in which services were being delivered. According to the chair of this PCG, "GPs have the potential to turn around and say I'm not playing your game and this will not work without general practice".

Assuming Board level responsibilities would necessitate GPs taking on collective management responsibilities while continuing to work as practitioners. In addition, expectations of PCGs developing a corporate identity would demand shared decision-making rather than the autonomy enjoyed as independent contractors of service and a move away from their traditional operationally focused and patient centred roles. In many ways the position of the GPs on the Board was ambiguous; as part of the PCG they were both purchasers and providers of services and involvement in commissioning on a locality basis might well have been in conflict with the needs of their own individual practices. Specific to patient and public involvement, there was the belief that this was uncharted territory for GPs given their relatively poor track record in respect of this (Audit Commission, 1996).

General Practitioners were very significant players and without their commitment the government's modernisation agenda could not work. The transition to thinking and planning in a corporate way across the PCG constituency required, as the chair of the PCG pointed out, an incremental approach that simply wasn't compatible with the timescales that PCGs were faced with.

Securing ownership of other professional interests was also perceived as difficult with both of the nurses referring to this as an aspect that was underdeveloped. As one of the nurses pointed out:

I would very much doubt that even a handful of them in the whole practice would know I was the Board nurse member of the PCG.

Given that all community nurses and members of allied professions such as physiotherapists and speech and language therapists had been given the opportunity to nominate and vote for their representatives, the perception that few colleagues knew who they were is perhaps surprising. More importantly perhaps was the issue of how effective this Board level representation could be if this group of practitioners were not engaging with their representatives.

The experiences of GP fund holding and the combined management and clinical role this had necessitated had highlighted a number of concerns that the introduction of PCGs had perhaps failed to address. Specifically, evidence from GP commissioning and total purchasing projects had indicated difficulties in terms of securing the involvement of all GPs but also in respect of the heavy demands placed on lead GPs (Ham, 1999: 65). Capacity was a significant issue in this PCG. Nurse board members, for example, were also front line practitioners with existing jobs who were expected to take on this additional role. A number of the GPs also referred to the time consuming nature of combining Board work with other roles, as this GP exemplified:

You know I've got three jobs and they all want me in different things. They're all pulling on my time as we go through this. I keep asking myself what do you commit yourself to? So I haven't got much time for gardening at the present.

As well as taking on board level management and governing responsibilities the practitioner representatives (GPs and nurses) were also confronted with expectations in respect of their own professional development. Complying with the standards included in National Service Frameworks, clinical governance and the NHS Plan was not only the responsibility of the PCG Board, individual practitioners were also expected to comply and this might be perceived as constraining the time, energy and motivation required for Board level commitment.

The issue of capacity might also have been a fundamental issue in establishing a PCG in the first place. In crafting a governing body that complied with the minimum composition set out by the government, this PCG had chosen to take advantage of the maximum number of General Practitioners but had only succeeded in recruiting six. This number was subsequently reduced to five as one of the GPs resigned in

the year preceding transition to Primary Care Trust status. In addition, despite having a high number of single-handed practitioners, it had not been possible to recruit any of them on to the Board.

The inclusion of Social Services on PCG Boards was intended to underpin the partnership between and integrate the services of primary and social care. This relationship, however, was a somewhat complex issue. Although the local authority had nominated an officer they considered to be an appropriate representative, Social Services were organised around countywide boundaries at odds with the local district wide constituency of the PCG. The Social Services member reflected that involvement in decision-making at a local level was compromised by having to get central approval before making any commitments and more specifically noted:

I think to a certain extent, Social Services representatives may be a little bit hide-bound or maybe a little bit inhibited by directives from their main body. The hindrance, as I see it, is it's difficult to commit without having to go back and check with the centre to make sure that commitment is allowed or allowable.

This perception might indeed imply the potential for a degree of compromise in the contribution of the Social Services member and add to the ambiguities of Board membership

The health authority non-executive Board member of the PCG had been nominated by and seen as the link between the health authority and the PCG that would ensure and report on issues of probity and accountability. This member might be considered as bringing the most experience of working at Board level and taking on a corporate role, given that these representatives by their very nature were already serving members on health authority boards.

Specific to this PCG, the issue of co-opted membership might be deemed a significant factor; the Board had a large number of co-opted members, some of whom had relatively more experience of working at Board level than a number of full Board members. The range of co-opted members included senior officers from the health authority, the local NHS Acute Trust, the local authority, the Ambulance Trust and the Community Health Council. When compared with the nurse members, both of whom were frontline practitioners, the lay member and a number of GP members, the relative experience of working at Board level of the co-opted

members might be seen as having the potential to influence or even undermine the contributions of those less experienced. Ultimately, the sheer numbers involved might have served to ensure that lay representation was overwhelmed.

Co-opted Board Members

The PCG Board had taken advantage of the power to co-opt members to the Board for their knowledge of specific areas of work. Guidance for PCGs was clear that co-opted members would be associate members and would not have voting rights. The PCG constitution went further and spoke of co-opted members being allowed to contribute during Board meetings only at the discretion of the Chair. Such direction would appear at odds with the notion of co-opted members contributing specific knowledge to assist with PCG tasks. Contributing only at the discretion of the Chair might well impact not only on developing a corporate identity and joint ownership of decisions but also the range and quality of debate if the power to veto input was used. Of the co-opted members interviewed, only one reflected on their relative position:

I think as a co-opted member, and this is probably one of the reasons for my lack of consistent attendance, is that co-opted members appear to be add-ons, afterthoughts.

That only one co-opted member commented on this is perhaps indicative of the relationships that had evolved. Other co-opted members either did not acknowledge the difference between themselves and full Board members or felt their contribution was as welcome and of equal value. Additionally, while the constitution of the PCG referred to reaching consensus decisions rather than the use of voting rights, the participation of co-opted members and their role in influencing these discussions and subsequent decision-making was never referred to. In practice, there was no evidence that during Board meetings co-opted members were viewed, or expected to participate, differently to full members.

Specific to patient and public involvement was the relationship between the Community Health Council co-opted member and the lay member. While Community Health Councils had traditionally taken on the role of patient "watchdog", the role of the lay member was very clearly seen as fostering opportunities for local involvement (HSC 1998/139, DoH 1998) not simply to act as

the local representative. How the two perspectives would be managed was, to a degree, dependent on both the confidence and understanding of the lay member as well as the relationship forged between Board members and how individual contributions were valued. Clinicians have often been criticised for their failure to accept the value of lay contributions. The hostility that these are often met with is on the basis that they undermine the traditional autonomy of medical professionals as they alone have the capacity, knowledge and expertise to make judgements about care (Baggott, 1998:132-159). How relationships developed would depend on a number of factors particularly, as the chief executive pointed out:

I suppose another factor in the PCG Board that will influence the level of input is the status of an individual. I think the position of the lay member is actually very different and you've got to have a very strong personality to be able to make a significant mark.

Achieving a corporate identity would suggest that all board members would contribute to the totality of the work being undertaken with individual input not restricted to any particular interest or speciality. Equally, acting corporately might assume sharing responsibility for identifying and achieving priorities and targets and shared governance of the organisation in terms of ensuring business was conducted in a manner compatible with guidance and expectations. Underpinning these responsibilities might also be the assumption that a set of shared values had been established and that attitudes and beliefs have been negotiated agreed and communicated. An examination of perceptions surrounding roles and responsibilities indicated that this was an aspect that would require particular attention given the different background and levels of experience among board members.

ROLES AND RESPONSIBILITIES

There have been significant changes in the nature of NHS Boards in recent years. As Klein (1995) notes, up until the early 1980s membership of NHS boards was designed to introduce greater representation, however, by the end of 1980, the argument that managerial and representative tasks were not compatible had resulted in the introduction of executive and non-executive members rather than representatives. Conservative management reforms had displaced the representation and consensus management arrangements introduced in 1974 by

replacing administration with management. While previously, health care professionals had been served and supported by administrators, in the new arrangements they would be managed (Nettleton, 1998:132).

The composition of PCG boards was in direct contrast to the non-executive and executive arrangements and the separation of management and representative roles that had previously existed. Primary Care Groups did however reflect the recommendations of the *Griffiths Report* (1983) that, wherever possible, responsibilities should be devolved and continued previous attempts to instil a management culture into the medical profession. There was however some interesting features inherent in PCG boards.

PCGs were, in many respects, virtual organisations. Their legal status was that of a committee of the local health authority and as such they were directly accountable to the health authority for their actions. Health authorities still had the power of veto over plans and were responsible for ensuring propriety and value for money. The health authority was responsible for decisions regarding delegated power and budgets albeit in agreement with their PCGs. The freedom to identify and achieve local priorities was therefore somewhat constrained by the nature of the PCG position in relation to the health authority but also by the national agenda. One board member summed this up as:

With PCGs, the Health Authority needs to balance letting them go, letting them have flexibility to deliver the Health Improvement Programme, while reflecting local needs but at the same time, to hold them accountable and make sure whatever the PCGs are doing is in the same direction of the national guidance

Notwithstanding this, PCGs had a significant role to play in terms of resource allocation and commissioning services. Indeed, as Ham (1999: 96) points out, PCGs were expected to take a greater responsibility in priority setting despite evidence that GPs were unwilling to engage with the rationing of care between patients. Primary Care Groups had three core functions:

- ┘ Addressing the health of the population
- ┘ Developing primary and community health services

┘ Commissioning secondary care services

As discussed in previous chapters, the medical profession has often been seen as reluctant to adopt anything other than medical models of health that focus on the diagnosis and treatment of ill health. If medical practitioners were to act as agents for change, what would this mean in terms of improving health and addressing inequalities.

In this study there appeared to be a continued focus on delivery of health services with few references to the wider health agenda that included health promotion and addressing inequalities. The GPs, who held a majority membership, retained a service-dominated view and spoke of delivering the best possible health services and providing primary care. One GP described the role of the board as:

Basically to provide primary care for the people and to try and make sure that that's of the highest quality available.

Additionally, the responsibility to strike a balance between what people would like to have and what people needed was expressed, implying that the PCG was still able to exercise control over decisions regarding perceived and real need.

The precise form of PCGs had been left flexible to reflect local circumstance and ensure a bottom up, developmental approach (DoH, 1997:32). It is perhaps precisely because of these somewhat fluid arrangements that differences existed in the perceptions of Board members. By their very nature, relatively fluid arrangements are susceptible to roles being shaped by the individuals involved and create the potential for ambiguity and confusion.

In general, reflections on the collective role and responsibilities of the PCG Board ranged from very clear concise accounts of strategic decision-making, ensuring the PCG met its obligations in relation to the wider health agenda, achieving best value and financial probity to relatively abstract accounts such as "moving things forward" and "serving the population" as two board members described.

These different views were in many respects linked with the individual's experience of operating at Board level. The different views perhaps also highlight the difficulties encountered when attempting to develop a corporate identity in the presence of

such a diverse group of people. The two nurses, for example, who admitted to having very little experience of working at Board level, provided very simple definitions of the role and responsibilities, describing the PCG as an approachable group that could move things forward and an opportunity to get nurses involved in making decisions that they had never been included in before. The perceptions of the GP members were in most cases focused on descriptions of providing or supporting primary care, ensuring the best possible services and finding the balance between what people would like and what is needed.

Those who might be deemed to have relatively more experience of working at Board level placed very clear emphasis on governance and strategic development. In contrast, the view of one member was that:

I sometimes think it's just like a rubber stamp process.

The perception of the Board as a rubber-stamping mechanism raises the question of where decisions were actually being made and views on this were varied. Some members clearly saw the Chief Executive and the Chair as the ultimate decision-makers and others felt that one or two individuals led debate at Board meetings. Both of these views imply processes at odds with the guidance that individuals or groups of individuals should not dominate PCG proceedings (HSC 1998/139, DoH 1998:8-14). One co-opted member in particular pointed out:

It would appear to me that the debates that I've been party to have been significantly led by one or two individuals and I wouldn't necessarily call it a democratic system. Whether it ever will be or whether it ever can be is a debating point.

The various interpretations of the role of the Board in many ways reflect the relative awareness of members of the powers and influence vested in the governing bodies of PGGs. Although this had to be balanced with the relationship and accountability to health authorities, PCGs were still considered to have a significant influence in how health and health services would be developed locally.

Individual Roles and Responsibilities

The changes to NHS board membership heralded by *Working for Patients* had led to managers being appointed as executive directors and a small number of non-executive members appointed, not because of their links to, or membership of, designated organisations but for their personal contribution (Ham, 1999:37). In contrast, members of PCG boards were selected precisely because of their links to particular interest groups.

The interpretation of individual roles and responsibilities were consistent with the expectation that members would bring their own lay and professional perspectives. Individual members all referred to responsibilities in an advisory, technical or professional capacity. Despite this, there still appeared to be a sense of uncertainty among some members who spoke of the need to support each other, in the case of the nurses, and some GPs who saw their individual role as simply to carry on doing what they had always done.

In attempting to create an holistic process for improving health and health services, PCGs were intended to bring together the perspectives of the various groups of people involved in planning, delivering and using them. In this PCG there was an implied role not simply to make sure the different perspectives were taken account of but of "fighting one's own corner". Nurses spoke of raising the profile of nursing while GPs referred to promoting the difficulties experienced in general practice and making sure that the things being planned were practical and achievable. The perception of one of the nurses was:

Individually, I'm there as one of two nurse members to try and bring along issues, from the nurse reference group and any other channels, queries and questions and also to feed back on what the PCG decides. To be there in a supportive role as well towards the other nurse member in the PCG Group because I think we need to stick together.

Equally, the view of one GP was that they were there to provide the clinical angle but also to highlight service problems relating to general practice and introduce a bottom up approach in relation to general practice issues.

A key element of the role of individuals was supposed to bring to the Board not just the perspectives of Board members but also those of the wider PCG. Yet only a few

people made reference to the wider group of people they were technically representing, those that did reflected on the difficulties in engaging with them. As one member pointed out:

You'll always get the people who don't want to know and don't want to get involved and just get on working in their own little environment.

A consistent feature in the NHS has been the perceived dominance of the medical profession and various reorganisations in the NHS have attempted to address this. Whether the 1997 reforms could, or would, support a more even distribution of power is questionable. Ham (1999: 64) describes the rationale behind the introduction of PCGs as being a means of empowering GPs, community nurses and others to bring about improvements for their patients. The *New NHS* explicitly referred to the intention to delegate decision-making to those who were closer to patients while also promising patients and members of the public more power and influence over health and health services. Baggott (1998: 158-159), as noted earlier, argues that, in terms of increasing opportunities for local people to influence decisions, delegating decision-making to a local level is ironic in that the medical profession is most powerful at this level.

The issue of perceived inequalities in levels of influence was evident and nurse members in particular, expressed the opinion that while they were able to do so much, GPs could do so much more. Equally, as another member pointed out, the traditional divide between the status of nurses and doctors was always present:

Distinctions continue to be drawn between the GPs who are culturally in the driving seat. That's not a phenomenon of the PCG but comes from the culture of the health service, the doctor always comes out on top.

Constructing Roles and Responsibilities

The perceived level of influence held by individuals was a major theme when discussing roles and responsibilities and several members referred to it. While there were a number of indications that the role of individuals had been constructed according to their own background and experience, there was also evidence that to an extent, the roles and responsibilities of certain members had been shaped by the context in which they were working.

Individual PCG Board members came with a variety of roles, some of which might be deemed as conflicting, confusing or ambiguous. The relationships that are forged and associated expectations are often governed by how these roles are seen by others. Perceptions about the relative influence of individual Board members, conflicts of interest and examples of Board members either withdrawing or being withdrawn were all evident in this study and this questions whether a corporate identity had, or could have, been achieved. These conscious or unconscious assumptions about the role of individuals might also suggest that the way in which PCGs had been organised would have implications for the establishment of co-operative or collective working based on the sharing of skills and experience and compatible with a national agenda attempting to introduce a broader range of perspectives into decision-making. As Dahl (1968) would argue, it is not always necessary to exercise power, simply believing that certain individuals or groups hold more power is often enough to influence behaviour.

The view of the nurse members was that the chief executive and the chair were responsible for setting the PCG agenda and this might imply a self-fulfilling prophecy by accepting that some members had more influence than others. The historic difference in status between doctors and nurses was further complicated in this study by one of the nurses being an employee of another Board member and the other an employee of an NHS Trust responsible for delivering many of the services commissioned by the PCG. The complexities of these relationships and the impact they could have were particularly evident in examples where nurses felt that they were not able to contribute as equal members of the Board without their objectivity being questioned.

Despite a number of comments being made about the traditional status of doctors and nurses, the GP members made no reference to this and were the only group not to speak of other Board members in terms of relative influence. A non-GP member however reflected on the comparative status of managers and clinicians describing managers as “culturally, not so high in the pecking order” compared with General Practitioners.

In addition, describing the chair as a very strong personality who, along with the chief executive, provided leadership, one member referred to this as dominating proceedings, particularly at Board meetings, and having a significant impact on

whether or not others could contribute to the agenda. In contrast, another member saw this as a major strength that had led to more being achieved by this PCG than in many other PCGs.

Only a few people mentioned the role of the Board in relation to patient and public involvement and yet significant differences were evident in the interpretation of this. While the lay member felt that her role was to be “representative” of the community while the Community Health Council co-opted member spoke of “representing” patients and the wider public. Nurses also spoke of representing patients and their role as a “go between” or “in between lay person, between the doctors and patients”.

Inherent in these different interpretations are the very distinctive models they imply. The representing role suggested by being the “public voice” almost reinforces a somewhat traditional “proxy” representation, while the “representative” role described by the lay member appeared to be associated with the notion of bringing a patient and public focus to discussions rather than speaking on their behalf. One Board member referred to this when reflecting on the role of the lay member:

She [lay member] does have to keep reminding us. It's very easy to get blinkered into your own professional way of doing things and not keep coming back to what we are doing and why we are doing it. I think if she [lay member] did nothing else on the Board, she has to keep bringing us back to that all the time.

The lay member herself spoke of not representing local people but rather reflecting how issues that are discussed would affect the local population and the need therefore for the PCG to ensure they create structures that allow everyone who wants to be involved the opportunity to do so. The creation of these structures however appeared to rely on the relative priority given to the various tasks to be undertaken. As one Board member pointed out:

It's an easy issue to say, “well yes it's very important but we've got to do this, this week and maybe we'll think it about it next week”.

In relation to involving patients and members of the public, guidance for PCG boards had been very clear that this was not the sole responsibility of the lay

member. The primary aim of including lay membership had been to foster opportunities for involvement. How this was interpreted not only by lay members but also by other Board colleagues would be an important aspect in measuring the effectiveness of the opportunities fostered. Equally, that this member had been appointed rather than elected was perhaps an example of the control that the PCG, through the health authority, had retained at the expense of local democracy. Nevertheless, the way in which the role of the lay member had been constructed would be a key issue in the development of patient and public involvement. Equally important would be the way in which the role of the Community Health Council and my own role as the Community and Partnerships Development Officer had been interpreted.

The Role of the Lay Member

Aspirations for the role of the members of PCG Boards was arguably a key issue in relation to developing patient and public involvement. Simply including lay members does not necessarily shape involvement; a more important issue is the relationships that are forged and the way in which roles are interpreted (Callaghan and Wistow, 2002). The lay member in this PCG was very clear that she was not representing but was representative of local people while other members viewed the role more in terms of bringing a patient or public focus to discussions that were often clinically or professionally focused.

The role of the lay member however, was somewhat ambiguous. Described as a means of fostering opportunities for local involvement, for a number of Board members, this appeared to have been interpreted as simply reminding the Board of their responsibilities. Even this seemed to have been undermined by the relative importance attached to this aspect of the lay member's role. During Board meetings although frequent references were made to the need for further community involvement, these were rarely followed up and often not reported in the minutes of the meetings. Equally, while the lay member attended Community Reference Group and Quality Group meetings, they were never asked for reports from either of the groups in terms of patient and public feedback, nor was it offered voluntarily.

The inclusion of lay membership on PCG Boards was also intended to be a means of promoting cultural change (Anderson, 2001:29-42) and yet the value of a single lay perspective among a group of clinicians and managers is somewhat doubtful.

The potential to promote cultural change by the inclusion of lay representation will necessarily rely on the value placed on their contribution. Lay knowledge and experience is often defined negatively and used passively in terms of it not being professional knowledge, they are judged, not on the positive contribution they can make but on how representative they are (Hogg, 1999:84-110). How much of an impact an isolated individual can make when surrounded by professionals who perceive themselves as being able to make objective decisions based on their superior knowledge rather than the personal or anecdotal experience passed on by lay people is questionable (ibid).

While the role of the lay member was clearly important in relation to involving patients and the wider public, the lay member in this PCG expressed doubts about the value placed on this role. Describing a PCG seminar that was being planned to discuss application for Primary Care Trust (PCT) status, the lay member, in theory responsible for encouraging the involvement of patients and members of the public, had seen this as an opportunity to involve members of the Community Reference Group in planning for Trust status, and had suggested that members be invited. The suggestion, however, had apparently met resistance and, as the lay member explained:

It was the very first PCT seminar and I had said at the Community Reference Group "it's on at 2pm and everybody's welcome". But everybody wasn't welcome; it was very much for PCG Board members.

The reasons behind the decision not to include Community Reference Group members were not explored further and the example is used in this context simply to highlight the perception of the way in which the role of particular Board members might have been constrained by their perceived status. The example might also imply, however, that involvement had still not been embraced as a core part of PCG work and as such could not influence major decisions such as the application for independent Trust status.

The Role of the Community Health Council Member

During the time of the study, Community Health Councils (CHCs) were still in existence and the nature of their role provides an example of the complexity of the relationship between the providers and commissioners of services.

Established to provide a mechanism to keep people informed of NHS activities and to give a voice to local people, CHCs were aimed at enabling the views of different sections of the community to be heard (Hogg, 1999:109). A CHC representative was a co-opted member of the PCG Board but had made no attempt to forge a relationship with the Community Reference Group and, as the earlier example demonstrates, when the CHC was consulted on proposals to reduce the availability of the minor injuries service there was no evidence to suggest that this had been the subject of wider consultation with local people.

There was little indication that the CHC member had developed a relationship with the lay member but rather their very different views on their roles had served to keep them at opposite ends of the scale - while the lay member considered their role to be facilitating involvement, the CHC member felt that they were representing the public. This situation clearly placed the PCG in an ambiguous position when attempting to balance the statutory rights in relation to CHCs, and other NHS organisations reliance on this, with their attempts to introduce local arrangements.

The Role of the Community and Partnership Development Officer

Practitioner research not only unearths issues in relation to the practice of others but also the researcher's own practice. Examining structures and processes in action highlighted a number of issues directly linked to the interpretation of my role and how this had perhaps shaped my own practice. The role of the Community and Partnerships Development Officer had been developed prior to the introduction of PCGs and was a legacy of earlier policies seeking to develop greater joint working between health and social care agencies. Prior to the establishment of PCGs, my role had largely been focused on the development and support of planning groups that would contribute to the production of local Community Care Plans developed in partnership with social services, the local authority, voluntary organisations and local people.

Community Care Plans were focused around a number of key areas including services for older people, mental health, learning disability, physical disability, children and carers. The work undertaken had resulted in the establishment of multi-disciplinary groups relating to the development and delivery of these services and whose membership included representatives (including lay members) from

those sectors mentioned above. The process had been considered to be successful and a model that the newly established PCG could build on in terms of both partnership working and patient and public involvement.

Reflecting on my own role in terms of developing and supporting patient and public involvement in the PCG, this research identified that it had, to a large degree, been limited to identifying and advising on the necessity for and mechanisms to facilitate involvement and developing opportunities. Whether any account was taken of the advice, or the opportunities capitalised on, depended on the way in which my role had been constructed and the subsequent impact it would have on the nature of involvement.

When reflecting on examples of opportunities to involve local people that had not been converted into tangible outcomes, questions surrounding my own role were raised. Despite having a job description that made explicit reference to the development of patient and public involvement, how this was to be undertaken and supported within the PCG had never been discussed, negotiated or agreed. This had resulted in the role evolving into one that would develop opportunities for involvement but failed to address weaknesses surrounding the absence of agreed outcomes and only limited attention being paid to patient and public contributions.

In explaining how roles evolve, Dalrymple and Burke (1995:10) subscribe to the view that it is often the context in which we work that shapes the construction of our roles. PCG Board members, while advocating the desirability of patient and public involvement had concerns over how feasible this was. These concerns reflected the various dimensions of the role of the Board in relation to patient and public involvement. The various roles identified in the examples discussed earlier included justifying and supporting decisions made by partner organisations, such as the Acute Trust; managing the conflict between meeting national targets and locally perceived need; providing evidence of compliance with the national agenda for patient and public involvement and consulting on certain PCG plans. With these confused and often conflicting situations to manage, it is perhaps not surprising that the Board's responsibilities in relation to patient and public involvement and subsequently my own role had become blurred and difficult to establish.

Although certain Board members had referred to my presence and that of the lay Board member as being important this was often referred to in terms of introducing

a patient focus into otherwise clinically dominated discussions. Only one Board member referred to my work with the Community Reference Group being the most important of all the sub and reference groups:

The work that you're doing (the PCG Community and Partnerships Development Officer), the Community Reference Group and so on, actually, in my view, has more influence than any other group.

There was little evidence to suggest that this had made a case for patients and members of the public to be partners in decision-making rather than simply observers. Earlier discussions have referred to minutes of meetings that failed to record the contribution made by Community Reference Group members and the subsequent failure to bring the issues raised to the attention of the Board, particularly in respect of the consent to treatment and examination policy. As a participant in the meetings concerned and therefore privy to the discussions, it might be argued that I had a duty to draw this to the attention of the Board. It might equally be suggested that by not choosing this course of action, either consciously or unconsciously, I was colluding in processes that served to undermine attempts to include patient and public views. As a practitioner researcher it is important to reflect on why this was the case.

As the person in the PCG who "did" patient and public involvement, my work was linked to, and driven by, needs identified by a variety of people. Undertaking the study provided evidence that involvement was still a peripheral activity of the PCG that was relatively uncoordinated and often introduced during the later stages of planning and decision-making. While PCG Board members expressed commitment to involvement, in practice there appeared to be different levels of ownership. There was no real framework in which involvement sat and as a result, my own work had been allowed to develop in a similar manner. In particular, while I was attempting to champion and develop patient and public involvement in much broader terms, a large proportion of my work was taken up responding to requests for patient and public involvement to be arranged for specific issues.

Crucially, that the nature, level and outcome of involvement was never challenged, either by PCG Board or Community Reference Group members meant that these issues were never addressed. This aspect was also linked to the way in which I had attempted to develop my own role. From my perspective, my role was not to

advocate or mediate on behalf of patients and members of the public but to facilitate opportunities that would enable people to speak for themselves. Reflecting on the research highlighted the need to examine this way of working more closely and to seek absolute clarity on expectations surrounding the role I was being expecting to play.

THE COMMUNITY REFERENCE GROUP PERSPECTIVE

The Community Reference Group had been in existence for almost two years when members were asked their views on the role and responsibilities of the Primary Care Group. Despite the Community Reference Group being part of the PCG structure, most members admitted to being unclear about the role and responsibility of the Primary Care Group. Several members described themselves as having only a basic knowledge, being unsure of the role, wanting to know more, being unclear about this aspect of the PCG or simply making assumptions as the following responses exemplify:

I assume that they are making decisions and putting them into effect. They are people who know what they're doing as they are working in the health service.

I think it's about healthcare professionals coming together to discuss problems in the area and decide what can be done better. I only have a very basic understanding of what they actually do.

The PCG doesn't promote itself very well or very often in certain areas. The areas on the edge of the district are often passed by when services are planned or consultation undertaken.

I'm not fully aware of the role of the PCG and I'm interested but most people don't want to know unless it affects them personally. Then it becomes important to them to know how to get involved.

The view that people aren't interested or don't want to know unless or until it affects them personally is a common theme in respect of patient and public involvement and yet the local focus of PCGs presented an opportunity to address this issue. As Hogg (1999:95) points out, and the previous quote reinforces, people are more

interested in involvement if they feel decisions are directly relevant to them and they are likely to see an impact.

Primary Care Groups were focused on much smaller populations than health authorities and local people were more likely to identify with these smaller localities. The issue for the Community Reference Group was how the PCG promoted their presence and the nature of their responsibilities. Given the semi-rural nature of the area, a number of people referred to the fact that smaller geographical communities were often overlooked when any consultation activities were undertaken, for example. Equally, there was a view that it was the responsibility of the PCG to promote their role in health and health care as well as informing the expectations of people in terms of what was and was not possible to achieve.

Overall, while acknowledging that at least a basic understanding of PCG roles and responsibilities encouraged those who wanted to be involved, more importantly, from the Community Reference Group point of view, was that people were made aware that PCGs were accountable to them and that this should be acknowledged as a key responsibility for the PCG. Referred to by the majority of Community Reference Group members, this view was summed up by one who suggested that:

The biggest responsibility for the Board is to promote itself as accountable to the people. People don't always realise this and so don't get involved.

Hogg (1999:84) suggests it has become increasingly difficult to become involved in the planning and monitoring of health and health services because of complicated new structures. The number of bodies involved in purchasing or providing health can prevent the involvement of local people because they are not sure where or how decisions are made and are therefore not convinced that their views will make a difference. In responding to the patient and public involvement agenda, a key issue would be whether the introduction of more local bodies such as PCGs would make a difference. The responses from Community Reference Group members suggest that this clarity over the role and responsibilities of local NHS bodies had not yet been achieved.

CONCLUSION

By examining structures and processes in action and the extent to which this had been shaped by perceptions of roles and responsibilities a number of key issues were identified as being in need of attention if patient and public involvement is to be developed as an integral part of decision-making.

Power and influence can be distributed and mobilised in a number of ways and the structures and processes in place in this PCG, whether intentional or unintentional, displayed a number of characteristics evident in two-dimensional theories of power. Even though the PCG structure implied a co-ordinated approach, the processes in operation had clearly affected how patient and public input could or should be incorporated and subsequently had weakened the impact that could have been achieved. Fragmented and disjointed structures and processes make it difficult to establish where decisions are actually being made and this is compounded by undertaking involvement activities but failing to take account of the contribution made by patients and members of the public. In the examples of activity highlighted in this study, involvement was arguably a one-way process whereby views were sought but not necessarily acted upon. Subsequently, the ultimate aim of democratic involvement, to be party to decision-making or at least be able to question and call to account those making decisions, had been compromised by the existence of structures and processes that allowed the PCG to retain control over the issues raised and decisions made.

The distinction made between 'professional' and 'community' interests, particularly where more emphasis is given, and importance attached, to the professional and managerial perspective than that of patients and the public adds further complexity. Power can be mobilised in a number of ways that are not necessarily deliberate but more by default. Specifically, in this study there were examples of decisions being made based purely on clinical need, meetings that were framed in professional and managerial priorities, the use of jargon and technical terms, low priority being given to patient and public involvement or even disregarded and exclusion from certain parts of structures and processes. While the establishment of the PCG had brought decision-making closer to local people it appeared to have done little to enable local people to contribute.

The implementation of structures and processes that are insensitive to facilitating the involvement of patients and the public are often a symptom of the way in which roles and responsibilities are constructed. It is arguably the absence of discussion and negotiation to reach mutual agreement over roles and responsibilities that perpetuates the role conditioning evident in three-dimensional power theories by allowing “expert” or power by “reputation” to flourish. Although a key issue in the NHS has been reconciling the different interests of stakeholders and achieving a more balanced distribution of power, different levels of influence were still evident among PCG board members in this study. Whether real or perceived, it is perhaps inevitable that this would ultimately impact on the influence that patients and members of the public could bring to bear. Equally, as with other policy and reform in the NHS, changes in levels of influence continued to be within and between the medical profession and managers with little evidence to suggest that any change had been effected in the level of power that patients and members of the public could exercise. While intending to introduce a wider perspective into decision-making, the diverse membership of the Board appeared to add to the complexity of decision-making processes. The position of individuals was in some cases perceived as ambiguous, confused or conflicting. Several references to the traditional role of members indicated that, either consciously or unconsciously, the transition had not been made from a group of people with different interests to a corporate body.

Structures and processes are a key factor in facilitating people to take part in decision-making and at a local level PCGs had considerable influence in determining the structures and processes that were put in place. While this chapter has explored structures and processes in the context of whether they were helping or hindering involvement and how they had perhaps been shaped by the construction of roles and responsibilities, it is equally important to understand the extent to which the development of these were influenced by perceptions surrounding the purpose of involvement and the different assumptions that underpin the various intentions. The following chapter explores these perceptions and their impact on the development of strategies for involving patients and the public.

CHAPTER FIVE

INTENT, IMPLEMENTATION AND IMPACT

INTRODUCTION

Realism about the level of involvement possible is especially important if people are not to feel let down by the process (Anderson, 2001:36). The *New NHS* had advocated two levels; not only the right to see the basis on which decisions were made but also the right to influence those decisions and shape the way in which health and health services were developed. This chapter explores perceptions surrounding the purpose of involvement including issues such as who, how and when and examines the extent to which these had shaped the structures and processes discussed in the previous chapter and subsequently the way in which involvement had evolved.

The chapter particularly examines how each of these aspects can be used as instruments to develop or limit involvement, and subsequently affect the level of power and influence that can be exercised by patients and the public. Finally, the chapter discusses views and aspirations in relation to the impact that involving local people could make and the resulting outcomes.

Discussion in this chapter draws on data from semi-structured interviews with PCG Board and co-opted members, and members of the PCG Community Reference Group when the following questions were asked:

- Should patients and members of the public be involved in the work of the PCG?
- └ If so why should they be involved (if not, why not)?
- How should or could patients and members of the public be involved?
- └ Who should be involved?
- └ What can patients and members of the public contribute?
- └ What impact can involvement have?

DEVELOPING INVOLVEMENT STRATEGIES

Although it has been suggested that PCGs offered real opportunities for involvement because of their closeness to the populations they served (Anderson, 2001:29-42), it can be this very this proximity that engenders a reluctance to be too open, too soon. With people more likely to be interested in being involved if they feel issues are relevant to them and where they are likely to see an impact, if the impact is perceived as negative it can result in conflict and contentious debate that is not always welcomed or felt to be productive. Previous experiences of public interest in this study had clearly resulted in a reluctance to become embroiled in the contentious debate that ensues when choices are made that are not compatible with local opinion. This had perhaps influenced decisions on who, when and how people would be involved.

The debate between involvement as an incremental approach or as a spectrum that offers a variety of opportunities for people to take part in as they wished was also evident in this study. The difficulties in reconciling a spectrum of opportunities with the need to develop a coherent power base for patients and the public however remains. With multiple perspectives on need and priorities, developing complimentary approaches and mechanisms that enable negotiation between the different stakeholders and their diverse interests might prove difficult. While Community Reference Group and certain Board members saw the need to tailor developments to provide various levels of involvement, this might result in a fragmentation that is arguably counter productive if the patient and public voice is to be organised in a way that is sufficiently cohesive to challenge the highly organised way in which NHS bodies present their views.

There was also evidence of a somewhat selective approach to involvement implied by references to the capacity, knowledge and interest that patients and members of the public would need to develop if they were to be involved. It was difficult to establish, however, whether this was a result of the somewhat limited experience of involvement admitted to by certain Board members or indeed the opposite – that previous experience had instilled a level of cynicism that supported selective involvement rather than face potential conflict.

Agreement, or the absence of agreement, on the purpose of involving patients and local people can have a major impact on how it evolves in practice. There are

however, many other factors that are equally important if the links between intentions, implementation and outcomes are to be established. The issues of who, how and when are also crucial to developing strategies that result in mutually agreed outcomes.

While all of those involved in this study agreed that the involvement of patients and members of the public was desirable, accounts of why they should be involved varied considerably. These variations were reflected in subsequent views on who, how and when. Views on how people should, or could, be involved suggested that the PCG was more enthusiastic about developing models of involvement that would enable patients and members of the public to be included in organisationally determined frameworks rather than facilitating a process where mutually acceptable structures and processes were negotiated and agreed. This was reinforced by attitudes to information, knowledge and capacity, which were variously used to support the need to involve local people or to justify not involving them. That such perceptions existed might be an indication that PCGs were still able to control how people were involved. In particular, there were some PCG Board members who considered that before patient and public involvement could be developed, the PCG had first to engage with local GPs and their practices. This is perhaps an indication of where priorities might be directed and also a further reinforcement of the importance attached to the medical profession compared with patients and local people.

Perceptions surrounding who should be involved also varied and question the understanding of issues such as the legitimacy on which involvement is based. In particular, no distinctions were made between patients and members of the wider public but distinctions were evident in accounts that referred to 'people who have an axe to grind', 'knowledgeable' people and those who were 'interested'.

Ultimately, all of these factors would have implications for the outcome of involvement activities and the impact they could have on decision-making. They were also instrumental in explaining the way in which involvement had been facilitated in the structures and processes discussed in the previous chapter.

INTENT

Discussing the issues surrounding why people should, or should not, be involved were aimed at exploring PCG and Community Reference Group perceptions of the rationale for, and purpose of, involvement. As it is likely that the ultimate purpose of involvement will be fundamental to subsequent decisions about who, when, and how people should be involved this is a key issue. The *New NHS* (DoH, 1997) referred to patient and public involvement as a means of renewing public confidence by increasing transparency and accountability, communicating with the public and ensuring public involvement in decision-making about local health services. Despite the rhetoric of the *New NHS*, as earlier chapters have discussed, it is by no means certain that the medical professional and NHS managers have engaged with policy surrounding the involvement of local people in decision-making.

The *New NHS* also indicated that there would be a continued emphasis on the role of patients as consumers but that this should be combined with the development of democratic mechanisms that enabled people to have more influence over decision-making in health and health care. Despite referring to this combined approach, there were still two distinct approaches being adopted by PCGs in relation to the focus of their work, the health service model and the health improvement model (Callaghan and Wistow, 2002:10-11). While the health service model relates to seeking the views of those with experience of services and levels of satisfaction with them, the health improvement model is more centred around the involvement of the wider public and has a much wider role in terms of citizenship and promoting health through the actual process of involvement. As in Callaghan and Wistow's study, this PCG was not strictly speaking one or the other and there was evidence of both models in accounts of why local people should be involved. This dual approach however has implications for the implementation of strategies for involvement.

In many respects, governmental pressure to develop involvement means that the motivation behind an organisation's attempts to engage is not always clear. As Klein (1995:238) points out, the drive towards increased patient and public involvement in health care policy and reform can be seen as a top down agenda that might subsequently lack commitment at a local level. Despite this, all of those interviewed agreed that patients and members of the wider public should be

involved. There was, however, little evidence to suggest that the purpose of involvement had been negotiated and agreed among Board members.

Four main themes were evident in relation to why the PCG should engage with patients and members of the wider public:

1. Encouraging people to take responsibility for their own health and in the use of health services;
2. Educating people in the complexities of the health service and mobilising support for PCG decisions and the difficulties of prioritisation;
3. Securing best value;
4. Improving decision-making.

Each of these perspectives however, is underpinned by different assumptions and it is necessary to acknowledge this if clarity in terms of outcomes is to be achieved.

1. Encouraging people to take responsibility for their own health

Encouraging people to take responsibility for their own health and involving them in health education and promotion acknowledges people as producers of health and not simply users of health services. Reflecting a partnership approach, constructing involvement in this way sees people not only as passive recipients of services but as part of a team that promotes and improves health. Confusion, however, arises when this philosophy is linked with educating people in better use of health services. The motivation behind involvement then becomes less clear and might depend on whether this education is in the interests of patients and the public or those of the medical profession and NHS managers concerned with cost effectiveness and efficiency. While the former is more concerned with people and how they view and receive not only health services but also the broader determinants of health, the latter might be argued as being focused on organisational and management issues.

Several Board members had referred to encouraging people to take responsibility for their own health as crucial to making better use of services and subsequently reducing demand. One Board member suggested that:

The health service is not just about provision of health services, it's about health improvement and you've done enough to convince me that health improvement best comes from involvement of people in thinking through the issues, I think you dress it up as empowerment

Another Board member referred to "The more people understand the complexity of the health service, the better use they make of it". While not necessarily incompatible, how involvement is framed might well depend on the relative emphasis given to why people should take responsibility for their own health. Specifically, there are questions over whether the main aim is to empower people to take control of their lives or to contribute to achieving pre-determined targets in relation to reducing waiting lists, for example. This tension between local and nationally perceived priorities reflects the often-competing nature of these two agendas.

2. Educating people in the complexities of the health service and mobilising support for PCG decisions and the difficulties of prioritisation

Referring to the need to mobilise support for the difficulties that the PCG experienced in terms of resource constraints one Board member pointed out that:

If you actually educated people appropriately, if they knew the choices we were making, the choices we have to make because of the finite budgets, because of the demands on service, because of capacity issues with personnel, I think that the community actually would be quite supportive.

This mobilisation of support for pre-determined decisions is often the most contentious aspect of engaging with communities. By its very nature, seeking support for decisions that have already been made, regardless of how difficult these decisions have been to make, implies that priorities, and the means to achieve them, have been defined not by communities but by professionals. With the ultimate aim of validating decision-making, the assumption underpinning this model is that, while taking account of local views, managers have to be left to manage (Hogg, 1999:109).

3. Achieving best value

A number of Board members spoke of involvement in terms of consumerism and improving the quality and appropriateness of health services. The assumption was that those who provided or commissioned services needed to know whether these services were meeting the expectations of those using them. Two main reasons were suggested for involving people; firstly, if services are not meeting the needs of patients then the likelihood is that they won't be used to their best advantage and will therefore not be cost effective and secondly that the quality of services can best be improved if information is available on how they are perceived by recipients. As one Board member pointed out:

If they're not involved in the planning process, how are we going to get best value for our money? We could be planning something that the community won't use and is not relevant to them.

While this approach to involvement suggests an emphasis on consumerism - organisations seeking the views of those who use services in order to enhance or improve them – there were also references to the need to access information about the experience of living in the area. This approach lends itself to more democratic models that see involvement not just as the prerogative of those who use services but as the right of all citizens. As another Board member pointed out:

They can speak up for themselves and the rest of the people in the area and I suppose their local knowledge and an understanding of how the area has gone through the changes. If you're not local, if you haven't been here for twenty years you've never seen the Steel Company and the morale that was around then. You haven't got a real hold on the community unless you've been here for a little while.

Both of these perspectives are equally relevant but reflect different approaches, are underpinned by different assumptions and have different implications for the model of involvement developed. While consumerist models are characterised by separate, discrete episodes of involvement, democratic models lean more towards a developmental process that encourages people to broaden their perspectives and experience through collective action (Lupton et al, 1998:46)

Equally, the two views reflect the difference between models that are health service centred and those that focus on health improvement in a wider sense. While the former concentrates on accessing views of current services and how they are perceived, the other is an attempt to gain a much broader understanding of the issues that impact on communities and their health relating as much to the wider determinants of health as to health services. As already noted, while not mutually exclusive they will have different implications when developing strategies for involvement, which in turn will depend on the relative priority given to each of these priorities.

4. Improving decision-making

Only one Board member spoke of involving people in actually making decisions and this on the basis that it was often the specific interests of clinicians that influenced how resources were allocated rather than real need. The same member reflected that, as the health service had become more technical with more complex decisions to be made regarding resource allocation, the involvement of the public was even more important in order to balance the views of clinicians and other professionals.

This need to involve local people in decision-making was based on the perception that professionals make decisions out of vested interests and decisions on resource allocation could therefore be unduly influenced. In the interests of impartiality, the final decision it was suggested should rest with the community:

I think it's vitally important that the public actually makes the final decision. Given that there'll always be limitations on resources then who should decide where those resources are allocated. I think that should be the community rather than an individual health professional who will always have their own axe to grind. Cardiologists always want it spent on cardiology, geriatricians always say we're the Cinderella service and we need the money.

Whether it was the intention of the *New NHS* to take involvement this far is not clear. Describing patients as having new powers and more influence over the way the NHS works (NHS Executive, 2000:12), the guidance made no reference to patients and members of the public having ultimate decision-making powers.

Actually making decisions and supporting pre-determined decisions are at opposite ends of a spectrum in terms of involvement. In between these two somewhat contradictory models is taking part in and having the ability to influence the decision making process. The differences between the approaches are significant.

Although there have been attempts to introduce ultimate decision-making as a model of involvement, this has proved to be a very complex process and has focused mainly on the use of cost benefit indicators. The measures used by these indicators, for example "Quality Adjusted Life Years", have been criticised because they fail to take into account the way in which quality of life is assessed by patients and carers (Carr Hill, 1991:236-249) and are relatively untried in this country as a means to involving local people in decision-making.

Asking members of the public and patients to make final decisions on resource allocation is potentially to create similar issues as those involved when professionals make decisions. The difference between "patients" and "members of the wider public" is perhaps one of the most obvious tensions that exist. The government defined "patients" as those currently using health services while "public" referred to the general public as citizens (*Patient and Public Involvement in the New NHS*, DOH 1999). By that very definition patients are likely to come with their own personal experience of, and interest in, particular services. Equally, members of the public are not a homogenous group and would not necessarily be able to step out of their own personal experience be this past, present, personal or anecdotal, in favour of making impartial decisions. If professionals have their own axe to grind it is possible that patients and members of the public might also have an axe to grind albeit a different axe.

In addition, if people are asked to make decisions then the basis on which these decisions are to be made must be established. Decisions can be made on a variety of criteria including, cost efficiency, quality of life, emotional reaction or simply the persuasive powers of the health professional making the case. The critical issue must surely then be consistency and clarity about the process.

To a greater or lesser degree there is a sense that, while not totally abrogating responsibility, leaving the final decision to members of the public in some ways passes it on to people who may or may not want or feel able to deal with these complex issues. It is perhaps significant that the catalyst for expressing the view

that the final decision should be made by the public was a letter of resignation from a member of the Community Reference Group who felt that the increasing complexity of the health services militated against the involvement of lay people.

In contrast, one Board member argued that patients and members of the public would not and could not take ultimate responsibility for decision-making. Questioning the role of involvement in relation to often complex planning processes this member suggested:

You know if we're talking about the establishment of an MRI scanner what does the general public know about the protocols, the needs, the revenue consequences of the capital scheme – nothing. They know that scanners are good and diagnose quicker so let's have them.

The challenge for the PCG was to negotiate an approach that allowed local people to take part in and influence planning processes. The issue then is no longer to do with individual knowledge but rather in sharing information and negotiating mutually acceptable outcomes. It was to this end that Community Reference Group members felt involvement should be targeted. Members of the group spoke of wanting to contribute to decision-making by putting forward the patient and public perspective and having this listened to and taken account of in planning and decision-making processes.

Views from the Community Reference Group

The Community Reference Group perspective was much simpler and a consensus had been achieved on the purpose of involvement. There was unanimous agreement that members of the public and patients should be involved in the work of the PCG and the reasons given were consistent. Specifically, that the experience of people who either lived or used services in the area was crucial if improvements to services were to be achieved but also that local accountability would be non-existent if local people were not involved.

Community Reference Group members referred to the knowledge and experience that people who are either residents of, or use services in, communities can bring to the decision-making process but also the need for local accountability mechanisms that encouraged citizenship as these two examples demonstrate:

People who live in the area are closer to community problems; we can identify things from a patient perspective and bring a general overview, not just medical issues. Also, it's about ownership and feeling part of society and not just second-class citizens.

Patients know their own personal circumstances and need to know the implications of decisions that are being made. Professionals have knowledge and skills that are different. It's local people who are using services and if they are involved it can take the emphasis off complaints and make contact with professionals more positive.

A number of Community Reference Group replies included reference to the need to take a balanced view of involvement and noted that there were limitations to expectations surrounding what patients and the public could or should be contributing. As one member exemplified:

There needs to be a line drawn between what the public is told and what the professionals know and do. It can be a disadvantage to know too much, the public can be more worried by knowing too much, so we should be involved but not at the highest level.

Overall, Community Reference Group views suggested an approach more compatible with a model of involvement that would acknowledge and respect the different contributions that individuals bring. Involvement should not be seen as one partner sacrificing control in the interests of another, but rather a sharing of the skills; knowledge and experience that results in mutually agreed outcomes.

Although perceptions surrounding the purpose of involvement varied, the *New NHS* (DoH, 1997) had also made a number of pledges including the renewal of public confidence by increasing transparency and accountability, communicating with the public and ensuring their involvement in decision-making about local health services. In achieving these expectations, PCGs would need strategies that encompassed a range of purposes if these promises were to be fulfilled.

IMPLEMENTATION

Irrespective of the purpose of involvement, the outcome of strategies for involvement will be influenced by the methods used and decisions regarding who is to be involved as well as how and when. While NHS policy is, in theory, agreed at a national level and is the result of negotiation between relevant stakeholders, implementation, as noted in chapter two, relies heavily on the medical profession and managers at a local level. In terms of implementing policy in relation to patient and public involvement, the questions asked of PCG Board and Community Reference Group members were particularly aimed at finding out the level of understanding of the relationship between models of involvement and how they would be shaped by the implementation of strategies to achieve the level aspired to. The purpose of involvement as described by the *New NHS*, implies two distinct models of involvement – a consumerist model that introduces choice, information and redress and a democratic model that has at its core the universal rights of citizens to be involved in decisions that affect their lives.

Although not mutually exclusive, these different models require different approaches to, and methods of, involvement. Those interviewed were asked how people should be involved and specifically who should be involved. The question of how people should be involved was linked to the theme of the nature of involvement and its use as either a management tool that enables organisations to identify the preferences of its consumers; a means to empower local people, involving them not only in identifying need but also being part of the solution; or simply a mechanism for legitimising predetermined decisions made on their behalf.

The issue of who should be involved is closely linked not only with the purpose of involvement but also the nature of the involvement on offer. If the purpose is consumerist in nature then who to involve is relatively straightforward - those who use, have used, or will potentially use services - because the focus will most likely be on services. If on the other hand, involvement is seen as an empowering exercise, it is the collective involvement of local people that will be the ultimate goal, enabling them to define issues of concern and be involved in identifying solutions. The emphasis in this would include a much broader view of health than just health services. More fundamentally perhaps is whether views on who should be involved are related to the development of mechanisms that facilitate a collective approach that will help to establish cohesive, rather than competitive contributions, patient

and public contributions. If, as Alford (1975) suggests, it is the absence of a power base that results in the continued repression of community interests, without attention to this at a local level, the ability of patients and members of the public to exercise influence can be compromised.

Achieving the “involvement” promised by the *New NHS* is arguably a very complex issue. Developing models of engagement that satisfy the needs of the very different groups of people in the community in terms of delivering promises of local involvement in decision-making, increased openness and transparency and communication with the public was a challenge that PCGs would have to rise to if they were serious about engaging people. Not only were they faced with bringing about the cultural change necessary to achieve commitment to engaging with communities but also the lack of tried and trusted models for the achievement of effective user involvement (Gillam and Brooks, 2001). Equally, in addressing the issue of why should people be involved, Hogg (1999:108-109) suggests that the question of why people bother to be involved should also be addressed. People may exert their right as citizens to give their views or not as they wish and they will vary in their motivation and ability to do so. The question of who should, or would want to, be involved and how this would be facilitated is therefore a key issue whichever method is favoured. Underpinning this issue is whether patients and members of the public would have a say in decisions on the models and methods employed or would the PCT have ultimate control.

While agreeing that patients and members of the public should be involved, several PCG Board members expressed reservations about the realities of patient and public involvement. These reservations ranged from explicit questions about the ability of members of the wider public to contribute in any practical way to acknowledging that while, in a democracy, everyone had the right to be involved in decisions that would or could affect them, there were issues about just how realistic this was in practical terms. As one Board member pointed out:

The process of getting people involved and people being enthusiastically involved is extremely time consuming and at the end of the day it calls into question why you have managers and Boards in the first place. Why pay a manager fifty thousand a year or whatever, when decisions are being taken by the general public? Whether you like it or not there is a way of working in organisations, which is there for good reason. Some times the reasons are

less good than others but you know we have to dance to the political tune, we have to recognise professional standards, requirements coming from the Royal Colleges of this, that and the other. All of which constrain the way we think.

Methods of Involving People

While some references were made to specific methods of involving people, there were also references to wider issues surrounding power, culture and organisational development. Recognition of the realities of involvement in terms of commitment, time and resources was evident but it was also apparent that some members were focused on the mechanics of involvement rather than outcomes. There was also evidence that involvement for some continued to be framed in terms set by the PCT agenda rather than those negotiated with patients and local communities. In many respects, reflections on the need for training, information and knowledge appeared to be based on the need to 'professionalise' people who wanted to be involved rather than establishing a shared appreciation of issues. Equally, there were a number of references to the need to engage with GPs and their practices before the patient and public involvement agenda could be developed. If this engagement was a pre-requisite for the involvement of local people it is perhaps an indication of where influence was being exercised at a local level in terms of helping or hindering the development of involvement.

The methods described for involving people included structured meetings, events where Board members met with the public, stakeholder presentations, networking with the voluntary and community groups in the area and sustaining the involvement of the Reference Groups already established by the PCT.

While there was little to suggest that any views on methods had been linked to expectations in relation to aims, objectives and outcomes, several Board members spoke of the developmental process necessary to encourage and support it as this examples demonstrates:

It's about creating an environment where they can take part and feel as though they can. It's almost having training for six months or a period where they can learn about how they can input into the PCG and the importance of that and what goes on in the PCG.

The growth in methods of involvement, as discussed in chapter two, has resulted in the production of a wealth of guidance on methods of involvement. While guidance on methods provides a very valuable source of reference, for newly established bodies such as PCGs simply presenting a menu of methods might be considered as doing little to encourage thinking about involvement as a developmental process. It is not surprising therefore that a number of different views existed on how to involve patients and the wider public.

Several Board members recognised that wider community and patient networks already existed and that these should be built on before any new structures were developed. As one member pointed out:

I think the only way of doing it is to keep going back to all the organisations we've got, I mean there are so many networks out there so many systems, that we have to keep going back to them.

The purpose of accessing these existing structures was twofold, firstly to capture the knowledge and information that was already held and secondly because the NHS was seen as always being in a state of change and the stability of any new structures was therefore questionable. With the move to Primary Care Trusts imminent, one Board member explained:

Maybe we need to wait and see how the Primary Care Trust works out and its structures before we can say exactly how we're going to involve the community.

Community Reference Group members were reluctant to identify methods and there was a general consensus that involvement should be tailored to particular issues so that the most appropriate mechanisms could be implemented in terms of who and how. Examples of these views are as follows:

Find issues that people are interested in, you can't generalise you must make it relevant. It takes time and is an incremental process

It needs to be context specific, particular things for particular people and related to personal experience

In discussing issues surrounding how to involve people, it appeared that to a greater or lesser extent, Board members views were focused on involving people in the PCT agenda while Community Reference Group perceptions suggested an attempt to turn attention to the particular interests of individuals and the wider community.

These different perspectives can present a dilemma when introducing mechanisms for involvement. Attempting to involve patients and members of the public in an already determined agenda rather than address the core concerns of those whose involvement is sought can result in failure (Brooks, 2001:1-13). This is primarily attributed to the very different nature of the issues of concern. While organisational discourse is most often concerned with policy, service organisation, management, efficiency and effectiveness, patients and members of the public are much more specifically and explicitly concerned with people's lives (Beresford, 1994:315-325).

If the potential for conflict in nature of these different agendas is not understood, strategies might be developed that, while continuing to consult on pre-determined issues, demand consistent commitment from those being consulted. If patients and members of the public question the value and quality of involvement, the issue of sustainability must be in doubt. While a number of those interviewed spoke of developing a shared approach to involvement and described it as an incremental process that would evolve over time, much of this was considered to depend on how comfortable PCGs, and their constituent GP practices, were with the concept. The chair of the PCG explained that:

I think it's mainly a culture thing, what are we happy sharing, I think that's a gradual process. I do think GPs, for instance, have come miles, they are sharing things between practices, they are still very wary about sharing things like prescribing information and referral information and budgets and things like that with members of the public. I think that will take time but it's building up trust and with a new organisation like the PCG people are worried that it is going to be used against them. So the trust is building up across practices, the next thing is building up that trust with the public.

This view is indicative of how *New NHS* policies had perhaps done little to address the relative priority given to engaging with the variety of stakeholders in the NHS.

From the Community Reference Group perspective, people had to feel that they were making a difference and that there was evidence that things were changing otherwise they wouldn't stay involved. Similarly and, according to the Chair of the PCG, as importantly, was the need to create a sense of ownership among constituent GPs because, as has previously been discussed, the reforms would not work without them. As the Chair of the PCG explained:

We are not a company, we do not have formal accountability to our shareholders right, but I'm not talking about shareholders as such, I'm talking about people who are members of this organisation. You've got to feel that it's better to be a part of this; it's better to be a member of this organisation than not to be a member.

In order to effect the cultural change and shared ownership that was required if patient and public involvement was not to remain at the margins of PCG work it was suggested that an incremental process had to be built in to allow the organisation to grow into its role and responsibilities. If the capacity to involve patients and members of the public was to be developed, attention had to be given to building up trust between clinicians who had traditionally worked autonomously before attempting to extend this to the wider community.

The Chair of the PCG was convinced that trust was beginning to be built up between the GPs and that they had begun to share information and decision-making. The next step would be to build up similar trust with patients and the public and begin to share information and involve them in planning and decisions. It was only by taking the time to nurture this trust that a commitment to involvement could be secured. The need for such a process implies that involvement was still viewed with a level of mistrust and that while PCGs had introduced new organisational structures there was still a significant way to go in respect of changing the prevailing culture in the NHS and the level of power associated with particular interest groups.

Patient and Public Involvement – Who?

The issue of who is to be involved is an aspect where there appears to have been continued confusion when addressing the patient and public involvement agenda. *Patient and Public Involvement in the New NHS* (DoH, 1998) was very clear that

involvement was not to be restricted to those who use services but that members of the wider public had also to be taken account of. Policy documents however often use the terms interchangeably without acknowledging the multiple roles that each brings. In both democratic and consumerist approaches, defining who is to be involved is a complex issue and is one that policy documents have tended to be vague about (Ong, 1993:65-82). While *Patient and Public Involvement in the New NHS* (DoH, 1999a) gave very specific definitions, there was no indication that account had been taken of the diversity of perspectives that are evident in each of the definitions or of the legitimacy on which each is based:

1. Patients - people who are currently using health services.
2. Users - people who make or have made use of health and related services that contribute to their health.
3. Carers - people who care (in non-professional circumstances) for those who are ill or disabled (usually family or friends).
4. Public - the general public/citizens.

Defining who is to be involved is an issue that can be obscured by the use of very broad interpretations. Changes in the organisation of the NHS have been matched with a shift from the representation provided by local authority and lay representation on NHS boards to the introduction of Community Health Councils and progressively towards broader statements that refer to the involvement of patients and members of the public. It is, however, the legitimacy on which the involvement is based that appears to lack clarity. Defining who should to be involved however, does not mean that involvement should be a selective process where people can be chosen, or not, at random but rather that involvement activities should take account of the very different contributions that individuals and groups of people can make.

The legitimacy of involvement in respect of consumerism is relatively straightforward and relates to the personal experience and knowledge of the services that individuals have used or wish to use. While strengthening the position of individuals, in relation to the services they use, is a key theme in consumerism, addressing wider health issues is only possible if there is collective involvement and the diverse perspectives on need this would provide (Hogg, 1999:158-174). In this respect, the legitimacy of involvement is the role of the general public as citizens not only to secure delivery of services but in the development of society as a whole

and providing information of their experience of the environment in which they live (Callaghan and Wistow, 2002:5).

While definitions such as “patients”, “carers” and “users of services” might appear to be adequate, they often fail to capture the nuances surrounding whether this includes those who are on waiting lists, those who have undetected or unmet needs, carers of those such as young children or elderly people who are potential users of services for example. Equally, there are more conceptual distinctions to be made in terms of whether they are viewed as passive recipients of services or partners in their care and subsequent decisions regarding planning, delivery and evaluation. Further distinctions can also be made between direct and indirect users particularly in respect to the concept of proxy consumers where the direct user of a service is not always the purchaser (Lupton et al, 1998:109-125).

Very broad definitions such as the “general public” and “citizens” do little to capture the very different groups, or communities, of people that make up populations and the different way in which involvement might need to be shaped if mechanisms are to be inclusive. Definitions typically used in relation to health are considered mainly to focus around geographically defined communities, those with shared characteristics, communities of special interest, administrative areas, at risk groups and GP practice populations (Jewkes and Murcott, 1996:555-563). Evidence however suggests that communities, groups and populations are fluid and not the static and sustainable units implicit in those defined by organisations. People move and create new networks to respond to particular issues at particular points in time but, as important, there are those who don't join networks or communities and subsequently are not heard because no one makes contact with them (Ibid).

It is perhaps precisely because of the complexity in capturing the various definitions of who to involve and the difficulties in pragmatic terms that this can create, that organisations attempt to identify and rely on those deemed to be representative. This reliance on representatives however has called into question just how accurately relatively small numbers of people can claim to be representative of the diverse views of wider communities and while they provide one avenue for securing a range of views and opinions the information delivered is likely to be too tenuous to be claimed as evidence of involvement (Baggot, 1998:248-269).

In seeking a representative view, voluntary and community organisations have often provided an important means of communication for NHS organisations. That these are typically focused on particular interests and can provide first hand knowledge and experience has to be balanced with the competition between them implicit in terms of securing resources for their particular interest. One of the dangers in relying on these groups when seeking representation is the argument that an elite group of people develops that health bodies feel comfortable with (Ibid).

Identifying who to involve will also need to take account of who wants to be involved and in this respect, it is often the practicalities of taking part that influence the level of interest shown by people. Developing an infrastructure that takes account of issues such as the time and venue of meetings, special support and information, language and communication needs are all issues that are deemed to be often forgotten and yet contribute significantly to whether people choose or are able to engage with involvement strategies (Hogg, 1999:84-110). Whether the lack of attention to these details is by default or deliberate, the outcome will be the same.

The issues surrounding who should and could be involved, and the mechanics of achieving this, are complex and are rarely addressed by the adoption of bland definitions. Both consumerist and democratic models of involvement require opportunities for involvement that are flexible and allow people to take part when they wish and at the level they choose (ibid).

The very broad definitions of who should be involved also fail to capture the difficulties of developing mechanisms that allow opportunities for even relatively small populations, such as the one in this study, to be involved. The tension between the development of democratic models of involvement and taking a pragmatic view was very clearly highlighted by the response of Board members to the question "who should be involved?"

While there was agreement in principle that patients and the wider public should be involved in health and health care decision-making processes, there were reservations about who should or could be involved. Although it was agreed that, in a democracy, everyone had a right to be involved in decisions that affect them, many Board members considered such a scenario as unlikely if not impossible. This view for many was justified by the assumption that most people were not

interested in being involved until or unless the issue affected them personally. Equally, there were questions over the desire, and in some cases the capacity, of ordinary members of the public to become embroiled in the technical nature of discussions when making decisions.

Notwithstanding the difficulties that patients and the wider public would have in contributing to discussions characterised by jargon and technical terms of which they had little understanding, certain Board members actually saw this as an obstacle to involvement. Subjecting lay people to very technical discussions was perceived as potentially contributing to a loss of confidence and self-esteem that could eventually lead to them opting out of the process altogether. As one Board member commented:

Many members of the community will not have the knowledge maybe, or the intellectual capacity even, to actually cope with that sort of situation. It could just become a front you know, we have people there from the community but as a matter of fact they're not really involved in the decision-making process.

The alternative to this approach is to focus on those issues that people were already knowledgeable about – their own experience of accessing and using services, but this was an area that appeared to relatively underdeveloped in the PCG in this study. While acknowledging the issue when responding to why local people should be involved, there was little acknowledgement to it in response to how and who should be involved. The lay Board member did however express the view that it was a responsibility of the PCG to provide the means for all those who wished to be involved at whatever level they felt comfortable with. Referring to the fact that the ability of people to make choices about the level at which they wished to participate was dependent on sufficient information being made available, the lay Board member felt strongly that it was up to the PCG to create routes for whatever level patients or members of the community felt comfortable with.

This course of action is likely to raise practical issues and in many ways is linked to Board members' perceptions of the limited resources and capacity available to meet all the demands placed on them. As Hogg (1999:108) points out, "it is hard to be involved if you are homeless, work long hours, have young children, are illiterate, have communication or access difficulties, or from a minority ethnic

group.” Not only are other things in life more pressing for these groups but also more resources are required in order to facilitate their involvement. At least one Board member however referred to it being the responsibility of the PCG to actively support the involvement of people who traditionally have not exercised their right to ask questions of public organisations.

Although the expectations outlined in *New NHS* policy appeared to be a combination of both consumerist and democratic models of involvement, for many Board members the time consuming nature of involvement was not compatible with the timescales involved in achieving top-down priorities. As the Chief Executive pointed out:

The politicians just don't understand the complexity of this in terms of the circulars you get saying by the end of June the Health Authority is expected to have consulted stakeholders on X, Y or Z and come to a conclusion about A and B. They just don't leave time in the cycle for that.

Decisions about who to involve were described as, in many circumstances, being driven by the time available to respond to national, regional or health authority directives. For many Board members this had resulted in an inevitable focus on a relatively small number of community or patient activists. This group of people were seen as those already involved in various activities and those who had more time to get involved; local elected members were given as examples. Continuing to focus on this group of people was however recognised as inadequate if involvement was to be seen as meaningful with one member suggesting that:

People who are prepared to join committees or the like are not unlike professionals, they come with their own preconceived ideas and will present their own thoughts which are not necessarily for the benefit of the wider population.

In addition, it was pointed out that if the focus continued to be on those who were already active it would always be the same people attending meetings and events and there was a danger that they would simply become quasi-professionals.

While some Board members acknowledged that everyone should at least have the opportunity to be involved, others were convinced that such an approach would be

counter productive. Past experience might well have been a factor in shaping views on who should be involved. Referring to a public consultation exercise some years earlier, one member reflected that:

The very wide general public is a waste of time, what you get is people waving shrouds at public meetings and holding skeletons up. People can't take a strategic view of things when asked to make what could be an emotional choice.

There was however the suggestion that the PCG, along with other public sector organisations, needed to acknowledge that it was no longer sufficient to hide behind perceptions that people either didn't want or were unable to take part in decision-making:

The PCG has a responsibility to get to grips with the inclusion of hard to reach groups as well as the ordinary people who never darken our doors because they don't know how to access us.

Community Reference Group members were also divided on the issue of who should be involved. For some members everyone should at least have the opportunity to be involved while others suggested a more selective involvement. As this member explained:

I'm tempted to say everyone but that's not what I mean. People who are interested in learning, working in a team and bring their own skills and experience; people have different skills and knowledge and will find their own level, it's instinctive. You need to have an enquiring nature

Similar to Board member views, there was a feeling among Community Reference Group members that a relatively small number of groups and individuals seemed to be involved in everything. One member in particular pointed out that this often resulted in the exclusion of other people and minority groups:

Already established groups seem to know and be involved in everything, what about hard to reach groups, they should be targeted.

There was also, however, a feeling among Community Reference Group members that attention was needed to developing an approach that was less generalist and tailored more to the interests of individuals or particular groups of people.

Neither Board members nor members of the Community Reference Group appeared to capture the complexity of identifying and defining the various stakeholders, nor was there any suggestion that thought had been given to how people define themselves. The references made to involving people who were “interested” perpetuate the view of Jewkes and Murcott (1998:843-856) that elitist groups of people develop that professionals feel comfortable with. Subsequently little is done to address the issue of involving those who have traditionally not been engaged with. That only a few of those interviewed referred to these hard to reach groups is perhaps an indication that neither the PCG nor the Community Reference Group had given this aspect much attention.

The difference between patients and members of the public is likely to be in the different purpose and outcomes that can be negotiated and agreed. These differences are most often reflected in the difference between taking account of patient experience in the development of services and the involvement of local people in wider, more strategic planning issues. Patients will invariably have self-interest and be concerned with their own needs; members of the wider public have a broader role that can be incorporated into priority setting and decision-making (Callaghan and Wistow, 2002). While the former reflects a more consumerist approach and focuses on health service improvement, the latter is centred on the democratic rights of people to contribute to society as a whole. Equally, these different perspectives are closely linked to the knowledge and experience that different groups of people can bring. In relation to how and who should be involved, one member summed up the minimum requirement as follows:

To provide a steady flow of accurate, understandable, no NHS jargon information about where we are at, where we are hoping to go, what are the problems on that road and what is the golden horizon, warts and all. Whether they want to do something about it is then up to them.

It is the context in which knowledge and information is framed, however, that is likely to be a key issue.

Knowledge and information

Board and Community Reference Group members acknowledged information as a fundamental issue in terms of involving people. What is of particular interest is the context in which the process of giving and receiving information was viewed. Responding to questions about the purpose of involvement, information was often related to meeting organisational needs rather than the needs of patients and members of the wider public hence there were a number of references to educating people in the complexities of the health service and mobilising support for difficult decisions regarding prioritisation. Equally, the emphasis on giving information to allow people to be involved was not matched with an equal regard for the information that could be provided by patients and members of the public to ensure an holistic approach to planning health and health services. The process appeared to favour giving information rather than receiving or exchanging it.

Several Board members made reference to knowledge, information, training and support in respect of involvement. While the emphasis in the past was perceived as being on health professionals needing to effect cultural and attitudinal change, certain Board members felt that if patients and members of the public were serious about becoming involved then a commitment from them to acquire different levels of knowledge was necessary. What this indicates is that involvement was not seen as a shared approach to decision-making but rather that patients and the public had to be inaugurated into professional ways of thinking.

For one Community Reference Group member access to information was a significant issue:

We need information; people can feel inadequate if they haven't got enough information to take part. It shouldn't be just a public relations job; agencies need to really want this. You need to give people confidence and make them feel valued.

Inherent in the difficulties of involving people with relatively little understanding of technical and complex issues, is a much more fundamental issue. Very little mention was made of informed decisions being as much about balancing the professional perspective with the patient and public perspective. The process is

then more about information exchange and achieving a balance of knowledge on which to make decisions.

A continued emphasis on giving people large amounts of information that includes technical terms and professional jargon could, as noted earlier, result in people opting out altogether not just because their somewhat limited understanding of the language used might result in undermining their contribution but because it is perceived as demonstrating the reluctance of the health service to allow people to contribute. It is perhaps symptomatic of the belief that organisations do not really want the public involved because they make it so difficult. This was a belief reinforced by Community Reference Group members who admitted that even after two years their understanding of PCG work was relatively limited.

The need to create an environment that would encourage people to participate had been referred to when discussing how to involve people but this also appeared to be focused on the training, awareness and education of local people rather than a two-way process. One Board member exemplified this by remarking that:

It's almost having training for six months or a period where they learn about how they can input into the PCG and the importance of that and what goes on in the PCG. So maybe that's something we can say, as a learning organisation we need to set up a programme of learning for that awareness.

A key question is whether this education was for the benefit of patients and the wider public or whether it was to allay the concerns that professionals had over involving lay people.

Information giving that is largely one way – from professionals to local people – might be criticised for maintaining passive involvement rather than a process of negotiation that can influence decisions (Florin and Coulter, 2001:44-57). The involvement of patients and members of the public in deciding the nature of the information used is necessary if active involvement is to be sustained. It is not that professionally determined information is not needed but rather that alliances are necessary to reflect both perspectives (Lupton et al, 1998:44-61).

Professionals invariably control health and healthcare information and this subsequently determines the nature of the information released. As a result of this,

the information passed on is not always felt to be geared towards those who use health services or have an interest in health in its widest sense but rather to those who act as proxies capable of defining need in order to achieve the right balance of services (Ong, 1993:65-82). This tendency to provide information from a professional perspective does little to address the balance of power between local people and professionals but is seen rather as a means of bringing local people around to professional thinking (Lupton et al, 1998:44-61). In this way it can shape the nature of involvement by giving the appearance of seeking only to educate people in the realities of decisions that have to be made and enlist support for those already made.

Without absolute clarity over the expectations of involvement those taking part can feel let down by the whole process and it is only the more participatory approaches that are felt to deal explicitly with issues such as the use and ownership of information that can result in shared power and control (Health Development Agency, 2000). These participatory approaches, however, are perhaps the most contentious when viewed within the context of the wider power relationships that continue to exist within the NHS.

Expert power is often associated with people who are considered more knowledgeable, better qualified or have expertise in a particular area and bestowed by those who might expect to have it exercised over them. As discussed in previous chapters, clinical control over knowledge and the traditional autonomy enjoyed by the medical profession has served to ensure continual dominance of expert power. The effective management of illness however is possible only when there is a partnership between the doctor and the patient (Coulter, 1999:719). While doctors are, or should be, experts in diagnosis, treatment, prognosis and preventative strategies, only the patient knows about his or her experience of illness, behaviour, habits, attitude to risk, values and preferences, they are experts in their own right.

The different way in which the importance of knowledge is expressed is a crucial aspect of the debate over involvement. Clarity over whether information is a tool to enhance involvement or simply a means of encouraging people to support organisational needs is particularly important. If the intention is to involve people in wider decision-making structures, then knowledge appropriate to the level at which they wish to be involved is essential. Similarly, if the emphasis is on eliciting views

about existing services then it is the personal experience of those who use them that becomes the central issue. Using information to support organisational needs will invariably mean that it becomes a one-way process and more concerned with the organisational priorities rather than those issues identified by patients or the wider public.

A number of questions remain unanswered in relation to perceptions of how patients and the public should be involved. Although some of those interviewed concentrated on methods of involvement, others saw a change in culture and attitude, the creation of an environment conducive to involvement and addressing the power element as being the fundamental issues.

The debate between best practice and best process is one that is perhaps forgotten when striving to comply with national directives. There is a danger that a concentration on best practice, in terms of developing methods of involvement, might result in a failure to put in place the developmental processes that ensure involvement is a means to an end and not just an end in itself. Whether this PCG was striving for best practice in relation to methods and mechanisms for involvement or best process in terms of embedding involvement in the culture of the PCG is difficult to assess. Equally, with little evidence of a collective view on these issues, it is likely that PCG Board members themselves had not addressed this aspect.

In broader terms, members of the Community Reference Group were united in the view that, irrespective of the methods used or models adopted, without clear evidence that their involvement was making a difference people would disengage. A view that the following comment exemplifies:

Involvement should produce evidence, people have got to feel they're making a difference otherwise they won't stay involved, there has to be evidence that things are changing as a result of our involvement.

IMPACT

It has been argued that it is often a lack of clarity over the expectations of, and outcomes from, involvement that results in the disillusionment or disengagement of all those involved. In the context of the impact that involvement could make there

were some conflicting views in this study, in particular about the issues that people could or should be involved in. For some, almost every aspect of PCG work should be open to involvement, for others it was a more selective process that excluded wider strategy and potentially contentious issues that needed refining prior to being exposed to the public domain. There were also differences of opinion over the level at which involvement was pitched in terms of simply giving information or allowing the opportunity to influence the detail of plans irrespective of whether the actual decision could be influenced.

Several comments were made advocating involvement at an early stage, although just what this meant in practice was not clear. One member, for example, reflected:

I don't think they should be involved in the larger strategy. I think it's virtually impossible to get any change effected by asking the public to make what could be an emotional choice. Look at Shotley Bridge Hospital now with the empty wards and everything. Well, by asking members of the public five years ago should we have a new district general hospital and should it be based on the Dryburn site you wouldn't get anybody, or very few, saying, "yeah that sounds sensible", because they wouldn't view it on a strategic view.

This view perhaps reinforces the need for clear interpretation and application of the term "involvement". Information giving, consultation, involvement and participation, as noted earlier in the chapter, are words that are frequently used interchangeably. The *New NHS* (DoH, 1997) was very clear that involvement was to be about patients and the wider public having more influence in the decisions that were to be made and not just about being consulted on predetermined plans. Simply making information available in an attempt to make people understand why decisions are being made implies that involving people is more to do with mobilising support for decisions rather than offering the opportunity to influence them.

One Board member offered the following perspective on why the timing of presenting issues to the public was a factor:

I think there are stages in the fulmination of decisions where there needs to be some behind closed doors thinking. The reason I feel the public should be excluded from that thinking is that if we're talking about options from the

totally draconian to doing absolutely nothing and we dispense with the totally draconian, this would serve to make the whole thing just vastly complicated and raise people's anxiety to a level that just doesn't need to happen.

This approach however, might be criticised because the more organisations delay the exposure of these sensitive discussions, the more they are open to claims of not involving people at a stage where there is still scope to influence plans. Notwithstanding this, certain Community Reference Group members also made reference to the fact that being given too much information can actually create anxiety for people as this member pointed out:

It can be a disadvantage to know too much, the public can be more worried by knowing too much, so we should be involved but not at the highest level.

If the purpose of involvement is to allow people a real say in the NHS, then denying them opportunity to be party to early discussions in many ways restricts the influence that they can have either in determining the options or over decisions regarding the detailed implementation of the preferred option. Equally, referring to raising anxiety levels unnecessarily might simply reinforce the NHS as a paternalistic body that continues to do things for and to people rather than with them.

The earlier reference to the local General Hospital was one of many made during the interviews. Of all local health service developments during the years preceding the establishment of the PCG, the most controversial had been a decision to change the status of the local general hospital to that of a community hospital and the resulting closure of accident and emergency and in-patient facilities. Not surprisingly, local residents fiercely challenged this decision.

It is often our own personal experience that shapes the way we view things and Stacey (1994:85-97) refers to learned experience, arguing that much of the cynicism displayed by members of the public when asked to contribute is a result of the abortive attempts to influence plans they have been consulted about. In a similar way, it was evident that the experience of consulting over the plans for the local General Hospital had coloured the views of those Board members who had been directly or indirectly involved. There was little evidence to suggest that the PCG wanted to get embroiled in taking contentious issues out to communities and

yet there were two contrasting views on this; on the one hand there was the recognition that these situations must be faced but that it should be on the basis of enough information being available on which members of the public could make balanced, informed decisions while on the other hand, certain members felt that only those without an axe to grind should be involved.

Community Reference Group members agreed that the impact of patient and public involvement should be demonstrated by planning and decision-making that took account of the views expressed by those who lived in the area and had first hand experience of what things were really like. The patient and public contribution was summed up by one member as follows:

It's the patient and public view that should make an impact, not just the clinical views. We can tell it like it is in reality and move away from standardisation.

If services really were to be shaped by the views of those that use them as promised by the *New NHS*, then involvement would need to be seen as a means to an end and not simply an end in itself demonstrated by an outcome that was measurable and tangible. If patient and public involvement were to be achieved and sustained, evidence that this input counted was seen by certain Board members as a critical factor. The view of one member was that:

What we've really got to show is that input counts but it feels very much like a top down agenda and we've got to make sure that the top down agenda meets the bottom up agenda.

The way in which patient and public involvement could make an impact was, however, viewed differently by different Board members and this could take the form of either direct or indirect impact. In addition, a number of constraints were identified as militating against involvement having any impact at all.

Direct and Indirect Impact

With PCGs having to comply with national priorities, national service frameworks and targets relating to access and waiting lists, the scope to make an impact on planning and decision making was, for many, considered to be limited. These

limitations extended not only to patients and members of the public but also to the PCG Board. The converse of this was that even with a preset agenda there was and should be scope for local interpretation and influence. Further, some Board members considered PCGs as the opportunity to allow greater impact to be made, if not in wider planning, certainly in the detail of how national priorities should be delivered locally. The chief executive was very clear that:

The agenda is set by national dictat from on high, tempered by local appreciation or interpretation of that agenda. Secondly, and one would like to think equally as important the agenda is identified by involvement with local communities and local agencies which reflect not just the interpretation they've put on the national agenda but those arising from people in the community.

This view however contradicted statements that suggested involvement was able to temper the professionals' approach though not necessarily redirect it. The lay member, for example, was seen as instrumental in reminding Board members of their responsibilities in terms of taking account of public views. In the words of one of one Board member:

I think she (lay member) plays a huge role on the Board, bringing them back down to earth. Normally we say, 'yes we'll do this' and then she'll say, 'hang on a minute where's the public perspective on this coming from'.

These two definitions of impact are in many ways two sides of the same coin, one being concerned with achieving direct impact through the involvement of people, the other seeking indirect impact by influencing the way in which professionals operate and encouraging the inclusion of a patient and public perspective.

Despite different views on whether impact was possible, there were some Board members who considered that community views had been able to influence and, to some degree, drive the work of the PCG. Issues raised by the Community Reference Group and the lay member of the Board it was suggested had been discussed and addressed and one member noted:

Patients' views are taken and there are a lot of things from your work [the PCG Community and Partnership Development Officer], the community

reference group and so on and actually in my view your work has got more influence than any other of the commissioning groups. The others haven't got that high profile or influence because you've brought in so many other issues and talked about them at the Board and a lot of them were approved.

Although it was difficult to identify any examples that supported this view, in the context of indirect impact, there is perhaps an argument that involvement does not have to be demonstrated by adopting particular methods or models. Often the introduction of methods is used as a means of evidencing involvement rather than actually listening to and taking account of people's views.

During the research, the PCG was in the early stages of planning a primary care estates strategy, deciding on the fitness for purpose of existing facilities and planning for future needs. Very little had been undertaken in terms of gauging patient and public views on this and yet reference was made to taking account of views expressed not in formal mechanisms but in the everyday contact that PCG members had with their local communities. Despite issues of cost efficiency being at stake and a national drive towards central primary care centres, decisions were clearly in favour of retaining very localised services and not developing centralised services that would achieve economies of scale and associated cost savings. In the opinion of the Chief Executive:

There is no doubt that it is better to organise health services in such a way that the patients come to the centre but that's completely at odds with the population of Castleside who've got to get five buses to get to Dryburn [the local general hospital]. It's completely at odds with, you know, Moorside and the Dene if we go ahead and create centralised primary care centres and ditch branch surgeries. I'm sure we won't do that, over my dead body sort of thing, but from an organisational point of view, from a pure efficiency point of view, we're completely at odds with local people who want services on their doorstep.

From this perspective, the views of local communities can and do have an impact without the need to take part in formal involvement mechanisms. The key to this, however, is consistency. If this approach to gathering, storing, analysing and taking account of opinions and perceived needs is to work then it must be consistent and people made aware of and included in the process. If people aren't aware of how

their views have been included then it is reasonable to assume they will have no ownership of the decisions and no incentive to “keep plugging away and changing little bits” as one Board member described it. Equally, if as another Board member noted “people have got to want to input, we’ve got to show that input counts” in terms of securing or sustaining credibility in the eyes of communities, it does the PCG little good if these discussions are not exposed to public scrutiny.

For some Board members the potential for members of the general public to make an impact on PCG decision-making was non-existent but if this was extended to pressure groups or special interest groups then the impact was considered disproportionate. One Board member summed up the potential for impact as:

If you’re talking about the individual man [sic] on the street, I suspect very little. The individual man [sic] on the street with a pressure group label and a vested interest can have a disproportionate effect.

Links were also evident between the ways in which models of involvement had been constructed and expectations of impact. A large number of Board members had viewed involvement very much in consumerist terms and so not surprisingly there were comments relating to the potential for patient and public involvement to influence changes in service delivery based on taking account of their experience. Caution was expressed, however, on the need to distinguish between perceived and actual need and the danger of raising expectations unrealistically with one Board member commenting that:

It’s trying to find that balance between what people would like to have and what people need to have and somewhere in there as well is what we can afford to have within the system.

This particular view calls into question the subjective nature of decisions regarding real or perceived need and who decides on this. Equally, the consumerist approach could be a double edged sword particularly when needing the support of independent contractors such as GPs who might see this form of involvement as a tool to criticise their services and disengage with the involvement agenda altogether. The chair, himself a GP, noted that:

With a new organisation like the PCG people are worried that it's going to be used against them.

This view of involvement as a tool that could be used against the organisation and members of it might be considered a factor in excluding patients and the public from certain aspects of work and exploring this issue revealed some differences of opinion.

Issues that Patients and the Public should not be involved in

While there was universal agreement that confidentiality of patients should be protected there was disagreement over whether financial discussions should be in the public domain. Although some Board members felt it was not appropriate or relevant to have patients and the wider public contribute to debates on finance, others felt that financial discussions were unnecessarily excluded from the public. In a number of cases this appeared to be associated with individual Board members' understanding of finance and not necessarily to do with providing a rational argument for keeping it private. As one member commented:

I'm not au fait with finance but I can see why some things, you know where the money goes, that's in the closed part of the meeting.

Others, clearly more comfortable with financial issues, expressed surprise that finance was kept confidential and noted that the health authority had also raised this as an issue of concern. While several Board members specifically mentioned GP finances as a confidential issue, none of the GPs mentioned this as an aspect to be kept from the public. The PCG finance manager reflected that:

That was backed up by the Health Authority Chief Executive as well, who gets to read through some of the confidential stuff and said, 'look there's no reason for this to be kept out of the public arena, it's just because a bit of income for a practice is named'.

Once again, the Community Reference Group perspective was much simpler with a consensus among those interviewed that very little should be kept out of the public domain. In the view of all members, the only areas that people could not or should

not be involved in were issues relating to named individuals. One member summed this up as:

The only thing really is personalised patient information; we have to respect the right to privacy and confidentiality.

Despite this, one Community Reference Group member did question the validity of members of the public being involved in clinical issues that required a level of expert knowledge commenting that:

Some clinical and financial issues need expert knowledge; there are different levels of information needed for different issues.

A key factor in developing patient and public involvement is clarity over the level of involvement that is on offer (Anderson, 2001:36). PCG Board members, as discussed in the previous chapter, were not always clear on the power they themselves held therefore difficulties could be expected in making explicit statements about the level that patients and members of the wider public could expect.

Board members questioned the ability of local patients and members of the public to influence national priorities and this, combined with the view of some Board members that the average person would not be able to contribute to the often complex business of planning health services, made it difficult to establish if thought had been given to the principles in the *NHS Plan* that supported the empowerment of patients. This lack of clarity might be deemed instrumental in whether or not involvement could be sustained.

Members of the Community Reference Group had pointed out that involvement had to demonstrate outcomes; if people could not see that they were making a difference there was little point in staying involved. Despite this, Board members felt there were a number of constraints that militated against this.

Constraints

One of the main constraints in terms of impact was considered to be the tension between national and local priorities and how local involvement could impact on or

influence the national agenda. The example given by the Chair of the PCG was the achievement of national targets in relation to GP access. The national target of providing access to a GP within 48 hours, superficially at least, might appear to be consistent with public views. Beyond the superficial, however, there was felt to be a much more complex issue that had the potential for negative impact in terms of the final outcome for patients. Access to a GP, it was suggested, could not be seen in isolation from issues of continuity and time spent with patients. Describing these complexities, the Chair of the PCG explained that:

Something that the public say they actually want and they say there's a target and we can measure and that's what we're going to do to the detriment of all sorts of other things, be it the quality of the service or continuity or whether I give a five minute appointment or a ten minute appointment. If you push access to the hilt you will completely destroy continuity because I will fill my day with having to see someone within 48 hours.

This is perhaps illustrative of where impact can most easily be achieved and common ground found – patients and professionals jointly discussing the implications of national targets, negotiating priorities and agreeing the compromise necessary to achieve the best fit between local and national needs. As the chair of the PCG continued:

You've got to sit down with the public and you've got to say, o.k. these are the issues; these are the conflicting issues that we've got – access, continuity and the length of time for consultations. We can get a balance of these but you can't have all three. It's not about rationing, it's about creating a system that you have ownership of, and that we have ownership of that is deliverable.

The suggestion is then that impact is not only about the impact that local patient and public involvement can make on services but also about how involvement at other levels – national and regional - impacts on those at a more local level. In working towards real impact, the example of access appears to suggest that the first step, and often the most difficult to achieve, is the initiation of discussion and negotiation rather than the traditional consultation that has so often been the

involvement tool in the past and on which national targets such as access have been based.

A further constraint was described as contentious decisions that were often beyond the control of the PCG but still had to be made, as the Chief Executive pointed out:

Sometimes the reasons are less good than others but you know we have to dance to the political tune, we have to recognise professional standards, requirements coming from the royal college of this, that and the other, all of which constrain the way in which we think.

If final decisions are beyond the scope of the PCG, and therefore patients and the wider public, to influence, involvement might still be seen as a crucial element of planning the detail of developments and perhaps minimising the impact on communities. Again reflecting on previous decisions regarding changes to the local general hospital, one member described the potential contribution that members of the public could have made:

I think a lot of things, if you bear in mind Shotley Bridge hospital, are things that have to happen. I think the public could have contributed to the how. I think the public could have contributed to the remedial action that needed to be put in place to satisfy some of their concerns about transport, accessibility and all sorts of issues.

There is an argument that, if the PCG felt constrained by the national targets and priorities being imposed on them and other external forces, focusing the process of involvement on small-scale initiatives might have allowed them to develop an incremental approach to involvement. As Stacey (1994:85-97) argues, if political decisions have already been made, meaningful large-scale involvement becomes almost impossible. Where it is possible to effect change is where individuals have personal concerns about the services they are receiving. These relatively low level interactions about specific issues can at the very least address the involvement of patients in their own care if not contribute to the wider health and health service agenda. The attention given to complaints, for example, might have provided some direction in terms of responding to the concerns of patients.

The way in which complaints were viewed might be seen to hold potential in terms of the impact that could be made in relation to service delivery. If complaints are

seen as highlighting issues that at best have to be justified and at worst that personnel have to be disciplined over in order to show that justice has been done then they contribute little to the bigger picture. If they are seen as rich sources of patient experience that can assist with improving quality and clinical governance as well as unearthing flaws within the system then they take on a much more positive role. Speaking of the complaints process, one Board member reflected that:

We didn't want them to come back and say nurse Bloggs has had her wrists slapped, we wanted them to look at the system and say why nurse Bloggs got put into the position where it happened. It should be a question about how we can change the system or should change the system.

It is perhaps significant that only one member mentioned complaints as a mechanism for patients to exercise influence and the subsequent impact this could have on planning and delivery of health and health care. It is also a matter of interest that no one referred to the involvement of individual patients in their treatment. Whether the limited references to these aspects is a result of those interviewed taking a much wider view of involvement or whether these elements are not recognised as mechanisms for involvement was not explored in this study.

The absence of a consensus in respect of why people should be involved and how this would be developed, given the diversity of views relating to why, how and who, suggests that patient and public involvement lacked the leadership necessary to facilitate negotiation and agreement on outcomes. Without this leadership patient and public involvement is unlikely to be embedded into organisational practice and subsequently be implemented in an ad hoc manner that is difficult to integrate into decision-making structures and processes. Views on how decisions regarding the involvement of patients and members of the public were made were mixed and the perception of some Board members was that no one was actually making them.

Championing Patient and Public Involvement

While some members felt the chief executive or chair of the PCG should make the decision of when and where patient and public involvement was appropriate others saw it as a Board responsibility. The lay member was convinced that it should be patients and members of the public who decided what they wished to be involved in

and how. Acknowledging that this had implications in respect of information and knowledge the lay Board member noted:

If people have the choice and knowledge then they can make those choices and decisions. So maybe it's not about what they shouldn't be involved in but about the training and support needed so that whoever wants to be involved has the right training and support to make the decision.

Perhaps the most interesting comment was that no one actively made decisions on this issue and that exclusion or inclusion was actually by default. One Board member in particular thought that the massive agenda that the PCG was faced with often resulted in particular aspects being neglected and responded to the question of who decided what to involve people in by saying:

No one. I think there's a lot of good will and a lot of acknowledgement that we need to. I think the confusion is being exacerbated by our massive agenda. There is so much to do and not a lot of cash to do it that it slips up the priority list and then sort of scatters down again.

Only one Board member referred to the guidelines about what should and should not be open to public scrutiny and involvement. Referring to national guidance, it was explained that this should be "Justly applied and not just because of the influence of someone saying it". Whether Board members were unaware of this, whether it was an example of the pressure that PCGs were under resulting in little attention being paid to national guidance or whether it was a reflection of the control that PCGs held is difficult to say. Since the last person to be interviewed had raised this issue, it was not possible to explore it further in this study.

Guidance on what and what not to involve people in, the philosophy that everything should be open to the public unless sacrificing patient confidentiality is at stake and the notion that people should be able to choose what to contribute were felt to take little account of the practicalities and according to the Chair:

If people say you're not telling me everything well, I don't know everything. I've got knowledge of a lot of things that are going on but you know the Board meeting's not three weeks long. The issues that come up cannot be debated in every arena, you've got to pick out the priorities that you're

dealing with that you think most affects you and which are the priorities that you want us to deal with and I think that's as good as we can get because, as I say, there is so much there that you can't have a say in everything.

The critical question surrounding decisions on involvement is perhaps whether involvement would bring with it an expectation that patients and the wider public should or would take part in discussions and decision-making or whether it was more a case of making information publicly available in order to encourage openness, transparency and public accountability.

Board members had varying perceptions on who was actually making decisions and on what they were based. The different perspectives evident on the philosophy, protocols and policy relating to such an important issue suggest that decisions were indeed being made arbitrarily. While in an ideal world members of the public should have been able to decide what they wished to be involved in and the PCG should have been creating routes to enable this, the reality was that the PCG, faced with output driven top down targets in relation to so many aspects of improving health service delivery, saw involvement as one more priority and according to one Board member:

It's an easy one to put on the back burner, it's an easy issue to say well yes it's very important but we've got to do this, this week and maybe we'll think about it next week.

CONCLUSION

If the rhetoric of involvement in the *New NHS* is to become a reality, much more needs to be done to address the complexities and implications of involvement in practice. Without greater clarity and guidance in relation to why patients and the public should be involved along with more prescriptive performance measures in relation to outcomes, there is a danger that it will continue to be controlled by NHS bodies and evolve as a disjointed process that lacks substance or the incremental approach that is necessary to embed it as a core principle and achieve more equitable relationships. National policy and guidance appears not to have sufficiently clarified issues such as why, how and who to involve at a local level and this can result in very different views on each of these aspects and a subsequent

lack of co-ordination between the intention to involve patients and members of the public, how this would be achieved and the ultimate outcome.

There were also indications that little had been done to challenge the control that professionals would have over the implementation of patient and public involvement. Specifically, nationally determined priorities and targets were seen as constraining involvement and although greater influence for patients and members of the public was included in these priorities there was little acknowledgement of this and subsequently questions the level of commitment that had been given to this issue. Reflections on the training, knowledge and experience that lay people would need to ensure meaningful involvement suggested that this was more to do with fitting patient and public involvement into professional frameworks rather than negotiating mutually acceptable frameworks.

While there might be general support for involving patients and the wider public, espousing a principle is not the same as enabling it or embedding it. Many of those interviewed identified a number of factors that they felt would constrain attempts to develop involvement. The following chapter examines these factors and seeks to determine whether they were in fact constraints, could they have been challenged by PCGs or were they merely being used as justification for inaction in respect of developing involvement.

CHAPER SIX

PATIENT AND PUBLIC INVOLVEMENT ACCOUNTABILITY AND DRIVING FORCES

INTRODUCTION

If the *New NHS* promises of more influence for patients and members of the public were to be fulfilled, the NHS would need to be transformed from a hierarchical, somewhat paternalistic, organisation into one that not only recognised the value of contributions that various stakeholders could make but also actively facilitated this. As already discussed, in this study there was evidence of a lack of clarity and consensus on the purpose and practicalities of involvement as well as structures and processes that had done little to facilitate the inclusion of a patient and public perspective. This chapter discusses the extent to which these factors had been shaped by policy that, despite promises in the *New NHS*, remained largely insensitive to the real issues underpinning the development of a more significant role for patients and local people. The chapter also examines the extent to which New Labour's 1997 reforms had introduced sufficient incentives and sanctions to ensure that the involvement of patients and local people would, or could, be developed as a priority in the NHS.

The chapter first explores the issue of accountability in the context of how promises of increased accountability to patients and members of the public had been interpreted locally. In particular, what changes had been introduced at a local level that would ensure that accountability to local communities was embraced as a priority. In examining what had shaped views on accountability, the chapter discusses perceptions surrounding what forces were driving the work of the PCG and how these were instrumental in decisions regarding the relative priority given to particular responsibilities.

Data for this chapter is drawn from interviews with Board and Community Reference Group members who were asked the following questions:

1. Who do you think you are accountable to both as an individual and collectively as a member of the Board?

2. What, if any conflict of interest is there?
3. Who or what drives the work of the PCG?
4. What influence do Board members or other individuals have over this?

ACCOUNTABILITY

While PCGs had brought together a range of different interests, little appeared to have been done to address how these interests would, or could, be represented or to encourage or facilitate reconciling the different interests, different perceptions surrounding status and the accountability frameworks of the various players involved. An emphasis on upward and peer accountability continued to dominate in this study and is perhaps evidence of how the *New NHS* had changed little in terms of developing the incentives and sanctions needed if traditional patterns of accountability were to be changed. Without any incentive to develop downward accountability to local communities, the enthusiasm with which PCGs would engage with the patient and public involvement agenda might be in doubt.

The NHS has in the past been criticised for its democratic deficit and the lack of accountability has been considered a systematic weakness of the NHS. The *New NHS* was intended to foster openness and transparency of decision-making and subsequently introduce new models of accountability. However, at a local level, PCGs had been given a degree of flexibility in terms of how determining structures and processes and it was perhaps inevitable that these would reflect PCG interpretations of openness and transparency. In addition, as the PCG Chair in this study had pointed out, the whole thing was riddled with conflicts of interest and how these were managed might be a critical factor in developing models of patient and public accountability.

The NHS has focused primarily on the appointment rather than election of board members and subsequently there has been no mechanism that enables local people to be involved in the process. While the *New NHS* was intended to foster openness and transparency and new models of accountability, there was no direct input of local people into the recruitment or appointment of PCG board members. In this study, peer group colleagues had elected the GP and nurse members. Both the health authority and social services had nominated their representatives and the lay member had been subject to health authority recruitment and selection procedures, as had the chief executive.

Democratic accountability in the NHS has remained through the Secretary of State with the public electing members of parliament as representatives to make decisions on their behalf (Hogg, 1999:84). This has meant that it is only at a national level that local people have democratically elected representatives – a level far removed from that at which most decisions are made that will affect them. The 1997 reforms placed an emphasis on local accountability but whether the establishment of PCGs at a local level would address this is for some questionable. Hogg (ibid) argues that the complexity of the NHS structure, to a large extent, makes it more difficult for local people to establish where decisions are made. While the *New NHS* was based on partnership and integration rather than the previous focus on competition between providers of services there was still an array of NHS and independent and voluntary bodies involved. Primary Care Groups are likely only to have added to the confusion in terms of accountability.

After the removal of local authority representation on district health authorities as a result of earlier NHS reforms, there has been an absence of local community representation in nearly all aspects of health services delivery (Leathard, 2000:168). Although CHCs were introduced in 1974 to address the issue of public and patient accountability, as discussed in earlier chapters, the introduction of general management and the internal market in the NHS had considerably weakened the position of these bodies.

The debate about public accountability in the NHS is therefore not new, particularly in relation to central versus local accountability (Klein, 1995). The nature and relevance of local forms of accountability is questionable given that the NHS has always been subject to central government control with the principal line of democratic accountability being through parliament. Despite this, it is argued that accountability to the local community has always been a consideration, though not the primary consideration, in most NHS reorganisations (ibid).

At its simplest, accountability is the process that provides the link between those who govern and those on whose behalf they do so (Lupton et al, 1998:33). In this relatively simple definition, accountability requires both giving account of actions and being held to account. What this perhaps fails to capture is the existence of the multiple levels of accountability often present in organisations.

In examining these two elements of accountability, giving account and being held to account, it is perhaps not surprising that some differences were evident amongst

PCG Board members. Collectively, the PCG Board had to give account of its actions and be held to account through various regional and national inspection and performance management arrangements. Individually, several members were aligned to professional bodies that also expected standards and performance to be maintained, for example the Royal College of General Practitioners and the Royal College of Nursing. In addition, certain members were employees of other organisations and considered themselves to be answerable to their respective parent organisations. It was therefore clear that multiple levels of accountability would be inevitable.

In the case of public accountability, although the *New NHS* claimed that new organisational structures would renew the NHS as a publicly accountable service, the traditional hierarchy of accountability appears to have been maintained. Primary Care Groups were accountable to health authorities and through them to central government and ultimately to members of the public. Despite the claims of the *New NHS*, it was only at a national level that members of the public could exercise sanctions in relation to voting governments in and out of power. Even at this level, as Hogg (1999:110-138) points out, it is not possible to use these sanctions against individual policy or actions as they invariably come as part of a much wider package.

Primary Care Groups had to demonstrate open and transparent decision-making processes and allow the public to see the basis on which decisions had been arrived at. In this study, although Board meetings were held in public and there was a degree of public involvement evident in the PCG planning structure, Community Reference Group members questioned just how many people actually knew that the PCG had a governing role on their behalf. If there was to be transparency, the right to call to account those who had governing responsibilities and opportunities created for this right to be exercised, people would first need to know where governing responsibilities lay. In the view of Community Reference Group members, as noted earlier, this was perceived as a relatively undeveloped aspect of the Primary Care Group.

Added to the imperatives surrounding compliance with national directives was the introduction of professional and clinical development included in clinical governance and National Service Frameworks, for example. Intended to drive improvements in quality and access to services, these nationally developed frameworks and

protocols might be seen as constraining thinking and inhibiting autonomy at a local level, thereby impeding the shared decision-making that *Shifting the Balance of Power* (DoH, 2001) had envisaged (Gillam and Brooks, 2001:146). The Chief Executive of the PCG had referred not only to these constraints but also those governing the conduct of members of the PCG such as the Royal College of General Practitioners and other professional bodies.

Overall, the establishment of PCGs might have been seen, as other NHS bodies have been in the past, as compromising accountability because members were either selected or elected not by the public but by their peer group colleagues, other organisations or the health authority. While the NHS has often been criticised for a lack of democratic accountability (Lupton et al, 1998:89) the introduction of PCGs appeared to have done little to address the limited opportunities available to the public to call to account those with governance responsibilities. The levels of accountability evident and the acknowledged potential for conflicts of interest along with the perceived inequities when attempting to manage these issues made the development of robust models of patient and public involvement even more important if PCGs were to rebuild patient and public confidence and achieve delivery of NHS services that were shaped by their views.

When asked about accountability, while Board members expressed a variety of views, members of the Community Reference Group were clear that the PCG should first and foremost be accountable to local people.

Levels of Accountability

Among Board members interviewed, there was a very powerful sense of upward accountability. Without exception, all Board members perceived themselves to be held to account by the government, the health authority and, in some cases, the secretary of state. The Royal Colleges, professional bodies and employers were also included in levels of accountability.

With the volume of priorities coming from the top down it is perhaps not surprising that upward accountability was for many the first priority. Each of the priorities came with targets and performance indicators that PCGs were to be measured by. Achieving the standards set out by the government was intended to drive efficiency by the introduction of a more rigorous approach to performance (The New NHS

Modern, Dependable, DoH 1997:11). It was this very approach however that appeared to favour upward accountability as one Board member noted:

I was thinking about accountability to health authorities and regional executive and the constraints and accountability set by National Service Frameworks, national strategies and what have you. It would be lovely to say we're all accountable to our local population but in reality, and I hate to use the word tokenism, but there is a lot of it about.

Despite the *New NHS* promise to renew public confidence in services that were accountable to patients, compliance with the national agenda in many ways was seen as an obstacle to developing the model of public accountability that was being sought.

Peer accountability was also perceived as being a priority. As well as the relatively straightforward accountability recounted in terms of their peer group colleagues, there was evidence throughout the study of the confused nature of peer accountability and the compromises that often had to be made. For example, when the local Acute Hospital Trust proposed plans to reduce the opening hours of the minor injuries unit, the PCG was faced with either rejecting the proposals until they had been subject to the involvement of local people and evidence provided of how the patient and public perspective had been taken account of, or endorsing them but promising greater involvement when a review was undertaken in the future. The decision to endorse the proposals without local involvement perhaps exemplifies the priority given to peer accountability within the wider NHS family.

In a study of executive and non-executive health authority members, Cairncross and Ashburner (1992) found that, despite evidence of multiple levels of accountability, the primary accountability in terms of the health authority as a whole was to the local community and to service users. Individually, non-executive members retained accountability to the local community as their primary concern while executives expressed individual accountability as being primarily to the chair of the health authority. Cairncross and Ashburner however, suggest that local accountability might be difficult to put into action unless there are appropriate structures to support it. The nature of PCGs given their local focus might have provided just such a structure and yet compliance with national priorities and targets and the introduction of various national standards and performance

frameworks had perhaps served to ensure that while local accountability was acknowledged, upward accountability continued to be given higher priority.

Although the majority of Board members spoke of accountability to members of the public there were significant differences in the level of priority given to this aspect. While some saw public accountability as their primary responsibility, others considered it to be unwritten, informal or indirect. The following examples illustrate the variety of Board members views on this issue:

The Board is accountable to the health authority and indirectly to the public.

Although there's no sort of written down formal accountability in that sense, the whole purpose of the PCG being there is to improve the health of the local population, so there's accountability there.

I think first and foremost we're accountable to local people. Within the Board I would say you're responsible to the Chief Executive but I mean it's difficult because I'm employed by GPs and actually one of my GPs is a Board member so it can sometimes prove quite conflicting.

Well, if I start from the top, professionally definitely the UKCC, because I take on a role that's extended the role of the nurse, the health authority, the Trust that I work in and also the PCG Board and to the nurse reference group, to the nurses that I represent and members of the community.

Without the accountability that locally elected representation brings and the sanctions that could be brought to bear by health authorities, regional executives and various department of health watchdogs for instance, it is not unreasonable to assume that PCGs would be more likely to focus on upward accountability to ensure their survival. In contrast to the hard targets included in the various frameworks, little had been done in relation to setting standards by which PCGs would be measured on the involvement of patients and the wider community. Even with the drive towards increased patient and public involvement, without the option to vote in and out of power, communities had few sanctions that could be used in response to concern or disapproval over PCG actions.

Patient and public involvement was an aspect that was still relatively undeveloped in terms of performance management and as a result, was described by one Board

member as a priority that could easily be sidelined while seeking to respond to central directives:

You can give the token remark about “yes we should have them here but we have so many other issues to consider that this is just not our main priority”. I think for most of them it’s just easier to put that issue on the back burner. They wouldn’t be able to put finances or clinical governance on the back burner like that.

For Community Reference Group members, although it was acknowledged that other levels existed, public accountability was of primary importance. However, echoing earlier comments about public awareness of PCGs, it was considered likely that members of the public might not realise this as the view of one member demonstrates:

Public accountability should come first. But do members of the public know this? I suspect not.

Equally interesting were the distinctions that some Community Reference Group members made between the different levels of accountability. Admitting that there would always be at least two levels of accountability, this member described them as:

For administration, PCGs should be accountable to the health authority and other central and national departments. For health care and the quality of services they should always be accountable to the public

This view of the need for separate accountability frameworks reflects a feature that has been apparent in the NHS for a number of years – the separation of management and political accountability. While political accountability is concerned with decisions about what is to be done, management accountability relates to how things are to be done (Day and Klein, 1987:224). The accountability of those managing how things are done is ensured by the imposition of a range of explicit targets and standards used to scrutinise performance. In terms of local delivery of health care and ensuring the quality of services it was clear that PCGs were to be held accountable. As these performance arrangements were all centrally

determined, it is not unreasonable to assume that upward accountability would remain the primary concern.

The organisational changes in the New NHS were intended to improve local accountability and increase openness and transparency. Equally, the composition of PCG Boards had been intended to introduce a broader range of perspectives into the planning of health and health care. However, as the Chair of the PCG had pointed out, the whole thing appeared to be riddled with conflict.

Conflicts of Interest

Conflict within and between organisations is not unusual but rather a symptom of the different interests, experience and motivation that people bring whether consciously or unconsciously. Conflict is therefore an inevitable part of any collaboration and rather than suppress it, ways in which the conflicts can be acknowledged and reconciled need to be explored (Hudson, 1999:235-260). Reconciling the different interests evident in the NHS has, in the past, caused considerable difficulties. As earlier chapters have explored, tension exists between medical and social models of health, between the medical professions perceived as striving to retain their autonomy and management initiatives focused on quality improvement, cost effectiveness, and in some cases cost containment, and the often-competing interests between local and national priorities. In this study the main conflicts identified focused on the following areas:

1. The tension between national and local priorities.
2. The complex relationships between Board members.
3. The conflict between community and organisational needs and requirements.
4. Personal and peer group interests of Board members, particularly GPs who, as independent contractors, had the potential to benefit from Board decisions.

The most obvious area for conflict was deemed to be the conflict between national and local priorities. The need to deliver national priorities, while taking account of local need was considered, in many respects, to compromise the work of the PCG in terms of involving local people. References to raising expectations by involving local people in decision-making but not being able to follow through with action on

perceived need was described as one of the major challenges if the credibility of the PCG was to be maintained.

Perhaps a less obvious area where conflicts were possible was among Board members themselves. Not only were certain members employees of other organisations but also, in some cases, their employer was a Board member colleague. The tension this created was very clearly highlighted by examples of members either removing themselves or being removed when decisions were being taken that could or would impact on their particular interests.

The conflict between the interests of the PCG and its Board members and that of the wider population, whether this was patients and members of the public or professional was evident in references to decisions regarding investment in secondary care as opposed to primary care.

A further contentious issue was prioritising the needs of the organisation against the needs of the community. One Board member pointed out that:

The biggest conflict of interest is always between the needs of the community and the organisational requirement.

The government was clear that in the *New NHS* decisions would be made in the interests of people and not institutions and yet, as many of the comments made by Board members demonstrate, the new reforms could not work without the support of those involved in primary care and GPs in particular. Referring to this, the chair of the PCG explained:

So whatever you do, whatever new ways of working, if you do not connect with those practices, if you do not make those GPs involved and you don't give GPs their head on some of those things, you will get nowhere.

An emphasis, then, had to be placed on engaging with those people perceived as crucial to delivering the PCG agenda and the tension that this could create in terms of balancing GP practice based issues against wider locality issues. The PCG needed the goodwill of the GPs if they were to deliver on national priorities, earn local freedom to manage and subsequently develop into a freestanding Primary

Care Trust. There was the potential therefore to favour developing this relationship by sacrificing or compromising accountability to the local community.

The views of Community Reference Group members supported what they perceived as the inevitability of this conflict with one member commenting that:

If members of the public were more involved, more conflicts of interest would be seen. Professionals don't like those considered not to know interfering.

Several members of the Community Reference Group described the potential for GP Board members to benefit from decision-making processes that those who weren't involved perhaps wouldn't be aware of. Issues of financial gain were referred to in relation to decisions that could affect the income of particular practices for example. This particular issue is in many ways similar to the point made by one of the nurses when describing perceived inequalities in status and conflicts within the Board:

If there's a conflict of interest for me looking at nurse grading or conditions or whatever, I don't think there's any difference whatsoever to looking at GP issues because in a way that affects all of the GPs on the Board. There's as much of a conflict but it's not seen as much of a conflict because there's five of them and only two of us.

Community Reference Group members were in agreement that most, if not all, conflicts of interest, could be avoided if there was clarity on both individual and collective responsibilities and if members were willing to forget their individual roles and work collectively.

Whether or not the real, or perceived, conflicts were, or could be, managed successfully is difficult to say. A number of Board members referred to the need for greater understanding of the PCG as a body that was far bigger than individual professions or services but that conflicts were unavoidable if it were to work, the skill it was suggested would be in how they were handled. Despite this, the only model described to manage potentially conflicting interests was that of removing Board members from situations where they could potentially be seen to have an interest, in the words of one Board member:

We get around that, as you know, by seeking to extract people who've got an interest in the decisions from the debate, making sure they don't take part.

The effectiveness of such an approach is questionable given the selective way in which some members felt it had been applied. With PCG Boards being predominantly made up of GPs, it would be impossible to "extract" these members from debate or decision-making because this would completely disable the Board by withdrawing the majority of members.

From the Community Reference Group perspective, one of the key strengths of PCG Boards was the diverse membership. Several members described PCGs as an opportunity to include a wider range of views, to integrate the different disciplines and engender change in professionals who were "blinkered by self interest" as one Community Reference Group member described it. The Community Reference Group view was that working collectively was more powerful in terms of improving and developing services, but as one member pointed out:

PCGs should make people more aware of their own and each other's roles and work together to the wider context, not just their own little bit.

In this respect, connecting to those who could constrain the success of PCGs, in particular GPs as noted earlier, and the establishment of processes that nurtured wider involvement and ameliorated conflict would be essential.

There appeared to be no mechanism within the PCG for addressing conflict of interests except the removal of those deemed to have potentially conflicting or personal interests in specific issues discussed at Board meetings. Crucially, if this technique is applied selectively, it might simply be seen as using perceived status as a tool to undermine debate.

The background of individuals appeared to be a key element in this study particularly in respect of the nurses. The nurses themselves referred to the traditional relationship between doctors and nurses and the relative status of each. Examples were evident where their role as employees of GPs, who were also Board members, had led to them voluntarily withdrawing from decisions that might be seen to benefit the practice they worked in. Equally, there were examples where

withdrawal had been imposed because of a perceived conflict of interest in matters that again might be seen to benefit them personally although ultimately intended to benefit the nursing service as a whole.

That GP Board members were not susceptible to this kind of withdrawal when issues were being discussed that might be seen to benefit their own practices in many ways reinforces the way in which the different roles and relative positions had been interpreted but also highlights the weakness of a predominantly GP-led Board. If GPs had been removed from potentially conflicting decisions, the absence of the majority of members would have made it impossible to make the decision.

The somewhat selective withdrawal of people perceived as having a conflict of interest, in many respects, demonstrates how role conditioning and imputed power inevitably affects the way in which people think of us and the way in which we view ourselves (Dahl,1968). While interpretations of relative status might have been more perceived than real, none of the GPs referred to it for example, it had apparently created a self-fulfilling prophecy by constructing the role of the GP members differently to that of the nurses.

With the various levels of perceived accountability, meeting the expectations of each of these stakeholders might be seen to depend on how the various strands were brought together into a framework for action. A significant issue would be whether the interests of the different stakeholders were compatible or pulling in different directions and what therefore would drive the work of the Primary Care Group.

DRIVING FORCES

In this study Board members made numerous references to the inability of the PCG to influence and control either the agenda or the pace of change and this raised further issues surrounding the involvement of local people. Compliance with national priorities and targets had resulted in PCG Board members questioning their ability to influence how NHS resources should be used to meet local health and healthcare needs. Subsequently, attempts to respond to perceived needs of patients and the wider public would be increasingly difficult and question how realistic the government's pledge to rebuild public confidence in the NHS as a

public service, make it more accountable to patients and shaped by patient and public views really was.

The Government had given PCGs the responsibility to develop prompt, accessible and responsive services for local people but had also promised the tools and incentives with which they could do so (*The New NHS*, DoH 1997:39). The reality was perhaps not quite as rosy as these statements would suggest. With an acceptance that health could not be achieved by simply treating ill health, improvements in quality and accessibility of health services had to be combined with health promotion and prevention of ill health. In addition, addressing inequalities in both health and availability of services was a high priority. Initiatives such as National Service Frameworks and the *NHS Plan* had to be implemented and balanced against tailoring services to local need and meeting greater expectations from the public in relation to issues of quality, choice and information.

Primary Care Groups were described as being closer to communities and therefore better placed to identify need and provide local solutions. To some extent, this was at odds with the array of national guidance that had to be complied with. The tension between local and national priorities, transforming the patient based models of planning, that local practitioners had traditionally been used to, into population-based models and attempting to manage both perceived and actual need were only a few of the challenges facing Primary Care Groups. Despite this, a number of those interviewed expressed the belief that PCGs were an opportunity to drive an agenda that could transform the NHS into the modernised service that had been promised in the *New NHS*. If PCGs were to be vehicles of change however, what would be perceived as the driving force behind their work and how susceptible would this be to both internal and external influence. In this study, the main issues identified were balancing national and locally perceived priorities and internal and external stakeholder interests but these were underpinned by concerns over the consistency and stability of any developmental processes initiated, particularly in relation to patient and public involvement.

National Versus Local Priorities

There was no doubt that the majority of Board members appreciated the enormity of the agenda facing them and there was also an acknowledgment that to a large degree this compromised their ability to respond to local issues. There was a

general consensus among Board members that the majority of their work was driven by top-down priorities and guidance. Beyond this however, there was also the recognition that PCGs were an opportunity to allow greater input at a local level, if not on what was to be delivered, certainly on how delivery could be achieved in ways more sympathetic to local circumstance. One Board member's view of this was as follows:

National dictat that comes down from on high probably provides too large a proportion of the work and local priorities; you know the work of the Community Reference Group concerns, particularly over access. So yes it comes from national and local level but I think at the moment we're getting far too many national service frameworks and national priorities. Secondly, and one would like to think equally important, the agenda identified by involvement with local communities and local agencies which reflect not just the interpretation they've put on the national agenda but those arising from people in the community.

While acknowledging the inevitability of having to respond to and comply with national priorities, it was evident that at least some Board members considered the PCG as the mechanism that could ensure bottom up priorities met those coming from the top down. Although the national priorities had to be met, PCGs should have been able to interpret these in relation to their local situations and to reflect local priorities not given consideration in the national agenda

The difficulties of combining national and local priorities were not insignificant. Pragmatically, delivering targets included in national service frameworks and the *NHS Plan* (DoH, 2000), for instance, without the necessary level of resources was seen as counter productive. Specifically, if insufficient resources were available to achieve the "must do" national targets then identifying local priorities that could not be met within available resources was likely to result in raising expectations unnecessarily. In many ways the combination of having to meet top-down targets combined with a perceived lack of resources could be seen as a disincentive to involve patients and the public. With PCGs already facing hard decisions regarding prioritisation, responding to issues identified by patients and local communities was considered difficult if not impossible as captured by this Board member:

I think there is an awful lot of lip service paid to it being locally led and locally driven and I think it's not. I think we are so busy trying to keep on top

of what we must do that we are really just tweaking around the edges of what we'd like to be doing if we had more financial leeway. I think there are other things we could be doing particularly around much more local issues.

Similarly, Community Reference Group members acknowledged that the PCG had to comply with, and was largely driven by, national priorities but that this should be combined with identifying and meeting local need. In addition, members also referred to individual members of the Board bringing their own agenda because of particular needs or interests and, on occasion, patient or community groups with vested interests. One member referred to special interest groups not only at a local level but also at a national level explaining that:

Different groups want different things, the press highlights all the controversial issues and governments, or even local organisations, have to respond if they want to remain in favour. It would be interesting to know the motives behind some of the national priorities and how they were decided.

Referring to the multitude of targets and directives that PCGs had to comply with, some Community Reference Group members questioned the level of involvement at a national level and reflected that local involvement was not always evident. The level of involvement at national level in itself needs clarification in terms of who and how and what opportunities there are for local people to challenge issues they consider to be incompatible with local circumstances.

Although *The NHS Plan* (DoH, 2000:30) referred to a variety of national bodies having citizen and patient representatives and announced an increase in the lay membership of all regulatory bodies such as the General Medical Council, just how effective this was considered to be was questionable particularly as the plan also spoke of the patient's voice still not being sufficiently able to influence the provision of services and local communities being poorly represented within NHS decision-making structures.

As important, were Community Reference Group perceptions of the way in which the PCG negotiated and decided priorities. There was a view expressed by several members that although the work of the PCG should be driven by local need, when competing with national priorities, it would always come second. Describing this, one member reflected that there were no reporting mechanisms to local people

except through national arrangements; the PCG did not have to provide regular reports to local people in the same way that they had to for the Department of Health for example. This would imply that, because the PCG did not have to directly account to patients and the public for its actions, compliance with national directives, for which the PCG did have to formally account, would always be the first priority. In addition, as the same member noted:

Patients and members of the public aren't aware that PCGs should be working for them so they don't ask for the changes they want or the things they need.

There was, however recognition of this tension between local and national priorities among Board members and a view that more robust models of involvement at a national level might succeed in reducing some of the contradictions evident in top down targets. Although "modernising" the NHS was intended to make services more responsive to the needs and preferences of patients, a number of the proposed changes were seen to undermine the relationship between professionals and patients. For example, *The NHS Plan* (DoH, 2000) had promised everyone access to a GP within 48 hours and to a primary care professional within 24 hours. The Chair of the PCG had pointed out that this target might be at odds with the wishes of those patients who valued continuity of care above the wait for an appointment.

In essence, it might be more important for some patients, particularly those with long-term conditions, to wait longer for an appointment but see the same professional rather than to have speedier access to another and have the perceived inconvenience of having to explain their history. The targets, as pointed out by the PCG Chair, militated against this because: " you will completely destroy continuity because I will fill my day with having to see someone within 48 hours".

Despite the acknowledged difficulties in respect of influencing predetermined priorities, a number of Community Reference Group members admitted that things had started to change in relation to people being involved in, or informed of, decisions regarding health services as referred to by this member when asked what drives the work of the PCG:

It should be, but hasn't always been, local people and a concern to improve services, but I can see some small changes now.

Despite the constant references to the difficulties surrounding compliance with national directives, there was also evidence of the commitment of certain members of the Board not simply to deliver the government agenda in relation to targets and priorities but to fundamentally change the way in which health and health services were designed and delivered. This view suggested PCG members wanted to drive the agenda rather than have it driven from the top.

The 1997 reforms had described the health service as being in need of modernisation and had been critical of bureaucratic structures that had led to decisions on health and health services being made too far removed from those who were to benefit from them (*The New NHS*, DoH 1997). Supporting this view, the Chair of the PCG pointed out:

The NHS is an organisation that suppresses any form of development whatsoever. It has got completely stuck in prehistoric ways of managing the system. The organisation is too bureaucratic and too big for itself and has got stuck in a cycle of supporting secondary care because of financial and historical reasons. That's got to change.

Any vision of the PCG as an architect of change, however, was tempered by the acknowledgment that the pace and complexity of change that PCGs were experiencing did not allow the time and space required, even with the strong leadership skills suggested by the above comment, to effect the cultural and attitudinal change necessary to achieve the expected outcomes.

A number of Board members described PCG work as being driven by their own desire to see services improve. It was this personal commitment perhaps that had allowed these Board members to persevere with the top-down targets, deadlines and performance agreements that were perceived as preventing them from engaging fully with locally identified need and, as one Board member noted:

This organisation, it almost jumps too quickly. We've still got to provide personalised continuity of primary care as well as concentrating on the population and as well as doing that we are also asked to do the

commissioning of secondary care and all the joined up working that's necessary to actually deliver the deal. We've got to grow into all those things.

Growing into the responsibilities and expectations of PCGs was as much about controlling the pace of change and taking the evolutionary approach promised by the government. The challenge would be to develop the infrastructure, resources and capacity necessary to deliver on the complex agenda. While the government had introduced organisational change, there were questions around how fundamental the changes in resourcing and capacity building had actually been, as this Board member explained:

I think, particularly at the moment, we're getting too many national service frameworks. National priorities are given to us without necessarily having the resources to meet them, which I think can be counter productive if people feel they are being asked to do things without being given the resources.

Delivering the national agenda had clearly had a major impact on perceptions of how much could be achieved at a local level. With issues surrounding the level of influence that the PCG could exert, just how instrumental other stakeholders could be, in terms of shaping the way in which the work of the PCG would develop, might also be questionable.

External Stakeholder Influence

For many of those interviewed, patients and members of the wider public were seen as having little opportunity to influence the agenda of the PCG. Commenting on the potential for patients and the public to exert influence one Board member reflected that:

At the moment I don't think there is any way to do this. We're all being asked to carry out the Health Authority and Government work.

Any influence was considered likely only if people were "prepared to fight and accept compromise" (GP Board member). Conversely, the CHC member felt that pressure groups and individuals with vested interests could have a disproportionate affect. The public voice was described as emotional and more to do with a

crusading role for particular causes rather than presenting an objective view of services generally. For some Board members, "influence" was seen as too strong a word to use to describe the input that patients and the public could have. Input was more likely to be concerned with listening to the views of patients, the wider public and other partner organisations, whether or not these could be acted upon.

The local authority co-opted member implied that the relationship between the PCG and other external stakeholders was constrained by having only limited access to the information necessary to take part and therefore influence decisions. This was explained as follows:

I think that without access to the corporate knowledge that is held within the PCG, demographics, health statistics, health issues, I think it's difficult for other organisations to participate in or influence decisions to a large extent. I mean I could be more positive and talk about health improvement plans and proposals in terms of partnership working, the local strategic partnership and those sorts of things, but I think there's got to be a sea change to achieve that more positive partnership working and the ability for partners to influence, particularly given the nature of the Board at the moment.

The implication of this, in the context of engaging with, and being influenced by, other organisations is that the PCG had yet to focus on the health improvement agenda in relation to the wider determinants of health and the role that other organisations had to play. This would suggest that joint work had perhaps not been given as much priority as other aspects and reinforces the emphasis, evident when discussing roles and responsibilities, placed on health services rather than health improvement. Equally important is the link between availability of information and the development of patient and public involvement. If other organisations were expressing difficulty in participating as a result of too little information being shared it is not unrealistic to assume that patients and the wider public would experience at least as much if not more difficulty.

Community Reference Group members had also referred to the effort required to access information. In addition, there were comments regarding the timescales involved and the fact that seeing evidence of influence can be long term. Equally, it was considered that individuals working collectively, rather than on their own, would be more likely to succeed in bringing influence to bear. Despite this, there was universal agreement that it was only the belief that they could exert influence that

kept Community Reference Group members interested and committed. The following comments from Community Reference Group members sum these views up:

You must be able to influence otherwise there is no point in taking part; you must be able to believe that.

People at community level, people like me, are tolerated. Community representatives have to work harder at meetings, you need to know what you're talking about and that takes time.

I'm sure that individuals can instigate change over time but this tends to be slow and not individual people but individuals coming together."

The perceived difficulties surrounding the influence that external stakeholders could bring to bear is somewhat at odds with the notion that national priorities could and should be interpreted by taking account of local circumstance. This apparent contradiction in many ways reinforces the traditional role of professionals as proxy consumers (Lupton et al, 1998:53) – PCG Board members acting on behalf of their constituents rather than patients and the public having direct input. Equally, if the Board was not convinced that involvement could influence the agenda, then it becomes a somewhat tokenistic exercise that suggests involvement is more of an end in itself rather than a means to an end and designed primarily to satisfy government directives rather than the means to ensuring services are tailored to local need. As one Community Reference Group member put it, "They can tick the boxes but they can't make the model".

In this sense, involvement might almost be seen as a barrier or a diversion from the desired outcome. If people need to believe that they have influence in order to remain involved or become involved in the first place, simply developing involvement as a way of complying with government directives, rather than a belief in the value of and commitment to involvement, can actually act as a disincentive for people to engage.

Internal stakeholder Influence

A further dimension in terms of influence is the nature of internal influence. Board members came with their own personalities, individual interests and motivation.

These factors had clearly had an impact on the work of the Board and consequently the level of influence that individual members felt able to exert. For some, the personalities of members were fundamental to the way in which the Board operated with one Board member explaining:

I think the PCG would be completely different by one member of the Board being replaced by a different person. Everyone on the board brings their own personality and priorities to it

Both Board members and members of the Community Reference Group agreed that the dynamics of the Board, the relationships that had developed and perceptions surrounding the status of individuals were factors that could influence the work of the Board. For example, although the role of the nurses on PCG Boards was described as giving community nurses and allied professions a voice, there was clearly some concern over the balance between this and what might appear to be the vested interests of individual Board members. A particular issue under discussion during the course of the research was that of developing the career path of practice nurses. One of the nurse members of the Board had put considerable time and effort into researching this issue and producing recommendations. Describing the position of the nurses as a “voice in the wilderness” most of the time, this nurse went on to say:

I had to hand that over and I feel that a lot of the work was and it's going to affect a lot of the practice nurses and improve their working conditions and pay scales and because I was a Board member they didn't want me involved. I can't understand the rationale, I've discussed it with people and I don't think it's any different to the GPs deciding what the prescribing budget's going to be set at because they have a vested interest.

As well as the suggestion that certain Board members needed to be removed from situations where their influence could be seen to favour particular interests, there was evidence that some Board members were relieved not to be faced with these situations. The second nurse member admitted that she had been relieved that she hadn't been at a Board meeting where finance issues were being discussed that would affect the GP practice to which she was aligned.

These two examples suggest almost opposing views in relation to influencing decision-making. Members that clearly had a role to play, because of their personal

and professional experience, and could inform decision-making were removed from the process to avoid accusations of vested interests. Not in itself unreasonable, if applied somewhat selectively, it highlights the relative levels of influence at work among Board members. The implication being that only some Board members were considered able to bring objectivity and so were not perceived as having a vested interest, or were immune to criticism of this nature, while others remained open to accusations of bias. Additionally, members removing themselves from situations where they might have an interest, whether this was personal or related to their work outside the Board, suggests that some members were still relatively unsure of how, when and why they should or would be able to bring influence to bear.

Crucial to the development of patient and public involvement was the level of influence that the lay member could bring to bear. Intended to be a means of fostering opportunities for involvement, the ability of the lay member to influence thinking on this aspect was of major significance and yet, as noted in chapter four, this influence could be, and had been, constrained by the action of other Board members.

In terms of the internal dynamics of the Board and, as a consequence, the level of influence that individual members could bring to bear, there was multiple and often conflicting views of what level of influence was possible and who was most likely to be able to bring this to bear. This confusion would have implications when developing models of patient and public involvement. How could patients and members of the public influence decision-making when certain members of the PCG were unclear as to how, when and why their influence was allowed or allowable?

While members of the Community Reference Group also referred to the different agendas that Board members would have and how these might impact on influence, all were in agreement with this member who suggested:

The agenda of the Board can be different to the agenda of an individual and this can cause an imbalance, but everyone should be working to the bigger picture.

Perhaps a much more fundamental issue is that of the stability necessary to encourage an incremental, developmental approach to patient and public involvement. The perception of the NHS as being in a continual state of change was a particular issue for Board members in this study. When first announced, there were a number of levels at which PCGs could enter, each with different levels of delegated authority. The ultimate level, Primary Care Trust status, was that of an independent body with total responsibility for providing and commissioning health care, improving health and addressing health inequalities for the population within their boundaries. In 1999 PCGs could choose at which level they wished to operate, by 2001 it was clear that developing into an independent body was no longer a case of “if” but rather “when”. The changes this would result in were perceived as putting in jeopardy any new mechanisms for involvement. One Board member summed up concerns over the stability of patient and public involvement in the PCG as follows:

I think it's difficult because the NHS is always in a state of rapid change and, particularly when we go into PCT status, the organisation is going to change and we're going to have a Board which has more lay representation anyway, while possibly losing some of the lay representation further down. So it will change and we maybe need to wait and see how the PCT works out and its structures before we can say exactly how we're going to involve the community.

A number of aspects of particular interest are evident in these concerns. Firstly, this perceived state of constant change in many ways reinforces the notion that involvement should be an incremental process that allows people to grow with the organisation, be informed about potential changes and be prepared for them in a similar way to those who worked within the PCG setting. Secondly, that decisions surrounding involvement can be led by organisations reinforces the importance of the power dimension.

The third aspect is the cynicism that attempts to justify not involving people might be met with. Similar to comments noted earlier regarding it no longer being acceptable to use the lack of interest shown by patients and public as an excuse to avoid involvement, delaying development because of constant change can become a self-fulfilling prophecy. The very fact that change is perceived as constant could mean that involvement is never prioritised.

Ultimately however, it is the following view of the lay member of the Board that perhaps reflects how much difference the introduction of PCGs had made to the development of patient and public involvement:

It's the power element for me because unless we, with our own structures, create routes of access they can't be involved. There's a certain power element in that it's us that allow contribution, which I get a bit uncomfortable with.

CONCLUSION

Multiple levels of accountability were identified that might be deemed to leave the PCG susceptible to criticism regarding the traditional democratic deficit often related to decision-making in the health service. That certain Board members described public accountability as indirect, informal or unwritten implies a relatively immature understanding of the government agenda to renew public confidence in health services.

The issue of accountability and the impact this would have on how the PCG approached their governing responsibilities and addressed local as well as national priorities was felt to be constrained by a number of factors perceived as being outside of PCG control. Top down targets and national priorities for many compromised the ability to respond to local issues and were seen as factors that militated against patient and public involvement being able to influence decision-making.

There is evidence that, in the past, governments have used a variety of tools to challenge the perceived dominance of the medical profession. The introduction of the 1997 reforms included a number of these already tried and tested tools. New structures, policy and guidance, strengthening accountability frameworks, performance management arrangements and devolved responsibility were all intended as a means of ensuring a more even distribution of influence between stakeholders and thus achieving the openness and accountability promised by the *New NHS*.

In this study, it was these very tools that provided justification for approaching the involvement of patients and members of the public with caution. Compliance with

top down targets and priorities were seen as constraints to addressing the concerns of local populations because of the lack of resources and the need to prioritise between nationally and locally perceived needs. As a result, the traditional hierarchy of accountability continued to dominate. At its simplest level, power is about deciding what is important and while devolving responsibility to those perceived as being closer to patients and local people offered more opportunities for robust models of involvement, a continued emphasis on achieving nationally determined priorities and targets had simply strengthened the power of local NHS bodies by providing them with justification for not engaging with locally perceived needs.

CHAPTER SEVEN

CONCLUSIONS

INTRODUCTION

This study has explored a number of key aspects of patient and public involvement in the context of one Primary Care Group. The way in which the intention to involve patients and members of the public would, or could, be implemented and subsequently contribute to planning and decision-making has been examined against a background of some of the key themes evident in the development of patient and public involvement in the NHS. In understanding whether PCGs were a vehicle for change as the 1997 reforms had promised, the structures and processes established by the PCG and how these facilitated or constrained involvement have been explored as well as the influence that the organisation and composition of the PCG had on developing involvement as a core principle. In addition, the relationships that underpinned involvement activities and the implicit levels of power and influence at play have been examined.

Although it is not possible to generalise from single case studies, a number of the key findings in this study reflect those from similar studies. Issues surrounding the relative priority given to developing patient and public involvement, the structures and processes in place to facilitate involvement, the absence of a consensus on the purpose of involvement and a subsequent lack of clarity with regard to models, methods and outcomes were all evident.

This chapter discusses the key findings of the study in the following areas:

1. Previous chapters have discussed how structures and processes are key instruments if patient public involvement is to be embedded into organisational practice. If these are controlled by NHS bodies rather than negotiated and agreed with patients and members of the public they are likely to continue to develop as professional frameworks that patients and members of the public have to fit into. This chapter discusses the key findings in respect of how structures and processes can shape opportunities at a local level and the implications of this for policy and practice.

2. Incorporating a variety of stakeholders into the governing bodies of PCGs was intended to ensure that a range of interests were included and taken account of. For a number of reasons this can be constrained; perceptions about individual and collective roles and responsibilities, aspirations for involving patients and members of the public, the extent to which various stakeholders are enabled to take part in debate, organisational capacity and perceptions surrounding levels of influence traditionally held by the medical profession are all key factors in the value placed on the contribution of different stakeholders. This chapter discusses the implication of this for involvement in practice.

3. While commitment in principle might be expressed, there are a number of obstacles to patient and public involvement that need to be addressed. Organisational capacity, centrally driven priorities and lack of resources were all described in this study as obstacles to involvement. Underpinning these issues were questions surrounding the reluctance of the PCG to challenge these obstacles on behalf of patients and members of the public and the relative level of priority afforded to patient and public involvement. This raises the issue of how far the introduction of these local NHS bodies had acted as a vehicle for change in terms of increasing the power and influence available to patients and members of the public. This chapter discusses how, or if, PCGs were indeed the architects for change envisaged by the Labour Government in 1997.

Similar to case studies, practitioner research can identify issues in relation to the researcher's practice as well as that of others involved in the study but this does not mean that they will be the same for all practitioners. Reflecting and learning from my own practice has significant implications for my role but not necessarily for other patient and public involvement practitioners. Nevertheless, having opened the role up to scrutiny, the implications for patient and public involvement in practice might arguably be similar to a great many other practitioners. This chapter discusses these issues in the context of the implications that the research has for policy and practice at a local and national level.

Although generalisations cannot be drawn from single case studies, they can contribute to a growing body of literature and this chapter offers reflections on the research process and the contribution the study has made to the body of research on patient and public involvement. The chapter ends by describing how the key findings have been applied locally and discussing some of the key changes that

have taken place since the study, in particular the transformation of PCGs to independent Primary Care Trusts.

KEY FINDINGS

The key findings in this study relate to four main areas; how patient and public involvement had been prioritised; the consequences of developing structures and processes that do little to facilitate involvement; the impact that a lack of clarity over the purpose and associated outcomes has on the development of involvement strategies and the implications this has for patient and public involvement practitioners; how stakeholder relationships had developed in relation to the PCG Board.

1. Patient and Public Involvement – One More Priority

Opportunities for involvement presented by the introduction of PCGs have been described as somewhat limited due to the different ways in which the issue is approached. In particular, while involvement is not seen as a marginal activity neither is there evidence that it is a key priority (Milewa et al, 2001:30-43). Board members in this study expressed commitment and presented various reasons why local people should be involved and while all of the reasons given were valid, a consensus had not been reached on the issue of why. In addition, a number of perspectives related to organisationally driven incentives rather than the development of democratic structures and processes.

Obstacles to involvement are well documented and there was no reason to suggest that the PCG in this study would not face similar difficulties of capacity, limited experience and a number of other countervailing forces that are perceived as preventing the prioritisation of involvement. The most common reason cited as militating against involvement was compliance with national priorities and targets. That involvement was itself a national priority appears not to have been given the same level of importance. More importantly perhaps, is that involvement had not been seen as a core requirement that would be an integral part of planning just as much as workforce and resource requirements for example. It is perhaps precisely because involvement remained at the margins that priority continued to be placed on the efficiency-led targets of the government.

Although new power and influence had been promised to patients and members of the wider public (DoH, 2000:88), the mixed response from PCG Board members regarding issues of models, methods and outcomes suggested that the exact nature of this new power and influence had never really been determined in a fashion precise enough for the PCG to have complied with this in quite the same way as other national priorities. There were clear indications that within the PCG it was seen as one more priority amongst many. Continued references to the large agenda, national priorities and the profound organisational change that PCGs were faced with had resulted in the involvement of patients and members of the public continuing to “slip up the priority list and then sort of scatter down again” as described by one Board member. Expressions of good will and commitment are not sufficient if action is not taken to embed it in structures and processes.

2. Structures and Processes

The importance of structures and processes is whether they have been developed to ensure that relationships can be forged and flourish in a way that encourages all stakeholders to articulate their interests and debate to take place in an open and transparent manner. If this is not the ultimate aim of structures and processes at best they can stifle the contribution of patients and members of the public and at worst they can be used to manipulate the level of involvement possible and ultimately control what issues are brought to the table and what, if any, account is taken of patient and public contributions.

The term “involvement” is often loosely applied to activities that include lay people with only limited attention being paid to what this means in practice (Emmel and Conn, 2004a: 1). Focusing involvement around the development of the Community Reference Group and the inclusion of a relatively small number of lay people in various aspects of the PCG structure in this study was somewhat at odds with seeking to develop a democratic approach to involvement, but equally could not claim to be robust in terms of the individual knowledge and experience of services required from consumerist approaches. Moreover the Community Reference Group was openly referred to as having an advisory function rather than being involved in making recommendations, suggesting that activity might be more concerned with consulting on issues defined by the PCG rather than those generated by their constituent population.

To a large extent, the ultimate test of involvement is whether aspirations are converted into measurable outcomes. In this respect, the introduction of PCGs had almost added to the complexity surrounding the involvement of patients and members of the wider public rather than facilitating it. Devolving power to clinically oriented professionals who were not used to involving members of the public, while holding them accountable for nationally driven targets and priorities, had left PCG Board members feeling powerless to engage their constituents in debates over resource allocation. Crucially though, as the lay member had pointed out, it was still the PCG that allowed involvement

Professionals are not always able or willing to understand the views of local people on their own terms, seeking only to put them in the context of the professional and as a result, structures and processes are not always designed to accept the value of all contributions (Popay and Williams, 1994:99-112). That the structure and associated processes in this study had been established without consulting local people, combined with the clinically dominated discussions at Board and sub-group meetings, indicated that they were designed primarily around the needs of the organisation and the professionals involved and not patients or members of the public.

The *New NHS* had pledged that the introduction of PCGs and associated organisational change was a move away from the central command and control models traditionally used by the National Health Service. To a greater or lesser extent however, hierarchical arrangements were still evident that might affect the engagement of patients and members of the public. Equally, there were relationships with other NHS bodies that had affected the level of influence that local people could mobilise.

The structure and processes at work in this PCG, although described as encouraging and facilitating the involvement of stakeholders, particularly patients and members of the public, appeared to have been more focused on the process rather than the outcome. For example, although there was evidence of at least a degree of involvement in the sub and reference groups there was no real evidence of the impact this had made or of outcomes being significantly influenced by the inclusion of a patient and public perspective.

The NHS, as discussed in earlier chapters, is not one single body but a federation of organisations that the *New NHS* would supposedly enable to work in partnership (DoH, 1997). Co-ordination of involvement across these partnerships was essential if PCGs were not to be faced with defending decisions that their local populations had not been a party to. In many ways, PCGs were vulnerable to the planning processes of other NHS bodies and situations were highlighted where proposals made by other organisations were agreed without further local consultation and justified with promises of additional involvement in the future. Developing involvement in this way - around support of professional or organisational priorities - might cast doubt on the credibility of the PCG and its commitment to involvement. Would the PCG be able and willing to champion locally perceived need or would they choose to support, justify and defend clinically or professionally determined decisions made by their partner organisations.

Overall, PCG structures and processes appeared to lack co-ordination and were at odds with a linear process of decision-making that moves from statements of intent to action (Ong, 1993:65-82). In the context of this study, and the different groups that were party to the processes, this was particularly evident in the dislocation between aspirations for involving patients and members of the public and how these were realised. It is the gap between intent and implementation that patient and public involvement appears to have fallen through and made it vulnerable to the different frameworks, philosophies and strategies that were at play within PCG processes.

3. Methods, Models and Outcomes

In common with the findings of many other studies, this PCG had failed to achieve a consensus on the purpose of involvement. This lack of clarity had clearly had an impact on the way in which decisions were made regarding the methods used, which members of the population would be engaged with and how expected outcomes had been framed. Without clarity over these aspects involvement can become selective and undertaken on the basis of compliance with national directives and not for the contribution it can make to ensuring appropriateness of services or, perhaps more importantly, improving the health of local populations. Notwithstanding this, if involvement of local people is to be secured and sustained then a clear understanding of how decisions can be influenced and tangible evidence of change is an essential ingredient.

The lack of clarity over the nature of involvement can result in it evolving into a somewhat immature exercise that lacks the developmental processes that demonstrate a long-term commitment. Opportunities were observed in this study that had not been converted into concrete examples of involvement that could be evaluated and used as a tool for learning and influencing future practice. Involvement continued to be seen as a series of events rather than a process that would evolve over time by learning from and building on previous experience.

If the challenge of developing models and executing methods that have the scope to address the often conflicting nature of involvement is not met, then there is the danger that involvement continues to be a marginal activity carried out at the discretion of organisations rather than a process that will ultimately enable local people to influence decisions. Addressing these difficulties however requires a change in attitudes to the qualitative and often subjective nature of the contributions made by local people. PCG Board members were just as uncomfortable with attempting to balance decisions on cost effectiveness and efficiency with the perceived needs of local people as other NHS bodies had been before them. Equally, that the PCG still had the luxury of deciding on models, methods and outcomes is indicative of how limited the 1997 NHS reforms had been in terms of realising the influence promised to patients and members of the public.

Confusion, a lack of clarity and consensus on issues such as why, who, how and when have significant consequences for the patient and public involvement practitioner in terms of how the role evolves. A number of different roles can be identified that include championing involvement and ensuring that a systematic approach is taken to the development of involvement strategies as well as the more obvious role of advising on and supporting the development of models and methods of involvement. This support and development however, should include helping to build the capacity of local people to contribute but perhaps more importantly, increasing the capacity of those in positions of authority in NHS organisations. Without these parallel strands of capacity building, there is a danger that the existence of very different perceptions of involvement is not highlighted, and mutually acceptable interpretations negotiated and agreed. The consequence of neglecting this issue is likely to be that involvement will be sustained as an activity that is undertaken on an ad hoc or selective basis.

An additional, and perhaps more contentious role, is to challenge involvement activities that are not integrated into decision-making or that patients and the public to fit into structures and processes that are primarily established to meet the needs of organisations. This area of practice is potentially more contentious because it raises the issue of perceived accountability in respect of patient and public involvement practitioners. While ultimate accountability must be to patients and the public because this is, or should be, the nature of public services, this could result in further conflicts being added to those already identified. Can practitioners ever be sufficiently distanced from their organisational priorities, policies and principles to take on this role of challenging and if they are, would existing power relationships mean that these challenges could simply be ignored if they were not compatible with organisational priorities and imperatives.

4. Representing Stakeholder Interests

Although PCGs were seen as a means to ensure representation of a broad range of interests, relationships were evident within and out with the PCG Board that question the extent to which this could be achieved. Perceptions of inequity among Board members and compliance with the national agenda dominated views on how effective the PCG could actually be in respect of responding to local need and representing the interests of their local population. Seen as an obstacle to involvement, perceptions about the limited power and influence held by PCG Board members was described as constraining involvement and often cited as a reason for not involving people.

Constructing a very narrow definition of power, the PCG had continually questioned the level of influence that could be exercised against a backdrop of national directives. This very narrow definition of power had failed to recognise that the PCG retained control over how, or indeed if, patients and members of the public would be able to articulate their interests and what, if any, attention would be paid. By continuing to shy away from involving local people in issues they themselves felt powerless to influence, the PCG might have been accused of collusion in denying access to decision-making. Simply continuing to cite external circumstances as an excuse for non-involvement merely focuses attention away from the more complex power relations that exist when what is needed is to acknowledge and address the issue.

If those who are expected to facilitate a change in the relationship between those who purchase and deliver services and those who use them do not acknowledge the different dimensions of power and the ways in which it can be mobilised, it is questionable whether changes in traditional patterns of power and influence will ever be secured. This failure also raises doubts over the extent to which the government's vision of PCGs as a vehicle for change could be realised.

PRIMARY CARE GROUPS AS A VEHICLE FOR CHANGE

Primary Care Groups were seen as a demonstration of the government's commitment to developing a primary care-led National Health Service (Gillam, 2001:17-27). With the introduction of governing bodies made up primarily of GPs, not only was the role of primary care changing but also the role of those delivering primary care services. Family doctors and nurses were, in theory, given the opportunity to shape local services on the basis that they delivered or referred patients on to most local health services and therefore had a better understanding of needs (DoH, 1997). Combining a primary care-led health service that was predominantly shaped by GPs with an increased commitment to the involvement of local people in decision-making was in many ways a contradiction - while openness and public involvement were seen as a key feature of the *New NHS*, decisions about the use of resources would still be made by those who treat patients.

General Practitioners have traditionally been seen as proxies for their patients (Lupton et al, 1998:93-108); the challenge for PCGs was to move beyond this proxy role and develop the shared decision-making promised by the *New NHS*. Organisational and structural change, however, does not necessarily lead to achieving these outcomes; PCGs could not simply be crafted then left on autopilot. Sufficient time was needed to allow these new bodies to grow and develop into their roles and this, according to a number of PCG Board members, was just not compatible with the timescales they were working with. Managing the potential for conflict of interest was a fundamental issue in this respect.

Members of the Community Reference Group had referred to a major strength of PCGs being the different perspectives and levels of experience that could be brought to decision-making. Combining these multiple perspectives had the potential to enrich debate and encompass a much wider range of need than focusing on single perspectives can. Professionals, managers and lay people

come with their own interests, experience and motivation and as a result there was the potential for conflict within the PCG. Without resolving, or at least managing, these conflicts, capturing the richness of debate is unlikely to be achieved.

In respect of patient and public involvement, the composition of PCG Boards was in theory based on the premise that, given their proximity to local communities, local doctors and nurses were best placed to identify local needs and make decisions about resource allocation (DoH, 1997). In practice, the recruitment of Board members based purely on their profession, as in the case of GPs and nurses, might seem relatively ad hoc with the final composition being left more to chance than choice – interested people rather than those with the commitment, attributes or competencies to lead and deliver change.

The multiple roles that were involved for many PCG Board members would inevitably have consequences in respect of how roles and responsibilities specific to the work of the Board had been interpreted. It is not unusual for people to have multiple roles; the important issue is how the individuals concerned manage these often overlapping roles. In this PCG there was evidence of confused and conflicting roles that had resulted in certain Board members either choosing to withdraw or being withdrawn in order to avoid participating in contentious decisions.

To a greater or lesser extent the construction of roles is linked to implicit levels of power that exist in organisations and it would be naïve to discuss patient and public involvement without reference to these. The issue of power is fundamental to patient and public involvement. While policy documents relating to the *New NHS* make numerous references to patients and members of the public having more power and influence and the NHS becoming more accountable, it might be argued that it is the way in which power is defined that provides the key to understanding the models of involvement that the PCG had attempted to develop.

In this study, members of the PCG Board themselves questioned the level of power they held, particularly in relation to setting their own agenda and this is perhaps symptomatic of the way in which power had been constructed. While strong views were expressed in terms of making sure that, in delivering the national agenda, local need was taken account of, this was often described as either tokenistic or paying lip service. External forces were deemed, in many instances, to be

contradictory in terms of devolving power to local bodies such as PCGs and counter productive if services were to be developed to meet local need.

Despite the promises of local people having more influence included in *Shifting the Balance of Power* (DoH, 2001), obstacles such as the traditional levels of power, organisational practice and culture evident in the NHS would have to be overcome if this was to be a reality. The membership of the PCG Board was predominantly people steeped in these organisational practices and cultures and this was perhaps reflected in the structures and process evident in this PCG.

The expectation that PCGs would increase openness and transparency and provide opportunities for local people to have more influence over health and health services had perhaps resulted in confusion. Developing open and transparent processes assumes the democratic rights of people to know what decisions are being made on their behalf and to call to account those making those decisions. Democracy, however, does not necessarily mean that everyone decides everything but rather that decision-making is entrusted to someone else but that those who have given their trust can also withdraw it. This withdrawal however rather depends on the sanctions available to enforce the withdrawal.

The weakness of this model in the context of the PCG was the various layers of accountability and the lack of sanctions available at a local level. As described by Board and Community Reference Group members, the different levels of accountability had added to rather than addressed the complexity surrounding this issue. With the weight of national targets and priorities, compliance with regulations from their professional bodies and the perceived need to engage with their peer groups, it was perhaps not surprising that public accountability for many Board members was seen as indirect, informal or unwritten.

Sharing decision-making and being involved in generating the issues requiring decisions is an equally complex issue that, as Hogg (1999:109) points out, assumes the empowerment of local people to identify and articulate their needs and be party to achieving them. The devolution of decision-making to a local level to a degree unleashed the potential to develop this model of involvement particularly with references to PCGs being the vehicle to identify and tailor services to their local populations (DoH, 1997). The continued emphasis on achieving top-down, centrally driven targets and priorities was however, described by those involved in

the study as militating against this. While Board members described these as constraining the development of patient and public involvement, another explanation could be that they chose not to challenge these perceived obstacles because they continued to serve the interests of the most influential players.

While PCGs had been encouraged to play an active part in community development and improving health in its widest sense (DoH, 1997:39), there was a very clear emphasis on health services in this study with very little evidence of priority being given to wider issues of health improvement or inequalities in health. That the Community Reference Group was also focused on services rather than wider health issues might be indicative of how it had been shaped by PCG expectations. In this respect, it is clear that the PCG held at least a degree of influence that allowed them to prioritise their functions, develop a structure that was weighted in favour of health services and subsequently influence the work of the Community Reference Group.

A key factor in developing involvement is a commitment to a more balanced distribution of power between patients and the wider public and those who hold the knowledge necessary to make informed decisions (Stacey, 1994:85-97). The implied inequities and references to perceived status of individuals might suggest that this was an issue not only in relation to patients and the public but also among the Board members themselves. The knowledge, expertise and status held by professionals can act as a powerful force that militates against the partnership inherent in democratic involvement and limits the rights promised by consumerism. The nature of information as well as how it is given, exchanged and shared becomes a key theme when implementing strategies for involvement and will have clear implications for the nature of the involvement on offer.

The issue of power is one that is likely to continue in the debate over the involvement of patients and the wider public in the National Health Service. Although the *NHS Plan* (DoH, 2000:12) outlined clear expectations that for the first time patients would have a real say in the NHS with new powers and more influence over the way the NHS works, it is clear that the power evident in relationships can either frustrate or contribute to the development of involvement. The establishment of PCGs had been aimed at empowering local doctors and nurses in respect of decision-making about resources, a by-product of this was the opportunity to control the level and nature of power to be shared with local people.

If this control is to be overturned, a number of issues in relation to policy and practice at both a national and local level will need to be addressed.

IMPLICATIONS FOR POLICY AND PRACTICE

While an understanding of the status quo of patient and public involvement at a local level is, or should be, an essential element of developing future strategies, equally important is developing explanations for trends and patterns of activity. In this study, by contextualising the analysis of how the involvement of patients and members of the public was being shaped and operationalised at a local level within a theoretical framework of power and control we can begin to understand why and how the status quo was being sustained.

Individually, the findings of this study reflect those of many other studies concerned with patient and public involvement - immature structures and processes, confusion over the why, how and when of involvement activities and concerns about how practical the government's involvement agenda is when there is a continued focus on top down, centrally driven targets and performance management arrangements. Collectively however, these might all be considered symptoms of the much more fundamental and complex issue of power – how it is distributed, exercised, sustained and, crucially for patient and public involvement, how it can be challenged.

Examining patient and public involvement in the context of theories of power indicates that there is a range of cultural and historical issues relating to the power and control held by the medical profession that impinge on perceptions surrounding the role of patients and members of the public. A clearer understanding of these issues will be crucial if the power and influence promised to patients and members of the public is to become a reality. While there might be a number of presenting problems of a practical nature, these are underpinned by much more complex issues. The top-down emphasis on the need to involve patients and the wider public and placing the responsibility for its implementation in the hands of managers and the medical profession at a local level has ensured that involvement remains locked into the structures and culture of the NHS and this has clear implications for its future development.

Involvement is required at the level of health policy and strategy as well as at the operational level of health care provision but this has to be a co-ordinated process. If there is a dislocation between strategy, policy and delivery, there is a danger that this gap will continue to be used as justification for inactivity. On the one hand, local practitioners (managers and the medical profession) blaming unrealistic national priorities and targets for their failure to engage and on the other hand national bodies and politicians absolving themselves from blame by using these same national priorities and targets as evidence that they have engaged with local people and developed appropriate responses. Local patients and members of the public continue to be sandwiched between these two camps. What is not apparent is that anything other than minor progress has been made on creating the conditions necessary to enable all stakeholders to identify, articulate, negotiate and argue for their perceived needs.

While clinical, managerial, patient and public control might be seen to be in conflict, ways need to be found to negotiate mutually acceptable outcomes that do not alienate any of the stakeholders. Developing the capacity to respond to the involvement agenda in a meaningful way will necessitate three separate but parallel strands of activity – national policy makers, local managers and medical professionals and local patients and public – so that any top down imperatives are matched with those from the grass roots. There will however be the need to acknowledge that compromise and the forming, dissolution and re-forming of alliances, as in the open and transparent mechanisms described in one-dimensional theories of power, will be an essential part of involvement.

Ultimately however, these issues of power will only be addressed and traditional levels of power and control challenged if ideological as well as technical and process driven restructuring takes place.

The introduction of new organisational structures and processes does not necessarily mean that policy will be interpreted and implemented in a manner that is consistent with the promises made in respect of patient and public involvement. A number of issues will need to be resolved if the involvement of patients and members of the public is to achieve the promises made in the *New NHS*. Specifically, issues surrounding the devolution of power and influence and the ultimate aim of involvement, putting involvement into practice, developing

organisational capacity and the role of those leading change in the NHS have significant implications for policy and practice at both a national and local level.

1. Devolving Power and Influence

In terms of changing traditional patterns of power in the NHS, structural and organisational change is unlikely to achieve additional benefits for patients and members of the public unless policy is sufficiently prescriptive. Devolving decision-making to local clinicians and managers does not necessarily mean that they will extend this to their local population and this is no longer simply in relation to cultural factors. While much has been written on the reluctance of the medical profession to engage with involvement, in this study there was evidence to suggest that members of the medical profession involved were knowledgeable on, and sympathetic to, developing ways of including local people in decision-making. A number of factors however were seen as very powerful constraints to this. In particular, the actual level of power to invest resources locally when there are national priorities to comply with needs to be addressed. To resolve this, clarity is needed over the level of negotiation and compromise possible when balancing local and national priorities.

Separately, there is the issue of where power is held within and between organisations. While Alford's theory of power (1975) identifies managers as challenging the medical profession, the power that managers hold in relation to involving local people also needs to be examined. In this study, there were examples of the medical profession encouraging involvement only to have this thwarted by managers. A consensus on the purpose of involvement and subsequent implementation of strategies is a critical factor. Without a genuine consensus on objectives and outcomes, the development of an infrastructure that supports and motivates people to engage with involvement activities is difficult to achieve – those involved are neither sure of the aim nor convinced of the necessity.

2. The Purpose of Involvement

The *New NHS* had promised people the rights associated with consumerist models of involvement with the responsibilities inherent in democracy. The question must be whether the development and application of these models can realistically or pragmatically be achieved in terms of health and health care.

While in many respects the concept of consumerism is easier to grasp because the legitimacy of those involved is more identifiable, that is the focus is on those who are using services, there is no real incentive to develop this approach at a local level if there is a continued emphasis on measuring performance against pre-determined national targets. Such an approach might indeed be seen as counter to the *New NHS* promises of services tailored around local need and individual preferences. For example, national targets in respect to 48-hour access to a GP, as pointed out by those involved in this study, take little account of patients who value continuity of care by the same medical professional rather than fast access.

In relation to democratic models of involvement, the lack of clarity relating to 'rights' and 'responsibilities' allows local interpretation that may or may not capture the fundamental issue of democracy - that people have the right to be involved in decisions that might affect them. Equally, the issue of who should be involved is less clear in democratic models of involvement in the NHS because of the absence of local accountability mechanisms. In organisations that are both hierarchical and federal, such as the NHS, without local accountability, it is increasingly difficult for people to see where decisions are actually being made and therefore to hold to account those who have made them. As discussed in chapter two, there is evidence of the reluctance of GPs to take responsibility for prioritising and rationing services (Ham, 1999) and in this study there was evidence that this was addressed simply by approaching the involvement of local people with caution rather than raise expectations that could not be met.

3. Involvement in Practice

If the PCG in this study had put in place an implementation plan that focused on involvement as a developmental and incremental process this might have resulted in a more proactive approach to involvement rather than what appeared to be a reactive response. If involving local people had been embraced as a developmental process where previous experience and activity was evaluated and used to influence future action, then the structures and processes might have been more sensitive to patient and public involvement in terms of how local views were incorporated into decisions and feedback given to those who had contributed.

Ong (1993:43) suggests that the Government is not always prescriptive about how policy should be implemented and that the onus is on those with the responsibility to manage change to fashion the most appropriate way to meet policy objectives. Primary Care Groups were faced with a significant agenda and Board members in this PCG constantly referred to this. There is an inherent tension between the need to balance the rationale for involvement in the context of a national agenda with the wider issues surrounding public accountability (Lupton et al, 1998:51-43). The relatively limited performance management mechanisms in respect of implementing policy on patient and public involvement compared with the targets and performance management frameworks relating to other aspects was perhaps an underlying weakness of Primary Care Groups.

The absence of a developmental process in respect of patient and public involvement is arguably a symptom of a more fundamental issue in respect of the organisational development necessary to transform a diverse group of people into a vehicle that would be able to lead and deliver profound organisational change.

4. Organisational Capacity

The ambiguities evident in this study, in relation to the construction of roles and responsibilities, might in many respects be related to the flexibility given to PCGs in terms of how they organised themselves. Although the core responsibilities of PCGs had been defined, flexibility had been allowed in developing the structures and processes considered necessary to undertake their tasks. The consequence of flexibility is often the development of relatively fluid roles that are shaped by individuals themselves rather than the tasks to be undertaken thus creating even more ambiguity and complexity. This flexibility is also a major factor if the relative levels of power and influence are to be addressed. It is possible that NHS bodies predominantly made up of one interest group will inevitably gravitate towards their particular interest to the relative exclusion of other related interests that might be just as relevant.

The business of achieving a collective understanding of issues appeared not to have been addressed in the PCG in this study. There was little evidence of this having been negotiated and agreement reached on the nature and scope of individual and collective roles within the whole organisation. If PCG Board members

had given more attention to this aspect during their formative stage, the lack of clarity and consensus on a number of issues might not have been so apparent.

There is the potential in any new organisational structure for conflict and confusion unless there is absolute clarity over the issues to be pursued and prioritised. It is therefore not surprising that the PCG had prioritised those areas of work that could be measured objectively, such as access and waiting lists, rather than issues of patient and public involvement where outcomes could be defined more subjectively. While a well-attended public meeting might be a successful outcome for some, for others it is how the results of the meeting had been incorporated into decision-making that would be an indicator of success.

When embarking on any organisational change an understanding of the social systems of those involved is an essential ingredient. How roles are created, re-created and maintained and an understanding of the dominant values and emerging expectations are all elements that need to be understood if change is to be successfully implemented (Ong, 1993:43). As suggested in this study, in the context of health services, different groups of people with different and sometimes opposing interests and philosophies exist alongside each other, if there is not consistency of goals and standards it is not unreasonable to suggest that this might result in dissonance in the interpretation and implementation of strategies to achieve them. Given the absence of a national framework setting out the exact expectations of how involvement would be operationalised, the control over the nature and level of this aspect of responsibilities was still held by the PCG.

5. Developing Roles and Responsibilities

The role of professionals and managers, in the development of involvement strategies needs to be clarified. While Arnstein (1969:216-224) argues that the involvement of professionals in any circumstance leads to the disempowerment of local people, because the professionals will always have the ability to wield more power, the reality is not quite as clear-cut. Involvement strategies need to take account of and be clear that it is only by combining professional expertise and lay knowledge and experience that shared outcomes and subsequent decision-making can be achieved. Clarification is required in terms of whether professionals are allies, adversaries seeking to undermine the interests of wider stakeholders, or a resource acting on behalf, and in the best interests, of patients and members of the

public. In the latter model, professionals would act at the request of and on the wishes of patients and members of the public or at the very least, as facilitators for change. For this model to become a reality however, a fundamental rethink is required not only of the nature of involvement but also of the way in which health and health care decisions are made.

Irrespective of the organisational structures and processes that exist and the strategies for involvement that are in place, the difficulties of defining need remain – needs will change over time and vary according to circumstance and across different groups of people. As has been argued in previous studies (Gillam and Brooks, 2001, Popay, 1993) without an ethically coherent framework that defines the central values on which health policy is based, involvement in decision-making and resource allocation will continue as a political expedient with local people more audience than actors.

APPLYING THE FINDINGS

Using the findings from this research, relatively simple changes have been made in the case study PCG that have begun the process of developing involvement in an incremental way – testing particular methods, learning from the experience and, perhaps most importantly, sharing this learning throughout the organisation. The inclusion of front line staff, for example, is considered to have been particularly successful in developing a collective approach to involvement.

The PCG in this study is now a PCT and initiatives have been negotiated that attempt to move away from simply providing evidence of compliance to developing processes that actively encourage the involvement of local people while recognising that each might require a different approach and have different characteristics.

Primary Care Trust Board meetings are still meetings that are “held in public” rather than “public meetings” but there are now mechanisms in place that enable members of the public attending meetings to raise issues, ask questions or make comments. In addition, a member of the Community Reference Group is now a co-opted Board member. This has enabled a more consistent response to be made to issues raised by the group and a more co-ordinated approach taken to establishing and taking account of patient and public views. For example, the Clinical Governance Committee (the Quality Group replacement) was asked to develop a

PCT policy for responding to “Living Wills” (or advanced directives). A draft policy was presented to the Community Reference Group for comment and a number of comments were made along with suggestions for amendments. When the draft policy was presented to the PCT Board for approval, the involvement of the Community Reference Group was not mentioned and nor had the comments and suggestions been referred to or incorporated into the policy.

Previously, this would have most likely have gone unnoticed, as in the case of the consent to treatment and examination policy discussed in an earlier chapter. Under the new arrangements, the co-opted Community Reference Group member was able to question why account had not been taken of the views expressed when the policy had been discussed. As no satisfactory answer could be given, the Board insisted that the policy was taken back to the Community Reference Group, for further consideration and debate and a consensus reached on how the policy could and should be amended to reflect the comments and suggestions made. It was only after this had taken place that PCT Board members gave the policy their approval.

The quality sub-group has been replaced with a clinical governance committee that has made explicit reference to patient and public involvement in its terms of reference and has regular reporting arrangements on this with the Professional Executive Committee and the PCT Board. This means that patient and public involvement now sits within the framework of clinical governance and as such is regularly reported on. Monitoring and evaluation processes in respect of patient and public involvement are being discussed There are still representatives of the Community Reference Group attending these meetings but their role is now being discussed and negotiated in terms of expectations and accountability.

Recommendations and proposals that are put to the PCT Board now follow a standard format that includes a report on the arrangements for involving local people and how these have been, or will be, incorporated into the final recommendations. This has resulted in those reports that do not make reference to patient and public involvement being questioned either by Board members or members of the public attending Board meetings.

Examples of major service reconfigurations and strategy development have provided evidence of how processes have taken account of involvement in terms of

both the additional time allowed and the support provided to ensure that patients and members of the public are able to contribute to the work involved.

When first commissioning the development of a business plan to replace an existing health centre, it was agreed to allow three months for the process to be complete. Taking account of the need to have patients and members of the public involved in this, and the additional time this would require in terms of supporting people through the process, it was agreed that timescales would be left fluid to reflect my advice that patient and public involvement was not a scientific process that could be given a deadline for completion.

In addition, an early piece of work was to establish the processes involved in developing a business case so that this could be taken to an open public meeting to enable those attending to decide what and how they wanted to be involved. The public meeting itself was widely advertised and well attended and the outcome was a plan devised by members of the public outlining how they wanted to be involved and kept up to date with progress.

The process agreed was that four members of the public would attend each of the formal meetings needed to develop elements of the plan as well as the project board established to oversee the process, these members elected by the wider group of people attending the public meeting. A series of open meetings would be arranged for those not wishing to be part of the formal process; those attending the public meetings would also receive regular written updates in between meetings. Separate meetings would be organised to allow debate of key issues such as possible sites for the new facility and services that would be delivered; these meetings would be widely advertised and open to the wider public. Equally, the role of those attending the business meetings was made clear in that they were not there to act as representatives of the wider population but to ensure that public perspectives were taken included and taken into account.

Having initially agreed that the process would be complete within three months, this was extended to more than twelve months as a result of the additional time needed to take account of involvement activities. In addition, the process took account of each level of activity in the planning and provided a co-ordinated approach to the inclusion of patients and members of the public.

The development of a nursing strategy is another example of how involvement was negotiated and agreed with patients and members of the public rather than determined by the PCT. A similar process was followed as described above but an additional element was the inclusion of front line members of staff. Once again, the timescales in which to complete the work were extended, public and patient representatives were included at all levels of planning and feedback mechanisms for those not wishing to be involved in formal meetings were agreed. With the nursing strategy, the process was begun with a meeting jointly attended by front line staff, patients and members of the public to establish issues that needed to be addressed in the strategy.

The lesson learned from this approach was in the value of including front line members of staff. In this case, staff such as district nurses, health visitors and school nurses worked alongside patients and members of the public to identify how best to develop a process that included and took account of both sets of views. Equally, these members of staff, in many cases, had access to people that might ordinarily not take part in activities such as this and could promote the work, encourage people to take part, offer support and importantly, provided a mechanism for feedback. An equally important lesson was the value of including a range of people from the organisation who would "own" the process and again ensure that it became part of the "corporate bloodstream" as advocated by the Commission of Health Improvement (2004:12). If patient and public involvement remains the domain of senior officers, Board members or staff who "do" involvement, it is unlikely to be embedded in whole organisational practice.

Overall, the study provided the catalyst needed to reflect not only on the way in which the successor to the PCG, the PCT, wished to engage with and develop patient and public involvement but also individual practice in relation to this aspect of work. Reviewing the findings of the research established not only how involvement was evolving locally, but was also a key factor in beginning the process of agreeing collectively owned aspirations.

As a practitioner researcher, the way in which my own role had evolved and been shaped by the assumptions of those involved with the PCG at a variety of levels became apparent. As a result of this, my role has been redefined and it is now clear that I am not the person who "does" patient and public involvement; the role is now to advise, support and monitor patient and public involvement. The monitoring role is still somewhat ambiguous given the very different ways in which people view

outcomes and this is an aspect that is being addressed within the clinical governance framework. Specifically, recording of all patient and public involvement is now required and this is reviewed by the clinical governance committee every three months and reported in the annual clinical governance report.

A patient and public involvement strategy and action plan have been developed that outline clear responsibilities for all members of the PCT. A patient and public involvement task group has been established, that includes patient and public membership, the PCT Chief Executive, a non-executive Board member and senior officers from all directorates. This group is responsible for producing policy and practice guidance on patient and public involvement

What has also become clear, given the diversity of perspectives identified as a result of the study, is that patient and public involvement is in need of demystification. Since completing the research changes have been introduced that encourage the commitment of senior officers to include a patient and public perspective, advice and support is offered to middle managers who can nurture front line members of staff and give them opportunities and space to “try their hand” at involvement and learn from the process, as in the above example of the nursing strategy. However, by distancing themselves from involvement on the basis of the tension between national and local priorities, the lack of time and resources and a reluctance to raise expectations unnecessarily, there is the danger that NHS bodies will continue to develop tentative activities that offer only limited opportunities.

REFLECTIONS ON THE RESEARCH

The contribution that this study has made to research is considered to be threefold. Firstly, it has added to the growing body of literature on patient and public involvement by identifying key factors that had shaped the development of patient and public involvement at a local level. The research tells the story of one PCG as it was at a particular point in time. As a qualitative case study, the intention was not to test hypotheses, or to generalise, but to examine in detail one particular case (Patton, 1990) to gain insights into the relationships and processes. While the presenting problems of involving patients and members of the public in the NHS are well documented, this study has examined a number of underlying issues specifically in relation to the debate surrounding the issues of power in the NHS and

how the 1997 reforms, rather than addressing these, had served to reinforce traditional patterns of influence.

Secondly, the study has opened up to scrutiny, and asked questions about, the role of practitioners such as myself who have a specific remit for developing patient and public involvement. As a practitioner researcher, the study provided the opportunity to reflect not only on the action of others but has also raised awareness of my own role in the power structures that existed. This has significant implications in relation to how, consciously or unconsciously, patient and public involvement practitioners are susceptible to accepting, or even perpetuating, prevailing values and assumptions and the subsequent impact this will have on the development of involvement. For such practitioners, the study has emphasised the importance of continued learning by analysing practice to further our understanding. It is not sufficient just to be practising – being there does not equate to learning (Palmer, Burns and Bulman, 2004). Equally, as a result of the gap between theory and practice, a reliance on empirical research and evidence-based theories are not always enough to develop competencies. The very nature of patient and public involvement means that it involves interaction with a multitude of people with diverse interests and practice is therefore likely to be inherently unique and complex. To rely on research-based empirical knowledge and attempt to apply this to all situations is to ignore the fact that there might be situations of uncertainty, instability and complexity that are insoluble by the application of technical, rational approaches (Schon, 1983). Based on this, patient and public involvement should be seen not as a science but rather an art.

Thirdly, this research has been instrumental in identifying weaknesses in the way in which patient and public involvement was evolving locally and has facilitated the process of addressing these while unearthing issues that would benefit from further exploration. The case study recorded here is one of many that have identified and described themes emerging from the development of patient and public involvement in the National Health Service. While case studies are important in terms of contributing to the development of policy and practice at both macro and micro levels, Taylor and White (2000:35) argue, that this does not go far enough. Specifically, while many studies refer to the different ways in which involvement is interpreted, this study has identified the need for further exploration of the level at which key players are aware of and acknowledge the assumptions they are making and how this is reflected not only in their own practice but also the way in which this

shapes the commitment to involvement throughout the organisation. In doing this, a better understanding of how policy and practice needs to be refined to encourage and support strategies that are consistent with national and local expectations should be possible. A major theme of this research was the different ways in which a number of issues were interpreted and constructed by key players and this has identified that further research into the assumptions surrounding patient and public involvement, particularly in respect of the different ways in which constructs of the purpose, models and outcomes are applied and the way in which key players shape the practice of others in the organisation would support the development of strategies that facilitate patient and public involvement.

INVOLVEMENT IN THE NHS – 2002 ONWARDS

Since the study, PCGs have evolved into fully-fledged Primary Care Trusts (PCTs) that are “serious NHS institutions with the full weight of corporate governance responsibilities” (Gillam and Brooks, 2001:40). Primary Care Group Boards are replaced with NHS Trust Boards and in the process; lay members have been lost in favour of non-executive directors, although these will have a majority membership. While the focus of these Boards will be on scrutiny and governance, Professional Executive Committees will be responsible for ensuring the business of the PCT is carried out (Ibid). There is no doubt that in controlling a significant proportion of the NHS budget, PCTs will be more powerful than PCGs and this is a further step in devolving power to a local level.

Although patient and public involvement is described as one of the key principles underpinning PCTs (DoH, 1999b), it remains to be seen whether they will share this locally devolved power with the populations they serve. A number of issues will need to be resolved if this is to be achieved.

The replacement of lay members with non-executive directors has significant implications for patient and public involvement. While the role of the lay member on the PCG Board was to foster opportunities for wider involvement (HSC 1998/139, DoH, 1998) the role of the non-executive director is, as noted earlier, clearly focused on scrutiny and governance (Anderson, 2001:40). Patient and public involvement becomes the responsibility of the Professional Executive Committee, made up of, as the title suggests, health professionals. There is an expectation that

this group will lead an effective dialogue between the organisation and the local community on its plans and performance (NHS Executive, 2000).

Whether these Professional Executive Committees will succeed in addressing the complexities of involvement will depend on their willingness and capacity to address some of the fundamental issues that PCGs had to grapple with. Despite a policy environment that is favourable to embracing involvement, developing the mechanisms and procedures to achieve this will almost certainly depend on local commitment and support.

Primary Care Groups were predominantly led by GPs, professionals that were perceived as having no real history of involving patients or the wider public (Klein and New, 1998, Barnes, 1997). Professional Executive Committees also have a clinically dominated membership that will include GPs, nurses, dentists, pharmacists and optometrists. Faced with the challenge of assuming managerial responsibility as well as their clinical role, it is perhaps not difficult to see how patient and public involvement might not be given priority or even, as Gillam and Brooks suggest, attention could be distracted away from engaging with local people (2001:146). As one PCG Board member had pointed out, it was easier to put involvement on the back burner rather than issues such as clinical governance. There is no reason to expect that this will not still be the case for Primary Care Trusts.

The pressure on PCGs to perform in relation to *NHS Plan* targets and comply with national directives was seen as limiting the amount of capacity available to focus on patient and public involvement. Primary Care Trusts face similar pressure in terms of the national agenda and will be equally susceptible to the top-down targets and priorities that often restrict activities of local health organisations (Hogg, 1999:84-110). While there might be a willingness to involve local people there is also the fear that this could result in a loss of control over services (Baggott, 1998:248-269). Primary Care Trusts might be just as reluctant to raise the expectations of their local populations if the capacity to deliver is constrained by the need to comply with centrally driven objectives.

In terms of accountability, there are still few foundations for developing effective public accountability (Hogg, 1999:175-187). With PCTs, and PCGs before them, the opportunity is available to develop more public oriented models of accountability precisely because of their local focus. If there continues to be an emphasis on

achieving top-down efficiency led targets, however, priority will inevitably continue to be given to upward accountability rather than to local communities.

Although very powerful players, PCTs will need to foster partnership and encourage compatible strategies for involvement across all NHS organisations if they are not to be put in a position where they have to defend or justify decisions made elsewhere. Equally, this will be necessary to ensure that all perspectives are represented in decision-making processes. It still remains to be seen however if PCTs will establish these harmonious working relationships with partner organisations (Webster, 2002:241-245).

Primary Care Groups appeared to have done little to address the complexities of involvement in terms of agreeing why, who, how and when. Although an emphasis on patient and public involvement in NHS policy might continue to foster an interest, the reality, as Baggott (1998:248-269) points out is likely to be a diversity of arrangements that are questionable not only in terms of the techniques and mechanisms used but more importantly, the impact they have on policy and practice. It seems unlikely that PCTs will, in the short term at least, reach a clearer consensus on these issues. Yet more organisational change and the subsequent development issues, if PCTs are to be allowed to grow into their roles, might serve to limit rather than foster opportunities for involvement (Gillam and Brooks, 2001:146-152).

Community Health Councils are a casualty of the new arrangements and this will also have a significant impact on involvement. Patient Advice and Liaison Services, Independent Complaints Advocacy, a national Commission for Patient and Public Involvement in Health and local Patient and Public Involvement in Health Forums and the introduction of a Local Authority function in respect of scrutiny have replaced Community Health Councils. While it is not proposed to discuss each of these mechanisms in detail, as Webster (2002:208-258) suggests, the way in which they were introduced is significant. These new arrangements are arguably a vastly over complicated substitute for Community Health Councils that might be seen as an indication that the government, while declaring a commitment to patient and public involvement, will ensure that it remains on terms determined by the state (Ibid).

Whether PCTs will succeed where PCGs had struggled remains to be seen. Although more powerful in terms of holding resources and relative autonomy, they are faced with similar compliance with top down priorities, targets and timescales. While the national agenda is intended to improve the NHS by developing it around the needs of patients and members of the public (DoH, 1997) the issue for PCTs will be whether they hit their performance targets but miss the point in terms of patient and public involvement by continuing to develop it on the periphery rather than incorporating it into mainstream mechanisms.

The early indications are that, while NHS organisations are getting better at some aspects of involvement, it is still not part of everyday practice, does not lead to improvement and is not having a major impact on policy and practice. Reporting on the findings of 300 inspections of NHS bodies, the Commission for Health Improvement found that, although there were examples of impressive strategies and plans relating to patient and public involvement, these were not rooted in reality nor linked to operational priorities (Commission for Health Improvement, 2004). The Commission also reported a lack of evidence that demonstrated patient and public feedback had influenced decisions – while involvement activities were increasing, they remained at the periphery of decision-making. Although there was evidence that NHS bodies were getting better at finding out the views of patients and members of the public, they were less good at doing anything with this information. In short, the report concluded that patient and public involvement had still not entered the “corporate bloodstream” (2004:12)

Despite this, patient and public involvement is developing and, although still driven by national policy and directives, a great deal of progress has been made. There is evidence of a variety of methods being employed to involve local people and although some of these might be questionable in terms of appropriateness and the links between aims, objectives and outcomes, if these initiatives do nothing else, they are likely to be a significant factor in raising awareness of local people in respect of their right to contribute.

Debate over issues such as methods, models and definitions of involvement will, and should, continue but this should not deter PCTs from introducing small scale changes that encourage patients and members of the public to take an interest in and contribute to both local and national issues. At the very least, the relationships that develop as a result might alleviate some of the fears that professionals have over raising expectations that cannot be met. Equally, they might resolve issues

surrounding patient and public perceptions of professional superiority and traditional patterns of power in the NHS although questions will continue to be asked about the unequal distribution of power.

Revolutionary approaches to patient and public involvement, however, are perhaps neither feasible nor desirable. Patients and members of the public need time and space to grow into what is still a relatively new role and to get used to, what can seem to the uninitiated, very complex organisational structures and processes. Organisations, and the people within them, also need time to balance what should be a continuous learning process with the weight of national performance frameworks.

Patient and public involvement practitioners can make a significant contribution to the development of involvement. Not only can they support, advise on and facilitate opportunities for involvement, they can assist with the process of agreeing collective aspirations and outcomes in relation to involvement activities. Crucially, if given the opportunity to undertake practitioner research, as I was, they can establish local issues that need to be addressed, assist the process of identifying potential solutions and avoid the inaction that is so often a result of the gulf between external research and local implementation of key recommendations.

The one constant factor in the NHS is change. Primary Care Groups have developed into free standing Primary Care Trusts that are more powerful, controlling the major part of the NHS budget for their local populations (Webster, 2002:241-245). Primary Care Trusts have the opportunity to learn from and build on the experience of PCGs but there is also the danger, as Gillam and Brooks (2001:146-152) point out, that any gains made by PCGs might be swept away with the introduction of yet more organisational change.

DERWENTSIDE PRIMARY CARE GROUP - PUBLIC INVOLVEMENT SURVEY

Name:

Address:

.....

.....

.....

1. Are you a:

General Practitioner Practice Manager Practice Nurse

Other (please state)

.....

2. How would you describe your knowledge of Primary Care group work/responsibilities?

Good

Average

Limited

None

3. How involved are you in the work of the Primary Care Group Board ?

Very

Limited

None

4. How would you describe your knowledge of Primary Care Group responsibilities in relation to public involvement?

Good

Average

Limited

None

Appendix Two

5. Compared with other Primary Care Group priorities how important do you think it is to involve members of the public in the planning and provision of health care? (please tick)

Very Important

Important

Fairly Important

Not Important

6. Does your practice currently operate a patient participation group?
YES/NO

7. Is the practice considering establishing a patient participation group?
YES/NO

8. What do you think are the advantages of involving members of the public in the planning and provision of health care?

9. What difficulties do you foresee in involving members of the public?

10. How do you think these difficulties can be overcome?

11. Have you ever used any of the following methods to involve patients?
Please indicate those that you currently using

	<u>Used</u>	<u>Currently Using</u>
Patient Panels	<input type="checkbox"/>	<input type="checkbox"/>
Focus Groups	<input type="checkbox"/>	<input type="checkbox"/>
Patients Councils	<input type="checkbox"/>	<input type="checkbox"/>
Patient Participation Groups	<input type="checkbox"/>	<input type="checkbox"/>
Seminars/Workshops	<input type="checkbox"/>	<input type="checkbox"/>
Lay representatives on practice committees'	<input type="checkbox"/>	<input type="checkbox"/>
Citizens Juries	<input type="checkbox"/>	<input type="checkbox"/>
Newsletters, Leaflets, Media Campaigns	<input type="checkbox"/>	<input type="checkbox"/>
Public Meetings	<input type="checkbox"/>	<input type="checkbox"/>
Community Health Development Projects	<input type="checkbox"/>	<input type="checkbox"/>
Futures Conference	<input type="checkbox"/>	<input type="checkbox"/>
Suggestion Boxes	<input type="checkbox"/>	<input type="checkbox"/>

12. How would you define the following?

Consultation

Involvement

Participation

13. Do you have any further comments?

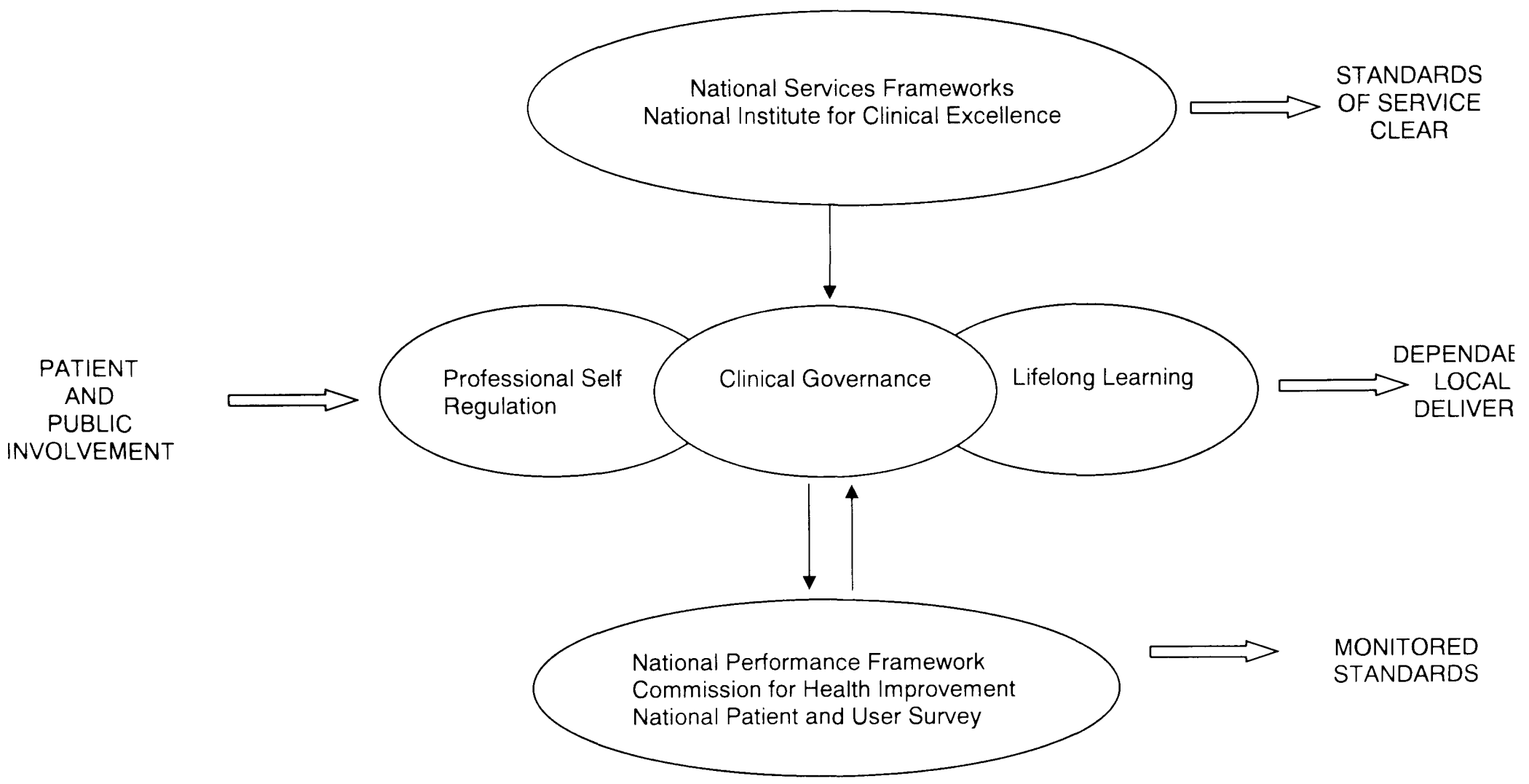
14. Would you be willing to discuss these issues further? YES/NO

Please return to

Verna Fee
Community and Partnerships Officer
Derwentside Primary Care Group
5th Floor, Tower Block
Shotley Bridge Hospital
Consett
County Durham DH8 0NB

INTERVIEW SCHEDULE

1. What do you see as the role and responsibilities of the PCG Board and associated sub and reference groups?
2. What do you see as your role and responsibilities as an individual member?
3. Who do you think you are accountable to both as an individual and collectively as a member of the Board?
4. What, if any conflict of interest is there?
5. Who or what drives the work of the PCG?
6. What influence do Board members or other individuals have over this?
7. Should patients and members of the public be involved in the work of the PCG?
8. If so why should they be involved (if not, why not)?
9. How should or could patients and members of the public be involved?
10. Who should be involved?
11. What can patients and members of the public contribute?
12. What impact can involvement have?



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